



#SpeakUp : A Review of Home Care – The African Caribbean Perspective

What is #SpeakUp?

#SpeakUp is Healthwatch Sheffield's micro grants programme, offering funding to not-for-profit, voluntary, and community groups. The purpose is to run a project which will reach out to people across Sheffield, and hear what matters to them in relation to health and social care.



By working with groups which are already trusted partners in their communities, we can make sure we're hearing from even more people, including those whose voices aren't often heard by decision makers.

SACMHA Health & Social Care

SACMHA is a registered charity which delivers a specialist service to people in need of assistance with their health and social care needs. We aim to make community-based health and social care more accessible, particularly to those who feel marginalised or who struggle to access mainstream services, delivering a responsive and culturally sensitive service to all our customers, exercising discretion and confidentiality at all times.



SACMHA had its genesis in the African Caribbean community – we still have a specialism with that community, though we now offer services to all of Sheffield's communities.

Healthwatch Sheffield

Healthwatch Sheffield helps adults, children and young people influence and improve how NHS and Social Care services are designed and run. We're completely independent and not part of the NHS or Sheffield City Council. We want to understand your experiences, and help your views to influence decision-makers in the city.

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Foreword

David Bussue – Service Director, SACMHA Health & Social Care

One of SACMHA's key pillars is wherever possible, to collaborate with key partners in the City. In recent years we have forged a positive partnership with Healthwatch Sheffield, so we were particularly gratified to be able to provide a report as part of the Healthwatch Sheffield work on home care.

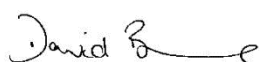
Though SACMHA works across all communities in the City (particularly Communities of Colour), we have the deepest roots in the African Caribbean community. This report seeks to provide the African Caribbean perspective with regard to Home Care.

It's always a risk setting out to articulate the view of a specific community; we are therefore mindful of the limitations of this report. Nonetheless, we firmly believe that it has real authenticity and makes a valuable contribution with regard to the steps those leading Home Care commissioning, provision and delivery in Sheffield can choose to use to improve the service.

We are aware that some of the recommendations of this report are custom and practice within the council and with some providers. We have not edited them as they are the participants' recommendations and it is our view that with some 'tweaking', existing practice could be enhanced and serve as 'quick wins' in light of this work.

I am particularly grateful to the members of the community, home care staff, the researchers and Healthwatch Sheffield for partnering with SACMHA in this endeavour.

For ease we have provided an Executive Summary to this report, however, we strongly urge all into whose hands this report comes to read it all; especially commissioners, senior managers and home care providers.



David Bussue, Service Director, SACMHA Health & Social Care



Executive summary

Why did we do this work?

Healthwatch Sheffield has done previous work on homecare in the city. Together, we wanted to build on this to focus in on the specific experiences of the African Caribbean Community receiving care. We wanted to know:

- What works well for people receiving care
- What doesn't work well for people receiving care
- What does 'good' care look like for people from the African Caribbean Community?

This would help us make recommendations that would set out actions designed to improve the experience of care for people in this community.

What did we do?

We talked to 19 people about their experience of care. We ran 3 sessions in May-June 2021:

- A Users & Carers Forum – a cohort of African Caribbean service users and carers who shared their views and experiences of current home care provision in the city
- A Professionals Forum – a group of African Caribbean social workers, care managers and social care staff who talked about their experiences and challenges in providing support that is authentic and inclusive
- A Consolidation Forum – a final session all together, where we asked 'in a world with unlimited resources, what would a good domiciliary care service look like to you?'

We also followed up with some telephone and video call interviews with those who could not attend the Zoom meetings.

Key findings

What went well

People Receiving Care and Family Carers told us:

- Employing Personal Assistants (PAs) via Direct Payments led to better experiences
- PAs coming from the same cultural background as clients was valuable
- Where people had become familiar with carers and knew who was coming to provide their care, this was a positive experience

Professionals told us:

- First contact assessment and care planning allowed care to be put in place quickly
- Short term intervention and support often worked well (e.g. after hospital discharge)
- Where they were involved (as black professionals) they were able to support people effectively and build relationships

What didn't go well

1. In relation to **care providers** we were told about a range of issues which included:

- Lack of experienced staff
- Staff who were not caring or respectful



- Lack of time allocated to tasks
 - Carers not giving individualized or person focused care
2. In relation to **Personal Assistants and Direct Payments**, issues included:
- The challenge of findings PAs and the need to rely on personal recommendations
 - Complex administration
 - Difficulties sourcing holiday and sickness cover
3. People talked about **poor communication** and the impact it had, for example:
- Agencies not listening to personal preferences relating to care, and not accommodating needs relating to religion
 - Clients and families having to spend much time 'chasing up' agencies
 - Delays to care calls not being communicated
 - Carers talking over the cared for person, not communicating with them well
 - Family members feeling that they couldn't complain in case it made things worse
4. Lack of **Culturally Appropriate Care**:
- Not enough carers from different cultural backgrounds
 - Not enough time is taken to understand the cultural needs of an individual
 - Professionals closing cases when care 'breaks down' instead of exploring why
 - Culturally appropriate care being harder to access in some areas of the city
5. **Finance**:
- Participants feared losing money they had worked for in order to fund their care
 - Costs of care are unclear - people don't know in advance what they will need to pay
 - Professionals told us that sometimes people turn down care because of the cost
6. **Training**
- Not enough (mandatory) training in providing empathic, person-centred care
 - Professionals reported that staff are not trained in working with diverse communities, or how to deliver culturally appropriate care

Our recommendations

A full set of recommendations can be found on page 21. They are shaped by the findings in our report, and the section entitled 'What Would Good Look Like?'. They set out actions related to:

- Raising standards in the care sector
- Recruitment, and increasing the diversity of the workforce
- Delivering client focussed and culturally appropriate care
- Monitoring of care providers, transparency around commissioning
- Support around accessing personalised care such as direct payments
- Developing understanding and support around the costs of care
- Culturally appropriate advocacy

Background

Introduction

In some respects this has been a difficult project - there was a very real reluctance on the part of many of the people that we approached to participate in the research. As many of them said, “we’ve taken part in this kind of thing before and we haven’t seen any change, so we don’t want to go through it all again and still see that nothing changes”.

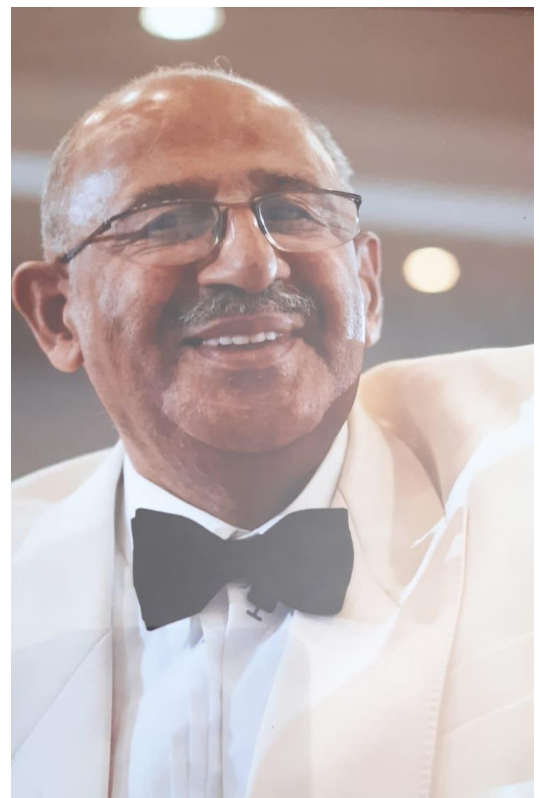
For those that did agree to participate, they have done so only in the very strong belief that this time we expect it will be different; that the powers that be are really interested and listening; and that we expect the participants and the African Caribbean Community to be able to see distinct and discernible improvements. We want this research to improve the care experience for people in the community accessing Home Care now or in the future.

In an attempt to ensure that there is actually some improvement and that they have evidence to hold someone to account, participants have requested that the report comes back to them so that they can “sign off” on it before it is issued. They also want it to be published far and wide and readily available within the community – which we have agreed that we will ensure happens.

Some of the participants in the research agreed to participate even though their family member(s) who were recipients of care have passed away; because they are to some degree still traumatised by the whole “Care experience” and they want to ensure that significant, discernible and measurable improvements are achieved so that others do not have to continue experiencing such negative situations, at a time when people are vulnerable.

The African Caribbean Community (especially our Elders) are a very private, proud, dignified and independent community, who have been used to providing for themselves and their families, and don’t like people/authorities ‘up in their business’.

They are part of the Windrush Generation who were invited here to help rebuild the UK – the ‘Motherland’ - after the war. Upon arrival in the UK, by and large they were not welcomed and in fact the majority were treated appallingly, having to face and deal with overt racism – such as being met with notices in windows: “No Blacks, No Dogs, No Irish!”





Consequently, for many years they experienced severe hardship and had to live in very cramped conditions. They had to choose Owner Occupation as a means of providing for one of their most basic needs – the need for shelter. This was achieved in the first instance by the few who could pool their resources on arrival to buy a property. They then rented rooms out to other immigrants from the Caribbean, which meant that several families occupied one dwelling as the only means of survival and obtaining housing. Then as each family worked hard and scrimped and saved hard they bought a property for themselves.

This was the only available source of housing for many, as they were not eligible for City Council Housing, and were unable in most instances to access privately rented housing - most of the indigenous population were not willing to rent rooms or accommodation to “Blacks”. This Owner Occupation alternative is why for most of our African Caribbean Elders they own their own properties. Now, they are again placed at a disadvantage, as they are expected to sell their homes to finance/afford Home care.

In addition, they were employed in jobs that the indigenous population didn’t want to do; in spite of this they continued to give selflessly to the ‘Motherland’. They often were and still are in many cases treated as “less than”; “less deserving of” – although they have worked hard, paid their taxes and contributed to the wealth and progress that the UK has achieved.

They have lived here long enough now to be elderly themselves, and to have developed health conditions, which mean that they now need access to the care that they have contributed towards for others for so many years. Many people worked in the care system themselves and this was not a positive experience; they now feel that they are again being treated less well than the indigenous population, with their choices significantly limited due to their race and a total lack of understanding of their cultural needs:

“One size does not fit all, it needs to be person centred, person focussed and culturally specific care”.

How did we speak to people?

Due to Covid-19 restrictions we were unable to meet with participants face to face. Instead, we organised and ran 3 online Zoom meetings on consecutive Tuesdays from the middle of May until the beginning of June, to ascertain the lived experience of members of the African Caribbean Community who have been in receipt of Home Care.

The meetings were organised as follows:

- African Caribbean Carers/Users of Home Care
- African Caribbean Professionals working in the Home Care Space
- A joint meeting with the 2 groups
- Telephone and video call interviews with those who could not attend the Zoom meetings



Who did we speak to?

16 recipients of care or their representatives took part in the research: 12 females and 4 males with a range of ages (the oldest participant was 90 years old) and health conditions. They all accessed home care through local authority systems, except for 1 Male recipient, whose family went directly to a small Private Care Company offering Home Care, and was only latterly involved with the system that everyone else described, at the “end of life” stage. This recipient’s experience was very different from the other participants and the family’s comments are outlined in a separate section below. All of the participants are in need of care - care that is courteous, that maintains their dignity and attends to the specific needs of the person, including their specific cultural, dietary and religious needs.



3 African Caribbean Professionals also took part in the research, all of whom were Female.

The authors of this report also have direct experience as family carers, and have worked professionally in council and health services, as well as in relevant voluntary roles. SACMHA has ongoing relationships in providing support for people receiving social care. Discussions from the sessions have been set in the context of the wider depth of understanding that this brings. The numbers of participants may not be huge, but the discussion has reflected and substantiated many experiences we were already aware of in our community.

What did we ask?

We asked the following questions of each group:

- What went well?
- What was poor/didn’t go so well?
- What would ‘good’ look like? – based on an assumption of unlimited resources
- An additional question was asked of the Professionals related to what would give them confidence in recommending services.

Terminology

- In the report we have used the terms Recipient of Care and Clients interchangeably
- Where we have used the term Care Provider, Agency or Company, we are referring to the organisation that employs the Carers
- Where we have used the term Carers, we are referring to the direct frontline staff that enter people’s/clients’ homes to actually deliver the care
- Where we have used the term Elders – this is the respectful way that we in the African Caribbean Community address our Senior Citizens

What people told us – What went well?

This question elicited the fewest responses. The most positive comments came from participants who were able to source their own Personal Assistants via Direct Payments.

Key Points from our discussions:

- It is good that there is a service available to support families
- Some carers were able to meet the needs of the client and give a good experience
- Direct payments made it easier for funds to be managed

Personal Assistant (PA) via Direct Payments

The importance of having PAs who were known to the family was strongly agreed by all. The consensus was that *“It was good to have family members providing care because there was more flexibility and continuity”*. Because the Carers were from the same cultural background, food, religion, language, personal care and general awareness was culturally appropriate. The PA’s employed were said to be mature, patient and caring.

Care Providers

3 participants expressed that the Carers were generally caring and efficient. The time the Carers spent at the home was adequate for 1 participant, who also liked the fact that she was now familiar with the team and knew who would be visiting each day.

1 participant shared her experience of the benefits of having a black carer who was able to meet her needs and that she was able to establish a good relationship with her. Another person reported that due to one member in the team of Carers being of African Caribbean origin and being previously known to family, the care was better as the black Carer set the standard of care and the other Carers followed.

What Works Well For Professionals

The Professionals felt that the first contact assessment and care plan for needs were being met and that the skilled workforce put packages of care in place quickly. They had a knowledgeable community who were able to provide the right care in the right areas of Sheffield. The short term intervention was said to work well in providing home care when leaving hospital and the first contact prevention works well in monitoring the type of care to expect.

What people told us – What didn't go well?

The question 'What didn't go well?' generated the most feedback. Many participants felt they shared the same experiences, and themes began to emerge. Some of these were specific to the community, while others would apply to the general client population of Sheffield but would have a greater impact on the already disadvantaged African Caribbean community. When we spoke with recipients of care on Zoom and in 1-1 interviews, they were not afraid to share their stories, even though some of the experiences had left our Elders and families members traumatised.

We divided experiences into 6 recurring themes:

- Experiences with Care Agencies
- Personal Assistants via Direct Payments
- Communication
- Lack of culturally appropriate care
- Finance
- Training



Experiences with Care Agencies

This area generated the most discussion. Every participant had much to say and all had negative experiences with Carers from Agencies. We have included a selection of quotes from participants in order that their voices and range of experiences are heard:

- "Too many young and inexperienced Carers"
- "There is a quick turnover of Carers"
- "Expectation of preparing breakfast and giving medication in 15 minutes was not possible for Carers"
- "Poor moving and handling techniques for my terminally ill and fragile father, family often had to assist with turns to minimise pressure sores"
- "My terminal and bed bound Father was afraid of one of his Carers"
- "Carers are not caring - the job is a means to an end"
- "Good personal care was dependant on which Carer attends"
- "Carers are unwilling to embrace how to give individualised care"
- "Poor personal hygiene of some of the Carers"
- "I have to remind them over and over re wearing of gloves, aprons etc "
- "Carers have no mind to care"
- "The Carers don't have the time to listen and understand the client"
- "There is no option to have a Black Carer"



- “I have to act as a trainer to the Carers”
- ‘I have observed that the more vulnerable my mother was the less care she received”
- “Male Carers appeared to be more caring”
- “I feel that I needed to be present or have cameras when care was given, but why have Carers if you need to be there?”
- “I want to respect my father’s dignity so installing a camera is not an option for me”
- “It was much better when family did the care”
- “I had to have many meetings with their supervisors”
- “Carers not respecting client’s space”
- “One size does not fit all; care needs to be person centred, person focused and culturally specific care”

Personal Assistants via Direct Payments

Where people had negative experiences of employing PAs through Direct Payments, a lot of this was due to challenges finding PAs and sorting through administration. They said that it could be difficult to find new PAs if someone left, and that it was hard to source holiday and sickness cover. There isn’t a database of PAs so people need to rely on personal recommendations and word of mouth.

1 participant reported that payment was often late or not at all. One of the night shift workers was not paid for 2 months. The Care Provider said the Council hasn’t paid them. When the PA complained she was told not to call in to Care Provider anymore when complaining.

Communication

Participants gave many examples of poor communication – between the Agency and the client/family, as well as the Carers and the client/family. One participant expressed that it was “hard work to be forever chasing things up.” Another participant felt that an initial interview and assessment completed over the phone was “unprofessionally done.”

One person stated: “I requested to have no male carers but they [Provider] have sent male carers without any prior communication. I had to refuse care and contact Social Service.”

The same person voiced that for religious purposes she requested that on 1 day a week the Carers call before 9am. However, she was told that this was “not a priority so Carers can come at anytime up to 11am for a morning call”. She had to contact Social Care who in turn had to contact the Providers.

Many of the participants agreed that the information given at the initial assessment is not always adhered to. On one occasion Carers didn’t turn up on time to give an insulin dependent diabetic her breakfast. Participants recognised that Carers will be delayed from time to time, but this was reported to be a regular occurrence. More often than not, they said that delays were not communicated and frequently lame excuses were offered on

arrival. One particular agency that was reported to do this constantly no longer operates, but this led to a different challenge - there was no communication between the old provider and the new one, so the initial assessment took 3 months to complete. During this time the Elder received only very basic care.

Communication between the Carer and the client/family members was said to be inadequate at times. There was no engagement from Carers with one client because he was a quiet man and so they would “talk over him”.

Participants also acknowledged a fear that complaining may make care worse. One family member was told that her standards were too high, as amongst other things she felt the need to do laminated instructions for each Carer to follow.

There was said to be poor record keeping by some Carers, especially if English was not their first language. One client was left in bed and unresponsive by a carer, who just wrote that “He didn’t want to get out of bed”, without informing family members or seeking medical assistance.

Lack of Culturally Appropriate Care

It was generally agreed that Sheffield offers a poor culturally appropriate service.

Participants said culturally appropriate care available through Direct Payment can take too long and puts many clients off. The professionals in attendance reported that: *“There is not a large percentage of BAME, especially West Indian Carers to offer sensitivity towards culturally appropriate care needs. Also there was not enough time invested in understanding client’s frame of reference (what is important to them) e.g. clients saying they do not want care when they experience care they feel may be culturally inappropriate or uncomfortable for them and this could lead to a case being closed unnecessarily.”*

There is no Home Care agency on Social Care’s list to provide culturally appropriate care and the workforce is not necessarily African even in African-owned organisations.

One Participant felt that *“Non West Indians were unable to meet mother’s needs. Therefore there is a lack of consistency in type of care delivered”*

Carers not representing the culture of service users was somewhat dependant on the location of the client. In some areas of the city, Elders may not get appropriate care because of what the local service can offer.



Finance

There was a real fear amongst the participants of losing all that they had worked hard for in order to fund their care. The Elders felt that *“Social Care are always wanting to know about how much money you have.”*

They reported that Costs for care are unclear prior to the service being provided (clients are billed after rather than before the service they receive).

Training

Participants felt there is not enough (mandatory) training in providing empathic, person-centred approaches for culturally appropriate care. The Professionals reported that diversity training is limited in Sheffield, and there is not a large percentage of BAME representatives to respond to the cultural needs of West Indian clients.

What about Private Care Companies? - A Participant Experience

1 participants' family went directly to a small private care company to provide home care. Their experience was markedly different from all of the other participants. The family shared the things they thought were particularly good:

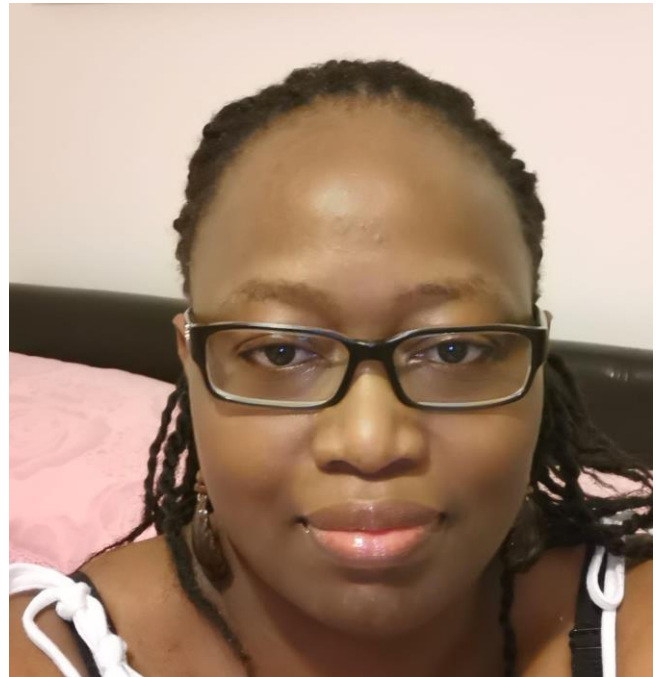
- The Care Company and the carers provided were from a similar cultural background which greatly eased the transition into Home Care - the recipient's needs and preferences were understood and met. For example, on some days the recipient didn't want to eat, but Carers knew the type of food that he liked and how to prepare it, so they could encourage him to eat before they left
- If Carers had time after they had completed their tasks they would sit and talk with the recipient - they engaged well with the client, which he really appreciated
- Carers delivered very person centred, person focussed, personal care
- The Company worked very closely with the family to develop the care package, taking into account all of the client's needs and preferences, so that the family felt confident knowing that if they were unable to be there every day, the recipient would be well treated and well provided for by the carers
- By using a Private Company, the family felt they had more say in determining what care the recipient needed and for how long. They said it didn't feel rushed.
- The Company provided care for more than a year. During that time there was only ever one problem with consistency, where one of the carers was experiencing their own issues with childcare. However, the issue was soon resolved and everything ran smoothly subsequently.

What people told us – What would ‘good’ look like?

“The Service is broken and needs to be overhauled; and in reality, good doesn’t look good until it looks good for Everyone!”

We asked people what ‘good’ care would look like for the African Caribbean community in order to ensure that our recommendations would be shaped by their experiences and would improve the care that they receive in the future. Recipients of care, families, and professionals shared similar visions of what ‘good’ should look like, so these have been grouped together rather than presented separately.

We have also set each suggestion in a descriptive paragraph in order to give necessary context, and so that those who are expected to take action based on this report are fully aware of why these suggestions have been made. With that said, people’s vision for good home care broadly fit into the following categories:



Raising the standards in the Care Sector

Care work would be considered a vocation, and employees in the Sector would be treated, funded and valued at least as well as those working within the NHS. Carers have to demonstrate in some ways a higher standard of honesty, sensitivity and integrity, as they are entering homes at a time when their clients are at their most vulnerable. Often there are no other ‘eyes or ears’ around to report back on what they have done, and they are in the position of lone workers, often with no direct immediate support on hand, unlike in a hospital environment or care home setting.

Remuneration for Carers would be improved to reflect the importance they hold, and the direct responsibility they have for people’s wellbeing when they are in their homes. As well as being properly paid, a system of improved career progression would be introduced - with competencies, qualifications e.g. NVQs, additional training, incentive schemes and rewards for completing them. This would give Care Workers something to aim for, as well as knowing that their work is recognised, appreciated and valued.



Recruitment Practices & Procedures

Recruitment would be rigorous and reflect Best Practice – employers would construct Person Specifications which require an applicant to demonstrate (through application, interview, and testing) the appropriate Attitude, Skills, Knowledge, desire, enthusiasm and aptitude for working in the Care Sector.

Good management practices

Good management would include regular supervision and monitoring of Care Providers and their staff to ensure that what is being delivered matches what has been promised, and what is expected by the Clients, Commissioning bodies etc.

Client focussed care

Care would be person centred, with the focus being on the needs of the client rather than on profit for the organisation. The family of the recipient of care would also be fully involved in the assessment process, as the necessity for the provision of Home Care for one person impacts on other family members too.

Client focussed care requires individual cultural needs assessments to be undertaken as part of drawing up a Care Plan for clients. This would also include the means by which care providers will ensure that specific cultural needs are being met. Carers would consult the care plan on arrival and ensure notes/records are completed at each visit.

Client focussed care would also require Care Providers and their staff to operate in a manner that ensures that recipients of care are treated with respect and dignity at all times. For instance, that male carers are not sent to provide personal care to female recipients if this has been requested.

Proper channels of communication would also be established, to ensure that care recipients are listened to and heard – i.e. communication is a two-way process, which does not just consist of information giving. Effective communication means that information needs to be received, processed, understood, accepted and adjusted if necessary.

Values and behaviours of care staff

Carers would be well trained, well presented, and have a desire to deliver first class care. They would take pride in the care they provide; they wouldn't carry on personal conversations with other carers, but would focus on the client and try to engage with them, asking them questions, and trying to build a rapport with the client and their family. They would also ensure good standards of personal hygiene.



An emphasis would be placed on the fact that everyone should be treated with dignity and respect regardless of their need for care, with Carers aware that they are entering someone's home and interacting with them and other occupants.

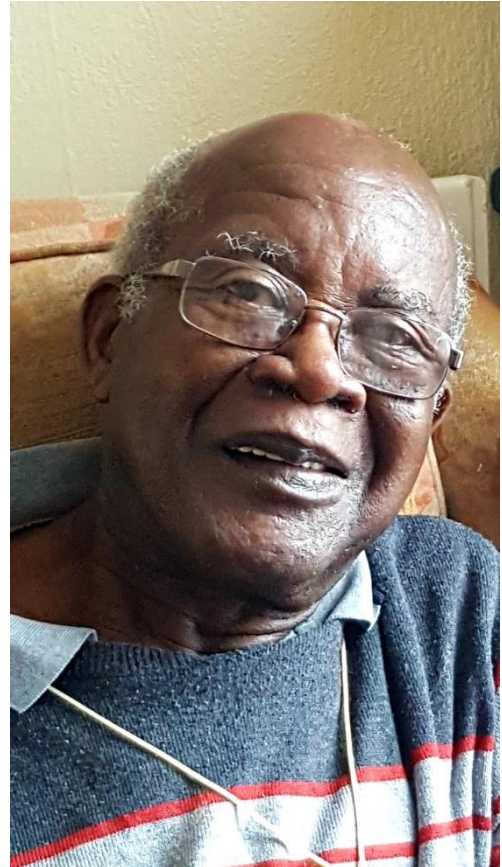
Carers would not assume – they would verify and ask questions. For example, clarifying who you are there to provide care for, especially on the first visit. Carers would have to demonstrate competence in all of these areas before being sent into someone's home.

Monitoring of Carers

Carers would be monitored to ensure that they are reaching and maintaining the expected standards, e.g. via spot checks, recipient surveys, complaints monitoring.

Monitoring of Care Providers

Competencies, Performance Targets, and Training would be a mandatory part of delivering work in the Sector. These requirements/standards would have been demonstrated before contracts could be awarded to Care Providers. This would require regular supervision, monitoring, review and appraisal of the Care Providers at all levels (upper management to frontline staff) by Commissioning and Statutory Bodies locally e.g. Sheffield City Council, Healthwatch Sheffield, as well as the Care Quality Commission (CQC). This would force/encourage/enable everyone in a company to **'Strive for Excellence as Standard'** rather than waiting until things have gone wrong, and clients and their families have suffered needless trauma, before something is done to put things right.



Employed Advocates from the African Caribbean Community

The racism that some of our Elders have suffered since arriving in the UK and that they continue to experience day-to-day has coloured their expectations. Consequently, when a Carer arrives to allegedly deliver care, but makes no effort to understand a client's accent and just says "I can't understand what they're saying", this causes the recipient to say that they don't want care even though they need it. At their most vulnerable, they don't want to allow people/Carers into their home who treat them with disrespect, as a nuisance, a burden or incoherent and so they often just say that they don't want/would rather not receive care. No effort is made to get to the bottom of why they are refusing care or why the care package has broken down.

In a vision of 'good' care, Advocates would be employed to support care recipients who are unable to fully articulate their needs or advocate for themselves. They would also ensure



that a case cannot just be closed if a client feels uncomfortable, without attempting to get to the root of the problem beforehand. The Advocate would work with the Care Providers, the Carers and the recipient and their family to ensure that proper consideration is being made with regard to the client and their needs and that a solution is found.

Staff training and development

Training would include a proper induction programme – not just shadowing someone for a day who may themselves be operating poorly. It would include, for example, what to do/not to do in someone's home; how to engage with clients; record keeping e.g. completing clients' care plans, MAR charts; personal hygiene and the like.

Carers would also be trained in other areas, such as Cultural awareness; Diversity awareness; Unconscious bias; Moving & Handling and other specific training to be able to deliver care to clients with certain conditions e.g. Dementia; Mental Health issues; Stroke; Colostomy care; Awareness of Autoimmune diseases/conditions that affect the African Caribbean Community e.g. Lupus, Sickle Cell Anaemia.

Refresher Training would be regularly undertaken by all staff, including managers.

Employers often see training as expensive, however there are many benefits to having a properly trained workforce, such as:

- Increasing productivity as staff are able to interact with and assess the needs of the client more quickly and effectively
- Improving the quality of people's work – staff feel they are valued enough to invest in, which increases loyalty to the Care Provider
- Improving standards – increased training accompanied by increased monitoring means that Carers can be held to account for the standard of care they give. This can reduce the number of customer complaints
- Increasing staff morale, motivation, confidence, competence, and job satisfaction – staff are encouraged to see their work as worthwhile, and are given opportunities to “breathe” e.g. staff meetings, and suggestion boxes, brainstorming; where they get to meet up to share ideas, best practice, things that work for them and given credit/rewards for their ideas and suggestions when they're implemented
- Reducing staff turnover, sickness absence; it can increase efficiencies in processes & procedures and encourage a willingness to learn; it can also positively affect CQC, Sheffield City Council, and Employers monitoring, reports etc.

Enough time to provide good care

Some carers want to do a good job and deliver a good standard of care. However, they are hampered by the sheer number of clients that they are expected to deliver care to over the course of a day. In a vision of 'good' care, Carers would be allocated enough time to deliver care to each individual. This means care would be allocated/assessed with the person receiving the care and their needs in mind, rather than trying to cram too many visits into as short a time as possible. Care for recipients would be the focus, not profit for the Company.

Travelling time

Related to the point above – time between visits would be built into a Carer's work schedule. It is not possible to deliver good, timely and punctual care to all clients in a day, for example, if a Carer is allocated three 20 minute calls to be completed within one hour, without the recognition that they need to travel to each home. Staff are immediately put into a situation where they are 'playing catch up'. By mid-morning they arrive at a client's home flustered and tense, trying to get in and out of the home as quickly as possible, so that they don't fall too far behind. Both the client and the carer are then in a poor position – the recipient feels the stress and anxiety of the carer to get them 'over and done with' and the carer feels the constant pressure of arriving late and rushing to their next appointment, and so, ultimately on many occasions, does a less than good job.

Handling late arrivals

In relation to the above points, a 'good' service would recognise that sometimes there will be delays. However, if a Carer is going to be late arriving at a clients' home, they would let the client/their family know by the expected time of the visit, as well as giving them an estimate of when they will now arrive. This would allow people to make other arrangements if necessary, rather than the client waiting with no contact, which causes unnecessary stress for the recipient of care and their family.

Cost of Care

Care costs would be calculated quickly. They would define specifically what care is to be provided and at what cost, so it doesn't come as a shock to the recipient. Clear information about costs would be consistently provided, with appropriate support put in place for people to understand it. One of the participants said "Who would ever order or buy something without knowing the cost beforehand?"



Continuity/Consistency of care

Recipients would have the same carer/small group of carers coming in to meet their needs. This would enable the carers to get to know and understand the needs and preferences of the recipient and for the recipient to be able to relax and become confident that they won't be faced with a host of different carers each day. This becomes even more important when caring for recipients with particular conditions e.g. Dementia, Mental Health needs - it can be confusing and disorientating for a recipient to deal with multiple new people every day.



Care Providers – Number of Clients allocated

Agencies are often swamped because they take on too many clients and end up not doing anything well. In an ideal system, providers would be monitored more closely to see how well they are performing, staffing levels, number of complaints received about them etc before being given more clients.

Each complaint about a Provider would be investigated quickly. One of our participants described that a complaint took more than 3 months to be investigated - it is very traumatic for the recipient and their family when care goes wrong!

Carers – Number of clients allocated

The number of clients allocated per carer is often too many to properly care for in a day, therefore, they end up not caring for any of their clients particularly well due to a lack of time, which leaves both client and carer frustrated and dissatisfied.

As part of 'good' care, the number of clients per carer/small group per day, would be limited, so that they are able to deliver care in a sensitive, caring, professional way rather than, as at present, often rushing in and out and not delivering the level of care that the client should or expects to get.

It would be arranged that as much as possible the same carer/group of carers would work on the same "patch" each day. This would enable the carers to become more client focussed, better acquainted with their clients' needs and to establish a rapport and good working relationship, which actually meets the needs of the recipients and maintains their choices and dignity.

Approved List of Care Providers

There would be an Approved List of Care Providers that is regularly reviewed to ensure that they are providing what they promised during the commissioning stage. This monitoring would be based on CQC assessment but also more local assessment processes, e.g. by Sheffield City Council, Sheffield Healthwatch and/or contracted out to Partner organisations.

Responding to complaints about a Provider

There would be a limit on the number of complaints that can be received about a Care Provider before action is taken. Complaints would be investigated in a timely fashion, appraisal-style improvements would be mandated, and no more care opportunities would be allocated to the Provider until they have demonstrated improvement. There would be a probationary period and reassessment before they are reinstated as an Approved Provider, and ongoing monitoring would be carried out by the Council and partner organisations.

Providing culturally sensitive care

Care Providers would make an effort to attract carers from diverse backgrounds to work for them, so that they are better able to provide culturally sensitive care to their clientele.

Whilst it is often preferable for recipients of care from a particular community to receive care from people from their own background, this is not always possible. Therefore, in a system of 'good' care, Providers would ensure that all of their staff have some cultural and diversity awareness and unconscious bias training as standard, as well as employing/training carers who have undertaken additional training that would allow them to be equipped to specialise in providing care to certain communities e.g. African Caribbean.

This would be treated in a similar way to the additional training undertaken so that Carers are able to deliver appropriate care for clients with certain conditions e.g. Dementia, Stroke, Cancer, Colostomy care etc. For the carers undertaking additional specialised training, they could be remunerated at a higher rate, again enhancing the opportunity for carers to progress further and view it as a career choice, rather than a 'stop gap'.



Direct Payments

Many participants felt they could only receive a good standard of care by employing a Personal Assistant (PA) via Direct Payments. However, the overall feeling was that the management of Direct Payments, advertising for, interviewing and appointing a PA is quite onerous, challenging and off-putting. Not everyone is able to manage all of these challenges, and so they have to continue receiving poor standards of care. It cannot be right that something necessary to so many of our elderly and vulnerable communities can be tolerated when it is currently so far from a good experience for so many recipients.

Where there is the opportunity for an organisation to manage Direct Payments on a client's behalf this works well, but in an ideal world the actual process of accessing Direct Payments and employing a PA would be simplified in an effort to ensure that those who would prefer to have a PA and be more in control of their own personalised care are able to do so.



A Database of PAs

To facilitate people taking greater control over their care, a database of PAs, and organisations that can help to manage Direct Payments, would be readily available (along the lines of the Approved Lists mentioned earlier in the Report).

Contracts/Commissioning

Contracts and Commissioning Bodies would have specific criteria and objectives that they use when engaging Care Providers which the Providers have to demonstrate that they are capable of achieving before they are awarded contracts.

Contracts and Commissioning bodies should also ensure that the contracts that they let to Care Providers are properly monitored, that the Providers have independent reviews, measurable standards and criteria that prove their performance regarding regular sustainable levels of service to their clients and that if/where problems occur, they have systems in place to quickly and easily remedy the problems, thus causing the clients and their families the least stress and inconvenience possible.

In addition, the Contracts and Commissioning bodies should seek to attract staff to their organisations from as wide and varied a background as possible in an attempt to better represent and to further enhance their provision, understanding, letting and monitoring of contracts for clients from different backgrounds and communities.



Recommendations

The recommendations below are based on our findings in this report, as well as from participant suggestions of what good care looks like.

Our recommendations are as follows:

1. That Sheffield City Council (SCC) produce an **action plan** in response to the report, with clear timescales put in place and named leads for each action area. This action plan should be published and shared with relevant stakeholders, and a regular mechanism established for sharing progress updates with SACMHA and the African Caribbean Community.
2. That SCC sets out a framework for **raising standards in the Care Sector** in Sheffield and uses contracting as a mechanism to embed this with providers. Any model developed should:
 - Support social care as a career where people feel valued and there is a route to career progression
 - Ensure appropriate levels of remuneration for social care staff, at least in line with the Real Living Wage – but seeking to go beyond this also
 - Establish a minimum level of mandatory training for staff with a central focus on providing person-centred care and understanding the needs of diverse communities.
3. **Travelling time** should be built into a carer's work schedule for the day so that they are able to consistently provide good, timely and punctual care to all their clients as the norm, rather than as the exception.
4. **Recruitment** - that SCC leads a focussed piece of work to promote and encourage candidates from diverse backgrounds into care, and also into all levels of organisations linked to social care. HR processes and procedures within SCC and partner organisations should be reviewed to ensure they are in line with Best Practice around recruiting, supporting and developing a diverse workforce.
5. Care should be **client focussed and culturally appropriate**:
 - Care plans should be based on specific cultural needs assessments and ensure everyone is treated with dignity and respect. In developing care plans, staff should be prompted to set out specific information about how they have considered cultural needs, and case supervision should routinely explore this aspect of workers' practice



- Recipients of care are seen as human beings, who still have dreams, goals and aspirations, some of them simple e.g. “that I can manage to walk around the block” – which should be encouraged, enabled, and celebrated.
6. There should be an **Approved List of Care Providers** or similar, that is regularly reviewed to ensure that they are consistently delivering good care. If they are not, they can be removed from the List until they improve sufficiently.
 7. **Continuity and consistency of care** – clients should receive (as much as is practicable) care from the same carer/small group of carers, in order to build a rapport, and for the carers to get to know the needs and preferences of their clients. This will help deliver good standards of care that recipients and their families are happy with.
 8. **A family approach** - Ensure that clients and their families are as fully involved as possible in deciding on a care plan for a client, so that *all* the needs of a client and the family are fully taken into account; care delivered to one person can impact on the whole family. There should be a ‘wrap around’ service for clients and their families with multi – disciplinary team support to ensure the best level of care for clients.
 9. **SCC Monitoring of care providers** should be regular, and routinely include:
 - Feedback from people cared for, and their carers/relatives
 - Information about diversity of workforce in providers
 - Information about staff training undertaken
 - Staffing levels
 - Complaints received and evidence of learning from complaints
 - Management practice of providers
 10. **Transparency:**
 - Contracts and Commissioning bodies should have specific criteria and objectives used within contracts to Care Providers that are readily available for clients to see
 - Where monitoring identifies concerns, people using services should be kept informed of action taken and given opportunities to provide feedback on how actions have impacted on quality of care.
 11. All care providers should have easily accessible information on **how to raise a concern or complaint** about their service, eg on their website, and in paper information left with clients. SCC and partners such as Healthwatch should give clear information about other routes to raising concerns, eg through CQC or the ombudsman.



12. Finance and cost of care:

- People should be given good, up-front information about the costs of care
- They should be offered access to independent advice and support to understand the process and their rights within it
- SCC should collect and monitor data (including ethnicity data) on people who decline care due to cost, and consider doing a 'deep dive' exercise to better understand the impact this has on the individual and on other services.

13. **Advocates** should be employed from within the African Caribbean Community, so that they can fulfil the role of being a Link/Advocate for clients who are unable to fully articulate or advocate for their own needs. They would work with the Care Providers, carers, clients and their families to ensure that the needs of the clients are properly met and that care packages do not break down without some investigation into the cause of the failure and some attempt has been made to reach a satisfactory resolution.

14. **Choice and Control** – Direct Payments offer a good route to get care that is right for an individual, but it is not appropriate for everyone. SCC to develop use of other mechanisms offering choice such as Individual Service Funds, which place less responsibility on the individual accessing them.

15. **Direct Payments** – more support should be developed around Direct Payments, including:

- A comprehensive database of PAs, promoted and actively maintained
- Provision of standard templates for PA adverts
- Culturally appropriate support for people in different aspects of managing a direct payment, provided by organisations rooted in different communities.

16. That **Central Government** should be approached, if necessary to help with funding some of the recommendations within the report.

Conclusion & Acknowledgements

Conclusion

Valerie Grossett and Joan Bussue, Report Authors

The participants in the research have been very gracious in allowing us to explore with them some of the less positive and in some cases very painful and humiliating experiences that they have had to undergo when at their most vulnerable.

Many of the participants that have let us “dig” through their lives have worked in the NHS and care organisations in Sheffield – often being abused by some of the very people that they have gone to deliver services to e.g. “I don’t want a blackie washing me” and yet they have continued to serve these people. The achievements and contributions that our Elders have made to the wealth, progress and position that Sheffield is in should be celebrated and now that they are vulnerable and in need of care, they should have a Home Care Service that is worthy of them!

For our part, we have promised them that we will ensure that the Report is brought back to them for their “sign off” and that we will ensure that it is made available as widely in the African Caribbean Community as possible, as well as being shared with people who can make change happen. This is in an effort to make sure that there is accountability and change will be effected, and this does not become yet another report that sits on a shelf.

Disparities have been brought into extremely sharp focus during the Pandemic, when for example we were all out on our doorsteps at 8pm on a Thursday night clapping for the NHS. We don’t disagree this should have happened, but our question is - where was the clapping for the army of workers in the Care Sector, who throughout the Pandemic had to leave their homes and families to continue to go into clients’ homes to provide the very necessary and vital care that their vulnerable clients continued to need?

And while NHS staff didn’t initially have all the Personal Protective Equipment (PPE) that they needed to be able to carry out their role – frontline care workers had even less PPE, but still had to go out to provide care, with overstretched workloads, with no knowledge of whether the homes that they were going into could be a home where they themselves would contract Covid-19 or indeed potentially pass it onto one of their clients themselves, or take it back home to their own loved ones. It was also sharply apparent when the workers in hospitals from minority ethnic communities were disproportionately more likely to die as a result of their work, than were their white counterparts!

It is absolutely right that the NHS should be well operated and well funded, but it is equally vital that the Care Sector and minority ethnic communities are treated with parity. All of us, if we’re blessed enough to live that long, will potentially need to access Home Care Services!

The question for all of us, and especially for those involved in the management of; funding of; provision of; monitoring of; commissioning of; letting contracts for Care Services; and also for those who are the recipients of care is – Are we satisfied with and would we want to accept the standard of care that we currently see delivered?

And if we wouldn't want to accept these standards for ourselves – why do we think it's OK for those in receipt of care now, to simply accept these standards?

Even though this study is among the African Caribbean Community, our conclusions could equally apply to any other community, especially if that community is from a minority background. It is that:

“The Service is broken and needs a complete overhaul!”

“Good isn't good, until it's good for everyone!”

Albert Einstein is widely credited with saying:

“The definition of insanity is doing the same thing over and over again but expecting different results!”

The evidence presented in this report makes the point most emphatically that the same thing cannot keep being done over and over again – discernible, measurable change must happen in the Care Sector so that vulnerable people, especially from minority ethnic groups do not continue to suffer at the hands of what is termed “Home Care”.



Profile of the Researchers

Valerie Grossett

Val is the daughter of parents who were of the Windrush generation. Val's parents came to the UK from Jamaica in the 1950's so Val was a first generation British born child.

Val's Professional background was in Health, and she retired as a Health Visitor in 2015 after having worked within the NHS for almost 40 years. Since retirement Val has cared for her elderly parents who are now deceased, and some of the views shared by participants strongly resonated with her.

Val has always been involved in voluntary work within the African Caribbean Community and further afield. The work Val has done is varied and includes being a Health Educator, Lay Preacher, Community Worker and previously a Carers' Coordinator for the Sheffield African Caribbean Mental Health Association (SACMHA).



The way that the UK's history of racism continues to profoundly shape the experiences of Communities of Colour in the UK today is one of the reasons why Val was willing to collaborate with Joan Bussue and conduct this research for Sheffield City Council. Val's hope is that as a result services will improve for the Windrush generation and all who come after.

Joan Bussue

Joan Bussue was born and raised in Sheffield, by African Caribbean parents, who came to the UK as part of the Windrush Generation from St Kitts & Nevis in the East Caribbean.

Joan had a long and varied career with Sheffield City Council spanning 32 years from 1977 until April 2009, when Joan took Voluntary Redundancy, Voluntary Early Retirement. During Joan's time in the City Council, she worked in several departments – Housing, Personnel, DEED, Education, Legal & Administration, DEL Directorate – several of which have undergone name changes over the years.

Whilst working for the Legal & Administration Department, Joan had the opportunity to do a 6 month, 2 day per week placement with Northern General Hospital Trust. She was given access to any part of the Hospital that she needed to access – including the Chief Executive, Management, Patients and staff - to consider access to health services within the Trust.



Joan set up and ran a research project looking at access to trust services by patients from Black & Minority Ethnic Communities. At the end of the project Joan authored a report and presented it to the Management Board, which resulted in changes and improvements being made to the way in which people from these communities could access the Northern General Hospital Trust Services. For the last 10 years with the City Council before retirement, she worked as an Occupational Safety & Health Adviser in the DEL Directorate.

Shortly after retirement, in October of 2009, Joan's Mother, a retired nurse, was taken suddenly seriously ill and so along with the family, Joan started to help to take care of her Mother. Joan's mother rallied well from that illness until some years later when she was again taken seriously ill, to the point where they became involved with, and saw firsthand, some of the challenges and inadequacies of the Home Care system.

During the research, Joan could certainly identify with many of the views expressed by the participants. Joan views it as a privilege to be able to be involved with the participants and professionals, who opened up to her and the co-author, Val Grossett for the purposes of the research, in the sincere hope that what they were willing to share will hopefully make a significant improvement in the delivery of Home Care and thus a positive difference in the lives of others from minority communities.

Researchers' Acknowledgements

We are grateful to David Bussue, Director of SACMHA, for "luring us" out of retirement to take part in this very vital project; and in the faith that he and his organisation placed in us; entrusting us with the autonomy to organise and deliver the research project as we saw fit with a 'light touch' from him rather than him trying to steer us and offering support where we needed it and allowing us access to his PA.

We are grateful to Sarah Fowler and Lucy Davies from Healthwatch Sheffield for introducing a new word into our vocabulary – "Jamboard!" – and for acting as part of our 'Tech Team' in hosting and taking notes for a couple of our Zoom meetings.

Special thanks must go to Jack Silveroak, David Bussue's PA, for being part of our 'Tech Team' – setting up, hosting and note taking for 2 of the Zoom meetings; for the efficiency and speed with which he produced brilliant – incisive, succinct, coherent notes from the Zoom meetings within less than an hour of a meeting ending! Greatly appreciated in helping us to try and meet the very tight timescales of this research and Report.

Sincere thanks goes to the Professionals who made time in their busy schedules to participate and attend the Zoom meetings, to share their expertise in this area; to participate in a joint meeting where they had to listen to and try to respond to some of the hard questions posed by the recipients of care; and being willing to be contacted by telephone, email, Whatsapp or any other medium necessary by the Report Authors!

Our greatest thanks, though is reserved for the Recipients of Care, their families and their



representatives – for allowing us to delve into some of their most private, painful and personal experiences to understand what it is like to become vulnerable and in need of care and for that care, in most cases to be poor, inadequate and culturally inappropriate, and where they are again made to feel “less than”. And for the very brave among them to provide photographs of themselves to be included in the Report, so that the ‘powers that be’ can see that there are real people out there who are affected by the decisions that they do or don’t choose to make.

It is our solemn commitment as the Report Authors to do everything in our power to ensure that their contribution to this research project has not been in vain, that it will not just end up on a shelf or in a bottom drawer; but rather that there will indeed be discernible, measurable improvements in Home Care in Sheffield in the not too distant future.