**The *Care Cameos* series is designed to present short but challenging sketches of various issues and to provide a forum to encourage and foster debate on a whole range of issues important for the delivering of care and support for older individuals across Scotland.**

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ScottishCare
Voice of the independent care sector

# KEEPING BODY AND SOUL TOGETHER:

*reviewing the physical, emotional, cultural and spiritual care needs of ethnic minority older people in Scotland*

## A CARE CAMEO

**OCTOBER 2019**

## About the author

Rohini Sharma Joshi FCIH is the Equality, Diversity and Inclusion Manager for Trust Housing Association in Edinburgh.

Since 1999 Rohini has led an award-winning team, delivering equal opportunities projects which have both successfully tackled diversity issues in social housing at both local and national level.

One of the projects, the Older Peoples' Services Project, funded by Community fund has involved her and her team engaging with hundreds of ethnic minority older people across Scotland, to listen to their concerns about care and housing and to try and highlight what they need to restore their dignity, self-esteem and independence.

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# Introduction

***"We are failing our ethnic minority older people when we only think about meeting their practical care and support. We need to provide care services which meet their emotional, social, cultural and spiritual needs. We owe it to them.***

***Scotland is a small country. If we had the will and commitment and if we were prepared to look at our communities with honesty and integrity - we could be a small country with a worldwide reputation as an inclusive, multi-cultural nation."***

**Rohini Sharma Joshi FCIH**

**Equality, Diversity & Inclusion Manager, Trust Housing**

In 2019 Scotland's population of ethnic minority older people are the pioneering generation that came to Britain in the early 1950s, and some before, in search of a new and better life. They worked very hard throughout their lives, often building up businesses, creating jobs and paying taxes.

Now they are old and need care and support and Scotland is failing them.

There is equality legislation in place, but questions have to be asked as to whether both the policy makers and the services complying with it, are ensuring that it works to meet the needs of everyone.

The Equality Act 2010 requires public authorities, in the exercise of their functions, to have due regard to the need to:

- eliminate unlawful discrimination, harassment and victimisation and other prohibited conduct
- advance equality of opportunity between people who share a relevant protected characteristic and those who do not
- foster good relations between people who share a protected

characteristic and those who do not

The protected “characteristics” of the 2010 legislation are defined as:

- age
- disability
- gender reassignment
- marriage and civil partnership
- pregnancy and maternity
- race
- religion or belief
- sex
- sexual orientation

Scotland’s ethnic minority older people are covered under the characteristics of “age”, “race”, “religion or belief” and “sexual orientation”. The current legislation is meaningful and clearly states what has to be done to ensure that everyone has equal access to services, when they need them, irrespective of their background and origin. However, it is not able, within the current framework, to drive a holistic, comprehensive strategy that meets the very specific care needs of ethnic minority older people in our communities.

In practice, the legislation is implemented, at best, in fragmented, ad hoc ways across one-off projects or in a single region across Scotland. At worst, sometimes equality and diversity has been reduced to statements of intent, mission statements or corporate policy statements. Too many meetings are opened and initiatives launched which incorporate and highlight a commitment to equality and diversity. However, the majority of organisations do not follow through with any subsequent action or delivery.

There is a need for equality and diversity issues to be addressed and solutions integrated into the fabric of our Scottish systems. And

nowhere is this more urgent than in the care of our ethnic minority older people - who constitute some of our country's most vulnerable people.

We cannot afford, any longer, for action to be tokenistic. Scotland is going to have to start delivering.

This paper has been produced by drawing on the experience over 18 years of making observations and listening to ethnic minority older people talk about their personal experiences and life stories in their own languages and in places where they feel comfortable to speak openly about their struggles. These factors were crucial for a trust to be built, based on a confidence that they were sharing in an environment of mutual understanding, respect, impartiality and confidentiality.

But it is also important that the conversations are recorded not purely for the purpose of research, but so that every conversation should lead to actions that would help them access better services and make a difference to their lives. Ethnic minority older people are tired of being researched and then seeing no real change or improvements to the services they need to access. They are too accustomed to seeing a local or national "commitment to equality" begin and end with a report highlighting their needs. Far too often the real task of developing and implementing actions to deliver on the findings never gets off the ground.

The voices of the older ethnic minority people who have shared their stories have been incorporated into this paper, to highlight the often-complex issues facing Scotland's minority ethnic population as they age and need support. Whilst some of these issues are the same as those faced by all older people, many are compounded by the language barriers, not understanding the system, cultural practices and religious beliefs.

Scotland's ethnic minority older people have been engaged in the life and work of communities across Scotland for decades and it is time that their economic and cultural contributions are recognised, so that they can have the dignity they deserve in the later years of their lives.

It is hoped that by opening some windows onto the lives of Scotland's ethnic minority older people, that we will start a debate

on their current care needs. But even more importantly, we hope to drive action and deliver real and lasting change.

## Overview of Scotland's ethnic minority population

Scotland's population is becoming increasingly diverse. According to the most recent census in 2011, 8% of the population is now made up of ethnic minority people. 4% is composed of a wide range of white ethnic minority groups, including those of English, Irish and Eastern European origins. This total does not include gypsy travellers, refugees, asylum seekers or migrant workers.

Black and Minority Ethnic groups make up the other 4% of the ethnic minority population. 'Pakistani' (49,000 people) was the largest of ethnic groups, followed by 'Chinese' (34,000 people). There were roughly equal numbers of people who recorded their ethnicity as 'Indian' and 'African' (33,000 and 30,000 people, respectively). Other ethnic groups were much smaller, with the 'Bangladeshi' (4,000 people), 'Caribbean' (3,000 people) and 'Black' (2,000 people) groups being of similar size.

Looking more specifically at Scotland's ageing population, the 2011 census also shows that the number of older people in Scotland is increasing at a much faster rate than younger age-groups. This appears to be driven by people living longer rather than by migration, as there are relatively low numbers of immigrants amongst the older population.

Whilst older Scotland is predominately white, it should be remembered that the ethnic minority older population has nearly doubled over the last decade. The proportion of the ethnic minority population in the 75-79-year old age group has doubled between 2001 and 2011. The number of ethnic minority people in Scotland over 65 has increased from 4,162 in 2001 to 7,394 in 2011. This increase appears to be predominantly attributable to the Asian population.

Some ethnic groups have very low numbers in Scotland - there are only 53 Africans and 70 Black Caribbean over the age of 80. However, the Black African population under 50 is much larger than the Black African population over 50 and so this suggests that we

Source: Growing Older in Scotland, EHRC

will see increasing numbers of Black older people in coming years.

## Setting down roots, building a life

Back in the 1940s and 1950s, the first generation of immigrants who made Scotland their home arrived with high hopes for a better life. They worked long, hard hours to build a life, often doing the jobs that local people did not want to do. Some did not speak English and many were illiterate in their own language too. Those who had professional qualifications were only offered labouring jobs or door-to-door sales jobs with poor pay.

Almost all of these first-generation immigrants lived in overcrowded accommodation without their families. They ate whatever was available as there was no ethnic food available in Scotland. Many had to make choices which were against their beliefs - for instance Sikh men had to cut their hair to get jobs. However, they supported each other and persevered with this new life, even when racism was the norm. Despite the challenges, they were determined to succeed and build new lives. For many of them, the hard work and perseverance paid off and after a few years they had saved enough to send for their families to join them.

When faced with the difficulties of securing well paid employment, many became self-employed, starting their own businesses to provide a better life for their families. They were determined that their children should receive a good education, so that they would be able to have a better life than they had themselves. And to achieve this, they continued to work long hours, hardly taking any time off and not taking holidays.

81-year-old Mr S story is typical of many thousands of Scotland's immigrants.

*"I came to the UK 65 years ago from India. I worked in a factory for 25 years. There were four workers in my team and I was the only Asian. It was my uncle who sponsored me to come to the UK.*

*I was the oldest son in the family and I worked very hard and managed to get my family over to the UK. When I moved to Scotland I owned shops and was able to establish my boys with businesses."*

This generation of Scotland's pioneering immigrants is now in older age – many with multiple physical and mental health conditions. This generation never planned for their older age as they were too busy working hard to make life for their families.

65-year-old Mrs M is not unusual:

*"Financially I am not that secure because I am only in receipt of the state pensions and do not currently receive any other benefits. I do not spend on myself or the house.*

*I have not sought any help with benefits and was not aware which benefits I was entitled to. I have worked all my life whilst living in the UK. I worked for a food chain for the last 9 years and worked so hard that I received a medal for my services with the company. I had to give up full time work 7 years ago to look after my husband."*

Scotland's ethnic minority older people expected they would be able to live comfortably in old age. They expected to be looked after by their families. They expected to be able to access services.

The reality is very different.

## What are the key challenges facing Scotland's minority ethnic older people?

For many of Scotland's older people, life can present all sorts of challenges. But for ethnic minority older people these challenges of failing health and mobility are seriously compounded by complex issues related to their lack of availability of services or where to go for help. Cultural practices and behaviours, religious beliefs, traditions of family responsibility, language and communication all contribute to ensuring that every ethnic minority older person has a uniquely complex set of needs.

Some of the key challenges facing Scotland's minority ethnic older people include:

### *1. There is not always the political will to help*

Policy makers and service providers have never comprehensively looked at meeting their multiple, complex needs.

Admittedly, race equality strategies, which are a legislative requirement for the public sector, have been rolled out, but they have not been delivered with any significant insight into the actual day to day needs of ethnic minority older people.

In addition to the broader Equality Act 2010, The Scottish Government's *Age, Home and Community : A Strategy for Housing for Scotland's Older People 2012-2021* and *Reshaping Care for Older People : A Programme for Change, 2011-21 and recently published A Fairer Scotland for Older People – A Framework for Action* have been in place. However, they don't go far enough in considering, in an inclusive way, how the very specific care needs of ethnic minority older people can be delivered.

Some actions and initiatives, such as small funded short-term projects by the local authorities and other funders have been undertaken and then these one-off projects have continued to be used to showcase evidence of delivering for ethnic minority older people. These projects are then stopped, leaving them without support or no contact for advice and support. Some public sector

staff have worked hard with partner community organisations to provide a service to meet a need for some ethnic minority older people, but the learning ended with that case and failed to make part of the wider service delivery process.

We have a situation where the public sector agencies are not working together. For example, ethnic minority older people are often not being referred to social services when they are discharged from hospital.

There are number of reasons for this approach; numbers are too small to make sufficient use of a new resource; the language barrier is being used as an excuse to not do anything; the needs of different ethnic minority groups are not being properly understood; there is a fear of getting it wrong; discriminatory practices; and sadly, a lack of will to carry it forward.

Another factor driving inertia in the public sector is the belief by service providers that ethnic minority older people are looked after by their family. Whilst there are still some older people who are looked after by the family, the joint family tradition has been disappearing for several years now and this has gone unacknowledged and unnoticed.

### *2. There is a belief that they are "hard to reach"*

The "Hard to Reach" concept has been used in Scotland for over three decades now, often to give the impression that contacting ethnic minority communities to investigate their needs is difficult, challenging and requires considerable effort and resources. Policy makers and providers continue to use it as an excuse not to reach isolated and groups of people of different backgrounds.

In Scotland we must move away from the concept of "Hard to Reach" to "Reaching Out". Service providers must push out of their comfort zones, embrace the challenge, stop worrying about making mistakes and actively reach out to ethnic minority older people. It can only happen if there is commitment and a wish to learn and understand the needs of this vulnerable group of people in Scotland.

### *3. There is a belief that they are "homogenous"*

There is a tendency for organisations and policy makers to assume that ethnic minority people are a homogenous community. Whilst small in numbers, Scotland's ethnic minority community is made up from people from different parts of the world with different religions, cultures, traditions and dietary needs.

It is important that all differences are understood so that the appropriate services can be delivered that will ultimately create an inclusive society.

### *4. The tradition of joint families is disappearing*

Whilst some ethnic minority older people have no children, those that do are finding that their children who grew up in western culture are rejecting the tradition of continuing to live in a multi-generational household and are moving out of the family home – most have found jobs in other cities or countries, got married and bought their own family home. Those older people who live alone in the 3 or 4 bedroomed houses they lived in most of their lives are reluctant to move out as it is their home and they feel that moving in with children will mean that they will lose their independence.

Those who are cared for by their families face very real problems too, as these multi-generational relationships are increasingly under strain. Sons still often wish for their parents to stay with them, but the daughters-in-law find the caring role very difficult, especially when most of the caring is carried out by them when their husbands are at work. In some instances, four generations live together in big houses, but they are cash poor and not able to keep up with the maintenance of the houses and the accommodation is not suitable for the older generation with care needs. However, the ethnic minority older people often feel that options are not open to them as control is held by their sons or even their grandsons in some instances.

Some older people experience relationship breakdown with their children whilst some children find it hard to be a carer or meet the expectations of their older traditional parents. Within these family units, the carers will have their own families to look after too and perhaps are even ageing themselves with their own health problems

and challenges.

In the past, many ethnic minority families would have a daughter or daughter-in-law at home all day to fulfil the traditional role of a full time carer, but times have changed and in most families both the husband and the wife might be working full time.

So even in situations where ethnic minority older people are living with their children, they can still be left lonely at home when their family are busy working all day.

In some cases, an older person may know that they are not wanted in the family home, but the fear of change or living alone is much greater than living where they are not wanted.

### *5. Older people are reluctant to expose their vulnerability*

For many ethnic minority, older people who have worked hard over the years to build up a standing in the community, they feel ashamed to expose their vulnerability and their acute need for support. Some think that receiving benefits is charity and do not wish to claim anything even if their need for help is dire. They are not used to asking for or receiving help as they were always the people who provided the help and support.

For these people, who do not ask for help, it doesn't mean their care needs are being met but that they prefer to live a life of struggle and even in poverty. They feel ashamed and embarrassed, worrying about "what will people in the community say" if they sought help and support.

They will not come forward to seek help when it is offered as part of a group discussion and when they do eventually seek help, it is often too late.

### *6. There are barriers to accessing information and services*

Language remains the biggest barrier to accessing appropriate care for many ethnic minority older people. Although some may have some basic understanding of English, they are not sufficiently proficient to navigate the complexity of the system and to access and understand all the information they need to make decisions.

For Ms N, age 88, not being able to explain her symptoms to her GP resulted in childlessness.

*"When I was working in a kitchen of a food chain business, I had physical health problems which were ignored by my employer. At that time there was no language support for workers like me. I could not explain to a doctor that I had abnormal extensive bleeding which had been caused by an infection in my tubes. I eventually had to seek alternative treatment with a herbalist who was able to communicate with me in my native tongue. The delayed diagnosis and treatment led to a blockage in my tubes which meant I was never able to conceive."*

76 year old Mrs C had got used to having her children act as their interpreters for his daily needs, but when her children left home, there was no-one to provide language support.

*"There was a local government funded community interpreter but this was really for bridging the gap between medical professionals and patients. It didn't help people like me who cannot speak or understand English. We could not use it to book a GP appointment, make a phone call to the hospital for a test result or make an appointment with the optician or dentist. We know we have missed out on eye checks, dental checks and flu shots."*

Mrs F was screened three times during her pregnancy but was never given the results as she did not speak English. Her son was born with Down's Syndrome.

*"If only the medical profession had explained the abnormality at that time, I could have had the option to terminate the pregnancy. it was like receiving a death sentence when I was told my son was a Down's Syndrome child. I realised immediately that the impact of having a DS child was that I would be ignored, rejected, cut off and isolated by the community as people believe in reincarnation and that if a person did something wrong in the previous life he or she would suffer physical deformity as a punishment in the next life."*

For these individuals, the language barrier had very serious effects.

For thousands of other ethnic minority older people, the language barrier creates small, day to day problems and makes life a

challenge. Often it results in procrastination. Every task is so daunting, that there is a tendency for ethnic minority older people not to consider their care and support needs while they are able to make decisions and instead wait for the time when they need care and then let others decide for them.

Access to information and services is also thwarted because ethnic minority older people, who don't speak English, are unable to explain their issues and concerns. They don't fully understand what the system needs to know in order to assess their needs. The result is that they are likely to say that life is manageable, even when they are struggling and not coping.

### *7. Hidden issues – services are not appropriately dealing with them*

Mainstream services staff do not understand how to ask the right probing questions about hidden and unsaid issues relating to ethnic minority older people's needs and situations.

For instance, ethnic minority older people are rooted in the tradition that children will care for their parents and if asked by a service provider would be likely to create the impression that their children are looking after them well. Admitting to difficulties in the relationship between parents and children would be a stigma to be avoided at all costs.

Some practitioners do not understand and are not good at dealing with cultural sensitivities. They do not take a flexible approach in dealing with the different needs of ethnic minority older people and want them to follow the practices which are in place for all older people.

To take one example, a district nurse was adamant that an older Asian woman who is illiterate and can't speak English create a diary of her incontinence or asked her son to do so. Despite being told that the patient felt uncomfortable discussing this personal problem with her son, the nurse refused to change her approach, showing no consideration of the dignity and self-respect of the older woman.

Elder abuse can also go undetected as it is likely to be treated within some ethnic minority communities as a "closed door" matter.

88-year-old Ms N suffered misappropriation of her cash, pension and welfare benefits by her family.

*"When I confronted them on the improper use of my funds, I had to endure shouting and hurtful words and also the physical pain and distress of being pushed against the wall or pulled down onto a seat by family members. I was forced to survive without an income and live in poverty. I couldn't go out or meet friends at restaurants. I was lonely."*

Ms N never reported the abuse to the local authorities because she feared family support would decline even further or be completely cut off. Sadly, this is not an isolated example.

### *8. Ethnic minority older people can be dependent on their children*

A combination of the language barrier and culturally-related family dynamics can lead to decisions being made for an ethnic minority older person by their family, speaking on their behalf.

The older people allow this to happen as they fear upsetting their children due to the fact that their reliance on them grows with age.

They often rely on their family to look after their finances and do not know what they are receiving in benefits or the cost of care. In some cases, there have been incidents of financial abuse by the family.

Older ethnic minority women who have lost their husbands are particularly vulnerable and reliant on their families, as their husbands would have made the decisions and handled the finances. When they lose their partner, the finances are controlled by their children and again they have no control over their life or power to make decisions. They have to ask for small amounts of money from their children and are sometimes told "what do you need money for, you have everything you need", - even in cases when it is their own benefits they are asking for.

In a focus group discussion older people stated that they did not want to be a burden on their families. However, they also stated that they believed a nursing home was a place for people who had been abandoned by their children.

Some who live with their children said that living with their grown-up children under the same roof had the advantages of immediate attention and action taken by their children if they fall ill during the night. Even if it caused some relationship concerns, they reported that there was the comfort of having someone around.

### *9. Social isolation and Loneliness*

Social isolation for ethnic minority older people, just as it is for any older person, can be a very real problem - and losing a partner and/or limited mobility can make it very acute indeed. Their families are increasingly busy with their jobs and family responsibilities. They are not able to visit friends as their mobility might not be robust enough to use public transport or they may have lost the confidence to drive. Many older women have never learned to drive. Sometimes they are left alone for days.

Day Centres run for ethnic minority older people are life lines for many in older age, helping them overcome their social isolation and ultimately improving their mental health and wellbeing. Those who attend get a hot lunch, information on services and, most importantly, the opportunity to socialise with people of their age, who speak the same language, share their culture and have shared life experiences. Often, they sing, dance and pray together.

The staff are also multilingual and able to provide culturally sensitive services with information in the language they understand and food which meets their dietary requirements.

Service providers are increasingly pushing electronic solutions for ensuring the care and safety of older people in their own homes. But as the manager of a Glasgow day care centre, who understands the importance of people connecting, observed: “Ethnic minority older people just don’t want to know when it comes to electronic gadgetry. They want someone to pop into their house, a personal ‘hello’”.

### *10. There is a lack of ethnic minority carers and culturally appropriate services*

There is an acute lack of ethnic minority carers in Scotland.

The current care support package for older people at home allows

for a visit by a carer/worker. However, if that person cannot speak the language of the ethnic minority older person then the service is not meeting one of the most basic of human needs - to communicate. A care visit is not only about providing personal care, it's perhaps the only time the older person will see anyone during the day, and it's a vital point of engagement.

The other key issue is gender-related as an ethnic minority older man will not want a female to provide his personal care and a woman would not want a male carer. However, in most situations, this culturally important preference would not be accommodated.

Some older people have hired carers from their community but more often than not they are not trained or vetted. This situation puts older people in potential danger and at risk of abuse.

There is an urgent need for specialist, vetted agencies to be set up or a recruitment drive by existing carer providers to recruit multi-lingual carers who can deliver a service which overcomes language and cultural barriers.

For other ethnic minority older people - some will just do without a carer, even when their need is great, if they cannot access a carer from within their own community.

The lack of culturally appropriate services is also an issue in residential and home care.  If food is being provided as part of the home care service, for older ethnic minority people, it will not meet their dietary needs or observances. A sandwich or microwaveable ready-made meals would be the last thing they would want to eat.

## Current care provisions are not meeting the needs of older ethnic minority people

The two key options for ethnic minority older people who need some level of support are "Care at Home" and sheltered housing or care homes. For most ethnic minority older people, neither of these solutions in their current form, offer an appropriate solution.

So, let's look at these two models and identify some of the key problems faced by ethnic minority users of these services.

## *1. Care at home*

### *What are the issues faced by ethnic minority older people?*

Many families want to care for their older parents at home, in line with cultural tradition and expectations. However, this can be very difficult for many reasons such as:

**The house may not be suitable**

There are many reasons why a home environment may be unsuitable for supporting care at home. There may not be enough rooms or there may be too many stairs, the bathroom is upstairs or is too small for carer to help them. However, for ethnic minority older people there may be other reasons too.

For instance, Mrs L struggles with the support technology.

93-year-old Mrs L lives alone since her husband passed away two years ago. She is happy that the council has adapted her house for wheelchair access, raised electrical sockets and provided handrails. However, she finds she is increasingly challenged by the home security system.

*"I have been given a personal safety alarm to wear around my neck but I worry about the pull alarm and the personal alarm pendant. I don't understand it and I would not be able to use it to call for help. Sometimes if I pull the safety alarm instead of the light switch or activate the pendant by mistake when I'm asleep, I can't explain in English that it was a false alarm."*

Mr and Mrs A have a single room with a toilet and shower in the home of their extended family, because they feel that sheltered housing does not meet their cultural and religious needs. Mr A has cancer and dementia, and both have mobility issues. Bedding is hung out to dry in the room as the sheets are regularly soiled.

The desperate situation of Mr and Mrs A is compounded by the fact that, whilst their daughter-in-law cooks for them in the evening, she is out all day working.

Mr G is 92 and a hoarder. He has lived in the same house for 30 years and the conditions are now dire. However, despite the environment and mobility issues, he insists he can manage on his own. He was offered sheltered housing but did not accept it as he was not ready for change and the location was unfamiliar. The fact that he spoke no English was too great a barrier.

**Dementia issues are very challenging for families without experience, time or resources**

If a family member is caring for someone with dementia, it is likely to be a 24/7 responsibility and puts enormous stress on the carer and their relationships within the family.

One family managed to cope for a while with the son and daughter-in-law looking after an elderly mother with dementia and incontinence. However, the woman would not wear the necessary incontinence products, creating enormous practical and emotional challenges for the family.

76-year-old Mrs C believes her health suffered significantly because of the stress of caring for her husband who had dementia.

*"I think local government should play the main role in care, rather than using family members as unpaid carers as they do not have the skills and resources to look after a dementia patient. I went through endless form filling and meetings with social worker to try and find a way of sending my husband to a council-funded nursing home. However, each application was turned down after the assessment was conducted by nursing home staff. They all said the same thing - that my husband was not at a risk for self-harm or for causing harm to others. I suffer from a chronic illness and have been in and out of hospital much more often than my husband. I worry that if I am unable to look after myself, how can I manage my caring role looking after my husband?"*

**Different lifestyles**

In addition to the problems of enough space, older people living in the same house as their extended family, can cause all sorts of other conflicts. A home with three generations of family living in it has to accommodate three different lifestyles and timetables.

For instance, within one home there might be grandparents wanting quiet times to pray early mornings or evenings, grandparents waking early and disturbing sleeping children or teenagers coming in late at night and disturbing sleeping grandparents. And then the parents, in the middle, trying to co-ordinate their children's needs, their working life responsibilities while at the same time thinking about the needs of their parents.

A focus group of older people living in sheltered housings and living with families recorded that none of them wanted to be a burden on their children whilst they were capable of looking after themselves. Interestingly, they also all said they did not want to be full time babysitters for their grandchildren.

All of the participants living in sheltered housing agreed that the generation gap could damage relationships with the younger generation. They said that they have their way of life in the same way that the older generation has their way of life and that the best way to minimise conflict between the generations is not to live under the one roof."

**Suitable care at home not always available**

One of the most consistently expressed concerns by older people across Scotland's older ethnic minority community is the lack of care at home packages that meet their needs.

For cultural and religious reasons, the majority of older ethnic minority people will want to have their personal care carried out by an Asian woman if they are female and an Asian man if they are male. If this is not available, it is very likely that they will turn away a care at home worker who arrives on the doorstep to help. If this happens repeatedly, they not only don't receive the care they very much need, but there is the real possibility that the service is simply withdrawn because it has been refused.

67-year-old Mr L claimed that his parents had received a low level of support from their local authority for personal care which resulted in them withdrawing from receiving the service.

*"The local authority allocated a female worker to provide care for my father. However, he was unable to accept the concept of being seen naked by a female apart from his wife. He believed the*

*exposure of his naked body to other females was disrespectful to all females and that it constituted a dishonour to his long-term partner. The personal care allocated to my mother was also a disaster even though the local authority had allocated a female. The carer came at 7.30am each morning despite knowing my mother got up late and that she preferred a shower before bedtime rather than in the morning."*

In the end Mr L assisted his father with personal care and his mother hired a private carer for her personal care.

### *2. Sheltered housing or care home*

#### *What are the issues for ethnic minority older people?*

Many ethnic minority older people prefer to stay with their families. However, if they agree to move to sheltered housing or care homes, many experience significant difficulties and an absence of choice.

**Social Isolation & loneliness**

Many sheltered housing developments and care homes provide a good variety of activities and events to encourage residents to engage and socialise. However, ethnic minority older people who do not speak English can become very isolated and may even feel more lonely than they did in their own home as they are seeing everyone else in their environment making friends and engaging in activities together.

It is also the case that very often, activities for older people in sheltered housing and care homes are focused on "reminiscence" - revisiting songs, music and cultural references from their youth. Again, because often ethnic minority older people do not share these cultural references, there is a compounded sense of alienation.

In the following case, when an 87-year-old Chinese lady was discharged from hospital to a care home, it was imperative that some creative action was taken to lessen this alienation.

*"When Mrs L was in hospital after a fall she received an additional diagnosis of dementia. The social worker responsible for her case*

*in hospital recommended residential care, but was very concerned about the communication barrier as Mrs L does not speak English and it would be difficult for staff to know if Mrs L is in pain or needed to go to the bathroom. Led by the social worker, the team in charge of her care in hospital made a plan to deal with these very basic communication needs. Her son made some picture cards with Chinese on one side and English on the back.*

*Mrs L is now in a care home and all her care needs are being met and her son has peace of mind. However, Mrs L is not able to speak to anyone or engage in any social interaction as she is the only Chinese person in the development."*

Another family had a similar experience when an older Chinese woman was moved to a care home from an impossible living situation with her extended family. Her daughter said:

*"My mother has settled down well but every time I visit she asks me to stay overnight for a chat because there is no other resident or staff member able to talk to her. Although my mother's personal care needs are being met there are no social interactions or any reminder of who she is. She talks to staff and other residents in Chinese all the time, but they can only smile in response."*

**It is good to speak in your language even when you know English**

Of course, there are ethnic minority older people who speak good English and have had professional lives. However, some feel speaking in their own language is comforting and it could be tiring to speak in a second language all the time in later life. They often want to relax and be in a community where they can easily share ideas, food and culture and feel they are able to express themselves better in their native language.

If they are in a care home, where no-one else speaks their first language, they have to continue to work hard to speak in English.

Sadly, if even a fluent English speaker gets dementia, their English can disappear, and they can regress to only speaking their first language.

**Difficulty in expressing needs and preferences**

For all older people in a supported living environment it is essential that they are able to express their needs in order to live with dignity.

In order to provide older people in care homes and sheltered housing with a sense of dignity and choice, good service providers will try to give residents the opportunity to make choices as much as possible. They may be small decisions, but they acknowledge an individual's autonomy and their changing preferences from day to day. To an older person in a supported living environment, making a choice is important.

*Tea or coffee?*

*Would you like to go to bed now or after the programme has finished?*

*Where would you like to sit?*

*Do you want to change the TV channel?*

*What do you want to wear today?*

If the ability to make these small day to day choices is blocked by a language barrier, an ethnic minority older person feels isolated and depersonalised.

**Care of older people with dementia**

If ethnic minority older residents in residential care with no mental impairment are likely to feel isolated and lonely because of language barriers and cultural estrangement, they are even more vulnerable if they have dementia.

The needs of people with dementia are increasingly being recognised and understood and a great deal of very good research and therapy work is being implemented in care homes and respite facilities. However, central to many of these therapies is a reliance on focusing on the past, tapping into old memories through song, film, memorabilia, conversation and food.

For ethnic minority older people with dementia, these resources, particularly in a care home environment, are ineffective. There is a language and culture barrier. The cultural references are unfamiliar and there is no-one to help them step back into their own familiar pasts through song or story. There is no-one to help them access the familiar tastes and aromas of the food of their childhood and youth.

This means ethnic minority older people with dementia are often locked into a confusing world where there is little that is familiar to help anchor them. They have to rely on family, friends, community workers, social workers, benefit advisors to help them make sense of the confusing and often frightening world they find themselves in. Often there is no immediate access to anyone who can comfort them in a language they understand.

**Dietary needs not being met**

Care homes provide menus which feed their residents three times a day with nourishing food which is familiar to Scottish people. However, for ethnic minority residents it is very unfamiliar and does not provide them with a sense of comfort and familiarity. There is insufficient with some isolated examples of provision for ethnic minority residents to eat what they have eaten all their lives.

For many ethnic minority residents some of the food served in the care home such as beef or pork may be strictly forbidden in their religion. For others the food may not have been prepared according to their religious practices.

Many ethnic minority older people will simply become resigned to the their situation in residential are and will just eat what's in front of them. They don't feel they have a choice. Even if it's against their religion they will simply eat it - and for those with dementia - they may not even know what they are eating.

In some care homes, residents are given the menus for the whole week. For those, who can't read English the care staff often choose for them.

**Cultural needs are not being met**

For ethnic minority older people there has often been a cultural rhythm to the pattern of their lives - festivals and special religious

days and traditions. These celebrations might involve decorating the home, wearing something special, eating special food or saying prayers. These cultural events are not only religious observances but part of the very fabric of people's lives. When ethnic minority older people live in a Scottish care home, this important part of who they are is often stripped away.

At a time when older people particularly need to feel a sense of belonging and community, this cultural resource is not available for them.

**Spiritual needs are not being met**

As people age, they often become more spiritual and ethnic minority older people often want to be in an environment where they can be with those who share their faith.

## Sheltered and care housing for ethnic minority older people

The two housing options considered above need to be made fit for purpose for ethnic minority older people. But there is also a pressing need to communicate effectively with ethnic minority older people and their families so that they understand what these two options are and how they can best access the resources they choose.

There is overwhelming support for purpose built sheltered and care housing developments for ethnic minority older people. Older people feel that they would feel comfortable moving to a place where they can live with people who speak the same language, where they can enjoy their culture and food and where the staff speak their language and are able to provide direct services. They believe this would be a solution to overcoming social isolation and loneliness, and would allow them to rely reliance on their family

At the moment, there are too many barriers to accessing services including:

**All information is in English**

All the information about their care and housing options is in English and so many ethnic minority older people have to rely on others to explain or let officials or family members make decisions for them.

Even if the information resources were translated into ethnic minority languages, some older people can't read their own language or understand the jargon and complexity of the system. They need to have access to solutions which specifically meet their needs rather than be provided with general information. The benefits and support system is difficult to navigate for ethnic minority older people and their families and there is a lack of clarity across the system as to what resources and benefits are available and who is eligible.

**Too many unknowns**

Many ethnic minority older people are unable to make decisions as they believe there are too many unknowns. They are worried that they don't know where sheltered housing or care home options are

located and whether they can be easily accessed by their families. A lack of information leads to a feeling of not being in charge of their own destiny and often an increasing lack of confidence.

**Fear of making the wrong decision**

Many ethnic minority older people are fearful of embarking on the benefits and support journey as they are worried that they will make the wrong decision. Will their own home be sold to pay for a care home? If their house is in both names in a marriage, what happens if one moves to a care home?

**Reluctance to ask for help**

There is often a reluctance for families to ask for help to support their parents as they feel guilt and shame that they are not looking after their parents themselves.

**Needs not properly assessed**

The language barrier not only prevents ethnic minority older people accessing information but it also prevents social workers assessing the needs of older people properly.

Listening to an older person talk about their needs and wants is crucial if a social worker is to build up a comprehensive picture of an older person's physical and mental health. Language is the key tool used by a social worker to assess and evaluate needs and the efficacy of an assessment is seriously weakened if they are only able to observe behaviour or rely on translation or the input from family.

Sometimes, if social workers don't understand they make judgements and decide on the older person's behalf if or what services they need.  Other times ethnic minority older people simply do not want to go through the assessment process as they are anxious and worried that they might give the wrong information under stress. They also have a tendency to try to be polite and say that they are managing without explaining the difficulties and challenges they face to manage their conditions.

**The complexity of Self-Directed Support (SDS)**

As seen above, there are many areas where language and cultural traditions create serious barriers to accessing available and appropriate support. However, no-where are the barriers more overwhelming than in the area of accessing and managing Self-Direct Support.

Self-Directed-Support is arguably a minefield for families across Scotland, regardless of their ethnicity, with its inherent complexities compounded as they vary from local authority to local authority. However, for ethnic minority older people the difficulties are significantly increased by the language barrier.

82-year-old Mrs T is common and is a good example of the challenges SDS presents to ethnic minority older people and their families.

*"I look after my husband who suffered a stroke which then triggered dementia. He frequently suffers a type of seizure which has led to episodes of unconsciousness, incontinence issues and mobility problems.*

*I was unable to cope with the demands made by my husband's condition and called Social Care Direct to open a file for my husband. Due to language issues I requested language support from a non-profit organisation to act on my behalf and make the call. Social Care Direct allocated a worker who spoke to my husband about what he needed support with, carried out a community assessment and reviewed his needs based on the details he gave them. In the community assessment, I requested extra support for meal preparation and cooking because my husband often slipped out of the building when I was cooking and I was then unable to keep a close eye on his activities. Once he wandered off into the street, suffered a seizure, fell and was taken to hospital by the police.*

*I also said I needed extra support for domestic tasks because I had broken my wrist when I had tried to pull my husband up after he had had a fall at the flat. Also as I was constantly being woken up by Mr T for toilet trips, up to 3 times a night, I had no energy left for domestic tasks.*

*The assessment process involved a significant communication barrier as my husband was unable to explain in words his physical condition because the major stroke he had suffered had damaged his voice box muscles and I was unable to express the type of support Mr T needed because English is not my first language. I believe that a 30-minute assessment meeting was not sufficient to establish my husband's needs and the support for which he was eligible, particularly as his support needs were constantly changing."*

SDS is a reform that gives people more choice and control over the kind of support they receive. The objective of SDS is to create 'personalisation' of support, giving people greater control over their lives. However, personalisation does not involve a choice of which service to purchase but rather a choice of how local authorities deliver their support.

In Mrs T's case having care staff for cooking meals and domestic tasks is no longer deemed 'eligible needs' as social care services have stopped support for domestic tasks and meals on wheels service.

Mrs T required significant help to navigate SDS and she was critical of the slow pace of progress involved in an SDS application: there had been a long waiting time to allocate a staff member to start the process, a long time waiting for a community assessment report and a long waiting time for a final budget to come through. Mrs T commented that the process for an SDS application should be simplified as the lengthy process led to stress, anxiety and uncertainty for the applicant.

SDS offer 4 options for the way in which social care is delivered:

1. Applicant manages the budget

2. The applicant uses an agent or provider to arrange the care and support

3. The local authority arranges the care and support

4. A combination of the above options

For Mrs T as a Black Minority Ethnic (BME) carer, her options were

limited.  Mrs T was less likely to choose option 3 to purchase mainstream services as both Mr and Mrs T were unable to communicate with the care staff provided by the local authority. Care staff kept changing and new faces turned up at the front door, which added more confusion and anxiety for Mr T who had lost the ability to remember names and faces due to the advance of his dementia. Mrs T was unable to select option 1 as she wasn't able to manage the budget, keep track of all the invoices, purchase the services either by cheque or money transfer on the phone or record how the money was spent on a quarterly report in English. The only option Mrs T could have was to have a bi-lingual agent to arrange SDS.

## The way forward

Scotland's ethnic minority older people have never asked for help. But they need help now and they need it urgently.

They don't need more reports, more mission statements or more strategic frameworks. They need action with resources allocated to ensure delivery.

They need appropriate care services delivered in their own language, which afford them dignity and comfort in their old age. And they need to spend their later years in an environment where their care needs are met and where they can enjoy friendship and fellowship with people who share their culture, their language and their memories.

I believe there are three key areas in which we need to take urgent action:

### *1. Create barrier free access to information and services*

Information is the most important tool for anyone looking to make informed decisions and plan their later life. And in terms of considering the care needs of ethnic minority older people, this is the area which needs the most attention.

There are many reasons why ethnic minority older people come against barriers when they try to access information and services, and which result in them losing confidence in themselves and feeling

helpless in the face of the decisions they have to make to plan for their later life.

The most difficult of these barriers are:

**Language**

Language remains the biggest barrier. When ethnic minority older people are not able to access information themselves from a validated and trusted source, they usually accept information from their peers. They do not understand that each case is assessed according to an individual's personal circumstances such as their health and financial situation. The advice and support received by their peers would not necessarily apply to them, and creates additional confusion. Sometimes their peers may have had a bad experience and this compounds the problem.

**Complexity of services**

Ethnic minority older people are not equipped to navigate the complexities of the social services and benefits system in order to have their complex needs met. There are too many agencies involved, each requiring different information from older people and ethnic minority people find it all bewildering and are not sure how answer all the questions.

Often, services they believe will help meet their needs are not provided by the agencies as there are only specific tasks which are delivered as part of the personal care package. They find it difficult to understand why they have to agree to accept services they can manage and not receive the services they feel they need or want.

**Affordability**

Information on the cost of moving into care home is not readily available. There is an assumption in ethnic minority communities that it is very high and is only for people who have worked all their lives and have some savings and pension provision.

For a married couple, if one of them has high care needs, the other simply becomes the carer, even when they can't manage due to their own health and older age. They also worry that if their partner is admitted to a care home all their savings, monthly income and finally

their house has to be sold to pay for it and that the other partner will be left without any money and without a home.

***Urgent action required:***

- ☑ Recruitment across Scotland of ethnic minority information officers, who would work as part of local social work teams dealing with the support and care needs of older people.

- ☑ The role would be uniform across Scotland and integrated into every social work department. Information officers would work in partnership with social services teams, providing translation services, cultural advice and would ensure that ethnic minority older people had all the information they needed in their own language to make the best decisions for their care and support needs.

### *2. Meeting needs*

In order to enable ethnic minority older people to plan and make decisions about their later life there is urgent need for services which meet their needs. It must be recognised that being "looked after by the family" is a concept that no longer exists.

***Urgent action required:***

- ☑ Scotland's ethnic minority older people need choice. They need to be able to choose to stay at home where their care needs are met by carers who speak their language, understand them and can make their familiar food if needed.

- ☑ They also need to be able to choose purpose-built sheltered and care housing which meets their language, social, emotional, spiritual, cultural and dietary needs.

- ☑ Older people, especially if they are alone, need to be able to communicate effectively. Talking to other people helps maintain social connections and overcomes social isolation and loneliness. It can delay dementia or help mitigate its symptoms.

It is imperative that ethnic minority older people can talk to other

residents, carers or staff in their own language, with people who share their culture and life experiences.

### *3. Developing understanding and improving learning*

The time has come when social services and other care providers must start to learn to understand the care needs of ethnic minority older people and integrate the delivery of additional solutions which meet their specific needs within the mainstream services. Meeting their needs must be part of the comprehensive support service and not problems to be addressed on an ad hoc basis, in different ways in different regions.

### *Urgent action required:*

- ☑ Scotland's social services need to employ an "ethnic minority older peoples' tsar" - someone to champion the complex needs of the country's ethnic minority older people. This role would involve harnessing the existing understanding and learning of care providers and rolling out solutions as part of a national, integrated service.

- ☑ The team of ethnic minority information officers suggested above would be key to delivering the "tsar's" programme at grass roots level and also to feeding back recommendations on how the service could be improved.

## A final word

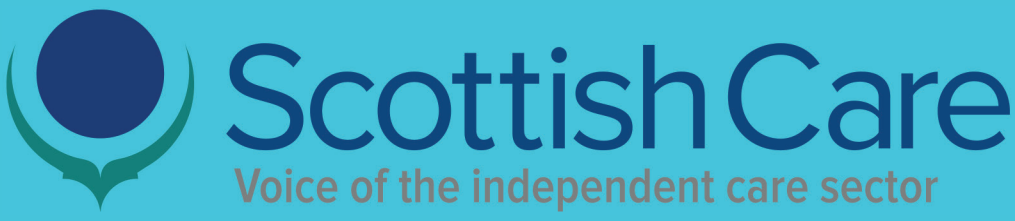
I said at the beginning of this paper that we are failing our ethnic minority older people in Scotland. I hope the stories I've shared have demonstrated what our ethnic minority older people need to live safe and fulfilling lives in their older years in the country they have lived and worked in for most of their lives.

We don't have to fail them anymore. There is so much that can be done. But the time for making ethnic minority older people's real, day-to-day lives simply part of a strategy or a discussion point is over.

I would therefore urge Scotland's political and social care community to embrace my suggested action points and take the first steps to making a very real difference to a vulnerable group of people in our country.

**Rohini Sharma Joshi FCIH**

**Equality, Diversity & Inclusion Manager, Trust Housing**


Scottish Care
Voice of the independent care sector