

The Unheard Voices of Derby's Diverse Carers



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A heartfelt thank you is extended to all the carers who contributed to this report.

Your voices have been heard, and your experiences have been acknowledged.

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Introduction

This report emphasises some of the views of Black¹ and South Asian carers located in Derby City.

The project was commissioned by Community Action Derby (CA) as part of its joint work with the Derbyshire Carers Association to improve the support for Black and South Asian carers.

This report will also recommend supporting Derby's Diverse Carers based on their lived experiences.

1 www.cjr.org/analysis/capital-b-black-styleguide.php

Language and Definitions

Firstly, it is necessary to explain how language and terminology is used in this report.

Language and terminology that is misused, or that contains assumptions, can perpetuate racial inequality. It is vital therefore, to understand the meaning behind any terms used to address people, reflect, and be open to changing language, to always be respectful.

Race and ethnicity are nearly always used interchangeably and often incorrectly, to describe oppressed, marginalised communities. It is essential to understand that they have developed in distinctive ways and have different meanings to different people.

Race is classified as grouping people into categories based on physical appearance, such as Black or white. Ethnicity is a broader term often associated with culture, religion, and language.²

It is widely recognised and reported that race is a social construct. This means that the categorisation and understanding of race is not based on biological or genetic factors, but rather on social, cultural, and historical influences. The concept of race varies across societies and is shaped by social perceptions, attitudes, and power dynamics, rather than being inherently fixed or scientifically defined.³

In this report, where the word Black is used, it refers to people from Africa and the Caribbean. When the term South Asian is used, it refers particularly to people from India, Pakistan, and Bangladesh. These communities are not homogeneous and differ in language, culture, religion, and social norms.

Defining a person's identity is multifaceted, and writing about a community identity is even more complex. The acronym Black, Asian, Minority Ethnic 'BAME' is reductive and therefore now widely deemed to be offensive and to perpetuate racist ideologies.

Community Action Derby agreed that the acronym 'BAME' would be removed and replaced by Derby's Diverse Carers, as this name would represent the communities positively, aiming to recognise and celebrate differences. However, some of the referenced literature still chooses to use 'BAME'.

2 www.diffen.com/difference/Ethnicity_vs_Race

3 www.vox.com/2014/10/10/6943461/race-social-construct-origins-census

Carer Definition

The NHS provides a general definition of a carer, which is:

“A carer is anyone, including children and adults, who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid.”⁴

The Care Act 2014 defines a carer as:

“an adult who provides or intends to provide care for another adult”.

This would not usually include someone who is paid or employed to carry out that role, or someone who is a volunteer.

The Children and Families Act 2014 defines a young carer as:

“a person under 18 who provides or intends to provide care for another person”

(Again excluding anyone who is doing this as part of paid or voluntary work)

and a parent carer as:

“a person aged 18 or over who provides or intends to provide care for a disabled child for whom the person has parental responsibility.”

Due to the general terminology used, the statistics may be influenced by individuals who may not identify as carers.

The literature on supporting Black and South Asian carers pays particular attention to how Asian carers do not recognise themselves as such, due to the word not translating into certain languages.⁵

⁴ www.england.nhs.uk/commissioning/comm-carers/carers

⁵ Race Equality Foundation (2018) Supporting Black and minority ethnic carers. <https://raceequalityfoundation.org.uk/health-and-care/black-and-minority-ethnic-carers-2/>

The Limitations

This project has certain limitations as it encountered challenges in capturing the perspectives of Black carers within Derby City, not because they were 'hard to reach' but due to them 'not being seen or heard'.

Due to limited access to secondary resources, it is important to acknowledge that there may be gaps in the literature review. The availability and scope of relevant literature may have been constrained, leading to potential limitations in the breadth and depth of the review. These gaps in the literature highlight the need for further research and exploration to fill the knowledge void and obtain a more comprehensive understanding of the subject matter.

It is recognised that the sample size used in this study was relatively small and may not be representative of the entire population of Black and South Asian carers. Due to the limited sample size, caution should be exercised in generalising the findings to the broader population. The experiences and perspectives of Black and South Asian carers may vary significantly within and across different communities. Therefore, future studies with larger and more diverse samples are needed to obtain a more comprehensive understanding of the experiences of Black and South Asian carers.

Community-based participatory research (CBPR) was employed as the research approach to gather information, which involved collecting data and information from various groups. These groups consisted of participants and individuals who had never met before. The CBPR methodology emphasises active collaboration between researchers and community members, ensuring their meaningful involvement throughout the research process. By engaging diverse groups and incorporating their perspectives, CBPR aims to generate more inclusive and community-driven knowledge.

The limitations of this project are recognised, but the views of the unheard and invisible carers highlight the desperate need for a joined-up approach to support Derby's Diverse Carers.



Summary of Findings

The study sample was limited to the lived experience of 83 diverse carers in Derby.

These communities are not homogeneous, and while conclusions are made, they may not apply to all communities.⁶

The services for the carers are fragmented, and most do not know where to seek support.

This report identifies three primary themes in terms of how carers from diverse backgrounds feel:

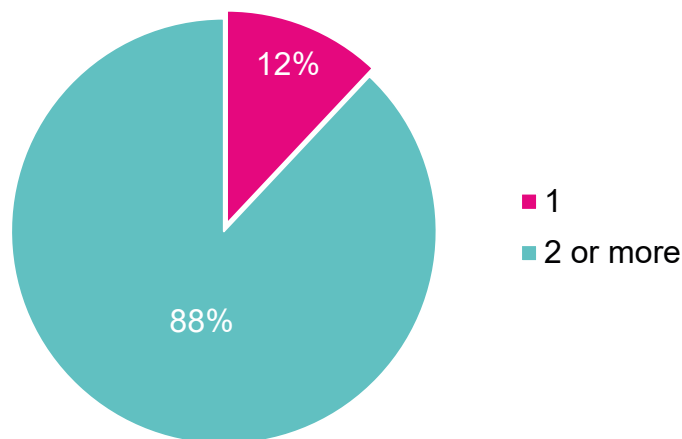
1. Isolated
2. Invisible
3. Excluded

⁶ Greenwood, N. (2018) Better health briefing 48: supporting black and minority ethnic carers. <https://raceequalityfoundation.org.uk/wp-content/uploads/2022/10/REF-Better-Health-484.pdf>



What Do We Know About Derby's Diverse Carers?

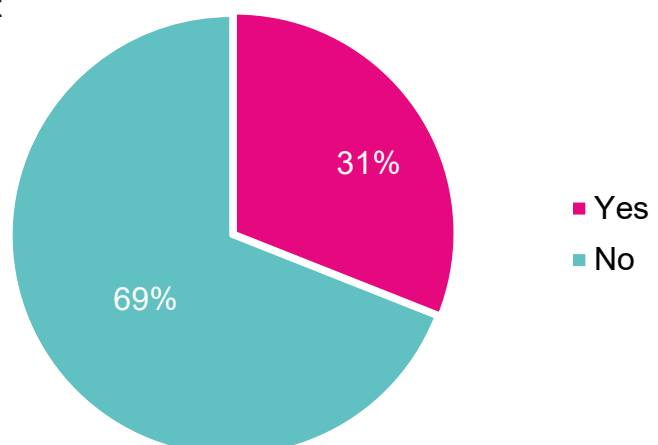
How many people do you care for?



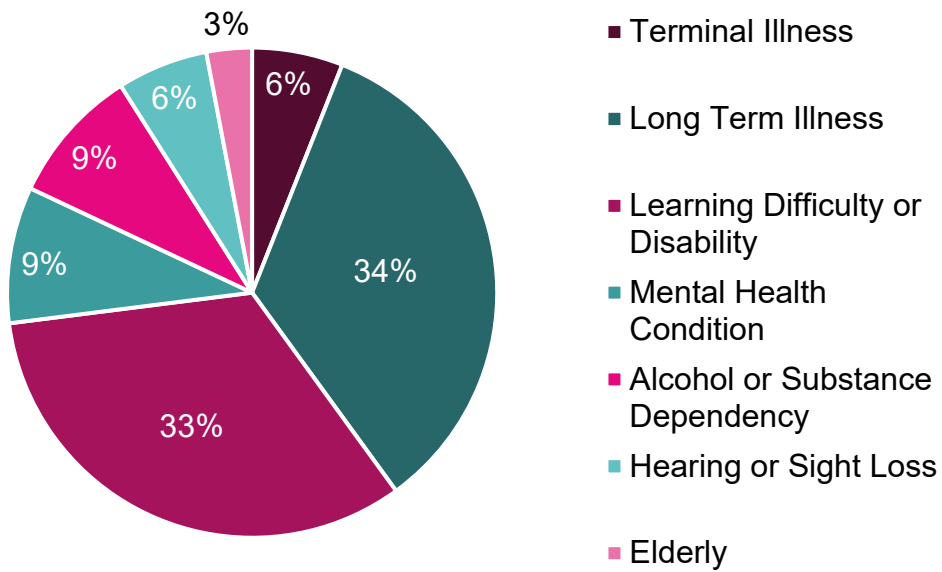
- Among carers, 50% reported dedicating between 41 to 50 hours per week to caregiving responsibilities, whereas only 17% spent 1 to 20 hours per week on such duties.

Do you enjoy being a carer?

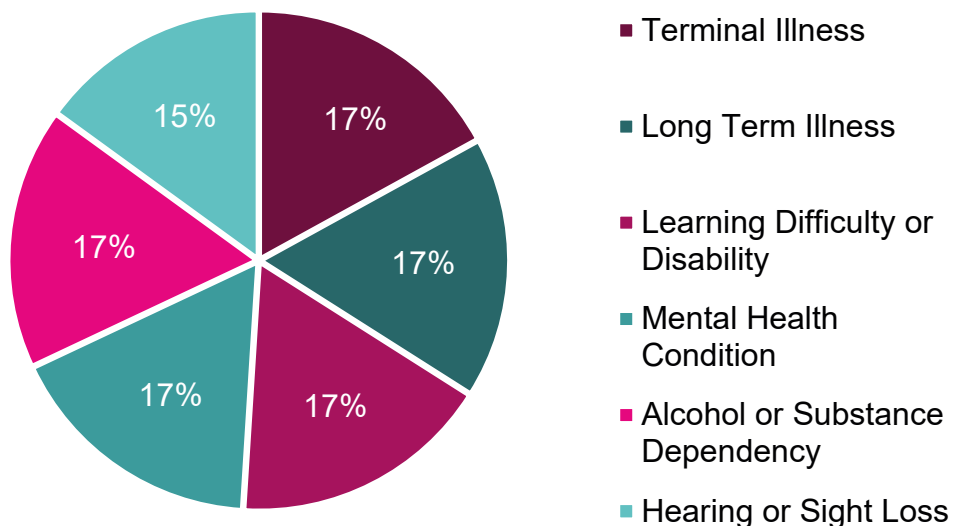
- Of the participants, 68% stated that caregiving had an impact on their health, while 32% reported that it had no impact on their health.
- Some participants expressed experiencing health conditions such as stroke and cancer, which adversely affected their well-being, including joint pain, feelings of loneliness, and even heart attacks.
- Conversely, some carers mentioned making efforts to maintain a positive outlook despite the challenges they faced.



What is the primary condition for the (1st) person you care for?



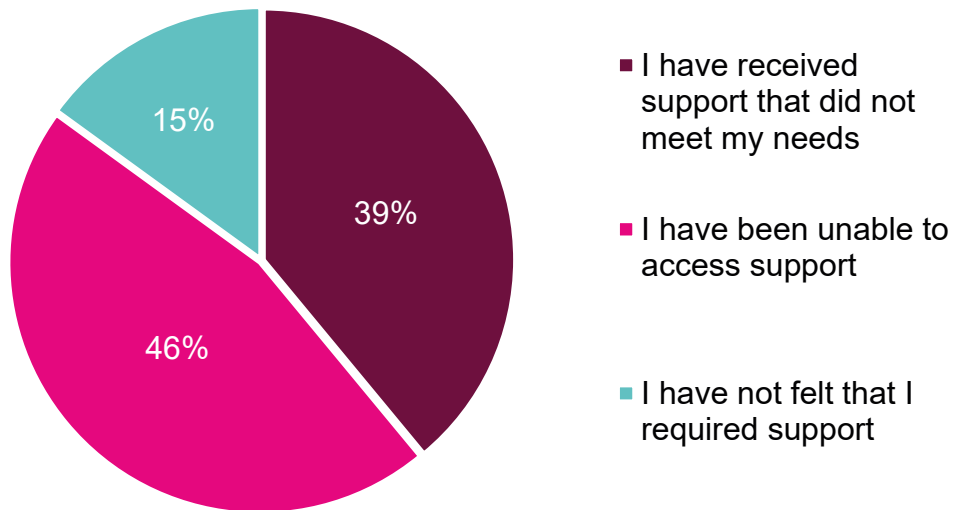
What is the primary condition for the (2nd) person you care for?



- In the case of the first person, the primary condition for requiring care was a long-term illness. In contrast, the caregiving responsibilities were evenly distributed across different conditions for the second person.

An overwhelming 85% of the participants disclosed that they had not utilised the carer services available in the city of Derby, whereas 15% reported having accessed these services.

What was your experience of the support you received?



Participant Demographics

- Among the participants, 59% identified as women, while 41% identified as men.
- Within the participant group, 3% fell within the age range of 18-24, and another 3% were aged 25-34, 15% were aged 35-44, 26% were aged 45-54, a significant 47% were aged 55-64, and 8% were aged 65 and over.
- Regarding ethnic identification within the surveyed population; 37% identified as Pakistani, 15% identified as belonging to another Asian background, 4% identified as Bangladeshi, 7% identified as Chinese, 37% identified as Indian, 75% identified as Caribbean, and 25% as African. 83% identified as Asian and white and 17% identified as white and Caribbean.
- 25% live in Normanton, 14% live in Littleover, 6% live in Oakwood, 3% live in Spondon, 6% live in Sinfin, 3% live in Abbey, 3% live in Allestree, 6% live in Alvaston, 6% live in Arboretum, 6% live Blagreaves, 6% live on Boulton, 6% live in Chellaston, 8% live in Derwent and 3% live in Darley.

The Literature

A review of some of the literature emphasises several difficulties faced by Black and South Asian carers, which include health disparities, language barriers and lack of cultural competence. The COVID-19 pandemic has adversely affected Black and Asian carers.⁷

The available evidence suggests that Black and South Asian families “look after their own” (Willis, 2008). What is meant by this statement is that it is incumbent on the carer to support and care for the family member regardless of the need, and sometimes to the detriment of, the carer. The literature on social care inequalities in England highlighted that Black and Asian people aged 65 and over would require more care than the white population.⁸

There have been reports indicating that Black adults tend to provide more support compared to white adults.⁹ However, this trend is not reflected in the data collected from the city of Derby. The data suggests a different pattern or distribution of caregiving support among the diverse population in the City. This disparity highlights the importance of considering specific local contexts and circumstances when analysing caregiving dynamics and patterns within different communities.

In line with the experiences shared by some of Derby’s Diverse Carers, an article from Black Ballad in February 2023 included the viewpoint of Anna, a Black Carer. Anna highlighted that the demands of caregiving can have detrimental effects on a person’s physical health, leading to issues such as weight gain or weight loss, tension headaches, hypertension, and other physical ailments. This echoes the sentiments expressed by Derby’s Diverse Carers, further emphasising the impact of caregiving on physical well-being.¹⁰

According to Fenney, Thorstensen-Woll and Botery, 2023¹¹, “Unpaid carers contribute the equivalent of 4 million paid care workers to the social care system. Without them, the system would collapse.”

7 The experiences of Black, Asian and minority ethnic carers during and beyond the COVID-19 pandemic, 2022. <https://www.carersuk.org/reports/the-experiences-of-black-asian-and-minority-ethnic-carers-during-and-beyond-the-covid-19-pandemic/>

8 Brimblecombe, N. and Burchardt, T. (2021). Social care inequalities in England: evidence briefing. https://sticerd.lse.ac.uk/dps/case/spdo/SPDO_Research_Brief03.pdf

9 Fingerman, Karen & Machia, Laura & Dotterer, Aryn & Birditt, Kira & Zarit, Steven, (2011). Support to Aging Parents and Grown Children in Black and White Families. *The Gerontologist*. 51. 441-52. 10.1093/geront/gnq114

10 <https://blackballad.co.uk/views-voices/black-women-on-navigating-the-struggles-that-come-with-caring-for-aging-parents>

11 Caring in a complex world. Perspectives from unpaid carers and the organisations that support them. The Kings Fund, 2023

However, the acknowledgement and assistance provided to Derby's Diverse Carers remains largely unrecognised in the city of Derby.

Carers UK published a report¹² in January 2023 which acknowledged that “carers from Black, Asian and minority ethnic background were:

- more anxious about their current financial situation
- more likely to be impacted by the closure of local services
- more likely to state that the services in their area did not meet their needs.”

The report made some significant recommendations, such as:

- Using interpreters at events or training
- Improving the accessibility of online content
- Avoiding terms such as ‘hard to reach’
- Holding information and advice sessions, or peer support groups, in trusted local spaces
- Avoiding stereotypes and treating carers as unique individuals
- Considering whether information and advice is culturally sensitive
- Speaking to organisations who have expertise in working with diverse groups.

It is noteworthy that the recommendations in the report have not been implemented within the city of Derby. Despite the recognition of these recommendations, there remains a gap between acknowledging the need for action and actually implementing the necessary changes. This indicates a potential lack of progress in addressing the concerns and needs of Derby's Diverse Carers.

When one thinks about the ontology of a carer and caring, we can see that being a carer plays a role in the broader sectors of society and is also a set of lived experiences. However, some of the experiences of the Derby's Diverse Carers are not pleasant:

“I feel constantly lonely and isolated.”

“We save the government so much money by not using Social Care services. Yet we are just forgotten about and left to be on our own, isolated from all.”

Caring sometimes becomes a set of tasks (such as personal care and cooking) to be completed rather than doing something for someone you love (Juttla & Moreland, 2009)¹³

12 Supporting Black, Asian and minority ethnic carers, a good practice briefing, Carers UK, Publication Code: UK4111_0123

13 The personalisation of dementia services and existential realities: understanding Sikh carers caring for an older person with dementia in Wolverhampton, 2009

The National Picture

Every year the charity Carers UK surveys unpaid carers, in order to report on carers' views in the United Kingdom. A total of 13,415 carers and former carers responded to the survey in 2022. 3% described themselves as Black, Asian or from a mixed/multiple ethnic background. According to the data, the report estimates that there are 10.6 million carers in the UK.¹⁴

“England’s half a million Black Asian Minority Ethnic carers save the state a staggering £7.9 billion a year.”

Half a million voices: Improving support for BAME Carers, Carers UK, 2010

“Carers’ support was valued at a £530 million per day during the pandemic, or £193 billion a full year – exceeding the value of the NHS.”

Unseen and undervalued, Carers UK, 2020¹⁵

The UK Government’s Family Resources Survey 2020 to 2021 reports, “Two in every 50 people are in receipt of care. Three in every 50 people are providing informal care to someone else, with almost half caring for someone living within their household.”¹⁶

The Charity Family Fund reported in October 2022 that “families with disabled children, struggling to recover from the pandemic, must now grapple with a cost-of-living crisis which places the vast majority in acute financial jeopardy. As families with disabled children have higher costs and are able to work less, their financial challenges have become largely insurmountable. Many are now at acute risk of experiencing poverty.”¹⁷

14 State of Caring 2022 - A snapshot of unpaid care in the UK

15 https://www.carersuk.org/images/News_and_campaigns/Unseen_and_undervalued.pdf

16 <https://www.gov.uk/government/statistics/family-resources-survey-financial-year-2020-to-2021/family-resources-survey-financial-year-2020-to-2021#:~:text=Three%20in%20every%2050%20people,someone%20living%20within%20their%20household>

17 The Cost of Caring – October 2022, Family Fund

The Local Picture - Derby City

A breakdown of the ethnicity of Derby Carers based on the latest Carer Survey in 2021¹⁸ is shown below:

Ethnicity	2021 / 2022		2018 / 2019	
	Num.	%	Num.	%
Any other ethnic group	4	0.7	7	1.2
Asian or Asian British (Indian, Pakistani, Bangladeshi, any other Asian background)	72	12.0	60	10.2
Black or Black British (Caribbean, African, or any other Black background)	22	3.7	28	4.8
Mixed /Multiple	2	0.3	4	0.7
White (British, Irish, any other white background)	433	72.4	468	79.7
Unknown	65	10.9	20	3.4

Most carers in the Carers Survey 2021-22 (72.4%) are from a white background. This is lower than the previous survey (80%).

¹⁸ Data provided by Derby City Council.



How we engaged with Diverse Carers

A community-based approach was adopted to try and gain complete and accurate information from the community.

How the data was collected

Mixed methods were used to collect the data:

- An online survey was shared with carers in Derby from April 2023 to May 2023
- A telephone discussion with a carer
- Small group discussions.

Quantitative research asks people for their opinions in a structured way and quantifies the problem by creating numerical data or statistics. Whereas qualitative research is primarily exploratory research. It is used to gain an understanding of underlying reasons, opinions, and motivations. (Punch, 2009)

All the groups were provided with the following questions designed by Community Action Derby, to gather the lived experiences of the carers:

1. What has been your experience with Carers Services in Derby?
2. What can be done better by Carer Services to support people like me?
3. Please tell us about health and care issues carers face within the community and your own family network.
4. Why do you think it is like this?
5. What stops you or your family from getting the help you need?
6. What would you like there to be more of, to support you or your family's health and to support with Caring?
7. What can we do to stop the unfair differences in Carer Services?
8. What do you enjoy about being a carer?

There were 38 people interviewed face to face across four small group sessions with South Asian carers, and one session with six Black carers. One carer's view was gathered via a telephone discussion. The carers spoke passionately about looking after their loved ones and the struggles they experienced as carers in the city of Derby. All interviews were transcribed verbatim.

All participants completed the survey to give their experiences of being a carer in Derby City. A total of 38 carers responded to the survey, which is too small a sample to represent the general population.

All the carers were over the age of 18. There were no responses from young carers.

What did we find out?

1. What has been your experience with Carers Services in Derby?

The carers could not access the support in Derby because it was not accessible, and this left them feeling isolated. As one carer said:

“There is no provision where I can go discuss my needs.”

These views are prominently showcased in research carried out by the Welsh Government.¹⁹

2. What can be done better by Carer Services to support people like me?

The carers reported that their cultural needs to be included, and that:

“We need to be heard and seen.”

3. Please tell us about health and care issues carers face within the community and your own family network

The carers experienced difficulties with making and attending medical appointments. They reported that their mental health had become a problem too. The feeling of being part of the community and receiving adequate support was important to the carers.

“Getting support with depression or thinking about ending my life due to the struggles of being a full-time carer.”

¹⁹ Welsh Government (2022) Evaluation of the social services and wellbeing (Wales) Act 2014: expectations, experiences of Black, Asian and Minority Ethnic service users and carers. <https://www.gov.wales/evaluation-social-services-and-well-being-wales-act-2014-expectations-and-experiences-black-asian>

4. Why do you think it is like this?

Carers expressed disappointment with the Local Authority and NHS not meeting their needs, and that they felt let down. They shared that they had to sacrifice their own health needs because they were carers.

“Nobody has ever asked what we need.”

5. What stops you or your family from getting the help you need?

Carers revealed that the language barrier was an issue in accessing support. They disclosed that as they were full-time carers, they could not investigate services in Derby. They expressed that they felt nobody cared and they were forgotten about.

“Bad experiences of individuals exploiting us.”

6. What would you like there to be more of, to support you or your family’s health and to support with Caring?

The carers want advocacy and culturally appropriate activities. They want the opportunity and time, and funding to form their own groups in their community. They want support so the whole family can live meaningful lives. They want to be able to visit other places outside of Derby.

“Set up self-help groups to improve our mental health and be able to discuss our daily struggles.”

7. What can we do to stop the unfair differences in Carer Services?

The carers want to be heard and seen. They want a venue for diverse carers to attend so they can network and receive support. They want support to assist with mental health issues. They feel disheartened that inequality for diverse carers is still prevalent in Derby.

“Better support needed all round, don’t know why it is like this in Derby.”

8. What do you enjoy about being a carer?

The carers reported that they wanted to protect their family members and wanted to help them to feel socially connected.

“Supporting them with their healthcare needs and giving them company so they do not feel lonely or isolated.”



Conclusion

This report identifies three primary themes that capture the feelings of carers from diverse backgrounds:

1. **Isolation:** Carers expressed a sense of being socially isolated, potentially lacking support and connection with others in similar caregiving situations.
2. **Invisibility:** Carers felt their contributions and challenges were often overlooked or not adequately recognised by the services in the city of Derby.
3. **Exclusion:** Carers experienced a sense of exclusion from mainstream services and decision-making processes, leading to a perceived lack of tailored support for their specific needs.

The UK is home to millions of unpaid carers, and a substantial and presumably increasing portion of these carers are from diverse backgrounds.

Failure to adopt a culturally competent strategic plan with the carers central to decision-making will mean that it will be difficult to eliminate inequalities.

The participants of this survey demonstrate a relatively reflective representation of the numbers recorded in the survey conducted by the city of Derby in 2021.

The lived experiences of Derby's Diverse Carers unequivocally indicate a sense of undervaluation and lack of recognition. 69% of carers reported they did not enjoy being carers, and 85% have never accessed the Carer Services in Derby.

As the number of carers in the UK rises, the number within the Black community in Derby appears to be falling, whilst the number in the South Asian community appears to be rising.

What Needs to Happen Now?

Additional research is necessary to ascertain the perspectives of caregivers from various racial and ethnic backgrounds, to ensure comprehensive coverage of all viewpoints.

Further investigation and research is required to determine the underlying reasons for the apparent declining numbers of carers within the Black community. It is essential to delve deeper into the specific factors that may contribute to this trend. Possible factors that could be explored, include barriers to accessing and utilisation of services, cultural or social dynamics, systemic inequalities, and community-specific challenges. Conducting in-depth studies and engaging with the Black community can help shed light on the underlying causes and inform the development of targeted interventions and support mechanisms.

To advance the debate and improve support for young carers within Derby's Black and South Asian communities, it is crucial to foster a deeper understanding of their unique experiences and challenges. This can be achieved through dedicated research and efforts that specifically focus on exploring the perspectives, needs, and circumstances of young carers from these communities.

It is imperative for the city of Derby to formulate a comprehensive carers strategy that outlines their specific plans for supporting Derby's Diverse Carers.

Facilitating access to digital solutions and technology is essential in providing support to both the carers and the individuals receiving care.

It is crucial to enhance and expand the involvement of Derby's Diverse Carers in the co-production, co-design, and monitoring of services. This can be achieved by actively seeking their input, feedback, and perspectives in decision-making processes, policy development, and service planning. Creating platforms for meaningful engagement, providing training and support, and fostering inclusive and collaborative environments, are key steps to ensure their active participation. By doing so, services can better address the diverse needs and experiences of carers, leading to more effective and responsive support systems.

The time has come to ensure that the voices of Derby's Diverse Carers are not only heard but also seen and acknowledged. It is essential to create platforms and mechanisms that actively listen to and amplify their experiences and challenges.

By providing them with visibility and recognition, the city of Derby can work towards dismantling the barriers they face and implementing meaningful changes that address their concerns. It is through active engagement, inclusion, and genuine empowerment that Derby's Diverse Carers can receive the support and appreciation they rightfully deserve.

About the Author

Marguerite Haye has a diverse background in education and a strong commitment to advocating for marginalised communities.

As a qualified teacher, she possesses the expertise and experience to work with individuals of all age groups and across various educational settings.

Her role as a Specialist Teacher enables her to provide specialised instruction to students with specific needs or interests. She is responsible for overseeing and coordinating support for students with special educational needs and disabilities (SEND), ensuring they receive appropriate accommodations and resources to thrive in their educational journey.

Her experience as an Assistant Head and Head Teacher at a special residential school for autistic children and young people aged 8-19 underscores her dedication to addressing the needs of SEND children.

Marguerite's advocacy for the rights of marginalised communities indicates that she actively works towards breaking down barriers and promoting equality in education and beyond. By championing the rights of these communities, she engages in actions that promote social and racial justice, striving to create a more just and inclusive society.





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