

# "Are Ethnic Minority Older People Invisible? - What more can we do?" - Forum Notes

## WEDNESDAY 27<sup>th</sup> JULY 2022 – 10am-11.30am via Zoom

Chaired by **Gerli Orumaa**, Policy Officer, All Wales Black and Asian Minority Ethnic Programme, EYST. Supported by **Twahida Akbar**, Policy Officer; **Judy Li**, Marketing and Communications Officer; and **Linus Harrison**, Project Officer EYST

Key Speaker/Panellist:

*Nicola Evans,* Head of Advice and Assistance, Older People's Commissioner for Wales *Rahila Ahmed,* Former Gwent Regional Coordinator & Ethnic Minority Community Engagement, in a volunteering capacity *Alex Osborne,* Disability Wales

Attendees (61 attendees total): Rafat Arhad-Roberts (NHS Wales), Gwen Anslow (All Wales Forum), Elaine James (SCVS), Helen Jones (Flintshire Council), Emma Langley (NHS Wales), Angela Jones (DWP), Mirain Roberts (Gwynedd Llyw), Owen Phillips (Swansea Council), Rajma Begum, Deiniol Jones (Age Cymru), John Moss (NHS Wales), Neville Davies (Alzheimers), Catriona Learmont (TNL Community Fund), Kyle McCarthy (Cardiff Met Uni), Haddijatou Sallah, Claire Reidy (Nuffield Department of Primary Care Health Sciences -Oxford University), Momena Ali (EYST Wales), Charlotte Ajomale-Evans, Michelle Lewis (Carmarthenshire Council), Fiona Evans (Macmillan), Bex Kentfield (Welsh Women's Aid), Jennifer Dowell-Mulloy (NHS Wales), Dr. Shadan Roghani (NPTCVS), Jake Smith (Carers Wales), Yvonne Howard, Menaka Kodur (Women Connect First), Nia Greer (Vision Support), Shabir Hussain (Newport Council), Carys Huntly (Ceredigion Council), Sibani Roy, Shelina Mohammed, Gulnahar Begum, Pauline Anderson, Shamim, Suzanne Duval (Diverse Cymru), Laura O-Keeffe (Race Equality First), Lisa Yokwe (The Care Collective), Farah Awad (Cardiff Mind), Sheila Hendrickson-Brown (C3SC), Joe Chalmers (Pembrokeshire Council), Samina Ali, Cordelia Okwusogu, Jorna Ali (EYST Wales), Pat Dunmore (Citizen's Advice NPT), Eirlys Parry (NWHA – North Wales Housing Association), Sara Mackay (Alzheimers), Kathy Lye (Age Cymru), Becky Ricketts (Care and Repair), Samantha Williams (Learning Disability Wales), Karen Phelps (Age Cymru), Rowena Maxwell (NWHA – North Wales Housing Association), Amy Williams (ateb Group), Christine Dobbs (Race Equality First), Siva Sivapalan, Fikayo Ilori (Swansea MAD), Zainab Mohamed, Debanjali Bhattacharjee (EYST Wales), Annette Snell (NHS Wales), Marilyn Bryan-Jones, Jarna Khatun (EYST Wales), Amira A



#### Summary of key issues highlighted

- Ethnic minority older people are facing additional barriers compared to majority of older people, e.g. poorer mental and physical health, poverty and low income, poor housing conditions, culturally appropriate care (sensitive to cultural identity and heritage).
- Gap between policy and implementation no real change in older people's lives achieved.
- Consultation fatigue too many consultations but no follow up and meaningful impact.
- Stop collecting more data build on the existing data on Black Asian Minority Ethnic older people and act now! Better collaboration needed to capture existing data in one coherent format.

#### Gerli Orumaa – Opening remarks

In July, the All Wales Black, Asian and Minority Ethnic Engagement programme delivered a forum discussing the challenges and issues affecting older people from ethnic minority communities in Wales. The Engagement team felt that the issues of ethnic minority older people in Wales have not been taken seriously enough to address the diverse needs of such communities.

Older generations are becoming more diverse, and the number of Black, Asian and Minority Ethnic people aged 50-70 is growing at a faster rate than the number of White people.

Studies on ageing suggest that older people from ethnic minorities are one of the most disadvantaged and excluded groups in society in terms of health, wealth and life circumstances.

Many of the ethnic minority people who moved into the UK in aftermath of the World War Two to fill the shortages of workers to rebuild Britain have endured a lifetime of disadvantage and deprivation, driven by experiences of structural, institutional, and interpersonal racism



and discrimination. As they approach later life, the complex interplay of social and economic disadvantages has contributed to ethnic inequalities in older age. For example, ethnic minority older people experience the following challenges:

#### Health

Ethnic minority older people have poorer mental and physical health compared with the ethnic majority ageing populations.

Around 86% of Bangladeshi people, 69% of Pakistani people, 63% of Indian people, and 67% of Black Caribbean people report having fair or bad health compared to 34% of White ethnic majority ageing population in the UK.<sup>1</sup>

This data shows that the health of White ethnic majority population aged 61-70 is equivalent to that for Caribbean people in their late 40s or early 50s, Indian people in their early 40s, Pakistani people in their late 30s, and Bangladeshi people in their late 20s or early 30s.<sup>2</sup>

## Poverty and Lower Income

Older minority ethnic people are more likely to work in their 50s-60s than White groups and are less likely to have retired, receive means-tested benefits, and less likely to receive private pensions.

They also have significantly lower wages than those of White ethnic backgrounds. In average, weekly household income is, on average, £100 lower for Black ethnic backgrounds (except older people from Asian backgrounds). More people from Black, Asian and Minority Ethnic backgrounds are struggling with their day-to-day bills than those from a White background.<sup>3</sup>

<sup>&</sup>lt;sup>1</sup> Neglect of older ethnic minority people in UK research and policy (bmj.com)

<sup>&</sup>lt;sup>2</sup> Neglect of older ethnic minority people in UK research and policy (bmj.com)

<sup>&</sup>lt;sup>3</sup> Poverty and low income among Black older people | Discover | Age UK



#### Housing

Older Black, Asian and minority ethnic people are also more likely to be tenants in retirement, living in deprived neighbourhoods, and less likely to own their home outright compared to White older people.<sup>4</sup> Additionally, social housing designed for older people living independently, may not include space for friends or relatives to stay making it harder to maintain their social and family lives.

#### Care

Traditionally, minority ethnic communities look after heir elderly family members without external support. Elderly parents with poor health may live with their adult children to receive support and assistance. Looking after elderly parents is particularly important among South Asian families and it is common for adult siblings to share the care-giving responsibilities among themselves, taking their elders to doctor appointments, shopping, offering companionship etc. The thought of placing an elderly family member in a care home was often not even considered due to cultural beliefs and limited access to such support in their country of origin.

However, there has been a shift in caregiving for older family members in Black, Asian and Minority Ethnic communities. This is contributed by the changing values between generations. There could be both a generational gap and a cultural gap between Black and minority ethnic older and younger people. This could leave older people feeling particularly isolated - often literally, living alone or being placed in the care home. These elders may

<sup>&</sup>lt;sup>4</sup> Ethnic inequalities among over 50s revealed in new research | Centre for Ageing Better (ageingbetter.org.uk)



struggle to adapt with the life in care homes with no access to culturally appropriate food, activities, social networks and care etc.

Also, younger generations are often all working or studying, raising families, leaving less time to care for their elders. It is not uncommon for families to live further away or in different countries leaving older people feeling isolated and limited access to support networks within the community.

## Culture, beliefs and values

The service provision for older people often doesn't meet the cultural needs and beliefs of different minority communities, e.g. lack of knowledge and respect for religious beliefs and practices.

#### Access to Services

Minority ethnic older people face barriers to accessing services; these include language issues, knowledge of what is available, and the attitudes and practises of service providers.

#### Language barriers

Language barriers and lack of access to translation services acts as a barrier to accessing services. For example, older people may be misdiagnosed or receive a late diagnosis because doctors may not have sufficient time and translation services in place for consulting with patients whose first language is not English.

**Presentation by Nicola Evans,** Head of Advice and Assistance, Older People's Commissioner for Wales – Commissioner's priorities



- Nicola Evans offered a brief insight to the work by Older Peoples Commissioner's office. The office of Commissioner for Older People in Wales was established in 2006 under the Commissioner for Older People (Wales).
- The Commissioner acts as an independent voice on the issues affecting older people who are 60 and over in Wales.
- Helena Herklots CBE is the serving Older People's Commissioner for Wales.
- The Older People's Commissioner promotes awareness and rights and interests of older people in Wales. She challenges discrimination and encourages best practice in the treatment of older people.
- The Commissioner has a set of legal powers to request evidence on older people from public bodies. The Commissioner has legal authority to enter premises other than private homes to interview older people with their consent.
- The Commissioner can publish reports on her findings and make recommendations, as well as request that the recommendations are responded to by the bodies reviewed.
- The Commissioner can publish guidance on the issues affecting older people and request for compliance to these recommendations.
- The Commissioner also has advice and assistance service for older people. She can represent the individual cases of older people if needed.



- The Commissioner's workplan pandemic changed some of the Commissioner's priorities. A new workplan was introduced consisting of previous priorities focusing on tackling ageism, abuse of older people and enabling everyone to age well.
- Protecting older people's rights and improving their understanding and awareness of rights is a key significance to the Commissioner's work. This is promoted via an advice and assistance service, so that individuals can get in touch. Currently, the team is dealing with six to seven hundred cases in a year, primarily focusing on health and social care.
- One of the key issues highlighted via casework is that older people do not know about their rights. The Commissioner conducted a survey few years ago discovering that about 23% of people surveyed (84 thousand respondents) had no awareness of their rights. Hence, the Commissioner is committed to make older people aware of their rights.
- In terms of ethnic minority older people, the Commissioner's advice and assistance service work closely with the Multilingual Helpline Wales to make sure the service is accessible to all. Nicola is keen to spread the message to get a more diverse range of people accessing the service as it is one of the main ways of tackling discrimination, and ageism. These issues were particularly evident throughout the pandemic, especially in the care homes. There were potential human rights breaches just because they were older people and may have not given the same level of thought as the rest of society.
- The evidence captured from advice and assistance service is being used to report back to the Welsh Government. Nicola is committed to using the evidence from the ethnic minority older people to better understand their needs and issues.



- The Commissioner is very keen to find out what are the issues and needs of older people from ethnic minority communities as the older people's population is becoming more diverse, and services need to respond to become accessible to all.
- In addition, Nicola suggests that in many ways ethnic minority older people are invisible because often we don't collect data about older people. There is a lot of Social Services data, but it is not disaggregated by age or ethnicity. Without data, it is difficult to plan services for older people.
- The Commissioner is pushing towards better data collection on ethnic minority older people. This data will help us understand what the needs are going forward and the gaps to better plan the services for older people.
- The Commissioner has launched a research project to gather the lived experiences of older people from Black, Asian and Minority Ethnic communities. The Commissioner's office has approached number of organisations who closely work with ethnic minority older people to support this piece of research. Currently, there seems to be insufficient evidence on the experiences of older people growing old from ethnic minority communities. The Commissioner is very keen to make sure that we are responding to the needs of older people from Black, Asian and Minority Ethnic communities and they hope to use this data to establish what the key needs and issues are so that more accessible services can be developed.
- The first phase of the research project is due to be completed by the end of October 2022. The Commissioner's office may be looking to adopt a second phase of the project to dive deeper into a specific area of concern.



• In summary, the Commissioner's office is very committed to making sure that the Commissioner's work represents all older people in all their diversity.

**Presentation by Rahila Ahmed,** Former Gwent Regional Coordinator & Ethnic Minority Community Engagement, in a volunteering capacity.

- Issues experienced by ethnic minority older people service providers appear to make assumptions that older people are not in need of external help as they are looked after by their families. In reality, not all older people live with their children and relatives and are isolated. Children often move away due to various reasons such as graduation, new job etc, and as a result many older people are left on their own.
- There are also significant challenges for older people accessing mental health services and other basic services. Older people waiting long hours in hospitals with various injuries - in one case, one elderly lady lost a limb as a result of waiting up to 11 hours to receive treatment. There was no communication between the patient and the healthcare workers.
- Older people also experience racism on a day-to-day basis.
- The public services are extremely difficult to navigate, especially those that are health related. Rahila noted that it took her a year to get Social Services to recognise her client's issues. People are reluctant to make complaints because they are worried about making matters worse, and making a complaint is often a very long and stressful process.
- Digital exclusion is an added challenge for older people as many feel unable to attend virtual healthcare appointments and prefer face-to-face engagement.



 Rahila continues to support ethnic minority older people within the community in a voluntary capacity helping older people with matters such as budgeting, appointments, food parcels. She recently helped an Asian lady to apply for a bus pass as she was unable to navigate the system herself due to her old age and added language barrier. Older people from ethnic minority backgrounds continue to face language barriers, and therefore need additional support when accessing services.

#### Alex Osborne, Disability Wales

- At Disability Wales, we engage with disabled people to explore the issues and barriers they are facing. We also deliver training for organisations to create an awareness of the needs of people with certain impairments.
- People from ethnic minority communities are faced with additional barriers in their day-to-day lives compared with other non-minority disabled people. Barriers to accessing healthcare has been particularly challenging because translation services are not always provided. During Covid, people who relied on their family for translation no longer were allowed to bring their family members to hospital appointments and when being admitted to hospital. At Disability Wales, we are working hard to draw attention to this issue as it was completely unfair. Covid-19 showed that disabled people from minority ethnic backgrounds were more likely to die and develop long term conditions. It was worrying to hear stories of BME people not receiving the high-quality care they deserved.
- Disability Wales has conducted focus groups to ascertain what barriers are disabled ethnic minority communities experiencing in their daily lives. One of the key themes identified suggested that BME people were not believed by the doctors and felt



brushed off as being `ridiculous`. Although, people kept returning to the doctors, they felt they were not getting anywhere. Not being believed seems to highlight the inequalities in our healthcare.

- Some people refused to attend their ongoing hospital appointments as they felt they
  were not able to communicate properly without family members acting as their
  translators. As a result, people can lose their place in waiting lists or being discharged
  for failing to attend the appointments. Disability Wales works hard to engage with
  Health Boards on this issue and have encouraged them to provide alternative
  solutions instead dropping people off from the waiting lists.
- Health statistics suggests that ethnic minority people are more likely to be affected by certain conditions compared to general population. The Covid deaths in BME communities are much higher and disabled people are most affected.
- Also, ethnic minority females feel being stereotyped by healthcare professionals where they are being told that nothing can be done before speaking to their male relatives. At Disability Wales, we continue hearing stories of the stigma ethnic minority women are experiencing in healthcare. This is particularly evident when looking at the higher death rate of BME women during childbirth.
- It is sad to hear that many BME people seem to have accepted that nothing can be done about their health. Disability Wales is working hard to counter such beliefs and create an awareness of rights disabled people have regardless of their ethnicity. We give people as much as information possible about their human rights and what steps to take to challenge healthcare professionals when they have been refused and/or received inadequate health treatment, e.g. right to a translator as a reasonable adjustment so that people can better engage with the services.



- Additional barriers are experienced by disabled BME people since the introduction of virtual healthcare appointments following the pandemic. Many of the ethnic minority people feel unable to attend the virtual appointments due to digital exclusion. This also appears to have increased the feelings of loneliness during the pandemic. Many disabled BME people admitted that they haven't spoken to people for ages because the support they were getting before the pandemic had stopped and nothing was put in place to continue with the support.
- Disabled ethnic minority people also struggled to understand the daily health updates by the government. The information was never given in accessible formats for different languages. This was particularly true of information from Westminster.
- In addition, hate crime towards disabled people during the pandemic increased.
   Disabled people were blamed on the streets for being responsible for further lockdowns. We are working hard to draw attention to increasing hate crime towards people with disabilities.
- At Disability Wales, we feel that disabled ethnic minority people ended up at the bottom of the list when Covid response strategies were created by the government and public bodies.
- We believe this reflects general attitudes to disabled people, and most of all BME people with impairments in our society in general.
- The priorities of Disability Wales are to deliver further focus groups to explore how the charity can better engage with ethnic minority disabled people. Also, Welsh Government consultations need to do better at consulting ethnic minority communities.



 Alex urges to get in touch with Disability Wales when they come up against barriers and are being refused additional adjustments. People with impairments are entitled to extra adjustments and support to live a good life.

#### **Questions for Panel**

#### Nicola Evans, Head of Advice and Assistance, Older People's Commissioner for Wales

**Gerli**: Nicola you mentioned that one of the core priorities of the Commissioner is "Enabling everyone to age well". As we all know, Covid affected the ethnic minority communities at a significantly higher rate, both in relation to catching the virus, to how ill people were to resulting deaths. What, if any, additional provisions (by Welsh Gov, LA's, your Office, etc) were provided for elderly members of minority ethnic communities during and after Covid to ensure everyone is given an even footing to enable them to age well?

**Nicola:** I guess this is slightly difficult one for me to answer because the Commissioner doesn't provide public services herself. She's there to scrutinize the work of the public bodies. So I think I wouldn't really be able to answer on behalf of Welsh Government or Local Authority.

Aging well should be about the quality of life. So, everybody in this society should be given that opportunity to have a good quality of life. The Commissioner is working with public bodies to make sure that they are working towards becoming an age-friendly community. So Local Authority must tackle problems that prevent older people doing things that matter to them, such as accessible public transport which can help to reduce loneliness. Also having services in place that would help older people to go out and attend medical appointments. In addition, rising cost of living is creating barriers to older people which can lead to fuel poverty and hunger. So I think, it is important to work closely with local authorities to make sure that they're working towards becoming an age-friendly community. And that means age-friendly, for all older people, all people more widely. So whether they have additional needs because English might not be their first language or they have additional needs, because maybe they have a disability. We want to make sure our work with older people from minority ethnic



communities is represented in our priorities, as age-friendly community is a community that benefits all of us regardless of the background and circumstances.

**Gerli:** The emergency legislation introduced during the pandemic, by the national and regional governments had a profound consequence for older people's rights, especially for people from minority ethnic communities. Do we need a public inquiry into the suffering of older people during the pandemic?

**Nicola:** The commissioner was very concerned as well when the Coronavirus Act, which was introduced during the pandemic, removed people's rights in relation to social care. We saw potential breaches of people's human rights, particularly for older people living in care homes. The Commissioner has called for a specific Covid inquiry. She's been quite clear in her position that we do need an Inquiry in Wales and she hopes to ensure that older people are able to participate in that inquiry to make sure that their voices are heard and their experiences are properly captured. Some people have worked through the pandemic, you know, in very stressful jobs, I think those experiences need to be captured. The Commissioner is keen to ensure that the voices and experiences of older people from ethnic minority backgrounds are heard by the Inquiry.

## Rahila Ahmed, in a volunteering capacity.

**Twahida:** In your experience and the people that you have worked with, do you feel that the care provisions in place are sensitive to Black, Asian and Minority Ethnic older people? For example, if carers are going into an individual's house to help care for an individual, are they trained up to understand cultural/religious needs of that particular client?



**Rahila:** No, not really. I think through my engagement and prior to lockdown, I feel there is lack of understanding amongst all professionals, but also healthcare workers who care for older people in their homes. People have different cultural needs around their care. For example, people prefer to eat their own cultural food, wear their cultural dress etc. But some carers refuse to do certain things that are unfamiliar to them as they lack that cultural awareness.

## Alex Osborne, Disability Wales

**Twahida:** Do we have enough cultural awareness in service provision to BME older people with disabilities? What more can be done?

**Alex:** No, I don't think there's enough at all. I think it's really lacking that awareness for all of us, including charities. We all need that training and awareness. and I think that's the answer. We need to deliver quality training around disabled people and how employers can support them in the workplace. We could deliver a training that combines both disability and cultural awareness. I think the answer is just more training and more engagement, so we're trying to engage more people from minority ethnicities, and train service providers about cultural awareness. We all just need to take a look at ourselves and see what we can do better.

#### **Open Discussion**

- Concerns over accessing services for older family members were highlighted during the open discussion. It was noted that elderly relatives continue facing discrimination and prejudice when trying to access the services.
- Some expressed their frustration over the frequent consultations to capture the lived experiences of older people, but despite having lots of data nothing changes. One



participant felt that social services have not improved over the last 15 years and that we are still discussing the same issues, yet nothing gets done. The care system continues to be culturally insensitive, discriminatory, and inaccessible to older people from ethnic minority backgrounds. There is no diversity in the care system and the cultural needs of BME older people are not catered for.

- One participant asked the panel to give examples of what has happened that positively impacts the lives of older people from ethnic minority communities
- Nicola volunteered to answer: We've got the social services and Well-Being Act so there are provisions in that Act that should mean that you should not experience those barriers. I think that organisations can fight on people's behalf because sometimes those rights in the existing legislation are not upheld and implemented meaningfully. So, I think there has been legislative changes in terms of positives, but implementation can be challenging. Nicola strongly feels that we need to make sure that people can claim their rights and organisations are held to account when they're not doing what they should be doing.
- One participant welcomed the changes happening in urban places in terms of creating more accessible spaces for the communities. However, she stressed the importance of creating spaces that are accessible to older people and people with disabilities. Currently, older people are struggling to access public transport as it is either not available or accessible, and these issues must be addressed according to the forum participant. In addition, she expressed her concern over the health and social care not delivering culturally appropriate care to minority ethnic older people. She agrees with Alex that public, and third sector needs to diversify, and professionals should receive training on cultural awareness when providing services to the ethnic minorities.
- Another forum participant agreed, suggesting that organisations and communities need to work together to educate each other about cultural differences and diversity



in Welsh society. Education on diversity and cultural awareness should underpin the training goals of service providers, including schools who need to teach about diversity.

"We don't know, everybody's culture properly either, right? We are still learning [...], [and] there's a lot of differences. I have been going around with various religious communities, trying to understand or improve my education and understanding [...] I think we need some organisations to take on that kind of task [...] get involved and the impact had to be promoted into the wider community".

• Furthermore, the existing data on ethnic minority older people should be pulled together in a coherent format so there is a foundation to work from. A number of forum participants felt frustrated for being constantly consulted on their lived experiences but have not seen any meaningful change happening as a result of these consultations.

"We need to take action now and stop collecting more data"

 Another forum participant welcomed the issues discussed in today's forum and offered her reflections on working with older people from ethic minority communities. She noted that the ethnic minority older people today are from a very different generation, a generation who moved to Britain after the Second World War to rebuild the war-torn Britain. For example, the survivors of Windrush generation who were brought to the UK from Jamaica, Trinidad, Tobago, and other Caribbean islands to fill the post-war labour shortages. These communities have shown their gratitude for the smallest gestures rather than standing up for injustice and claiming their rights. She feels that the next generation of older people are more likely to demand their rights and push for a change in society.



"All sorts of policies to push for social change will come from within that group and that's something I really hope. I will aspire that the next generation of older people feel more valued for who they are irrespective of their race, ability, disability, sexual orientation".

## **Closing Remarks**

**Gerli**: Thank you so much for attending today's forum. I found the issues highlighted very powerful and something we need to work towards now. I was especially interested to hear about your views on consultation fatigue and abundance of data available on the lived experiences of older people. Having done some research prior to the forum, I discovered that there appears to be a limited data on ethnic minority older people in the public domain. It appears that organisations and community groups working with ethnic minority older people may have internal data, but this has not been captured in one coherent format. Hence, I suggest we all need to work together as a team to capture the existing data on older people, and the Older People's Commissioner could take a lead on it as they are already working on this as part of their research project on exploring the lived experiences of ethnic minority older people. Perhaps there is a room for expanding their existing methodology.

Thank you so much for sharing your insights and experiences on the issues that affect ethnic minority older people. If you have any further questions or comments, please feel free to share them with us. Sending you all very warm wishes and thank you so much for coming. We will be finishing this meeting now.