



DISABLED CHILDREN'S PARTNERSHIP (DCP)

Unseen and Unheard

The impact of the Covid-19 pandemic on disabled children and their families from black and Asian ethnic minority backgrounds

Noreen Arif¹, Saira Asif¹ and Cath Lunt²

¹ Parent Consultant

² DCP Research and Evaluation Manager

July 2022

Introduction

The Disabled Children's Partnership (DCP) in collaboration with Pears Foundation established the Pears Learning Hub to research the impact of the Covid-19 pandemic on disabled children and their families. As part of this work, we set up a survey panel of parents and undertook a series of surveys^{1,2,3,4} between January and June 2021. The results provided an understanding of disabled children's and their families' experiences in real time. To date, 898 parents have taken part in the series of surveys.

The surveys revealed that, during the pandemic, parents with disabled children consistently experienced significantly lower levels of mental wellbeing, and higher levels of social isolation, anxiety and stress, compared with the general population. And families reported a lack of support from education, health and social care services.

The pandemic has both severely exacerbated the challenges that all families with disabled children were already facing and brought ethnic inequalities into sharp focus. The surveys found a strong association between ethnicity and poor outcomes for disabled children and parents from black and Asian ethnic minority groups: Disabled children from ethnic minority groups were more likely to be isolated than their white peers, and parents from ethnic groups were more likely to have high rates of anxiety, stress and isolation, and poor mental wellbeing than white parents.

To explore these differences further, we:

- Conducted a literature review to understand if wider evidence exists on the experiences of disabled children and their families from ethnic minority groups during the pandemic.
- Organised, two focus groups of parents of disabled children from ethnic minority groups about their experiences during the pandemic.

Key Findings

Despite the pandemic highlighting the structural inequalities that already existed for disabled people from black and Asian minority ethnic groups, the number of research studies specifically investigating the impact on disabled children and their families from ethnic minority groups is severely limited. They are also overlooked in the wider research agenda. From the few available studies, the detrimental impact of Covid-19 on disabled children and their families from ethnic minority groups can be grouped into four themes:

- 1) The additional risk of Covid-19 infection
- 2) Inequality in health protection measures
- 3) Impact of lockdown and restrictions
- 4) Access to services and support

The two focus groups confirmed the heightened and cumulative impact of the pandemic on disabled children and their families, from ethnic minority backgrounds. The reported higher risk to Covid-19 to most ethnic groups left families fearful, isolated during the pandemic, stigmatised, subject to increased racial abuse, and unable to access the support they needed.

The only thing they just kept saying was you don't meet the criteria. There's nothing we could do. You don't meet the criteria and it's constantly. Now you've got to be

under the floor, literally for them to support you.....because of my name, definitely..... there was no support from them at all when I really needed them.

Although parents acknowledged the valuable practical and emotional support they received from charities, the vacuum of support, combined with heightened fear of risk of racial discrimination and abuse, resulted in developmental regression for disabled children and severe mental health problems and isolation for their parents.

In summary during the pandemic:

- parents of disabled children from black and Asian ethnic minority groups were more likely to experience declining mental health and increasing levels of anxiety and isolation than their white peers
- parents of disabled children from black and Asian minority groups attributed increased anxiety, isolation and racial abuse to the increased reporting of and messaging around the higher risk of Covid-19 to most ethnic minority groups
- a lack of support alongside the increased risk of Covid-19 has had a long-term impact on families with disabled children from black and Asian ethnic minority groups

Recommendations

We have four clear recommendations on the findings of this research project

1. The Government must ensure that its response during future national emergencies includes designated, targeted support for families of disabled children that recognises the differential impact on families from ethnic minority backgrounds and is tailored to their needs. The Government should co-produce with local communities, and embed the lessons learned from charities approach during the Covid-19 pandemic.
2. The forthcoming Covid-19 Inquiry must acknowledge the experiences of families with disabled children from black and Asian ethnic minority groups. It is critical that it examines the role that ethnicity and ethnic inequalities played in their experiences, and understands the intersectionality between disability and ethnicity from the perspective of disabled children and their families.
3. Research funding bodies should ensure that future research includes the experiences of disabled children and their families from black and Asian ethnic minority groups and focuses on the intersectionality of disability and ethnicity in order to plug gaps in current knowledge. This research should explore:
 - the relevance, quality and level of information, advice and support available to different ethnic minority groups
 - how different groups access that support
 - the impact of experiences of discrimination, prejudice and abuse on children and families.
4. The Department for Education, Department for Health and Social Care and NHS England should review how they collect data to ensure that it can be analysed by ethnic group to support better research in the area. This includes data on access to services, assessments and waiting times, outcome data and qualitative data on patient/user experience.

Ethnic Inequalities Pre-Covid-19 Pandemic

Ethnicity-based health inequalities clearly existed before the recent Covid-19 pandemic. We know for example, that people from some ethnic groups are more likely to experience long-term health problems - for example, Bangladeshi, Black Caribbean, Pakistani people are estimated to live 6-9 fewer disability free years than white people⁵. And there was a higher mortality rate among ethnic minority groups during the 2009 pandemic influenza A(H1N1)⁶.

The same applies to disability: an increasing number of children and young people from ethnic minority groups are identified as having special needs and more profound disabilities than their white peers, but they struggle to access services. For example, a higher proportion of children from South Asian populations have been diagnosed with learning disabilities, but this is not reflected in service usage data⁷. There is also evidence that black children with special education needs are significantly less likely than white children with special educational needs to receive special education services⁸.

Inequality in access to services for children with disabilities is not confined to the UK. In the US, a study using the records of 2576 autistic children, aged between six and 18 years found racial bias in the provision of medication use⁹: children from ethnic minority groups were less likely to have access to medication to support behavioural and hyperactivity needs than their white peers. In social care, there is also evidence internationally that racial bias contributes to social care practitioners' perception that children from black and Asian ethnic minority groups are more at risk than white children, and children from these groups are therefore subject to safeguarding / protection services¹⁰.

The links between poverty and disability and poverty and black and Asian ethnicity are also well reported. Before the Covid-19 pandemic, around a third of people with disabilities (40% if the household included a disabled child) were in poverty compared with a fifth of the non-disabled population¹¹. And before the pandemic, in England 60% of Bangladeshi children, 54% of Pakistani children and 47% of black children were living in poverty¹². Children and their families from ethnic minority groups therefore experience multiple disadvantage.

At the onset of the Covid-19 pandemic in England, the threat to children was considered low. The narrative was dominated by the term '*underlying health conditions*' with older people deemed to be more at risk. This obscured the needs of those disabled people with communication and sensory needs, and those unable to adhere to social distancing measures. Disabled children from ethnic minority groups were therefore overlooked because of their age, disability and ethnicity as the pandemic progressed.

Part 1: Literature Review

Methodology

We searched online open access journals during April and May 2020 (see Figure 1 for key search terms) in order to understand the impact of the pandemic specifically on disabled children, young people and their families from ethnic minority groups. Key words for disabilities were based on the categories used in the DCP parent panel survey. However, due to the paucity of articles available, we undertook additional searches for specific disabilities such as cerebral palsy, down's syndrome, muscular dystrophy and sickle cell.

Figure 1: Key search terms

Disabled or disability or child(ren) with disability

Or ADHD, Autism Spectrum Disorder, complex needs, genetic condition, hearing impaired, learning disability, life limiting condition, life-threatening condition, physical disability, rare condition, speech and language and communication disorder, social emotional and mental health, visual impairment.

AND

Covid-19 or pandemic or coronavirus or lockdown

AND

Ethnic(ity) or BAME, or Black or Asian or Minority Ethnic or race/racial

Articles focused specifically on disabled children, young people and their families from ethnic minority groups were sparse. However, because we know from wider research that inequalities were exacerbated by Covid-19, we have drawn on relevant, findings from studies focused on one protected characteristic and drawn inferences. For example, findings about financial impact of the pandemic on people from ethnic minority groups give us some idea about the impact on adults in the families of disabled children from ethnic minority groups. Such studies may not focus specifically on parent carers but demonstrate the inequalities common for families from ethnic minority groups during the pandemic.

Figure 2

Cumulative Impact of COVID-19 on families with disabled children from ethnic minorities

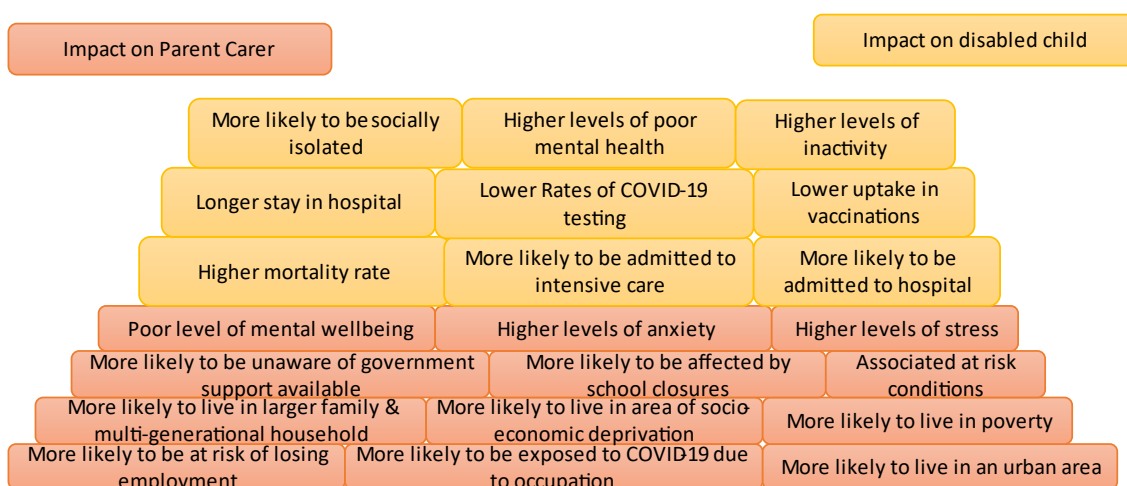


Figure 2, illustrates the cumulative impact on the family of a disabled child in further detail. The impact of the pandemic on families with disabled children are reported below across

four themes: Additional risk from Covid-19 infection; Inequality in health protection; impact of lockdown and restrictions and access to services and support.

Although studies generally refer to ethnicity not disability, the impact of the pandemic on those from black and Asian minority groups, gives an insight into the experiences of children within households, which would include those with disabilities.

Additional risk to Covid-19 infection

During the early part of the first wave, it became apparent that a person's ethnicity may be a risk factor for serious Covid-19 infection and mortality. For example, 21% of NHS staff were from ethnic minority backgrounds however 64% of NHS staff who died were ethnic minority groups¹³. It was reported that people from ethnic minority backgrounds were more likely to have the underlying conditions that put them at greater risk of Covid-19 infection and death¹⁴.

However, studies investigating the association of co-existing conditions within ethnic minorities and Covid-19 risk, reported that co-existing conditions could not fully explain the inequalities in infection and mortality. Social determinants of health and such as socio-economic status, employment, housing and access to health services¹⁵ were important factors.

Children in general were overlooked in terms of risk when considering serious illness from Covid-19 infection. However, although children may not be as at risk of serious illness from Covid-19 as older people, disabled children may also have co-existing conditions that make them more at risk of serious illness if infected¹⁶. A study reviewing the characteristics of child deaths from Covid-19 for those aged 0-17 in England, reported a higher rate of Covid positive deaths for children from ethnic minority groups than those from white populations¹⁷.

A study examining the hospital records of 2.6 million children in England, reported ethnicity specific disparities in Covid-19 hospital outcomes. Asian children were more likely to be hospitalised and more likely to be admitted to intensive care than white children. And black children and children with a mixed ethnic background were more likely to have longer hospital admissions¹⁸. Another study examining children's hospital admissions, confirmed that children with black ethnicity were significantly more likely to be admitted to critical care¹⁹.

As Covid-19 infection spread, the Government initiated an extensive number of clinical trials. However, despite increased risk of Covid-19 infection among ethnic minority populations, a systematic review of 1,518 Covid-19 related studies revealed that just six studies reported collecting data on ethnicity²⁰. There was some limited evidence of children infected with Covid-19, experiencing the onset of multi-inflammatory conditions similar to Kawasaki Disease, 80% of whom from ethnic minority backgrounds. An Italian study investigated this observation further but found that data was not collected about ethnicity.

Inequality in health protection measures

In England, the initial public health response to the pandemic was to reduce social contacts in an attempt to control the spread of the virus. This was later followed by the introduction of Covid-19 testing programme. During the first winter of the pandemic, older people were prioritised in the vaccine rollout; disabled young adults and children and parent carers were further down the list of priority groups. Many disabled young adults weren't included on the priority list due to the absence of a specific diagnosis listed under the banner of clinically extremely vulnerable or clinically vulnerable.

In England the Government introduced the ‘Stay at home, Save lives message, intended to reduce social contacts at the height of the first wave. There were reports that families from ethnic minority groups, who didn’t speak English as a first language and refugees and asylum seekers, had believed that the Government message was to stay at home despite a lack of food and medication²¹, putting children within those families at risk.

It was reported that racial disparities also existed in the testing rates of children: rates of Covid-19 tests usage were greater for white children than children from ethnic minority groups²². There was also a disparity in vaccination rates: a scoping review of the international literature reported that parents from ethnic minority groups were generally more cautious about Covid-19 vaccines for their children than for other groups²².

Impact of lockdown and restrictions

Disabled adults from ethnic minority backgrounds were more likely to say that the pandemic affected their health or impairment than white disabled adults (90% compared to 78%). They were also more likely to be concerned about the impact of the pandemic on their rights²³. In terms of school closures, it was reported that the impact of closures was more likely to be more severe for children from ethnic minority backgrounds. And employment risks for adults in the family, were greater for families from ethnic minority backgrounds¹⁴.

The DCP conducted four surveys, between January and June 2021 to understand the experiences of families with disabled children as restrictions eased. Parents were asked to indicate the number of social that their disabled children had during this period of time. The survey results revealed a strong association between ethnicity and social isolation: disabled children from black and Asian minority ethnic minority groups, were more likely to be socially isolated than their white disabled peers.

We used the research tool, the Lubben Social Network Scale²⁴ to assess levels of isolation for all members of the family. This tool allows you to measure the number of social contacts made by each individual. Low scores indicate higher levels of isolation and the tool also confirms categories of isolated and not isolated, used with family members.

Over the course of the four surveys, the isolation score for just 26% of white disabled children and 24% of disabled children from ethnic minority groups improved. Looking at the categories of isolated and not isolated, the experience of none of the disabled children from ethnic minority backgrounds improved to the extent of feeling “not isolated”, even as restrictions eased.

We observed similar patterns with parents’ levels of isolation: 68% of parents from ethnic minority groups reported the same or a worsening level of isolation over the survey period, compared with 53% of white parents.

We used The Edinburgh-Warwick Mental Wellbeing Scale²⁵ to understand the levels of wellbeing and the General Anxiety Disorder Scale²⁶ to understand the level of anxiety parents experienced. Analysis revealed that an association between ethnicity and level of mental wellbeing. 53% of parents from black and Asian ethnic minority groups experienced decreasing levels of mental wellbeing compared with 18% of white parents. There was also ethnicity-related difference with parents from ethnic minority groups more likely than white parents to experience worsening anxiety over time (38% compared to 31%).

A research study by the NHS mental health provider Kooth²⁷, reported a greater increase in calls for support from young people from ethnic minority backgrounds than white young people (26.6% compared to 18.1%). And significantly more children and young people from ethnic minority background experienced suicidal thoughts, self-harm and anxiety than those

from white backgrounds. Unsurprisingly, it was also reported that lockdown measures had had a detrimental impact on those already suffering with mental health issues. For example, refugees or asylum seekers living with mental health issues or PTSD due to past issues²¹.

In terms of physical health, children's inactivity has increased since the pandemic began and children from black and Asian ethnic minority groups are more likely to be less active than white children. 40.1% of black children and 41% of Asian children are inactive since the pandemic began compared with 35.3% pre-pandemic and 29.2% respectively pre-pandemic²³.

Access to services and support

We know that prior to the Covid-19 pandemic, families from ethnic minority groups weren't offered the same level of service and treatment as white families leading to worse health outcomes for these groups. Research shows that during the pandemic, families that did not speak English as their first language both struggled to follow government advice and access online and digital services, as well as specific services like 119 and 111²¹. Families with disabled children from ethnic minority groups therefore experienced barriers not just to Covid-19 specific treatments and advice but general health monitoring and advice.

During the pandemic there were 215,000 undocumented children in the UK due to their parent's immigration status, meaning these families had no recourse to public funds²¹. A small London based project reported that 20% of families in this situation had a disabled child (with a diagnosis)²⁸. We estimate that there are approximately 43,000 disabled children in the UK with no recourse to public funds.

The project, reported that 90% of all families receiving support and advice from them were from ethnic minority groups. Despite there being a wide financial package of Government support during the pandemic, the Government maintained the No Recourse from Public Funds policy during the pandemic, with just one amendment: undocumented children could receive free school meals. The project also reported that families with a disabled adult or child suffered additional discrimination as they were unable to work and therefore at risk of destitution.

In terms of financial impact, people from ethnic minority groups were more likely to have suffered a loss of income and less likely to have heard about the government financial measures introduced to protect against the economic impact of lockdown²⁹. A survey in 2020, by the charity Family Fund found that families from ethnic minority backgrounds non-white backgrounds were more likely to report a decrease in income than white counterparts (60% compared to 47%)³⁰.

Part 2: Parent Carer Focus Groups

In May 2022 we conducted two parent carer focus groups with 15 parent carers (11 mothers and four fathers) of disabled children from ethnic minority backgrounds to discuss their experiences during the pandemic. We shared the findings of the literature review, with each group as a prompt for this discussion. Here we present the findings from these focus groups.

Methodology

Charity and DCP member, Contact recruited parent carers via email. The project team comprised a white DCP member of staff and two parent consultants from ethnic minority backgrounds. The team developed the questions for the focus groups, facilitated the groups

and identified and analysed the dominant emerging themes. Key findings were agreed by consensus.

There were four key themes.

- Covid-19 and racial discrimination
- Lack of support for families with disabled children;
- Impact of lack of support and racial discrimination
- Future national emergency or crisis

1. Covid-19 and Racial Discrimination

Participants highlighted racism experienced throughout the various stages of the pandemic. The examples they provided that covered the emergence of Covid-19, infection and transmission of the virus. As Covid-19 was first reported in Wuhan China, participants reported racism initially towards Chinese people from other ethnic minority groups. Participants felt that gaps in information and poor communication from authorities meant that racial discrimination became overt towards particular groups. They also felt that reporting and Government announcements scapegoated and stigmatised people from ethnic minority groups.

“Chinese families I know got extra stigma because they were blamed for Covid, that they had got it [were infected with Covid-19] and although it was nothing to do with these families, well the language and then isolation from within other communities”.

“There were all these rumours everywhere there were so much misinformation, everybody was just, you know, everyone grabs at something. Nobody really had concrete information, so people used that opportunity to project how they really feel towards some certain type of people”.

The stigmatisation of ethnic minority groups in the narrative around Covid-19 compounded the fear in parent carers. Participants felt that this should be acknowledged by the Government.

“Because it was said that people of African descent and Africans mostly would be dropping down, like in large, vast amounts. And I think because there wasn't a lot of information about it, then it centred a lot on what we know about viruses like Ebola and what we see is black people”.

“They [the Government] should put a public apology for the distress it's caused, like the sweeping statements that they've made about ethnic minorities and how that's impacted on the lives of, you know, people who are ethnic minorities”.

Despite reports that people from ethnic minority groups were at greater risk of serious illness and death from Covid-19, participants felt this wasn't acknowledged clearly by authorities and that no subsequent advice or action was provided.

“So when in the first place because all the news, like the news outlets are reporting that people of black, Asian and minority backgrounds are more likely to be infected and die from Covid”.

“I think the major difficulty at the beginning was the one not acknowledging that there was a difference in this and people were making out that it was a myth. And they were saying that was due to poverty rather than ethnicity”.

“It should be that they were honest about whether ethnic minorities were more vulnerable to Covid”.

Participants expressed frustration at the lack of acknowledgement of black and asian ethnicity as risk factor in practical terms – for example, in access, vaccinations for disabled young people, and limiting working parents’ exposure to Covid-19 at work. This was particularly the case for key workers who were unable to work at home.

“My daughter is mixed race she was getting a lift to the day centre, but she was the last person to get inoculated along with 18 year olds, which would have been six months down the line and we were going back to say she's much greater risk because she is mixed race and black and because she has autism and they were saying because she wasn't classed as having a learning disability and just autism we couldn't get it done. And as much as you were telling people, race has got something to do with it, they would ignore it. That fact that happened at all points, and it took us four to five months to get her the first injection”.

“And I think by that point [September, 2020] I was quite furious that, you know, the Government had clearly announced and said that BAME people affected, but there was nothing put in place to protect my husband and his colleagues who had medical conditions who were from the BAME background”.

Participants described barriers to accessing support for their families on the basis of their ethnicity before the pandemic (see next section). As a consequence of such ongoing experiences, mistrust of authorities and organisations was evident during the vaccination programme.

“And then a lot in the, I would say in the black community because I'm black, there's a lot of mistrust for the vaccine and for it because it's like: when do you ever give me anything good? The things that I need that I desperately need that I literally beg you for. That it's obvious that I need for my survival, for my children's survival. You refuse? You outright refuse to give it to me. And here's the thing you're giving to me with very little explanation of what this is gonna do to me. What's gonna be the long term impact on me and my children. But here, just take it, because it's gonna save lives”.

Participants felt the Government’s communication strategy and their approach to restrictions and the roll-out of the testing and vaccination programmes wasn’t productive.

“If you have English as an additional language and you're not very clear and there's no one there to reach out to tell you what the guidelines are, then again, you're not gonna use the services that are available”.

They felt community-based approaches were more effective for families from ethnic minority groups. This included targeting families without English as a first language and ensuring messaging was clear. Families also highlighted the effective support provided by local disability charities.

“They opened up our Covid testing centre and they were basically working enormous 24 hours a day and it was very, very good for the Muslim community. The fact that in the mosque they were saying come and get vaccinated here - it became more acceptable because of that”.

"I feel like the they kind of pushed it really heavily on minorities like this is what you need because you're minority and I don't think a lot of explanation around things we're given. It was kind of like a lot of blanket statements".

"And I think one thing it wasn't clear when it said when they said vulnerable, you know, is it in care? Does it mean that, you know, your parents have disabilities and special needs? What does vulnerable mean? And so there was, like, schools were letting different types of children to come you know, it was just really confusing".

"And other disability groups were very, very good giving out things. What foods and parcels, but not within the government organisations".

2. Lack of support for families with disabled children

Families with disabled children reported feeling abandoned during the pandemic. Lack of support meant that additional pressures were placed on families at a time of increased stress.

"We're totally alone. And you have to just roll your sleeves up and just carry on with everything that you do".

"Support was not there. I have to shield my daughter but I was having to run into supermarkets and I didn't feel comfortable. I didn't want to do it because it took a good month before I was finally identified as being a parent who needs to shield so she needs to stay at home. And I finally got a supermarket slot but it took a month".

"It's the personal responsibility on our families and sometimes families like ours can't really take that extra burden and I hope that's acknowledged and I hope that is".

It was evident that a number of services, such as therapies, mental health and primary care, did not identify or meet families' needs during the pandemic. Parents of disabled children stressed the importance of their children being seen by clinicians face to face to avoid misunderstandings, especially if a clinician is unfamiliar with the disabled child.

"I think at the beginning it was harder to access healthcare and especially therapy, Speech therapy was really hard because for some assessments and therapies, well it can't be done over zoom or virtually, and it really needs to be carried out in a space where there's direct contact and direct interaction and just getting that was really hectic".

"And I struggled with my mental health. And I remember telling the doctor. I felt so tired and she said to me well, you may need to sleep".

"And for too long the GPs are still doing phone appointments. We are struggling to get face to face appointments even now when people are practically not even wearing masks anymore".

"I feel like the interaction, the interaction should be more. Back and forth. Like you should be able to you know, interact with these healthcare people".

Parents also described needs not understood by educational services, especially for younger children who had limited or no time in education before the pandemic started.

"I'm like, how - how - how does he start school in September? He's been out of nursery. He hasn't had a plan put in place no-one has spoken to me. He's not even

been diagnosed with anything. How are you sending him to school? And they were basically strong arming me and I had to be really firm. Said I am not sending him because if I was to send him, he would not cope. He has never been in an environment where there's 30 kids anywhere".

Racial discrimination was raised as a barrier to accessing support for disabled children during usual times. Parents from ethnic minority groups felt that services were less inclined to believe the diagnosis of their children.

"And I'd rang social care for some support, and the only thing they just kept saying was you don't meet the criteria. There's nothing we could do. You don't meet the criteria and it's constantly. Now you've got to be under floor, literally for them to support you.....because of my name, definitely..... there was no support from them at all when I really needed them. So I have no confidence in the system".

"With being black and the kind of issues that ...In my community, for instance, that don't believe that you, you can suffer from things like oh autism and stuff. And even when you show them the diagnosis and stuff. And this is the diagnosis but they're suspicious that they still don't have that".

3. Impact of the lack of support and racial discrimination during Covid

The absence of support, and additional pressures, such as risk of infection had a wide-ranging, multi-layered and cumulative impact on both disabled children and their parents from ethnic minority groups. Families described their children's development as not just stalling but regressing, and the detrimental impact on parents' mental health was a common discussion point.

"So I feel like they failed our kids in so many ways socially, medically, educationally, them being out of school".

Regression

"We closed their world out and shut it down and then it was like, OK. This proceeds as usual and it's like the damage that was done to everybody, but the damage that was done to these children, I don't even know how to start rebuilding. I mean now he's in school and I think he's settled, but I still to this day cannot leave the house without him having a mental breakdown".

"He'd had years of speech therapy from the age of two, and at the time when he had started school at four, he had a few words. And so when speech therapy was taken away, he lost all of his words. And the pandemic I would say traumatised him".

"That [no catch up for speech therapy] doesn't really help him one single bit, and I've reached the point where I feel he needs to move schools and I need to move somewhere else that can cater to his needs because he hasn't made any progress. He's regressed essentially".

Mental health

"I was so scared of doing the wrong thing because, you know, in the news it was very much about as an individual you have to do the right thing, you know, don't go near people, don't do this, don't do that. And it really like weighed down on me so much that anxiety and stress, so I was actually able to get some, like, free counselling. That was an offer at the time because I couldn't rationalise how scared I'd become".

“You know, my background is Bangladeshi. I was just hearing so many stories about people passing away or getting very ill, you have that sort of scaring you all the time. Like, what if I've got it? What if I catch it? What if I don't know I've got it? What if it's really bad if I get it? Those are the fears that are kind of hard to carry the whole time”.

Isolation

“Because they were telling us, weren't they you're more likely to get it, if you're from a minority background but no support was put in place with that, nothing was done to help you. I think it was just. Yeah. You're more likely to get it, so make sure you just lock yourselves away even more than you already can”.

Going into the pandemic, this was a child who didn't require settling in at nursery. He went on the first day and he was able to just go through. He was so happy. He would be able to stay with family members. All that stuff. I can't leave him. The only place I could leave him right now is at school. And that is like, it's devastating for me because it makes my world really small because I can't do anything unless I'm doing it with him.

4. Future national emergency or crisis

Parents reported that strategies to communicate with and support families with disabled children from ethnic minority backgrounds should be localised, tailored and sensitive to ethnicity, culture and disability needs. The vacuum in information and support experienced by families could be addressed by establishing designated contact points for families with disabled children.

“So I think if there was someone that parents and carers could reach out to, then even though it must have been a very difficult period for everyone and that would have been very helpful as well”.

Parents reported feeling supported by local disability charities and other parents of disabled children, with online support from other families during the pandemic highlighted.

“When things went online, like the charity work, went from having peer support groups and the community to online. And in actual fact, a lot of parents joined who wouldn't have been able to before because of childcare and things like that”.

Parents expressed frustration that support withdrawn in response to the pandemic has not resumed, leaving disabled children and, young people without the vital support that they need.

“I think we've got to go back to face to face services. Two years on, we've still got all our social workers, all our doctors working from home there. There's no reason services stopped for services like autism. There's now a three or four year backlog. And nobody's looking at it. So the only way we can improve services is by having workers back in the offices and providing us face-to-face services”.

It was felt that the Government should acknowledge the role parents and families of disabled children played throughout the pandemic in the absence of statutory support. The upcoming Covid-19 Inquiry in the UK provides an opportunity to do this.

“And then people like ourselves, we took a conscious effort to protect ourselves and our neighbours and our friends and family by making the right choice. So, it should be acknowledged, shouldn't it? We need this all acknowledged”.

Conclusion

This research project has highlighted and confirmed the serious and multiple disadvantage experienced by disabled children and their families from ethnic minority groups during the Covid-19 pandemic.

Families from ethnic minority groups are more likely than white families to have been at higher risk of exposure to Covid-19 and experienced serious illness or death of a family member from Covid-19. This is due to factors like the parents' occupation type, larger families or multi-generational households, and increased likelihood of living in a lower socio-economic, urban or deprived area and more likely to live in poverty³¹. They are also more likely to have lost their income during the pandemic. Therefore, disabled children from black and Asian minority groups may be at risk from the emotional and mental impact due to greater risk from adverse effects from the pandemic by way of their ethnicity.

The parent carers in the focus groups confirmed the heightened impact of the pandemic on disabled children and their families, from ethnic minority backgrounds. The reported higher risk of infection and serious illness was not addressed by authorities leaving families fearful and isolated. This narrative also led to their stigmatisation and increased racial discrimination and abuse.

Disabled children and their families from ethnic minority groups experienced isolation and much poorer mental health than their white counterparts but were less able to access support they needed. However, parents acknowledged the valuable practical and emotional support they received from charities.

The detrimental impact of pandemics on families from ethnic minority backgrounds or on disabled people is not a new concept; similar '*at risk*' groups have emerged in previous pandemics. Despite this, research on the impact of Covid-19 specifically on disabled children and their families from ethnic minority backgrounds is largely absent. It should be noted that such gaps in evidence can further compound inequalities, leaving high risk or marginalised groups excluded further from society³².

As well as severe mental health problems and isolation for parents, the vacuum of support for families, combined with increased fear of Covid infection and led to regression in their children's development.

Lessons learned from charities' approach to supporting families during the pandemic should be embedded in future strategies for managing such emergencies to ensure that the national response includes designated, targeted support for families of disabled children. And the delivery of any response should be managed by local communities and be tailored to the needs of disabled children, young people and their families from ethnic minority groups.

References

1. Disabled Children's Partnership (2021) The Longest Lockdown
<https://disabledchildrenpartnership.org.uk/wp-content/uploads/2021/03/The-Longest-Lockdown.pdf>
2. Disabled Children's Partnership (2021) The Loneliest Lockdown
<https://disabledchildrenpartnership.org.uk/wp-content/uploads/2021/03/The-Loneliest-Lockdown.pdf>
3. Disabled Children's Partnership (2021) No End in Sight
<https://disabledchildrenpartnership.org.uk/no-end-in-sight/>
4. Disabled Children's Partnership (2021) Left Behind
<https://disabledchildrenpartnership.org.uk/left-behind/>
6. Zhao, Harris, Ellis et al (2015) Ethnicity, deprivation and mortality due to 2009 pandemic influenza A(H1N1) in England during the 2009/10 pandemic and the first post pandemic season. *Epidemiology Infection* 2015, Dec; 143 (16) 3375 -83 <https://pubmed.ncbi.nlm.nih.gov/25850904/>
7. Foundation for People with Learning Disabilities UK (2022) Ethnicity and Equality.
<https://www.learningdisabilities.org.uk/learning-disabilities/our-work/rights-equality/ethnicity-and-equality>
8. Morgan, Farkas, Cook et al (2016) Are Black children disproportionately overrepresented in Special education? A Best evidence synthesis. *Exceptional Children*, 2017;83(2): 181-198 doi:10.1177/0014402916664042
9. Quebbles I, Solomon O, Smith K et al (2020) Racial and Ethnic Differences in Behavioural Problems and Medication Use Among Children with Autism Spectrum Disorders: *American Journal on Intellectual & Developmental Disabilities* Sep 2020, Vol125, Issue 5, p369-388
10. Keddell, E & Hyslop I (2019) *Child and Family Social Work*, November 2019, Vol 24, Issue 4, p409-420. 12p 4 charts, 4 graphs
11. Disability Rights (2020) Nearly half of everyone in poverty is either a disabled person or lives with a disabled person. <https://www.disabilityrightsuk.org/news/2020/february/nearly-half-everyone-poverty-either-disabled-person-or-lives-disabled-person>
12. Tucker J (Ed) (2020) 2020 Vision ending child poverty for good. London. CPAG <https://cpag.org.uk/policy-and-campaigns/understanding-and-responding-ethnic-minority-child-poverty>
- 13 Chaudhry FB, Raza S, Raja KZ (2020) Covid-19 and BAME health care staff: Wrong place at the wrong time. *Journal of Global Health*, 2020 Dec; 10(2) 020358 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7563090/>
14. Nazroo J, Murray K, Taylor H et al (2020) Rapid Evidence Review: Inequalities in relation to Covid-19 and their effects on London. University of Sussex, The Ubele Initiative and University of Manchester https://www.thebritishacademy.ac.uk/documents/3233/COVID-decade-rapid-evidence-review-inequalities-London-Nazroo-Sussex-Ubele-Man_sOP3HyK.pdf
15. Bamba C, Riordan R, Ford J et al (2020) The Covid-19 pandemic and health inequalities. *Journal of Epidemiology Community Health* Nov 2020; 74(11): 964-968.
16. UNESCO (2020) Another Covid-19 Front line: Parents of children with disabilities. <https://en.unesco.org/news/another-covid-19-front-line-parents-children-disabilities>
17. Odd D, Stoianova S, Williams T et al (2022) Child Mortality in England during the Covid-19 pandemic. *Archives of Disease in Childhood* 2022; 107:14-20
18. Saatci D, Ranger TA, Garriga C et al (2021) Association Between Race and Covid-19 Outcomes Among 2.6 million children in England - *JAMA Pediatrics* 2021; 175 (9): 928-938
19. Swann OV, Holden KA, Turtle L (2020) Clinical characteristics of children and young people admitted to hospital with covid-19 in United Kingdom: prospective multicentre observational cohort study *British Medical Journal* 2020;370:3249

20. Bodicoat DH, Routen AC, Willis A et al (2021) Promoting inclusion in clinical trials – a rapid review of the literature and recommendations for action. *Trials*. 22, 880
<https://trialsjournal.biomedcentral.com/articles/10.1186/s13063-021-05849-7>
21. Children in Need (2020) Understanding the Impact of Covid-19 on children and young people. Early Pandemic Period April - May 2020.
22. Pan F, Zhao H, Nicholas S et al (2021) Parent's decisions to vaccinate children against Covid-19: A Scoping Review *Vaccines* Volume 9 Issue 12 <https://www.mdpi.com/2076-393X/9/12/1476/html>
23. Activity Alliance (2020) Active Lives: CYP Data <https://activelives.sportengland.org/>
24. Lubben J, Blozik E, Gillmann G, Iliffe S, von Renteln Kruse W, Beck JC, Stuck AE. Performance of an abbreviated version of the Lubben Social Network Scale among three European community-dwelling older adult populations. *Gerontologist*. 2006 Aug;46(4):503-13.
25. Warwick-Edinburgh Mental Wellbeing Scale Tool.
(<https://warwick.ac.uk/fac/sci/med/research/platform/wemwbs/about/wemwbsvsswemwbs>)
26. General Anxiety Disorder (GAD-7) - NHS Health Scotland, University of Warwick and University of Edinburgh, 2008
27. Kooth. How Covid-19 is Affecting the Mental Health of Young People in the BAME Community. 2020;:9175
28. Woolley A (2019) Access Denied: The cost of the 'no recourse to public funds policy'
<https://static1.squarespace.com/static/590060b0893fc01f949b1c8a/t/5d0bb6100099f70001faad9c/1561048725178/Access+Denied>
29. Hacque Z, Becares L and Treloar N (2020) Over Exposed and Under Protected. *Runnymede*
30. Family Fund (2020) The Impact of Coronavirus UK Survey – BAME data unpublished.
31. Marmot Review (2020) Build Back Fairer: The Covid-19 Marmot Review. The Pandemic, Socioeconomic and Health Inequalities. Health Foundation and Institute of Health Equity.
<https://www.instituteofhealthequity.org/resources-reports/build-back-fairer-the-covid-19-marmot-review/build-back-fairer-the-covid-19-marmot-review-full-report.pdf>
32. Reed NS, Meeks LM, Swenor BK (2020) Disability and Covid-19: who counts depends on who is counted
[https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667\(20\)30161-4/fulltext](https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667(20)30161-4/fulltext)