Older people from an African, Caribbean and South Asian heritage - their views on support, information and advice

About Healthwatch Sheffield

We are here to help adults, children and young people influence and improve how services are designed and run. We are completely independent and not part of the NHS or Sheffield City Council.

We collate the feedback you give us so that we can make evidence-based recommendations to the organisations that design, pay for, and run our local services.

Preface

In the course of this work, we have spoken directly to older people who have either identified their heritage as African, Caribbean or South Asian. When we refer to what they told us, we name their heritage directly.

In this report, we also refer to the wider ethnically diverse communities who live in Sheffield. It has not been possible to speak to them all and we appreciate that there are complexities when trying to find common terms that will include everyone.

We would like to name the communities in Sheffield that we refer to when we talk about inequalities in our city, and also to whom we generalise in our recommendations. We hope this provides both clarity and transparency to our approach and promotes inclusivity.

According to the main Census classification, our ethnically diverse communities in Sheffield include (but are not exclusive to) those who define themselves as; Indian, Pakistani, Bangladeshi, Chinese, African – including Somali, and Caribbean. To this list we would also like to include people from the Roma community.

We would appreciate feedback if you have any questions or comments about our approach.

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Summary

This summary outlines the key findings and recommendations from semi structured interviews and a focus group undertaken by Healthwatch Sheffield with 31 older people living in Sheffield from an African, Caribbean and South Asian heritage, over the period of January – March 2023.

The work was commissioned by Age UK Sheffield, after they identified a lack of diversity in the demographic profile of their clients. Whilst the aim of our work was primarily to inform Age UK Sheffield, it was also to provide a wider snapshot of the concerns of this population in the city as a whole. The work has produced two reports, one specifically for Age UK Sheffield, and this one containing a generic set of recommendations.

We were interested in understanding the resources and places that people were currently accessing as well as the barriers they were experiencing. The findings support the development of more inclusive and accessible city-wide services for older people in our ethnically diverse communities living in Sheffield.

Our findings indicate that there are mixed perceptions of health and social care services; many people spoke about the difficulties of finding appropriate services that would understand their needs.

Changing social and family structures mean that people might not be able to rely on their existing support networks in the future. There were concerns about the cultural sensitivity of services and their ability to meet the needs of the communities we spoke to.

People from African, Caribbean, Asian and minoritised ethnic groups face additional barriers to accessing services. These range from the practical (lack of interpreters) to more structural and historical concerns around issues of racism and a lack of trust.

There are a number of principles that guide where people go for advice and information:

- People go to sources that they can trust
- Past experiences define where people will seek help in the future
- The lack of linguistic and culturally sensitive resources places limitations and determines where people can access services.

A service that would work well was **culturally sensitive**, used **appropriate communication** and **promoted independence**.

In addition:

- Older people need **more and better information** about what is available to them
- They want **services to be based in the communities that they know**

We have made a number of general recommendations for service providers.

Recommendations:

1. Services for older people to be planned and resourced to meet the needs of all communities – these need to include people from African, Caribbean, Asian and minoritised ethnic groups in the design and decision making.
2. Organisations should work with diverse communities to ensure that their information resources are designed and disseminated in an inclusive way. There are examples of recent work done in Sheffield that illustrate good practice, such as the Long Covid Community Grants Programme (Healthwatch Sheffield / Voluntary Action Sheffield).
3. Older people from African, Caribbean, Asian and minoritised ethnic groups to be better represented within the services that they access – services should create plans to increase diversity in their workforce, engage in racial literacy training, and ensure the service offer targets the needs of different communities, for example by providing women-only service options.
4. Where community groups are best placed to meet the needs of their local residents, this is where services should be located – funding for African, Caribbean, Asian and minority ethnic community-led organisations needs to be sustainable and secure.
5. The recommendations of the Independent Commission into racism and racial disparities in Sheffield[1] create a strong, action-based framework to address structural racism and disparities in Sheffield – over two years after its publication, there needs to be a clear action plan, with an appropriate budget for its application.
6. Consider funding for voluntary and community (VCS) organisations to enable them to reach those communities living in areas with the higher deprivation and lower life expectancy. Equitable services in the city should support people to live longer, healthier lives.
7. Continuously capture and learn from the experiences of existing clients from African, Caribbean, Asian and minoritised ethnic groups using existing or new feedback channels.

[1] Race Equality Commission (June 2022): An independent commission into racism and racial disparities in Sheffield

Introduction

There are significant challenges facing every community in 2023, from the cost of living crisis to the difficulties in accessing health services, many people are concerned about their ability to manage, for now and for the future.[2]

The data recently released from the 2021 Census shows that over the last 10 years, Sheffield has seen a changing population. We have an increase in the number of residents in the older age groups, most marked in those aged between 50 and 64 (a 2% rise). There has also been a 4.7% increase in the number of people from African, Caribbean, Asian and minoritised ethnic communities, with residents in these groups now accounting for 20.9% of the population.

This same data shows that Sheffield continues to be a city where there are ethnic and social class divisions running along a north – south divide. Whilst there are pockets of poverty affecting all groups throughout the city, there are higher levels of economic deprivation in areas to the north such as Firth Park, Fir Vale and Burngreave. These areas have higher numbers of people from African, Caribbean, Asian and minoritised groups than the more affluent areas in the south of the city such as Dore, Totley and Greenhill. It is however important to acknowledge that some communities (for example the African Caribbean community) are spread further across the city than others; this can create its own challenges when offering culturally appropriate services to a geographically dispersed group.

When thinking about inequality, we should look at a number of measures; the index of deprivation together with life expectancy and most importantly – healthy life expectancy. As an example, the healthy life expectancy of men living in the Firth Park ward is 53 years, compared to men living in Dore (70 years). The gap between the two areas is 17 years. This is slightly higher for women (54 versus 72 years). People in more deprived communities are less likely to live healthily beyond their mid-50s.[3]

The widespread inequalities existing in our city have been well-documented in previous reports that consulted with local residents from African, Caribbean, Asian and minoritised ethnic groups.[4] The most recent and important of these was the independent commission into racism and racial disparities in Sheffield conducted by the Race Equality Commission[5]. This collected over 150 pieces of evidence and spoke to over 165 witnesses at its hearing, concluding that "racism and racial disparities remain significant in the lives of Sheffield's citizens".

In addition, a recent Healthwatch Sheffield report on older people's experiences in care homes[6] identified a lack of representation of residents from African, Caribbean, Asian and minoritised ethnic groups, and the need to better understand their experiences of adult social care.

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[2] Healthwatch Sheffield March 2023: The impact of the cost-of-living crisis on access to healthcare

[3] Local area profiles for Firth Park and Dore areas. Sheffield City Council. May 2023.

[4] Hussein, Mohamed (2007) The right to be heard. Removing inequalities – Consultation event with Black and Ethnic minority elders. Sheffield Fairness Commission (2013) Making Sheffield Fairer

[5] Race Equality Commission (June 2022): An independent commission into racism and racial disparities in Sheffield

[6] Healthwatch Sheffield (2022) What matters to us: Older people's experiences of living in a care home

It is against this backdrop, and in line with a gap that we had identified through previous work, that Age UK Sheffield commissioned Healthwatch Sheffield to report on an identified underrepresentation of older people from our ethnically diverse groups accessing their services. They sought to understand the experiences and the barriers to accessing information, advice and support, and to reflect on the implications for their own service provision.

This report outlines what people have told us through the course of our research and forms the basis of a further report for Age UK Sheffield that focuses specifically on their service provision.

What we did

Altogether we consulted with 31 people from an African Caribbean and South Asian heritage who were over 50 and living in Sheffield.

We were interested in understanding the resources that people were currently accessing as well as the barriers they were experiencing. The findings would support the development of more inclusive and accessible city-wide services for the older African, Caribbean, Asian and minoritised ethnic groups living in Sheffield. This was to inform Age UK Sheffield and also to provide a wider snapshot of the concerns of this population in the city as a whole.

Who did we speak to?

We consulted with two different groups of older people:

- Group 1 consisted of 12 older people from the African Caribbean/West Indian community aged between 62 – 89 who attend a lunch group once a week. Five were male and seven were female. Each person had an individual semi-structured interview with a researcher or trained volunteer. All the interviews were conducted in English.
- Group 2 was a focus group attended by 18 women of South Asian heritage aged between 55-85. The focus group was led by Healthwatch Sheffield in English and translated into Urdu and Punjabi by two project workers.

We held further consultation on our findings with one additional local community leader.

What did we ask people about?

The interviews with people were semi-structured to cover these broad areas:[7]

- What services (if any) they currently access
- The role of informal support
- Barriers to accessing support
- Views and experiences relating to the cultural competency of services
- What 'good' would look like
- Level of awareness of Age UK services

[7] The full interview schedule is in the appendix

Findings

1. There are mixed perceptions of health and social care services – whilst everyone saw their value, not everyone thought they would cater to their needs.

Most of the people we spoke to were not in regular receipt of health or social care services. Where they needed help, they were supported by friends, family and their local community organisations or faith groups. In some instances, they were providing care themselves, or had cared for a family member in the recent past, but were no longer doing so.

In the African Caribbean community, many of the people that we spoke to were retired from an occupation in health and social care, or had children currently working in that sector. As a result, they generally felt confident that they knew either where to go directly, or that through their connections they had the people around them who would help them access the support they may need.

Nonetheless, when talking about using social care, many spoke about the difficulties of finding appropriate services that would understand their needs or those of their relatives. Only one person told us about a positive experience with the support that her father had received, because the care that the team had provided had been culturally appropriate:

"I supported my father through end of life up in Burngreave where the team of carers reflected the local community – they understood my father and I felt that I had nothing to worry about"

Some people in the African Caribbean group mentioned that social care was seen in negative terms by the community; there was a feeling that social care would be intrusive and that they would be monitored.

The perceptions of health and social care services appeared to be more positive amongst the South Asian women. Although they said that they had never used them, they felt that if they had access, the support would be comprehensive and helpful.

2. Changing social and family structures mean that people feel more concerned about their future care.

Some people felt that families and the community were meeting the support needs of their older people, and that they would continue to do so in the future. However there were many others who were concerned that their children might not be available to fully support them if they developed more complex needs.

Amongst these concerns are changing family structures, where young people are moving away for work or have many demands on their time. So, even though they did not think that it was a current issue, there were worries that in the future people may not get the help that they need, or that the support available might not be culturally sensitive. The South Asian women, in particular, were aware of these important changes and for the need for them to be more self-sufficient in their later years.

"We need our own resources to become independent"

3. People from African, Caribbean, Asian and minoritised ethnic groups face additional barriers to accessing services.

When contacting and engaging with health services, older people from African, Caribbean, Asian and minoritised ethnic groups face the same challenges that all older people are currently facing in the UK; people spoke of the inability to get a face-to-face service, the frustration of having to hold on the phone for long periods, the difficulties accessing health care appointments and long waiting lists, as well as being directed to websites and online resources from which they felt digitally excluded.

"Historically and now, there have been difficulties in my community accessing services for many reasons – racism, fear, lack of trust"

In addition, people also spoke of both historical and current difficulties and fears that were grounded in their experience of racism in the face of services. Many mentioned a lack of trust[8]

[8] The issue of trust in health and social care services is complex and perhaps best illustrated by the lower vaccination uptake by people from Black, Asian and minoritised ethnic groups during the Covid-19 pandemic. A recent BMJ article (BMJ 2021; 372:n513) cites institutional racism, historical medical mistreatment of black people and cultural segregation as contributing factors to the creation of this mistrust.

that affects how people from African, Caribbean, Asian and minoritised ethnic groups access health, social care and other support services.

"Before they recorded telephone calls, the receptionists used to be rude"

The South Asian women spoke specifically about their isolation and how this made them hesitant to ask for outside help as they were fearful that it might bring them shame.

"We've stopped talking with the outside, particularly about personal or financial issues"

"We can't share [problems] because we feel judged and so we don't ask for help which makes us feel isolated"

Maintaining honour and self-respect is extremely important amongst this group of women; the lack of cultural appropriateness in some services therefore limits their access.

"There is no female GP at our surgery, so I can't go there"

When discussing barriers to access, language was identified by almost everyone as a key issue. For the South Asian women, this included the difficulties in accessing community interpreters and the translation of information in a way that reflects the community in its language and images. However, almost everyone we spoke to also mentioned that the language barriers are not just linguistic. They are about communicating in a way that enables the older people to fully understand what is being said and gives them the confidence to say what they need to say.

"People who need the help don't understand what to say, they have to explain to a family member who can help with verbalising what the needs are"

One person, for example, said that her generation understands the barriers that exist for their community and know how to be assertive. She perceives a difference between the generations and believes that the older generation are not as confident at asserting their needs and would benefit from advocacy to get the services that they need.

"My generation don't have as many barriers, we can articulate needs a lot more clearly – the elders depend on us more to, they find it difficult to communicate needs using technology"

4. There is a lack of accessible and local information and advice services.

When asked where they went when they needed advice and information, overwhelmingly everybody mentioned going directly to family, friends and faith groups. The African Caribbean community were most likely to then mention direct contact with statutory services such as Sheffield City Council and Social Services, as well as calling the NHS number 111 or using the internet to find what they need.

Other than family and friends, the South Asian women were more likely to rely on their local community group or mention city-wide services for advice and information.

Although people spoke about the use of city-wide services in the voluntary sector, as sources that they trusted in principle. The reality of access to these services were very mixed. One person summarised the general experience:

"There is nothing [locally], I sometimes go to [city-wide service], but there is a long waiting list, no appointments, video calls that people don't know how to use because they have problems using Zoom and forms. There are language barriers and lack of transport. Many are carers and can't leave people at home, there is a 20 minute walk to the tram and the taxi is expensive"

Also mentioned amongst the difficulties in getting through to services were the hoops that people felt they had to jump through:

"I think that there are a lot of hoops to jump through, so you are passed from department to department to get to the information that you require. Then the person you speak to may not understand your needs or what support you require"

"...when you manage to get to it, find that it's not as easy as you thought it'd be"

Even though some of the people had no direct experience of seeking support for themselves, many of them had previously cared for family members and/or were actively volunteering in their local community group. In this context, they spoke about the generational differences in the older population.

Perceptions of city-wide voluntary services

Older people reported negative experiences with larger city-wide organisations, which have had an impact in how others of a similar structure might be perceived. This lead some of the people that we spoke to, to suggest that localised community services would work best for them.

"[Service] was a nightmare to get through to, I tried to get them to help me with daughter's PIP but never managed it, I see [all city-wide services] in a similar vein"

"I think [local organisation] should have more because they represent the community more than what [others] can do for us"

When the people that we spoke to were shown a list of services offered by a city-wide voluntary service, there was a largely positive response and interest in specific aspects of these. Almost everybody wanted to know more about the type of general advice and information offered, particularly in relation to pensions and benefits. Other areas of interest were the befriending and the dementia services, particularly the memory café. Overwhelmingly – and once it had been explained – almost everyone wanted to attend a digital drop-in.

Despite the positive response to the city-wide services available, realistically, most of the people said that they would want to be assured of some additional details before attending any of them. These questions can be summarised as:

- Are they easily accessible by public transport?
- Do they have interpreters?
- Will there be people there from my race and culture?

Principles that guide where people go for advice and information

The older people in both communities identified a number of principles that guided where they would go for advice and information:

- Everybody mentioned going to **sources that they could trust**. This is not just related to professional competence, but to people and organisations that make them feel good about themselves. For these reasons, there is trust in peer groups and connections through family and friends.
- **Past experiences** also define where people will seek help in the future. Within close communities where communication is largely done through word of mouth, this will also determine how and where older people access the services they need.
- The **lack of linguistic and culturally sensitive resources** places limitations on the ability of the South Asian women to (independently) access some services. This also determines where they can go to seek support, advice and information.

A service that would work well

The older people that we spoke to identified some of the key features of a service that they thought would work well for them:

- A service that is **culturally sensitive**. This means that there are people working there who reflect and understand both their culture and experience. People who they feel safe to express themselves to and who would understand their needs, be these religious, dietary or other.

"A service that works well is one that older people need – that has their people there to take care of them"

- People also wanted services that used **appropriate communication**. This means that there is access to community interpreters and translated materials, but it also uses language that is free from jargon, and so is easy to understand (and translate).

"The service would reflect my culture and experience. It would have simplified jargon and wording language. Pictures speak a thousand words"

- For South Asian women in particular, an accessible service would also mean creating options that **promote independence** - where they wouldn't have to rely on their families to have access. This might include good accessibility (locations that have safe and appropriate transport options), services with childcare support and women-only options that feel respectful and safe.

- Almost everyone that we spoke to said that they would like to have services that felt **respectful and safe**. At a basic level this is a service that is friendly and makes them feel comfortable. A good service, however, is one that is proactive and empowering, one that listens, supports and most of all – can be trusted.

The main consideration for people when thinking about their access to the services that they need can be broken down into two factors:

- Older people need **more and better information about what is available to them**

"We are limited in our communication and understanding of how to seek help"

"Now that I am aware of the services, I will use them in the future"

"Older people not getting more information just when they are older"

- Older people want **services that are based in the communities that they know**

"I would prefer a dementia memory café to be based in our community, generally for all services I'd prefer the local community, with people that I know"

"Now that I know, I would access some of these services... if there were people of my race and culture"

"More local services"

Recommendations

1. Services for older people to be planned and resourced to meet the needs of all communities – these need to include people from African, Caribbean, Asian and minoritised ethnic groups in the design and decision making.
2. Organisations should work with diverse communities to ensure that their information resources are designed and disseminated in an inclusive way. There are examples of recent work done in Sheffield that illustrate good practice, such as the Long Covid Community Grants (Healthwatch Sheffield / Voluntary Action Sheffield).
3. Older people from African Caribbean, Asian and minoritised ethnic groups to be better represented within the services that they access – services should create plans to increase diversity in their workforce, engage in racial literacy training, and ensure the service offer targets the needs of different communities, for example by providing women-only service options.
4. Where communities are best placed to meet the needs of their local residents, this is where services should be located – funding for African, Caribbean, Asian and minority ethnic community-led organisations needs to be sustainable and secure.
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6. Consider funding for voluntary and community (VCS) organisations to enable them to reach those communities living in areas with the higher deprivation and lower life expectancy. Equitable services in the city should support people to live longer, healthier lives.
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[9] Race Equality Commission (June 2022): An independent commission into racism and racial disparities in Sheffield

Acknowledgements

Thank you to Age UK Sheffield and all the individuals who shared their views and experiences with us, without you this report would have not been possible.

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Thank you also to Fir Vale Community Hub for providing input and acting as our 'critical friend'.

Appendix

Interview script

Theme	Question	Prompt
What services (if any) they currently access	Are you using any health and social care services at the moment?	What does social care mean to them?
	Who do you speak to when you need information about something important to you?	e.g. benefits
	Where do you go when you have a problem and you don't know how to solve it?	e.g. debt (Identify what type of services they tend to use, whether formal or informal and explore those further)
Informal support	What makes you go to.. (source of informal support)?	
	Why do you think they are better for your needs that anywhere else?	
Barriers to accessing formal support	Do you think your community (here at Community Organisation) experiences particular difficulties when contacting services?	Explore this, by asking further questions, how, why..?

Views and experiences relating to the cultural competency of services	What is your experience of getting support from bigger city-wide services for older people?	Explore this, by asking further questions
What 'good' would look like	What would a service that works well for you, look like?	
	Could you describe it?	
Level of awareness of Age UK services	(Show Age UK logo) Do you know this organisation? Do you know what they do?	
	Have you been to them for anything?	Examples of what they might have been to
	(Give a brief outline of Age UK services) Do you think you would go to them if you needed any of those services?	If yes – what services and why? If not – why not?
Social Care	Have you thought about accessing social care now or in the future? What are your concerns about getting access to care?	
	Do you know how to ask for care? Do you know where to go to for support with care?	
	Do you provide care to another person or receive it from a friend or family member? Do you get the support you need?	

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Healthwatch Sheffield is committed to providing a quality service.

Every three years we perform an in-depth audit to ensure we meet this high standard.