VODG
Voluntary Organisations Disability Group

A spotlight on injustice

Commission on COVID-19, Ableism and Racism

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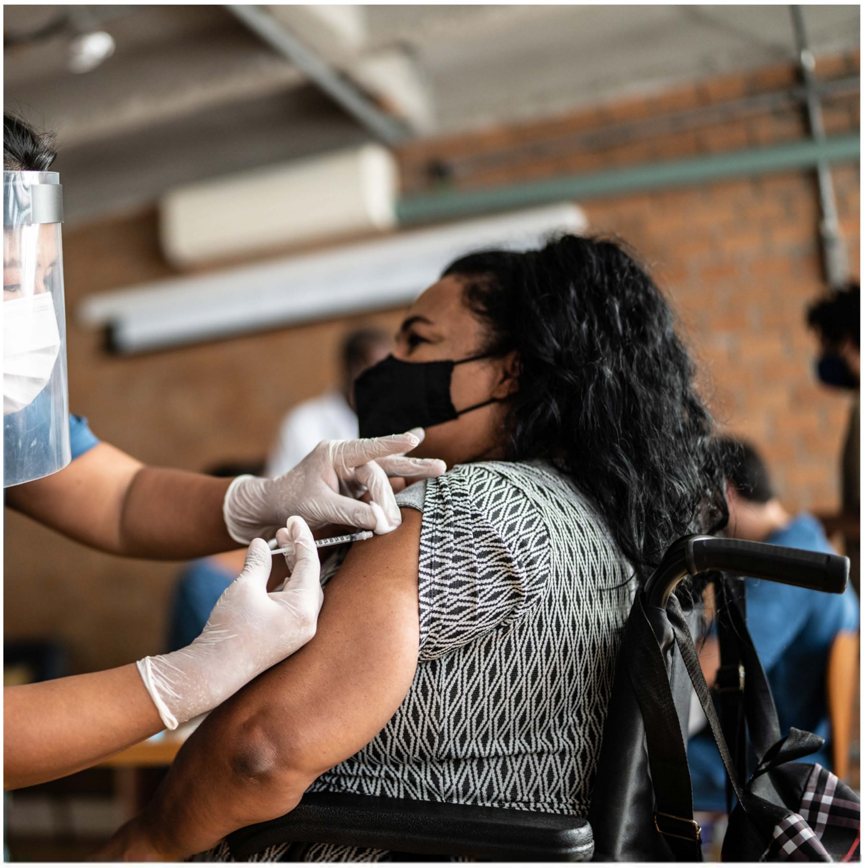

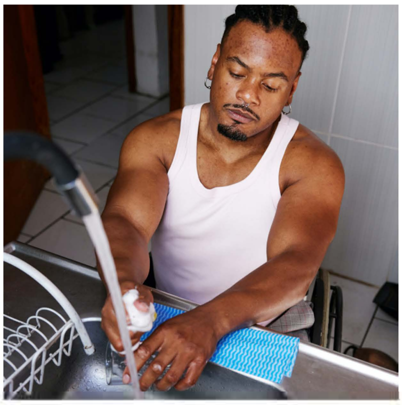

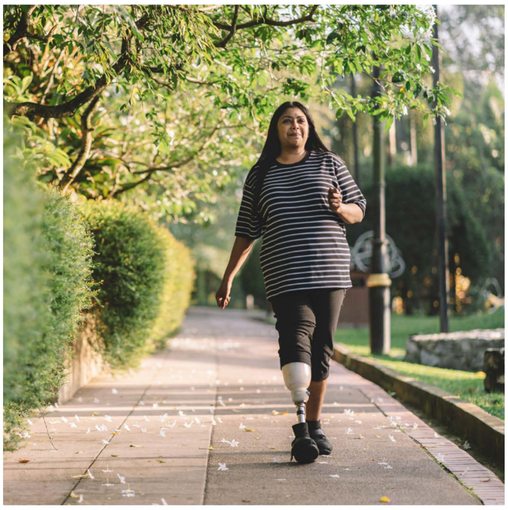

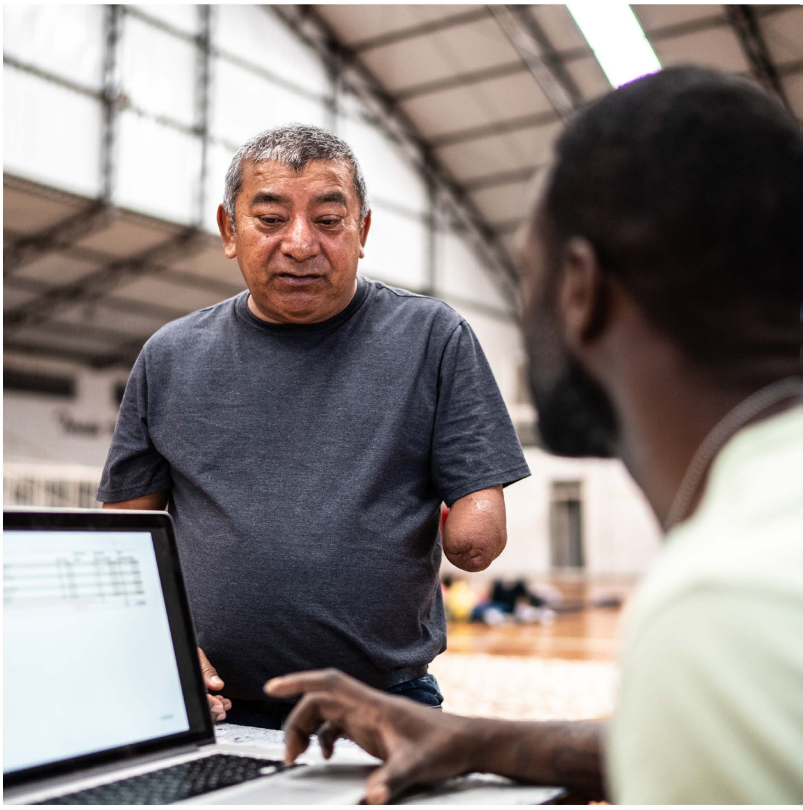

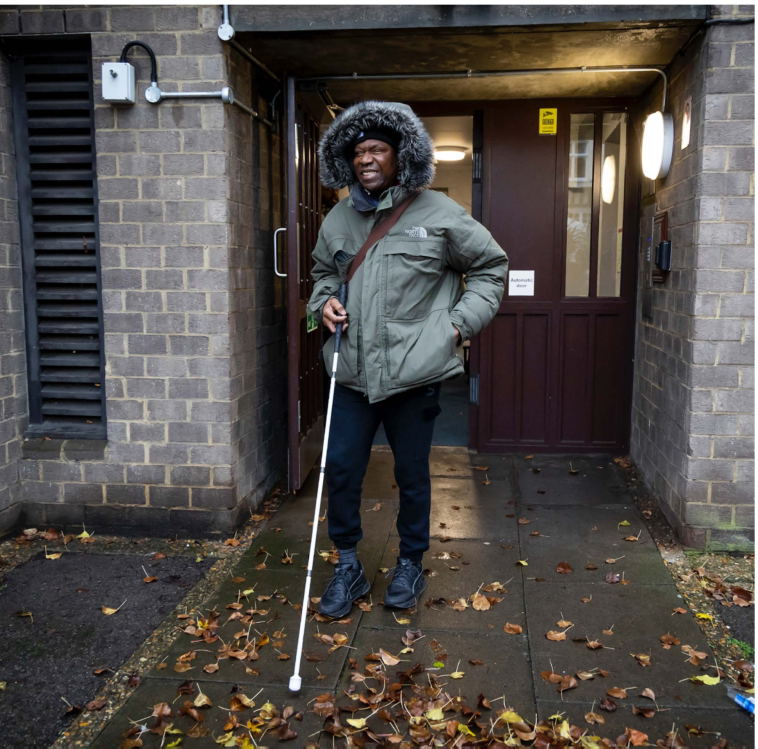

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Foreword

Fighting for Change

Thank you for opening this report. I want you to read it and know that the findings are based on individual Disabled people from Black, Asian and minority ethnic communities. Their experiences are behind the words that you will read.

Kamran Mallick
Commission Chair

My name is Kamran Mallick, and I am CEO of Disability Rights UK. I have worked in the Disabled people-led sector for over 25 years. I am a wheelchair user and have additional hidden impairments, mainly due to catching the polio virus when I was three years old.

I lived through the COVID-19 pandemic, and millions of Disabled people around the world have too. Here in England we know that Disabled people and those with long term health conditions paid with their lives, while many others experienced significant harms. The Office for National Statistics data for the period 24 January to November 2020 showed that six out of ten people who died of COVID-19 were Disabled. We were told that communities from some backgrounds were at greater risk. That Disabled people and those with long term health conditions were, too.

What we did not know was how the intersections of race and disability impacted people's outcomes, people's chances of survival. This report, commissioned by the Voluntary Organisations Disability Group (VODG), set out to find out what the impacts of the pandemic and decisions made by the government were on the lives of Disabled people from those communities. And what must change to ensure it never happens again.

I am grateful to VODG for having the vision to set up this Commission and I was proud to be invited to chair it. Thank you to Rhidian Hughes, CEO of VODG for your support and commitment to this work. To Katie Hipkiss and Sukhjeen Kaur and to the rest of the team who carried out the one-to-one conversations, analysed the surveys and put together the final report that you have in your hand.

VODG appointed a group of Disabled people from Black, Asian and minority ethnic communities as Commissioners. The insights and expertise shared by the Commissioners have allowed us to delve deep into the experiences of Disabled people during the COVID-19 pandemic. I thank them for their commitment to this work and for the work they do every day in speaking out on the inequalities we face.

This report would not have been possible without the individual Disabled people who shared their experiences with us. I express my profound appreciation to those who generously participated in the surveys and one-to-one interviews, openly sharing their personal encounters and the significant impact of the pandemic and decisions made by the government on their lives, families, and loved ones.

> **I lived through the COVID-19 pandemic, and millions of Disabled people around the world have too. Here in England we know that Disabled people and those with long term health conditions paid with their lives, while many others experienced significant harms.**
>
> **Kamran Mallick**

The government's response failed Disabled people of Black, Asian and minority ethnic communities because it failed to recognise them as citizens. If you do not see Disabled people, do not recognise the multiple minority ethnic communities that help to make up the whole of Britishness, then you cannot communicate with them, and cannot support them. You are destined to fail them.

My own experiences reflect some of the issues raised in this report. I believe the intersections of my identity as a Disabled Asian man affected how I was treated.

I was not placed in the clinically extremely vulnerable (CEV) group and so was not told to isolate despite the high risk due to my lower lung capacity. The knock-on effect of this meant that I was not prioritised for vaccines. I didn't get access to priority food shopping online so had to go out and get it myself.

> **I am grateful to VODG for having the vision to set up this Commission and I was proud to be invited to chair it.**

When I broke my leg in late 2020, the ambulance staff did not listen to me and left me at home in great pain, treating the break as bruising and a sprain. When they finally took me to A&E three days later, their first question was if I had a do not resuscitate order in place. In the hospital I could hear the nurses chatting with other white patients. They were polite and professional with me. But it was a lonely time. I often find it easier to campaign for the rights of others than to shout loudly for myself.

The time for talking is over. We must demand action from national and local government, and all our public services. The bodies responsible for ensuring equality must be given the powers and resources to hold the government and our institutions to account.

Our individual and collective experiences must not be silenced. There is power in our lived experience, and I am drawn to recommendation 5 in this report:

Creating a cross-departmental advisory board of Disabled Black, Asian and minority ethnic people to advise on the impact and implementation of policy, and for this to be co-chaired by someone with lived experience alongside a senior civil servant.

Bring lived experience in. It isn't something to fear but to embrace. We can do better if we hear people. Disabled people matter, our lives matter, we matter.

> **Disabled people matter, our lives matter, we matter.**

> **The time for talking is over. We must demand action from national and local government, and all our public services. The bodies responsible for ensuring equality must be given the powers and resources to hold the government and our institutions to account.**
>
> **Kamran Mallick**

Executive Summary

A Voice to be Heard

The Commission on COVID-19, Ableism and Racism was established by the Voluntary Organisations Disability Group (VODG) in April 2022.[1]

It was grant funded by the Joseph Rowntree Charitable Trust.

VODG appointed a Board of Commissioners to steer the work.

> We took an inclusive participatory approach, which means listening to people with lived experience.

Our objectives were to:

- gather evidence of the impact of COVID-19 on disabled Black, Asian and minority ethnic people in England
- look for evidence of systemic racism that worsened outcomes for disabled Black, Asian and minority ethnic people
- highlight injustice and propose ideas for sustainable change in social care.

We took an inclusive participatory approach, which means listening to people with lived experience.

We found that during the pandemic:

- A lot of government public health information was hard to understand for disabled Black, Asian and minority ethnic people.
- The government did not meaningfully engage with disabled people and Black, Asian and minority ethnic communities.
- The government said that COVID-19 was only serious for the 'vulnerable' – including disabled Black, Asian and minority ethnic people – but did not try to understand why this was, or to address the increased risk.
- Disabled, Black, Asian and minority ethnic people experienced increased discrimination and disruption when accessing health and social care services.
- Public conversations about social care concentrated on care homes for older people, which missed a great deal of other social care for other groups.
- Government pandemic policies made life hard for everybody, but some policies were especially hard for disabled Black, Asian and minority ethnic people.

The government has set up an independent public inquiry to examine the COVID-19 pandemic. We propose that this inquiry pays attention to intersectional inequalities, including the harms of ableism and systematic racism.

We have 18 recommendations:

1. Including British Sign Language interpretation and subtitles as a minimum for all public health broadcasts.
2. Using multiple formats for all written communications, whether printed or online, including large print, braille, easy read, and audio.
3. Contracting Black, Asian and minority ethnic disabled people's organisations (DPOs) to advise on diverse language use in addition to English.
4. Working with disabled Black, Asian and minority ethnic communities to use existing structures and recognised channels for information sharing.
5. Creating a cross-departmental advisory board of disabled Black, Asian and minority ethnic people to advise on the impact and implementation of policy, and for this to be co-chaired by someone with lived experience alongside a senior civil servant.
6. Ensuring that at least two Black, Asian and minority ethnic DPOs are funded to sit on each Integrated Care Board and Local Resilience Forums.
7. Undertaking an Equality Impact Assessment (EIA) in all public health emergencies to ensure that the needs of all citizens, including disabled Black, Asian and minority ethnic people, are considered. Action planning should be included as part of the EIA process, with annual review points to ensure that the plan is effective and inclusive.

8 Procuring suitably qualified disabled Black, Asian and minority ethnic people's user-led training providers to work with government departments and the NHS to ensure the adoption of the social model of disability and intersectionality. This should include GPs, the emergency services, hospitals and local authority commissioners.

9 NHS England and Skills for Care (through the Care Certificate) introducing a new minimum training module on understanding the social model of disability and intersectionality, such as disability and ethnicity.

10 Procuring suitably qualified DPO training providers to design and deliver a national digital literacy training program for disabled Black, Asian and minority ethnic communities.

11 User-testing the NHS app and all other digital health systems, to ensure that disabled Black, Asian and minority ethnic people are able to access accurate and reliable information.

12 Providing funding for Black, Asian and minority ethnic DPOs to purchase computers and tablets for use by members.

13 Ensuring adequate social care sector funding is available to meet the current £7bn funding gap in adult social care.

14 The Department of Health and Social Care (DHSC) commission a review of eligibility, access and delivery of social care for disabled Black, Asian and minority ethnic communities, including the availability of specialist services.

15 Promoting the availability of social care and how to access it to disabled Black, Asian and minority ethnic communities, using the range of formats and languages described in recommendation 1 (information and communication).

16 Ensuring that rules and guidelines are implemented appropriately and equally across all religious and cultural holidays.

17 Consulting with people directly affected by policies and seeking advice on the best approaches to implementation.

18 Ensuring that data collection methods that inform emergency response policies successfully retrieve relevant data from disabled Black, Asian and minority ethnic communities.

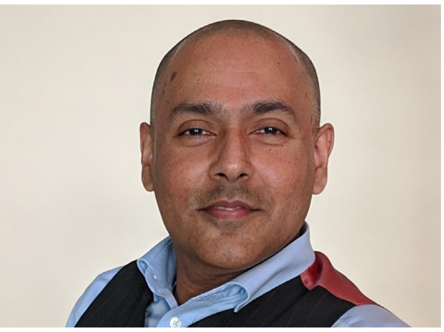
> **I tend to avoid using healthcare services unless I really need to for fear of discrimination or being seen as a burden... When you have multiple experiences (being Black, trans and autistic) it's sometimes hard to tell what is the cause.**
>
> **Disabled people's survey**

1

Introduction

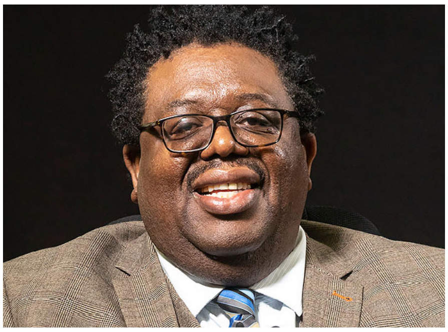
The Commission on COVID-19, Ableism and Racism was established by the Voluntary Organisations Disability Group (VODG) in April 2022. VODG is a membership body representing organisations within the third sector who work alongside disabled people.

The Commission comprises:

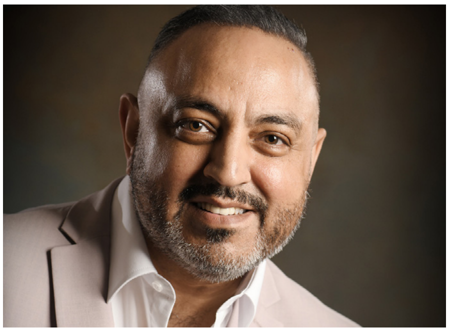


Kamran Mallick (Chair)
Chief Executive,
Disability Rights UK

Julie Jaye Charles CBE
Founding Executive Director,
Start Change



Clenton Farquharson CBE
Director, Community
Navigator Services and Chair,
Think Local Act Personal



Dr Amo Raju OBE
Chief Executive,
Disability Direct

Deborah Williams OBE
Chief Executive,
Creative Diversity Network

The Commission was also supported during its early phases by **Dr Halima Begum**, Chief Executive, The Runnymede Trust.

The Commission was grant funded by the Joseph Rowntree Charitable Trust (JRCT) as part of its programme to respond to the dual harms of the COVID-19 pandemic and systemic racism.

VODG conceptualised and designed the approach and as an integral part of that appointed a board of Commissioners, independently chaired, to steer the work. A VODG secretariat supported Commissioners with all aspects of project delivery.

The Commission's objectives were to:

- gather evidence of the harms that COVID-19 has caused disabled Black, Asian and minority ethnic people in England
- scrutinise policies and pandemic responses for evidence that systemic racism may have worsened outcomes for disabled Black, Asian and minority ethnic people
- highlight injustice and propose ideas for transformative and sustainable change in social care, based on justice and human rights.

This report is an overview of the Commission's work and findings, and includes disabled people from Black, Asian and minority ethnic groups talking about their experiences during the pandemic. It provides an overview of the experiences of ableism and racism during the COVID-19 pandemic and offers recommendations for intentional and inclusive actions for the future.

1.1 Language

Language is important. The definitions of words we use in this report are outlined below. We acknowledge, however, that language evolves and words have limitations, especially when applied to collective experiences.

1.1.1 Disability

We recognise and uphold the social model of disability[2] which says that people are disabled by barriers in society, not by their impairment or conditions. Barriers can be physical or caused by societal attitudes. Impairments may be physical or mental, and include long-term health conditions, for example, diabetes, arthritis and dementia.

1.1.2 Intersectionality

Intersectionality is inequality and discrimination resulting from the overlap of an individual or group's multiple social identities. This Commission is concerned with the intersectionality of disability and race within the experiences of disabled Black, Asian and minority ethnic people during the COVID-19 pandemic.

1.1.3 Ableism

Ableism is discrimination against disabled people based on the belief that non-disabled people are the norm. Ableism can manifest in attitudes, beliefs, policies, and practices that devalue and marginalise disabled people.

1.1.4 Systemic Racism

Systemic racism refers to policies and practices embedded in a society or organisation, which lead to unfair or harmful treatment of people because of their race.

1.1.5 Social Care

Social care is a broad umbrella term that encompasses all forms of personal and practical care and assistance to enable people to live independent and fulfilling lives.

Social Care Future says:

> **We all want to live in the place we call home with the people and things that we love, in communities where we look out for one another, doing things that matter to us.**

1.1.6 Minority Ethnic

Minority ethnic refers to all ethnic groups except white British. Minority ethnic includes white minorities, such as Gypsy, Roma and Irish Traveller groups.

1.2 Approach

The Commission took an inclusive participatory approach involving a wide range of sources including existing literature and direct calls for views and experience. Our findings were driven by what we have heard from people with lived experience. We augmented these findings with further investigation of key themes. Commissioners' own professional and personal experience and expertise has shaped both findings and recommendations. Together, our focus was on collectively identifying lessons to be learned from the COVID-19 pandemic and how we can initiate transformative and sustainable change.

1.2.1 Scoping

We conducted a literature review to explore:

- the impact of the COVID-19 pandemic on both disabled people and Black, Asian and minority ethnic people
- concerns with the government's pandemic response
- the impact of pre-pandemic government policy
- health and social inequalities and recommendations to address the issues raised.

We reviewed publications including academic research, reports by charities and think tanks, reports by government and other public bodies and commentary pieces.

Story

Chandni

April 2023

Chandni (43) is a business consultant and translator living with multiple physical and mental health conditions, including multiple sclerosis. She is passionate about the intersectional perspective in patient views.

"I felt that the pandemic had a strain on my whole household due to the dynamic disabilities and chronic illnesses that my family lives with. I also felt that the general population didn't understand the risks to those who were younger and clinically vulnerable, so I didn't think that extended family members would either, particularly given language and/or health literacy challenges.

I was concerned around ethnic minorities being told they were more vulnerable, but with no explanation as to why. It led to a feeling of panic. This resulted in me not wanting to leave our immediate household. I still continue to self-isolate today, due to the collective risk of our household to COVID-19.

I was disappointed with the terminology used throughout the pandemic, specifically with the term 'hard to reach.' It made me feel like I was being accused of not being accessible enough to the government.

The terminology used in the UK towards my disability, like 'clinically vulnerable' was not easy to convey to my family members overseas, which resulted in me having to explain things in more detail.

I believe that terminology should be chosen wisely so that people with language barriers, such as those whose first language is not English or those with certain disabilities, are considered. For example, using terms like 'high risk' or 'low risk' instead of 'CEV' would be more accessible.

With observing social distancing, self-isolation and other protective measures, I have missed multiple weddings, funerals and other family gatherings. This is isolating for me and has cultural implications with the wider community putting value on everyone being together for events such as this.

The forced decision to self-isolate and keep safe when being invited to weddings and funerals has had an impact on my parents, who have felt pressure from family.

I felt that family members struggled to understand the changes in rules, specifically around the Christmas period where rules were changing quickly and the messaging was confusing and unclear.

Now, I find that I am having to choose between social life, health, family life, work life, as one is always compromised. I have also had to turn down work opportunities due to them not being accessible online, which has already compromised my work life.

I am concerned that people will see me continuing to wear a mask and then ask questions as to 'why,' due to many people from a South Asian background not understanding the impacts of my health condition and disability.

A close family member, from a similar age group, had declared they were no longer getting vaccines after the first two as they didn't feel they were important to those who didn't have a lowered immune system. This came from an 'individualist' mindset that appears to be common in the UK. They also felt the vaccines were a 'shot in the dark' in terms of which strains they worked against. When I tried to explain about the vaccine efficacy, they disregarded the expertise I have in the area around healthcare and chronic illness."

We engaged with disabled people's organisations (DPOs), race equality organisations, social care providers and individuals with lived experience working to address issues of inequality for disabled Black, Asian and minority ethnic people. Through these conversations, we gathered insights about the key issues affecting disabled people during the pandemic and the themes we should investigate further through the work of the Commission. We also sought their expertise regarding how to ensure inclusive and meaningful involvement of disabled people. We ran a short survey, but much of the evidence in this report comes from conversations we hosted, and conversations we commissioned other groups to convene.

1.2.2 Call for Views and Experiences

Our Call for Views and Experiences ran from August 2022 to January 2023. We spoke to disabled Black, Asian and minority ethnic people, family carers and people who work in adult social care, seeking to understand:

- How have disabled Black, Asian and minority ethnic people been disproportionately impacted by the pandemic?
- In what ways did the government's social care pandemic response fail to mitigate this impact or actively harm disabled Black, Asian and minority ethnic people?
- What should be put in place to prevent further harm and address inequalities experienced by disabled Black, Asian and minority ethnic people?

We provided multiple ways for people to respond, across two phases:

- From August to November 2022, we launched three surveys designed by Commissioners and VODG: for disabled people, family carers and people who work in adult social care. We also invited people to send us a written response, or an audio or video file, via email, text or WhatsApp.
- From October 2022 to January 2023, we ran a series of conversations focussing on what needs to change:
    - A Commission researcher hosted one online group conversation and ten one-to-one interviews with disabled Black, Asian and minority ethnic people and family carers.
    - We commissioned six user-led organisations working at the intersection of disability and race, to host conversations with disabled Black, Asian and minority ethnic people and family carers within their networks, providing them with a conversations toolkit and financial resources.
    - Two partners hosted roundtables with people who work in adult social care.

Through these channels Commissioners sought people's views and experiences through predominantly open and qualitative questions. We wanted people to focus on what was important for them and use this as the starting point for developing our findings.

We analysed our evidence using inductive data analysis techniques, with the aim of identifying and focusing on the unique experiences and challenges for disabled Black, Asian and minority ethnic people during the COVID-19 pandemic. We triangulated these perspectives with existing research as well as drawing on the views and experience of Commission members.

The Commission heard from over 100 disabled Black, Asian and minority ethnic people and our engagement with all stakeholders was more than 200 individuals and organisations.

> **There have been a number of instances where people I work with have required health care and have had very poor outcomes, I believe this was not only due to their learning disability but also possibly due to their ethnicity. I think the fact that their carers are Black or Asian also compounded the issues with assumptions being made about their understanding of complex issues and I believe on occasions they were dismissed or not listened to due to this.**
>
> **Survey for social care staff**

Story
Shawn

April 2023

Shawn (37) is a researcher, an expert by experience, and a champion for people with learning disabilities.

"I struggled to keep structure during the pandemic as I lived alone and was not able to do things I usually did, such as meeting with friends and family, and I wasn't able to occupy time playing video games or watching TV due to financial constraints. I struggled to keep social support as a result. During the summer of 2020, I was quite frustrated from the amount of time I had to spend indoors, with little option.

I am a researcher and an expert by experience which means I speak to clients about supported living to ensure they have the right support and are happy with the support provided. I couldn't do a lot of this work in the pandemic.

I come from a British Bangladeshi Muslim background. I didn't feel that older generations of British Bangladeshi people or my parents were open to disabled people and followed the stigma British Bangladeshi have towards disabled people. As a result… I have to rely on my siblings for support, and I keep in touch with them regularly. I was able to see my siblings quite frequently during the first lockdown as I was babysitting one of my sisters' children. However, I saw them less during the second lockdown because I felt like I was stressing my sister as she was quite worried about my wellbeing and already had her own children to worry about.

When discussions around racism were prevalent during the pandemic, I experienced additional racism when showing support for Black Lives Matter. I experienced hearing racial slurs during this time but had not experienced that previously. This was upsetting and angered me quite a bit. I felt quite helpless … I needed to call my brother for emotional support. I didn't feel like I could call the police because they don't take matters like this seriously and it was a risk to call them during the pandemic."

2

Findings and Recommendations

This section summarises the main themes that emerged from the analysis of our conversations, surveys and the literature review. In each section, the findings are followed by a series of related recommendations.

2.1 Information and Communication

The government's blanket approach to providing public health information created multiple and overlapping barriers for disabled Black, Asian and minority ethnic people.

> **You know, as a Black disabled man this discrimination is something we have to learn to live with. Basically, it's everywhere.**
>
> Lived experience interview

For example:

- 78% of deaf people found government information to be inaccessible.[3]
- 29% of Bangladeshis said they were not aware of any of the government's messages, compared to 7% of white British.[4]

2.1.1 Accessibility

Most government communications about COVID-19 came through the Prime Minister's briefings on the BBC, the gov.uk website and Public Health England (PHE). This presented several accessibility challenges for some disabled Black, Asian and minority ethnic people and family members:

- Most information was not provided in accessible versions, such as British Sign Language (BSL), Easy Read or different languages. People were frustrated at the government's failure to provide the Prime Minister's briefings in BSL, despite persistent requests, and the fact that this was available in Scotland.
- When information was provided in other languages and communication formats, there was often a lag. This posed problems, given the speed at which public health information changed over the course of the pandemic.
- Digital literacy and access were assumed, though in some communities neither are a given. Much of the detailed information about COVID-19 restrictions, for example, was available mainly online, and not accessible to some people.
- The government used the BBC as its main media channel. However, the BBC is not the main source of news for some Black, Asian and minority ethnic people. For example, many Asian people receive their news through international or culturally specific channels where the latest news could be 24 hours behind the BBC.
- Many of the places that disabled Black, Asian and minority ethnic people might normally go for accessible information, such as community centres and places of worship, were closed for much of the pandemic.
- These issues were known early in the pandemic, with the SAGE ethnicity subgroup publishing a paper in December 2020 emphasising the importance of sharing information via trusted sources, in multiple languages, addressing religious and cultural concerns, as well as the importance of community engagement.[5]

These accessibility challenges led to:

- A reliance on getting information from family, friends, social media and informal networks. Our easy read survey identified that 41.7% of respondents received important public health information about the pandemic via their families.
- Inequalities in accessing COVID-19 support and resources, including advice, having care and support needs met, food deliveries and personal protective equipment (PPE).

Charities, national and local, played a key role in interpreting government guidance, and sharing information in a way that was more accessible and culturally appropriate and relevant to the needs and requirements of some groups of disabled people and/or their families.

2.1.2 Trust

The importance of sharing information via trusted sources was a key theme.

Wariness of government pandemic communications was attributed to several causes:

- There was pre-existing mistrust of the government and public bodies among some disabled Black, Asian and minority ethnic people due to past experiences and longer standing and generational experiences of discrimination and systemic racism.
- Health inequalities for some Black, Asian and minority ethnic groups are recognised by the government but have never been fully addressed historically and remain a cause for concern today.
- Constantly changing government pandemic information and advice led to further misgivings. Some had trust at the beginning of the pandemic and stringently followed government advice, but lost confidence as that advice became less consistent and coherent.
- Mistrust was further compounded by the actions of government during the pandemic that deprioritised disabled Black, Asian and minority ethnic people. In particular, not enough was done to address vaccine hesitancy.
- After the government lifted the restrictions, rapid lateral flow tests were made available for clinically extremely vulnerable (CEV) groups, excluding Black, Asian and minority ethnic groups that were previously told to be high-risk. This neglected the risks from COVID-19 to Black, Asian and minority ethnic groups.

This mistrust led to the rise of misinformation and disinformation, shared through alternative channels including personal connections and online spaces.

2.1.3 Messaging

Government messages about COVID-19 and pandemic policies were unclear, constantly changing and overwhelming. This exacerbated issues with the accessibility of that information. People were often unsure what was happening and what they needed to do to keep themselves and their loved ones safe.

Information and Communication – Recommendations

We recommend that the government ensures that public health communications are accessible to all, including disabled Black, Asian and minority ethnic groups. This includes:

- ☑ Including British Sign Language interpretation and subtitles as a minimum for all public health broadcasts.
- ☑ Using multiple formats for all written communications, whether printed or online, including large print, braille, easy read, and audio.
- ☑ Contracting Black, Asian and minority ethnic disabled people's organisations (DPOs) to advise on diverse language use in addition to English.
- ☑ Working with disabled Black, Asian and minority ethnic communities to use existing structures and recognised channels for information sharing.

2.2 Engagement and Representation

There was little meaningful engagement by government with disabled people and Black, Asian and minority ethnic communities, even though the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) requires the government to engage with DPOs.

Engagement is essential:

- to develop understanding of the needs of all communities that government exists to serve
- to build trust with those communities so that they, in turn, trust the information and advice shared by government and public bodies.

A lack of engagement led to:

- government pandemic policies failing to meet the needs of disabled Black, Asian and minority ethnic people
- mistrust and lack of confidence in government messages.

In June 2020 a PHE report highlighted the essential role of voluntary, community and social enterprise (VCSE) organisations in engaging and supporting Black, Asian and minority ethnic groups. It noted that improved awareness and impact that could have been achieved through community participatory engagement with Black, Asian and minority ethnic groups to produce communication material. It also reported the impact of historic reduced funding on the number, range and diversity of VCSE organisations across the country.[6]

Engagement and Representation – Recommendations

We recommend that the government includes representatives from disabled Black, Asian and minority ethnic groups in scenario and action planning for public health emergencies. This includes:

☑ Creating a cross-departmental advisory board of disabled Black, Asian and minority ethnic people to advise on the impact and implementation of policy, and for this to be co-chaired by someone with lived experience alongside a senior civil servant.

☑ Ensuring that at least two Black, Asian and minority ethnic DPOs are funded to sit on each Integrated Care Board and Local Resilience Forums.

☑ Undertaking an Equality Impact Assessment (EIA) in all public health emergencies to ensure that the needs of all citizens, including disabled Black, Asian and minority ethnic people, are considered. Action planning should be included as part of the EIA process, with annual review points to ensure that the plan is effective and inclusive.

2.3 Narratives

The government narrative concentrated on reassuring the public that COVID-19 only seriously affected the 'vulnerable' – including disabled Black, Asian and minority ethnic people. This created a false and harmful dichotomy between people living in potentially vulnerable circumstances and wider society. However, government did not make a proactive and substantial effort to:

- understand the cause of this increased risk
- implement measures to address it.

2.3.1 Vulnerability

A narrative was built on notions of vulnerability, focused on individual and cultural factors, ignoring systemic, intersectional and structural issues. This:

- inaccurately conflates disability with clinical vulnerability to COVID-19
- does not reflect the social model of disability, focusing on individuals' characteristics rather than structural barriers that disable people
- does not acknowledge that some Black, Asian and minority ethnic people have more prevalence of long-term health conditions, increasing the likelihood of disability for these groups[7]
- ignored known systemic and socioeconomic factors that were highlighted by the SAGE Ethnicity Subgroup in September 2020.[8]

Having defined COVID-19 as a disease of the vulnerable, government then failed to protect those vulnerable communities, which increased the harms to:

- disabled people, as scapegoats for the pandemic rules and restrictions
- Black, Asian and minority ethnic people, as scapegoats for spreading COVID-19.

The inaction of government and discriminatory policies – including concerns about the use of blanket do not attempt cardiopulmonary resuscitation (DNACPR) policies and the lifting of restrictions so that 'everyone else' can go back to normal – made disabled Black, Asian and minority ethnic people feel disposable.[9] These feelings were exacerbated by the 2021 report of the Commission on Race and Ethnic Disparities, which denied the existing of institutional racism.[10]

> **In terms of messaging, on the Afro-Caribbean side of my family there is a lot of distrust towards authorities and the medical profession. I felt like the psychology behind that fear and that distrust wasn't being investigated.**
>
> **Family interview**

Story

Kiran

April 2023

Kiran (39) is a health advocate specialising in Ulcerative Colitis. She is an inclusive dance instructor, providing various accessible methods of exercise to those that struggle with mobility.

“I felt that my experience of the pandemic was firstly impacted by my health condition, which labelled me as clinically extremely vulnerable and then by my race because I am of Asian heritage, and this was followed by other elements of my identity woven in, such as gender and marital status.

Terminology used in the UK was not easy to convey with family in other countries. Terms such as shielding or clinically extremely vulnerable were harder to explain because the language wasn’t translatable to people who don’t speak English, including some of my own family members. [Similarly] The terminology used in the UK towards my disability was not easy to convey to family members overseas which resulted in me explaining things in more detail. When explaining to family members overseas that my family was shielding, they often responded with ‘what does that mean?’ However, it was easier for me to use this language with people who were familiar with this language. For example, to get delivery drivers to understand the need to socially distance to keep me safe.

I felt that racial stereotypes were perpetuated due to the use of race identifying individuals as more vulnerable to COVID-19 with little explanation or support to understand why or provide support to manage the risk effectively. It felt similar to saying ‘Black people are less likely to feel pain’ or ‘Asian people are more likely to overreact or use a physical symptom to discuss a mental health issue.’ I also felt that the narrative surrounding ‘ethnic minorities being more at risk’ with little understanding of why and practical support to address this was potentially divisive.

I felt like I had to fight to be able to work from home, initially. However, I did see a positive change when my workplace requested those from Black, Asian and minority ethnic and other at-risk groups to support them.

I felt like the pandemic ‘outed’ me for living with a health condition at work, as there wasn’t a choice to disclose that information. This resulted in me having to prove myself as valuable and not to be perceived as unable to complete my job.

My social life has suffered due to the pandemic. It’s much harder to meet people or look for a partner when I still have to be careful around the risk of COVID-19. With South Asians, I often find that the judgement is harder on women to be healthy and to be a suitable partner.

I feel that the government is not acknowledging COVID-19 currently and many people aren't acknowledging it either. For example, I recently went to see my GP and noticed that nobody was wearing masks even though there were signs stating that masks were required in that setting.

I am currently being cautious when leaving the house by wearing a mask, meeting people in outdoor spaces, or requesting that tradesmen wear a mask when visiting the house. I have to ask multiple questions before attending places to make sure they are COVID-19 safe.

I think that health professionals should be required to wear masks, instead of it being an optional choice. This would help to ensure that fewer professionals take time off due to sickness, which would ultimately benefit patients.

I feel that the government should have modelled better behaviour when it comes to COVID-19 rules, so that the public would be more likely to follow them. Instead, I have observed that people are bending the rules to suit themselves – for instance, going on holiday and avoiding quarantine rules.

I believe that the government should provide accessible options in workplaces during the pandemic, to ensure that disabled people can access work safely. This would be an important step towards creating a more inclusive and accessible work environment."

> **There was a perceived sense of inevitability regarding the deaths of people who were at higher risk of dying from COVID-19 based on race, ethnicity or underlying conditions that amounted to a 'survival of the fittest' approach which effected other medical treatment or social care support that people received during this period. This approach was manifested in a multitude of policies and procedures such as oximeters that didn't work on all skin tones and blanket application of Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders against disabled people without discussion or consent. The overall effect of this made people scared of going to hospital.**
>
> Roundtable with social care staff

2.3.2 Anxiety and Anger

This marginalisation, coupled with data and news reports highlighting increased risks for disabled Black, Asian and minority ethnic people, caused anxiety. This was exacerbated by:

- a lack of information or guidance about how people could better protect themselves
- little or delayed action from government to protect those communities affected.

We encountered much anger about the lack of PPE to protect Black, Asian and minority ethnic health and social care workers, when data was coming out about the increased risks from COVID-19. Similarly, about the reduction of PPE requirements while we were hearing about the disproportionate deaths of Black, Asian and minority ethnic clinical staff.

Narratives – Recommendations

We recommend that the government addresses systemic disparities in health and social care provision by fostering an understanding of intersectionality and the social model of disability. This includes:

- ☑ Procuring suitably qualified disabled Black, Asian and minority ethnic people's user-led training providers to work with government departments and the National Health Service (NHS) to ensure the adoption of the social model of disability and intersectionality. This should include GPs, the emergency services, hospitals and local authority commissioners.
- ☑ NHS England and Skills for Care (through the Care Certificate) introducing a new minimum training module on understanding the social model of disability and intersectionality, such as disability and ethnicity.

> **It was so confusing and frightening as [pandemic guidance] was all in English, on TV or online. Most of us in this community can't speak or understand English, or use computers, so can't access information online.**
>
> **Community-led conversation**

2.4 Health Services and Pandemic Support

Experiences of discrimination when accessing health and social care services increased during the pandemic. Furthermore, the general disruption to health services had a great impact on disabled Black, Asian and minority ethnic people.

- Our survey showed 92% of disabled Black, Asian and minority ethnic people experienced discrimination during the pandemic, compared to 73% pre-pandemic.
- A study using English hospital admissions data found areas with larger numbers of Black, Asian and minority ethnic people faced greater disruption to services.[11]

We heard examples of people's personal experiences of discrimination, which included:

- being treated differently to their white or non-disabled counterparts
- having stereotypical assumptions made about them
- concerns not being taken seriously.

This meant people often did not receive the treatment they needed, or they received it after symptoms had worsened.

We also heard from disabled people affected by discriminatory policies, such as:

- having a DNACPR placed on them
- being told their everyday-use ventilator would be taken off them if they went into hospital
- being unable to take a carer or family member into hospital.

These experiences, combined with historical experiences of discrimination, meant many disabled Black, Asian and minority ethnic people were hesitant or anxious about using health services. And particularly fearful about going into hospital during the pandemic.

2.4.1 Appointments

Existing barriers to accessing health services were exacerbated during the pandemic. For example, the move to digital and phone appointments disadvantaged some people with communication needs, including language barriers, and others who are digitally excluded. This meant some people did not always access a GP when they needed to, and some found it more difficult to take in information from a telephone conversation. When accessing face-to-face health services, mask-wearing created a barrier to communicating with staff. There was a lack of a co-ordinated response or strategy to address digital exclusion. Although some charities provided support with this many disabled Black, Asian and minority ethnic people fell through the gaps.

Systematic reviews highlighted evidence that Black, Asian and minority ethnic people may be disadvantaged by the move to digital healthcare.[12] [13]

2.4.2 Vaccine

Some disabled Black, Asian and minority ethnic people were disadvantaged in accessing the COVID-19 vaccine. Barriers included:

- the accessibility of vaccine sites for people with mobility issues or visual impairments
- language barriers
- delays and complications inviting people who were, or were working with, at-risk groups.

Given the increased risks to COVID-19 in some ethnic groups, the government did not do enough to encourage and support people from those groups to get vaccinated. Vaccine information campaigns often relied on celebrities and religious leaders, which was insufficient to reach all communities and address mistrust and misinformation. The government should have worked more closely with locally respected leaders who command a higher degree of confidence in their communities.

2.4.3 Shielding and the Clinically Extremely Vulnerable List

There was variation in experiences of getting on the clinically extremely vulnerable (CEV) list and receiving support through the shielding programme, ranging from having a good and helpful experience, to not receiving any support even after being asked to shield.

Some were confused about whether they should be on the list. For example, receiving contradictory advice from different GPs. Others were left off the list despite having conditions that put them at a higher risk.

There were few accessible versions of letters sent telling people about shielding, for example in other languages or in easy read. This led to anxiety and confusion among people who did not understand what the letter meant.

Furthermore, the food provided through the programme maintained a 'one size fits all' approach, and culturally appropriate food was not given as a choice.

2.4.4 Lack of Reasonable Adjustments

Reasonable adjustments were not made to accommodate needs, including accessible information, seating and face-to-face appointments. This is disability discrimination. It mostly related to blanket COVID-19 policies such as mask-wearing, not allowing carers to accompany people, and the move to digital healthcare. For example, some staff refused to remove their masks for people with hearing impairments or to provide a BSL interpreter. Some people noted that this was also an example of differential treatment as they witnessed these adjustments being made for others.

Health Services and Pandemic Support – Recommendations

We recommend that the government takes steps to make health provision more digitally accessible. This includes:

- ☑ Procuring suitably qualified DPO training providers to design and deliver a national digital literacy training program for disabled Black, Asian and minority ethnic communities.
- ☑ User-testing the NHS app and all other digital health systems, to ensure that disabled Black, Asian and minority ethnic people are able to access accurate and reliable information.
- ☑ Providing funding for Black, Asian and minority ethnic DPOs to purchase computers and tablets for use by members.

> **I developed a skin condition and they wanted to talk to me via a video consultation. I don't even know how to use the smart phone let alone make a video call. Even now they want you to make an appointment with the doctor online. I felt that was/is so unfair to people like me who can't speak English and are digitally excluded.**
>
> Community-led conversation

2.5 Social Care

During the COVID-19 pandemic public conversations about social care tended to equate it with care homes only, and often care homes for older people. This missed a great deal of other social care for other groups, and for support offered to people in their own homes or in other ways outside of a care home environment.

Disabled Black, Asian and minority ethnic people were severely affected by changes to their social care and support during the pandemic. For example, two thirds of those who responded to our easy read survey said that their care and support had changed during the pandemic. Alongside this, wider support services, such as community centres and information centres, were shut down with no alternatives provided or suggested.

Challenges were exacerbated by a narrow policy approach to social care throughout the pandemic. This focused on large institutional settings, especially care homes for older people, and overlooked community-based support. For example, disabled people who employed their own personal assistants (PA) had little to no support throughout the pandemic, and faced difficulties accessing PPE and a lack of guidance about what to do if they or their PA became infected.[14] This contrasted with significant amount of guidance made available to care homes.

2.5.1 Delays and Reductions

There were delays and difficulties accessing new or changed support, as well as reductions in the care and support people received pre-pandemic. Mostly this was the result of social services reducing hours of funded support or staffing shortages impacting the quality and consistency of care. This included carers cancelling at short notice or stopping work entirely due to safety concerns for either themselves or their families.

These delays and difficulties resulted in long-term impacts on physical and mental health and a greater reliance on families taking on additional caring responsibilities.

2.5.2 Reliance on Families

Loss or reduction of social care increased reliance on family support. Family carers spoke of the lack of choice they had in taking on this role, and the impact it had on their mental health. We heard how assumptions were made that family members could take on additional caring responsibilities, even when they were already carers for other family members or had long-term conditions themselves. Racial discrimination, in the form of stereotypical assumptions, could be a factor in the experience of these families.

2.5.3 Additional Challenges

Disabled Black, Asian and minority ethnic people and their families faced additional challenges, including:

- digital exclusion and language barriers when using online processes for requesting social care support
- reduced provision of culturally-appropriate care, which was already limited pre-pandemic.

Similarly, it was noted that support to protect Black, Asian and minority ethnic social care staff came too late. Examples of delayed support included guidance, enhanced risk assessments and appropriate PPE, despite the COVID-19 Black, Asian, and Minority Ethnic Advisory Group advocating for such measures to be rolled out.

There was anger at the government's introduction of the Care Act Easements, stressing that there should be a greater focus on the health and well-being of those at risk, not the removal of requirements to meet their basic care needs.

A Department of Health and Social Care (DHSC) equality impact assessment (EIA) of the Coronavirus Act acknowledges that reduced or withdrawn care and support due to Care Act Easements may have been felt more by groups including disabled people and some ethnic backgrounds. However, no mitigating action was discussed, as the report states "negative consequences will be counterbalanced by the positive impacts", with those most in urgent need will receive care without delay.[15]

Social Care – Recommendations

We recommend that the government improves access to and the quality of social care. This includes:

- ☑ Ensuring adequate social care sector funding is available to meet the current £7bn funding gap in adult social care.[16]
- ☑ The Department of Health and Social Care commission a review of eligibility, access and delivery of social care for disabled Black, Asian and minority ethnic communities, including the availability of specialist services.
- ☑ Promoting the availability of social care and how to access it to disabled Black, Asian and minority ethnic communities, using the range of formats and languages described in recommendation 1 (information and communication).

2.6 Pandemic Policies

Blanket government pandemic policies made life hard for everybody, but some policies had a uniquely challenging impact on disabled Black, Asian and minority ethnic people. The unfairness of these policies was exacerbated by the anger felt when hearing reports of members of the government not following pandemic advice, rules and guidance.

2.6.1 Social Isolation

The variety of cultures and living situations in the country was not considered in the development of lockdown and isolation policies. In particular, the rules and guidance were impractical in cultures where inter-generational living in large extended families spread across multiple households is the norm. This was a particular challenge for extended families supporting disabled members.

> **People tend to not believe me when I say I am autistic due to my skin and gender, and I got a lot of stick for not being able to wear a mask if I did have to go somewhere. I was forced to wear a mask for a rare face-to-face GP nurse appointment even though I said I can't but they wouldn't let me in the building otherwise and I had a panic attack.**
>
> Disabled people's survey

Story

Ramone

April 2023

Ramone (45) is a writer and an academic. He has a life-long disabling health condition and uses a ventilator.

“The pandemic made me feel devalued, simply a number in a list of data that has little meaning. This instilled fear in me. I found it hard to cope initially, and I had many sleepless nights. From March 2020 to May 2021, I did not leave my house for fear of catching COVID-19. Other than essential carers I needed assistance from, I didn’t see anyone other than close family, who I live with. I experienced difficulties getting online shopping, until I was put on the priority lists.

Disabled people were told that they could not have carers during hospital visits, so I was concerned who was going to fight for me if I was admitted to hospital with COVID-19. I had assumptions made about me because of my race and my disability. For example, people assumed I was unintelligent.

I use a ventilator and I know other people who use ventilators were told they wouldn’t be sent filters because these were being prioritised for COVID-19 patients. I was told, in a letter, that I may have my ventilator taken off me. Some disabled people were told that they might not be considered for treatment. I was told that it was unlikely that I would be considered for life support. Imagine how devalued someone must feel being told you might not be saved?

Since the lifting of restrictions, I have been fearful and angry about what the days ahead hold for us. I understand why people want a return to pre-virus days. So do I. But the cost for disabled people is much higher than the rest of society. We know we are at an increased risk from the virus, and we are also aware that care backlogs are going to remain vast even though the pandemic is over.”

> **The government messaging was often complicated and difficult to understand for professionals, so trying to unpick and explain it to families could be very complicated and distressing.**
>
> Social care staff survey

2.6.2 Religious Festivals and Cultural Celebrations

There was a lack of acknowledgment of religious and cultural celebrations other than Christian ones.

- While efforts were made to protect Christmas Day, local lockdowns were imposed the day before Eid.
- The importance of communal religious practice, including paying respects to loved ones who passed away during the pandemic, was overlooked.

2.6.3 Applying Rules

Some government-imposed rules and restrictions were difficult to apply or had a greater impact on people with specific disabilities. For example, loss of routine was particularly disruptive for people with learning disabilities, and social care staff reported difficulties communicating rules such as social distancing and mask-wearing to this group.

A Personal Social Services Adult Social Care Survey 2021–22 showed a higher percentage of Black, Asian and minority ethnic social care users receive practical help from someone within their household.[17] The complex and frequently changing definitions of households, bubbles and who individuals could mix with were a particular challenge to disabled people who draw on social care.

Pandemic Policies – Recommendations

We recommend that the government takes steps to ensure that health policy in future pandemics or other health and public health emergencies is fair and equitable. This includes:

- ☑ Ensuring that rules and guidelines are implemented appropriately and equally across all religious and cultural holidays.
- ☑ Consulting with people directly affected by policies and seeking advice on the best approaches to implementation.
- ☑ Ensuring that data collection methods that inform emergency response policies successfully retrieve relevant data from disabled Black, Asian and minority ethnic communities.

> **Regarding intersectionality… I don't know if people are horrible to me because I'm Black or disabled. Hard to say why.**
>
> **Commission-led conversation**

3

Conclusion

The COVID-19 pandemic highlighted the intersecting impact of ableism and racism on disabled Black, Asian and minority ethnic people.

Responses to our survey evidenced the multiple layers of discrimination experienced by disabled Black, Asian and minority ethnic people, as half (49%) reported experiencing discrimination due to both their ethnicity and their disability. This impact is still being felt.

Pandemic restrictions have now lifted. Even so, many are still experiencing the fear and anxiety which was, in part, amplified by government and media messaging around disproportionate deaths. Fear from disabled Black, Asian and minority ethnic groups was heightened by the acknowledgement of existing health inequalities from the government with no actionable outcomes to prevent COVID-19 deaths.

Many people continue their isolation to protect themselves, entrenching the long-term impacts on their physical and mental health.

Moreover, the effects of losing social care support and access to health care during the pandemic are still felt, as in some cases those services have not returned to pre-pandemic levels. For example, people are still facing barriers accessing face-to-face GP appointments.

Reduced access to care, support and treatment has led to irreversible deteriorations in existing conditions, as well as the development of new conditions, such as diabetes and depression.

The COVID-19 pandemic has laid bare the stark inequalities in health and social care that have long affected marginalised communities. It is no longer enough to protect the status quo. We must confront the heart-wrenching reality of lost loved ones and missed moments. We must amplify the voices of those who have been marginalised and excluded, and work towards health and social care systems that are truly just and equitable for all.

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Endnotes

1 When the Commission started work we used the term disablism, not ableism. Disablism is discrimination against disabled people. People, organisations and policies can be disablist. As work progressed Commissioners decided to move to abelism, as it is increasingly used in contemporary discourse and fits with the social model of disability.

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Asian MS

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Disability Cornwall

Disability Direct

Disability Policy Centre

Disabled People's Voice

Disability Rights UK

Equality and Human Rights Commission

Healthwatch

Hopewell Manchester

Include Me TOO

MacIntyre

NHS Race & Health Observatory

Patients Association

Runneymede Trust

Shaping Our Lives

Sibs

Skills for Care

Start Change

Think Local Act Personal

West of England Centre for Inclusive Living

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Acronyms

BSL – British Sign Language

CEV – clinically extremely vulnerable

DHSC – Department of Health and Social Care

DPO – disabled people's organisation

EIA – Equality Impact Assessment

PA – personal assistants

PHE – Public Health England

PPE – personal protective equipment

UNCRPD – United Nations Convention on the Rights of Persons with Disabilities

VCSE – voluntary, community and social enterprise

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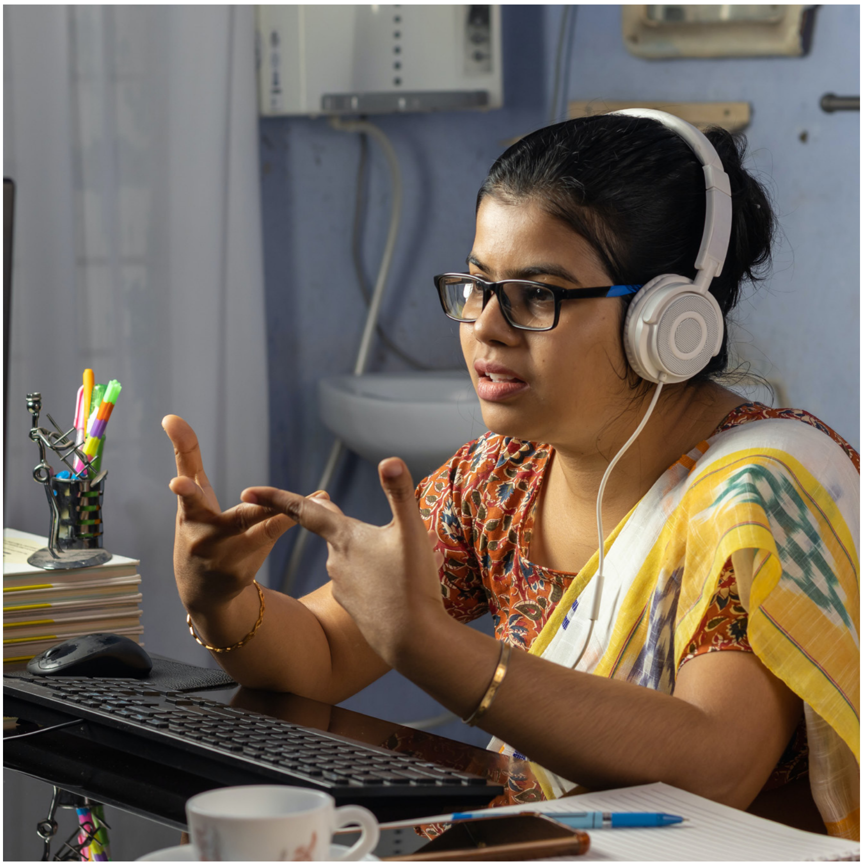

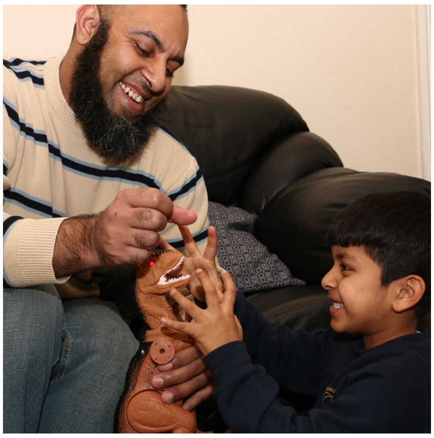

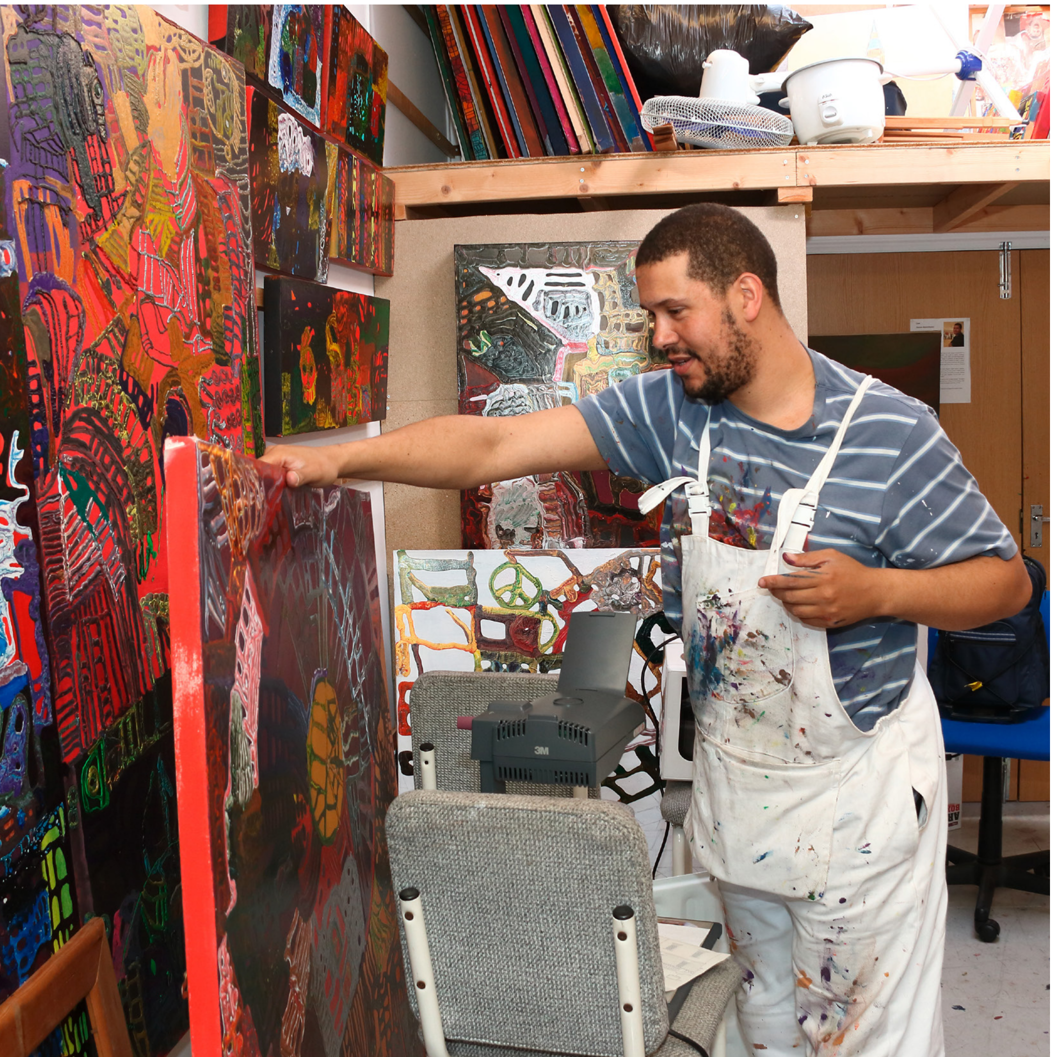

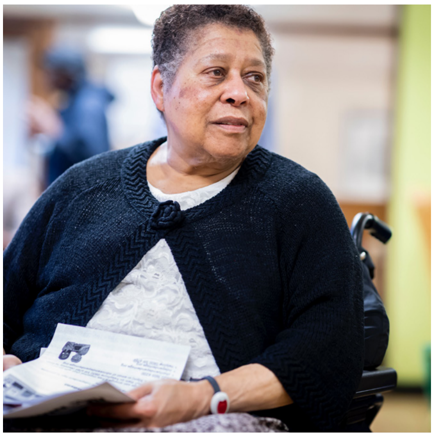

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