



Ethnic Minorities
& Youth Support
Team Wales

Tim Cymorth
Lleiafrifoedd Ethnig
& Ieuenctid Cymru

All Wales Black Asian Minority Ethnic Engagement Programme

19 January 2022

Topic: Race and Healthcare

“Inside Out: The Shortfalls of the Healthcare System.”

Minutes of the Meeting:

Attendees:

27 attendees in total, 4 of whom were the members of the All Wales BAME Engagement Team. The forum was opened up and attendees were invited to share introductions, either verbally or in the chat function.

Rahila Hamid, Suzanne Duval (Diverse Cymru), **Ann Spinks, Lisa Yokwe** (Carers Trust South East Wales), **Gwen Anslow** (All Wales Forum), **Peter Gee** (Health and Care Research Wales), **Sadia Malik** (EYST Wales – Multilingual Helpline), **Deborah Stauber** (Gypsies and Travellers Wales), **Himalee Rupesinghe** (Race Equality First), **Sandra Mitchell** (Hywel Dda UHB), **Ginger Wiegand** (EHRC), **Stephani Kays** (Hywel Dda UHB), **Faith Walker** (Friends of Sickle Cell and Thalassaemia), **Andrea Gray** (NHS Wales), **Lara Rowlands** (Bridgend Council), **Catriona Learmont** (TNL Community Fund), **Rhian Meaden** (NHS Wales), **Hassim Ganiyu** (NHS Wales), **Cece Harman** (Powys County Council), **Helen Ley** (Macmillan Cancer), **Sarah Bowen** (Carmarthenshire County Council), **Fateha Ahmed** (EYST Wales – BME CYP), **Patricia Ushie, Alina Joseph** (Friends of Sickle Cell and Thalassaemia), **Debanjali Bhattacharjee** (EYST Wales – Multilingual Helpline), **Nelly Adam, Sivagnanam Sivapalan, Richard Speight** (UNISON), **Dalia Alhusseini** (EYST Wales – Multilingual Helpline), **Afshan Morgan** (Aneurin Bevan University Health Board), **Abi Lasebikan** (Senedd Wales), **Karen Owen** (NHS Wales)

Key Speakers: **Allison Hulmes**, BASW. **Josh Law**, All Wales Forum. **Alex Osbourne**, Disability Wales.

Discussion on Race in Healthcare in Wales

EYST Presentation

Background of topic explained:

- Why this topic?
 - Inequality in accessing healthcare.
 - Inequality in employment within healthcare.
 - Lack of genuine engagement.
- Lack of research into effect of race on healthcare provision and services.



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- Lack of training provided to healthcare providers.

Areas covered:

- Covid-19 effects on mental and physical health
 - High rates of BAME employment in front facing roles.
 - Higher rates of BAME groups admitted to Critical Care and/or dying due to a Covid-19 related death.
 - Effect on Filipino nurses and the high death rate for those in healthcare roles.
 - BAME staff felt that they were expected to work on Covid-19 wards more so than their White counterparts, and that they were also unable to access PPE as easily as White counterparts.
 - Mental health effects.
- Employment within Healthcare
 - Background of BAME Healthcare Staff
 - Issues facing BAME staff.
 - Lack of training.
 - Passing off BAME patients to BAME staff.
 - Unequal job allocation and opportunity.
- Healthcare Services
 - Incorrect assumptions about BAME patients and their families cause issues with healthcare provisions, such as:
 - Interpersonal links.
 - Religion.
 - Internal Bias within healthcare.
 - Language barriers.
 - Economic inequality between BAME communities and peers.
 - Fear of reprisals.
- Barriers to asylum seekers and refugees accessing healthcare services.
 - People not knowing their rights.
 - Healthcare professionals not knowing the rights of asylum seekers and refugees.
- Mental Health disparities and effect on BAME population.
- Disparities within disability services.
 - Physical:
 - Medical and Social Model of Disability
 - Learning:
 - Learning Disability Diagnoses.
 - Access to support and services.
 - Wider Societal Impacts.



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- Social Care
 - Barriers facing carers
 - People don't realise they're carers
 - Difficulty in navigating the system
 - Lack of support from professionals
 - Assumptions that BAME communities "take care of their own"
- Reasons for not reporting issues faced.
 - Language barriers.
 - Fears of reprisals.
 - Denial of racism can be a coping strategy.
 - Unaware of the racism being targeted at victim.

Resources used:

- *"Who supports the families of black and minority ethnic children with life-limiting conditions?"* Dr Wahida Shah Kent, 2020
- *"Black and Minority Ethnic Groups, Learning Disability, and the Need for Ethnicity Data | University of South Wales."* Dr Wahida Shah Kent, 2021
- *first-ministers-bame-covid-19-advisory-group-report-of-the-socioeconomic-subgroup.pdf (gov.wales)*
- *Review of Evidence of Inequalities in Access to Healthcare Services for Disabled People in Wales (gov.wales)*

Allison Hulmes, BASW

Background of GRT community in UK

- First mention of Gypsies in UK has been found in a document dated 1514, and Roma migrants from Central and Eastern Europe arrived later in UK from 1990s.
- Consistent persecution from all European states, and especially effects of Holocaust from WWII, factor into mental health of GRT communities.

Lack of data

- Lack of ability to self-identify as Roma until 2011, and then statistics for GRT community are not disaggregated, despite having distinct ethnicities and identities.
- Reluctance to self-identify as GRT due to long history of oppression and persecution. Reluctance is growing due to impact of the upcoming PCCS Bill.
- Lack of data means that crucial information has not been gathered.

Health issues for GRT Community

- Average life expectancy of GRT populations in UK is estimated to be 10-12 years less than that of a non-GRT person (Parry et al., 2004)



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- Health status of a 60 year old GRT person is equivalent to that of an 80 year old non-GRT person.
- Why is this happening? This wouldn't be the case if GRT community could access adequate primary and secondary health care.
- 26% of Census GRT respondents who were of working age and economically inactive are disabled or long-term sick – highest % of all ethnicities.
- Access and navigating the system is difficult unless you have a good formal education. GRT communities have the lowest % achievement of all ethnicities at early years and lowest attainment of grades A*-C in GCSE. This leaves GRT communities at a disadvantage when navigating the healthcare system.

Issues that impact GRT community health

- Impact of hate crime
 - Correlation between experiences of racism and suicide in GRT communities as per 2020 Greenfields and Rogers Report, "*As right as rain.*"
 - Hate crime has impact on mental health of GRT community.
 - Traveller Movement, 2020, found that suicide rates in GRT community are 6x higher than that of non-GRT people.
- Impact of housing
 - Good housing underpins having good health care.
 - Local authorities are not investing in authorised sites, and lots of sites are next to roads and refuse sites with environmental pollution. This also affects mental health.

Work to help address health issues within GRT community

- *Enabling Gypsies, Roma and Travellers*, 2018 policy by Welsh Government was set out to improve the health of GRT community, but these goals have not been met.
- 'Missing Voices' of Disabled People in the UK was co-produced research to try and fill the gaps in knowledge of disability within GRT community.

Issues faced by GRT community with accessing disability healthcare

- Complex systems and long waiting times were deterrents.
- Mistrust of the healthcare system and not being taken seriously.
- Lack of knowledge.
- Shame and stigma.
 - Feelings of being 'outsiders' when in rooms with other people seeking help from disabled organisations. No issues with those running the schemes, but from peers.
- Presumptions about the caring capacities of GRT communities.
- Different services between those in housing and those on sites.
- Previous bad experiences.

How do we improve disabled healthcare for GRT community?

- Address language barriers by use of interpreters and use of videos in place of written text.



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- GRT specific disabled organisations.
- Reaching out to communities at an early age and engaging young men in particular in conversations regarding mental health.

Josh Law, All Wales Forum

Introduction to All Wales Forum

- Work with families and carers of people with learning disabilities and autism.
- Hoping to reach out and collaborate with different communities on current and upcoming work.
- Forum was born from wish of families to improve the lives of people and carers of people with learning disabilities, to strengthen their voices and have their needs met.

Who do AWF work with?

- Work with carers, but also indirectly help people with learning disabilities through their carers.
- Involved in the Learning Disability Ministerial Advisory Group and Carers Advisory Group; they share carers voices directly into the group regarding what's important to them, what they need, and community-based solutions. Aim is to improve carers lives through policies.

Inequalities that carers face

- AWF work on direct and indirect health inequalities facing carers.
- Caring Communities to Change project- Welsh Government funded project. This involves working with carers and running pilots that explore different solutions to issues carers face across 3 main themes:
 - Transitioning: Transitioning from home to independent living.
 - Respite and short breaks.
 - Community Activity.
 - All these issues require working in close partnerships with local authorities and health boards.

Types of pilots

- Respite Model
 - Last 18 months have been brutal on carers, with some having no breaks in this time.
 - With bricks and mortar traditional respites not being open there has been conversations about introducing the Respite Model, as seen in Scotland. This scheme links carers with the hospitality sector where businesses are able to donate breaks.
- Payments
 - What are the effects of direct payments and the role of pooling people's direct payments budgets to access shared breaks together.

Health-based work



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- Focus on what digital platforms and resources are available to families and carers.
- Worked with Learning Disability Wales to look at Health Equality Framework. This Framework is used by those with learning disabilities to ensure equitable access to healthcare.
- Focus groups showed that carers were interested in the Framework but, while useful, is never presented to them. Shows that the Framework needs to be embedded into practice in order to be utilised as effectively as possible.
- How do we work with Welsh government, local authorities, health boards, and regional partnership boards to ensure that this Framework is embedded in practice consistently? Inconsistent use of the Framework exacerbates health inequalities that exist now, as help and access to healthcare is a 'postcode lottery' currently; where you live and what community you come from can affect the quality and quantity of healthcare you get.

Connectivity

- Connect parents and carers to various research projects, such as being part of a group who supported parents and carers in accessing Coronavirus and people with Learning Disabilities Study.
- Working with Learning Disability Wales, University of South Wales and All Wales People First in the UK wide research project, with AWF representing Wales and connecting parents and carers to the research to answer on behalf of a loved one who may not have capacity to answer the questions themselves.
- As the pandemic raged, things did not change much for parents and carers. There were peaks and troughs where the world started to open up a bit more, allowing people to have more freedom, but levels of stress, anxiety, and depression remained quite high.
- There were unique challenges for carers and parents of those with complex or high health needs to access services that are available, such as:
 - Transport
 - Personal Assistance
 - Aids to fix these issues nosedived during the pandemic, causing extra stress and anxiety for carers.
- This has led to the need for research on the impact of the pandemic on parents and carers, which is being done in conjunction with Queens University, Belfast. The aim is to develop:
 - Resources and ways to improve connectivity and networking between parents.
 - What resources were required during the pandemic.
 - What resources they need going forward.
 - AWF want to take this information to the Learning Disability Ministerial Advisory Group and Carers Advisory Group to influence change within policy.

BAME communities and research projects

- The first research project failed to engage with BAME communities in any sort of way; not for lack of trying, but connections with communities weren't there.



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- This lack of BAME input means that any recommendations from the research in policy won't reflect the needs of the BAME communities, as said by Allison Hulmes.
- AWF aim to link in with different organisations and communities to ensure that the research undertaken and information shared is as diverse as the communities it represents.
- AWF are looking to widen their networking to get insights from everyone to help shape policy so that the policy that is introduced will accurately reflect the diversity of parents and carers of people with learning disabilities in Wales.

Upcoming projects

- Parents ID project with Queens University, Belfast.
 - Previous research really highlights the gaps in services and how the parents and carers of Wales feel.

EYST

Forum is opened for questions.

- Selima Bahadur explains that All Wales BAME Engagement Team can help with:
 - dispersal of information, surveys, posters etc.
 - The team has a wide network that can be used to share opportunities for BAME communities.
 - Share information in the Stakeholder Newsletter.
 - Attend advisory groups.

Allison Hulmes, BASW

- Offers similar services to assist in getting in touch with GRT community, as well as following organisations:
 - Travelling Ahead
 - Gypsy Travellers Wales
 - Romani Arts

Participant comment

- Policy and implementation of equality policies needs to be done properly, as without action there can be no change.
- Health boards and health services need more diversity, as people are being shut down when attempting to make face to face appointments with a GP due to the pandemic. If they do not have the confidence to challenge this decision and call for their request to be taken seriously, their health can be affected.

Josh Law, All Wales Forum

- Social Services and Wellbeing Act is a great piece of legislation, but it is not implemented properly in practice all the time.
- Element of culture change is needed in healthcare, and it's very important to use the research and information collected to effect positive change.



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Selima Bahadur, EYST

- People do not have time to waste, as said in attendance of meetings and groups. People attend and share their information because we need policy and practice change in Wales.
- If BAME communities and organisations, such as the attendees today, do not speak out then change will not happen. Events like today spur tiny changes, which can lead to bigger changes.

Participant comment

- We are doing a lot of research and closed doors work is happening, but this needs to go to funders and identify who can take the findings and research onwards to people in authority who are in a position to effect real change.

Participant comment

- The system needs to change, separately to policy change. Certain things can be changed by listening to what these communities need.
- Ongoing work is happening within the health inequality umbrella.
- Participant's project has been extended as there is evidence that they are needed and am glad that the health board sees the work that is happening and how needed it is for the BAME communities.

Participant comment

- Communities need to be contacted, otherwise how else will they know about what they're entitled to?
- Resources exist, but they're no good unless people can access them. There is no need for people to struggle or go without when there is facility and ability to help.
- Participant's project connects and help people get in contact with those that can help them, as well as providing literature in multiple languages so people can get information in their own mother tongue.

Alex Osbourne, Disability Wales

Background of Disability Wales

- Disability Wales are the national organisation for disabled people in Wales.
- DW attend Government sessions, work with other organisations, and conduct research into where disabled people are excluded.
- Disabled people's rights have taken a nosedive through the pandemic, and Covid has highlighted how some groups are ignored and sidelined more than others.
- Language is crucial within policy and has an impact of how people view themselves and others, and for this reason DW use *The Social Model of Disability*. People think of disability as negative, exclusionary thing, but DW use the model to show how society fails to make the world accessible for disabled people so that they can partake in everyday activities.



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Disability Wales' work

- DW is all about accessibility:
 - Documents are sent in Microsoft Word as often as possible as those who use screen readers have difficulty in using these in conjunction with PDFs.
 - Large, clear text is used for ease of reading.
- One of the largest pieces of work was the 2013 publication of *Know your Rights*, which includes information such as the Equality Act and the Wellbeing Act to strengthen people's knowledge and empower them to ask for help and services that they are entitled to when speaking to bodies such as local council.
- 2020 survey of DW's members whilst doing work around the elections and the writing of their manifesto highlighted that of the 120 people surveyed:
 - 68% people responded that their rights were not adequately enforced.
 - Of these people, 78% believed that their rights would not improve in the next 5 years.

What rights do people have?

- Reasonable adjustments within:
 - Homes, such as stairlifts being fitted by landlords.
 - Workplaces.
- When it comes to local authorities, quoting your rights seems to trigger quicker responses and quicker implementation of rights and services for disabled people.
- An example is in North Wales, barriers would be erected during 9am-6pm which would shut vehicular access to the High Street. However, this would unfairly affect disabled people as those with mobility issues found the parking spaces too far from the High Street. With the *Know your Rights* pack, the member was able to get the local authority to open the High Street one hour earlier and close one hour later to allow vehicles to access the High Street, therefore safeguarding disabled people's access to the High Street.

Disability Wales' work with the Welsh Government

- The Government will be forming the Disability Task Force, as recommended by DW.

Participants comment

- Highlights how Sickle Cell is the world's most common blood disorder, and it is a life limiting condition.
- Extends thanks for the platform today to share their information and highlight how it took 22 years of fighting for a specialist commission for Sickle Cell and Thalassaemia.

Hasminder Aulakh, EYST

- Agrees that more funding needs to be given to organisations helping those with Sickle Cell and Thalassaemia as the prevalence of the diseases does not align with funding allocated to organisations.
- Conclusion of the session, and thanks extended to the attendees and speakers.



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End of session