

Let's Talk about Dementia - End the Stigma

**A report on Diverse Cymru's BAME Dementia Event
held on 19 September 2019**



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Background

On 19 September 2019 Diverse Cymru welcomed more than 100 people to “Let’s Talk About Dementia – End the Stigma”, an event organised by Diverse Cymru’s BAME Dementia Project to mark World Alzheimer’s Month 2019.

Held in Butetown Community Centre, Cardiff, the event was aimed at BAME (Black Asian and Minority Ethnic) people who live with dementia or care for someone with dementia, service providers and anyone wanting to find out more about the condition. The purpose of the day was to raise awareness of dementia, and available services; find out the experiences of BAME people around the condition and to identify ways of improving services and so ensure that BAME people receive fair and equal treatment.

Dementia is one of the most challenging health issues we face and the number of BAME people affected by dementia is expected to rise significantly and at a more rapid rate than that for White people.

The All-Party Parliamentary Group on Dementia suggested that the current estimate of nearly 25,000 people with dementia from BAME communities in England and Wales will grow to nearly 50,000 by 2026 and over 172,000 people by 2051. This is nearly a 7-fold increase in 40 years. It compares to just over a 2-fold increase in the numbers of people with dementia across the whole UK population in the same time period. (The British Psychological Society 2016)

For members of our BAME communities the challenges brought by dementia can often be overwhelming and they can face significant barriers when accessing services. At our event we explored the reasons for this: including lack of awareness of dementia among BAME communities; institutional racism / inequality; and a lack of culturally appropriate assessments by service providers. We also listened to people attending the event (a large proportion of whom were BAME people) including people living with dementia, carers and professionals working in the field and found out about their experiences and suggestions on how dementia provision for BAME people in Wales could be improved.

“Let’s Talk About Dementia – End the Stigma”, was the first event to be held by Diverse Cymru’s BAME Dementia Project which has been funded by Welsh Government to research dementia care for BAME people in Cardiff, Newport, Swansea and North Wales. With an emphasis on being “dementia friendly” the event included speakers, music and sensory activities, discussions, and an opportunity to visit a Reminiscence Pod. It was rounded off by a wonderful multicultural lunch during which people could socialise and visit information stalls.

This report outlines the event planning, presentations and feedback from discussion groups and is a first stepping-stone to raising the voices of BAME people and their carers on dementia service provision in Wales.

We believe that collaborative working between local authorities, Welsh Government, the NHS and the voluntary sector is essential to ensuring that BAME people and their carers are no longer missing from dementia service provision. This is a wonderful opportunity for Cardiff to respond to the challenges highlighted at this event and lead the way to achieving fair and equal access to dementia services for BAME people in Wales. Progress will not be made unless statutory, private and third sector service providers work together, and with BAME people, to ensure that dementia services are accessible, inclusive, fair and equal for everyone. We hope that our “Let’s Talk About Dementia – End the Stigma” event is the start of this process.



Pre-event planning

Diverse Cymru set up a **planning group** and invited organisations with links to BAME people, dementia and mental health issues to join.


Members were Diverse Cymru, Alzheimer's Society Cymru, CAVAMH (Cardiff and Vale Action for Mental Health), F W Consultancy, National Training Federation Wales, Nexus, Race Council Cymru and the University of South Wales. The group met from July to September 2019 and focussed on the aim and format of the event, and promotion. The emphasis was on holding a dementia friendly event that would be accessible, inclusive, informative and enjoyable for a range of participants including people with dementia, carers and service providers.

The theme of the event, "Let's Talk About Dementia – End the Stigma" was chosen to link in with World Alzheimer's Month, the international campaign that takes place every September to raise awareness and challenge the stigma that surrounds dementia.

The **objects** of the event were to find out about the experiences and knowledge of BAME people on dementia and dementia support services; to raise awareness of the condition and of available services; and to raise the awareness of service providers on the issues affecting BAME people in relation to dementia and the need to provide culturally appropriate and dementia friendly services. It was also important that the event provided an opportunity for BAME people and service providers to meet each other and share experiences with a view to taking things forward in a spirit of coproduction.

The **venue** chosen for the event was Butetown Community Centre in Cardiff, a well-known and well attended community venue that has been at the heart of one of the oldest BAME communities in Wales for more than 100 years.

The planning group was conscious of the need to ensure that the event was **dementia friendly**, inclusive and accessible. This was considered in terms of physical requirements, communication, catering and expenses with the aim of providing a safe environment particularly for those people living with dementia. The event was held on the ground floor of an accessible building to minimise any confusion people might have moving between different storeys. When setting up the main hall, care was taken to ensure that there was room for people using wheelchairs or mobility aids to manoeuvre.



A hearing loop was provided and the speakers were encouraged to use microphones. They were also asked to ensure their PowerPoint slides were visually accessible. Paper copies of the slides, including large print, were available if people needed them. Information in the event packs was also in an accessible format.

In addition to the main hall, 2 rooms were booked to provide quiet spaces for anyone who needed to take time away from the hall. In one of the rooms, Cardiff Libraries provided a **Rem Pod Vintage Shop** – a pop up reminiscence room. The other quiet space was also designated as a prayer room should anyone require this.

Care was taken to ensure that the **Event Programme** was dementia friendly and not too long in length with a mix of activities, songs, speakers, discussion, regular breaks and opportunities for socialising and lunch. Speakers were invited to speak for no longer than 10 minutes and included those speaking in a personal and a professional capacity. The presentations were interspersed with sensory and musical activities, and discussion so that there were a range of opportunities for involvement. Lunch was an important part of the event giving people the opportunity to socialise and visit the information tables.

The event was held in the morning with arrival and refreshments from 10 am, for a 10.30 am start as people, especially those with dementia, may need extra time to prepare for their day, or for their support workers / carers to start work. The event concluded with lunch to ensure that it was not too long a day for participants.

The **Welcome Letter** in the information pack included details of the quiet rooms and hearing loop and included **event ground rules** to help ensure the smooth running and inclusivity of the event.

Arrival refreshments and lunch were offered and drinks were available throughout the event. People were asked if they had any dietary requirements prior to the day. Lunch was multicultural with a mix of African Caribbean, Asian food and a sandwich buffet. Hospitality was key to ensuring that the event was welcoming and a way of demonstrating that the organisers appreciated the contribution of those attending.


Although a community venue, Butetown Community Centre is a little way from public transport and there is limited car parking in the area. To help overcome this barrier **travel expenses** were offered to participants, including taxis, mileage and car park fees. Travel expenses were paid in cash on the day to those who required them so that people were not “out of pocket”. In addition, taxis for women from a community group were paid after the event.

Access and replacement care costs, including childcare, were also offered to participants.

The **Information Pack** was printed in a visually accessible format. It included a welcome letter, programme, speaker biographies, an information booklet and leaflets about dementia and the BAME community as well as a song sheet for the musical activity.

Event invitations were sent to a wide range of individuals and organisations in Cardiff and the Vale of Glamorgan including BAME community groups and health and social care service providers. The event was promoted on social media and a Twitter “Thunderclap” was organised for the day of the event.

Staff were available throughout the event to provide support and assistance as required.



A **free event** for BAME people who live with dementia, care for someone with dementia or would like to find out more.

Let's talk about dementia — end the stigma




Image: Alzheimer's Disease International

Thursday 19 September 2019, 10 am — 2 pm (starts 10.30 am)
Butetown Community Centre, Loudoun Square, Cardiff

On the Day

Let's Talk About Dementia - End the Stigma

Suzanne Duval BEM, BAME Mental Health Manager at Diverse Cymru chaired the event and welcomed everyone.

The first speaker, Cllr Daniel De'Ath, Rt Hon Lord Mayor of Cardiff highlighted that the number of BAME people with dementia is increasing, and at a faster rate than for the White British community; dementia is less likely to be recognised by BAME people and is often seen as a natural part of ageing; inequalities between and within communities have a significant impact on BAME people living with dementia and their families. They are less likely to be diagnosed than White British people and if diagnosed they are less likely to access support services and more likely to face challenges at all stages of the dementia pathway. People from BAME communities are also more likely to experience a range of risk factors associated with dementia than White British people including diabetes and heart conditions.

The Lord Mayor concluded by speaking about the importance of good service and Cardiff Council's commitment to this as one of the largest service providers in the county. This includes fully engaging with and understanding people from all backgrounds who use council services. He called for a partnership approach between statutory, private and third sector service providers so they all work together and commit to meeting the needs of BAME people. He said that the voices of BAME people should be at the heart of this partnership approach and he hoped that they could share their experiences and ideas on how services could be changed to best meet the needs of BAME people and those who look after them.



Dementia, Culture and BAME communities

Mohammed Akhlak Rauf MBE

Mohammed is a Dementia Consultant with the Bradford-based Meri Yaadain (My Memories) Community Interest Company. In his presentation he highlighted that approximately 20 – 25 000 BAME people are living with dementia in the UK and a 7 to 8-fold increase is expected in this number. Also, there is no in-depth awareness of dementia within communities; and there is no in-depth awareness of community needs by service providers. Additionally, BAME people usually present late with dementia and usually at crisis point whilst already managing complex health care needs.

Mohammed said that **culture** might affect BAME people's experience of dementia in terms of carer upbringing and expectations; the role of faith; the role of spirituality; and societal / family expectations and stigma.

Migration also has a significant impact on experiences of dementia. For example, if a person with dementia had recently arrived in the country, the alien environment could cause space and time disorientation. In terms of language, people could revert to their mother tongue / first language and this could also affect their ability to communicate with the second or third generation of their family.

Racism is also a factor – there is a difference of perspectives as to whether institutionalised racism affects access to information / services and their quality eg, do BAME people with dementia feel welcomed or uneasy in a new environment? Service providers may also have a **“one size fits all”** perspective because of a lack of awareness of communities within communities. Therefore, person-centred support is more vital than generic, and there is the question of whether this should be relationship-centred. This could be with the person with dementia's family or a person(s) who has a close relationship to the person with dementia, and who is not necessarily the next of kin.

The service issues that arise are around whether assessments are culturally appropriate; whether they should be provided in a different setting; whether service providers have assumptions about carers' behaviour / expectations or prejudices eg **“they look after their own, don't they?”**

There are also **cultural issues** around dementia transition for the person and their family / community. For example, if a change in a person is noticed, should it be tackled? There is the notion of respect for an elder; it might be noticed that something is definitely wrong with the person and then it has to be decided whether this should be mentioned to the family / GP. There might also be the belief that dementia is part of the ageing process — has the person gone mad, are they possessed, should the Imam or GP be informed, should the situation be dealt with quietly?

Feelings within the family once a person has been diagnosed with dementia might include: “we’ll manage, because it is our duty to care, and we can’t send them to someone who might not look after them properly”. They might consider how they can provide home-based support in terms of adaptations to the physical environment. They might feel “we can’t cope anymore – who should we turn to for help (eg, social care, district nurse or respite services)?” In terms of end of life care the family can pivot from “we need institutional care support” to “we’ll do the best we can”.



Caring for a Person with Dementia – Personal Experiences

At the heart of the event was the voice of those with personal experience of caring for people with dementia from a BAME perspective and 3 speakers, Humie Webbe, Faith Walker and Gaynor Legall, focussed on their own experiences of **“Caring for a person with dementia”**. All gave powerful stories of love, heartache and hope, and their views on how services for people with dementia can be improved.

Humie Webbe - “Seeing the Person”

Humie spoke of her experience of caring for her father who has been diagnosed with Alzheimer’s disease and the challenges of navigating care services and working with health professionals to ensure her father receives appropriate support.

As a carer in fulltime employment, Humie highlighted the difficulties of juggling care responsibilities and work commitments and the benefits of having supportive employers and networks. She also stressed the need for health professionals to **“see the person”** and to **“work positively with families who may be able to impart vital knowledge on how to reduce anxiety in loved ones if they experience bad days”**.

Humie highlighted the challenges around communicating her father’s needs and called for **“health and care professionals to undergo cultural training to improve their understanding of the importance of personal care as a vital contributor in maintaining wellbeing for people living with dementia”**.

Humie stressed **“the need to be a ‘positive nuisance’** and for families to raise concerns, ask questions and inform health and social care policy makers of their experiences – good and bad - to improve their understanding of how to procure and deliver appropriate dementia care support services for BAME communities.

Faith Walker — “All mi ave a luv fi yuh”

Faith Walker gave a personal account of her life as a carer for her mother. Her presentation, “**All mi ave a luv fi yuh**”, is Jamaican Creole for, “All I have is love for you”. Jamaican Creole / patois (an English based creole language with West African influences) is the language of Faith’s mother who was born in Jamaica. Faith’s mother made Port Talbot her home in the 1960s. Now 78 years old, she is an inpatient at Tonna Hospital, which is managed by Swansea Bay University Health Board.

Faith introduced a PowerPoint presentation of photographs of her mother and her family to the sound track of Stevie Wonder’s beautiful song, “Yester-Me, Yester-You, Yesterday”. The presentation illustrated the impact of dementia on the family and the fact that the illness devastates the whole family not just the person living with dementia.

Faith gave a personal account of her experience as a carer for her mother and the challenges and the complexity of navigating through the care pathways that she faced. **She emphasised the importance of service providers understanding people’s culture and ethnicity, the significance of co-production and the interdependent approach to well-being.** She spoke of how crucial the knowledge, skills, values and expertise of mental health staff are when caring for a family’s loved ones in hospital when they cannot be cared for in the community.

Yester-Me, Yester-You, Yesterday

What happened to the world we knew
When we would dream and scheme
And while the time away
Yester-me yester-you yesterday
Where did it go that yester glow
When we could feel
The wheel of life turn our way
Yester-me yester-you yesterday

- Stevie Wonder

Gaynor Legall

“Caring for a person with dementia”

I suspected there was something wrong with my mother, her behaviour was different, so I went to see her GP to ask for a referral to “the Memory Clinic”.

That was the first of many arguments or battles. The GP was very reluctant to make the referral and it took 2 visits to him before he agreed. At the hospital my mother was diagnosed with Alzheimer’s disease. I insisted she was not told and argued that I knew my mother better than the doctor who had met her for the first time, no matter how many years’ experience he had had.

We held a family meeting – all of us who my mother had brought up, brother, cousins, foster sisters, nieces and nephews. They all agreed that my mother would not want to know about her diagnosis and we all agreed that WE would take care of her no matter what.

We quickly set up a rota, making sure my mother was never left alone and always had company. Things went well until she had a stroke and was admitted to hospital.

We, the family, thought we would continue the 24 / 7 care. We distrusted the level of care and compassion available in the NHS. We had had previous experiences and had seen stories on the TV.

The nurses were very much against one of the family being with my mother at all times but we insisted that we would retain our rota system, even staying overnight, because that was what we had been doing.

It was a battle but it was also our right, so we persisted and the nurses were, at first, very hostile to us. For the first few weeks there was a constant string of incidents and complaints but gradually that ceased. The staff saw that we were only there looking after the welfare of someone we loved very much. They began to see us as a help rather than a hindrance, allowed us to make ourselves a drink and brought in a recliner chair for us to sleep on during the night.

By the time my mother was discharged we were all firm friends and we were very pleased and grateful for the way the staff, all of them, shared the care of my mother with us.

Lessons Learnt or a Plea to Service Providers

Work with families not against them. Listen to them and think about what they are saying. If you don't agree, please give clear answers as to why not, don't give stock "the computer says no" replies. We know that the NHS cannot respond to each individual's needs, it is set up to deal with the masses, so accept the help of those that know that individual best.

Gaynor Legall

Musical Activity

Jacky Ayres of Alzheimer's Society Cymru led everyone in an inclusive musical activity. Each table had a range of percussion instruments and Jacky led everyone in singing the uplifting song "Yellow Bird". If people could not sing, they could join in using the instruments or enjoy listening to the music or watching people take part. Music is an important therapy used by practitioners to connect with people with dementia, bringing pleasure, evoking memories and emotions and improving mood. Based on the music therapy that Jacky delivers to people with dementia, the activity helped energise everyone and provided an opportunity for people with dementia, carers and service providers to join in an enjoyable activity, create music together and experience music therapy.

Rem Pod Vintage Shop

Throughout the event, people were able to take time out and visit the **Rem Pod Vintage Shop** operated by Cardiff Libraries in one of the quiet rooms. Reminiscence pods can provide a therapeutic environment, helping to provoke conversations and spark memories for people living with dementia, and so help to improve health and wellbeing. People visited the Rem Pod and were inspired by images of shop goods from days gone by, to share their memories of going shopping.



Workshop and Sensory Activity

The aim of the workshop was to find out about people's experiences around dementia, their understanding of the condition; their good and bad experiences of dementia related services and their ideas of how services could be better provided. Workshop participants were a mix of people with dementia, carers and health and social care professionals. There was a broad range of views and experience.

The workshop began with a taster **sensory activity**, devised by Jacky Ayres of Alzheimer's Society Cymru. This was an example of a therapeutic activity that can be used to connect with people who have dementia. The activity helped to make the workshop inclusive by providing another way for people to participate in the group.

Each group had 3 jars containing certain smells, eg, grass, lemon and coffee. The group facilitators passed the jars around and asked participants to identify the smell and share any associated memories or feelings that the smell evoked for them. The activity led into a discussion around people's experiences of dementia. Participants could also write their views on post it notes and place these on flip chart paper on the wall if they felt that they had not had their say in the group discussion.

Workshop Discussion Summary

There were different levels of knowledge and experience amongst the participants. **Most had heard of the word "dementia" but they did not necessarily know there were different types of dementia or the symptoms of the various conditions.** Some people felt there was a **stigma** around the illness, others that it was a natural part of ageing. Others said that some BAME people think the **supernatural or evil spirits** are the reason for the behaviour of a person with dementia and not that it is because of illness. Others mentioned certain aspects associated with dementia, eg memory loss, confusion, forgetfulness, and aggression.

Some said they had **the fear of losing the person with dementia to the disease and of the person forgetting family members.** For the person living with dementia, some felt the illness meant a loss of autonomy, or that the person / their families may not accept that they have dementia or may fear rejection because of the illness. People felt that an individual with dementia was vulnerable and that their dignity would not be respected.

The impact of dementia on families was discussed. Family could be uncertain of how to deal with the person before a dementia diagnosis is made. They might think the person was mad or the victim of a curse, or that the behaviour of the person was an inevitable part of ageing rather than because of a disease. The family could also feel shame and stigma. Dementia was regarded as a cruel disease that can affect anyone and have a devastating impact on both the person diagnosed and their family. People spoke about the difficulties of caring for a family member with dementia and the resilience it takes. Family members who act as carers also need more support and information on services available to assist them as well as the person they are caring for. **It was important that information is not just provided online as many people are not digitally literate and have little or no access to the internet.**

There was a **mixed experience of families' interaction with service providers**. Issues mentioned included not enough information on where to get advice and support and difficulty accessing appropriate services. Even if a dementia diagnosis is obtained, the family can still feel isolated and lacking in support. Some felt that if a person with dementia was admitted to hospital, nurses are often not trained to deal with dementia patients. Some people said there was a lack of respect and dignity in services for older people. Other people said that minority ethnic communities tend to have a lot of respect for GPs, however GPs need more training and knowledge on dementia and support services. In addition, some people felt that there was often no continuity of service and that services were often inflexible and did not communicate with each other. There is also no standard provision of services by councils, with each council offering different services and facilities for people with dementia and their families.

In terms of **paid for care**, people said that some care provided is excellent, but that standards must be raised. They felt that care workers are underpaid for the work that they do and care services are frequently understaffed.

With regard to **BAME people and dementia** in particular, there was a suggestion that the tests for dementia are based on White European models and do not take into account people of other ethnicities. **There was also concern that not enough research is being conducted, or statistics collected, on the prevalence of dementia in BAME communities.**

Another issue raised was **whether domiciliary care workers are culturally sensitive to the needs of BAME people with dementia.**

It was also felt that there are not enough care homes in Cardiff and the Vale of Glamorgan that take into consideration the needs of people from BAME backgrounds, especially in terms of cultural awareness and language provision.

Language barriers could also be a concern within families, eg, an older person with dementia may not speak English or they may revert to their mother tongue when they become ill but their children may not be able to communicate in that language.

Suggestions on the provision of a good dementia related services included: agencies and organisations better understanding the individual's needs with an emphasis on person-centred care and building relationships, including listening to the person with dementia, and family members, with compassion and understanding and respecting the dignity of the person with dementia.

There should also be **more training for service providers such as GPs to increase their knowledge of dementia.** A good service should be open-minded and not defensive. It should be human. More funding is needed for services and they should be accessible. Good services should provide dignity, recognising that the person with dementia is still a person.

Access to early diagnosis of dementia would also help families to know what steps to take to support the person with dementia. Culturally appropriate assessments should be provided and services should communicate with each other in a joined up way.

Therapeutic services such as singing and reminiscence should be accessible and also take into account the cultural and linguistic needs of people with dementia.

Overall there was a demand for **more, and better, information on all aspects of dementia and dementia related services** and this would go some way to improving service provision.

Lunch, evaluation and expenses rounded off a wonderful event. People again had the opportunity to visit the information stalls and the Vintage Rem Pod Shop and to socialise.

Conclusion

“Let’s Talk About Dementia – End the Stigma” was an inspiring event bringing together people with dementia, carers and health and social care providers to focus on the experiences of BAME people with dementia and their families and carers. More than 100 people listened to speakers, shared their views and experiences and connected through music to explore the issues and suggest ways that dementia service provision can more fully meet the needs of BAME people in Cardiff and the Vale of Glamorgan.

The success of the “Lets Talk About Dementia — End the Stigma” event highlights the desire for more information, research and action around dementia and the affect it has on people from BAME communities in Wales. Diverse Cymru’s BAME Dementia Project aims to build on this event by holding similar events across Wales and also by interviewing BAME people with dementia and their carers about their experiences of the condition and dementia services.

Findings from the project’s research will be shared with Welsh Government, other statutory agencies, third sector and private sector organisations with the aim of ensuring that service provision for BAME people in Wales is fair, equitable and person-centred.

Diverse Cymru would like to thank CAVAMH (Cardiff and Vale Action for Mental Health) and Cardiff and Vale Integrated Health and Social Care Partnership for funding the “Let’s Talk About Dementia — End the Stigma” event via the Dementia Friendly Communities Small Grants Fund.

Recommendations Arising from the Event

There needs to be more research by service providers into how BAME people in Wales experience dementia. Statutory, private and third sector service providers must build relationships with each other to take this forward. It is also important that differences within and between BAME communities are recognised and there is not a “one size fits all” approach to providing services.

Service provision should be patient-centred and respect the dignity of the person with dementia. There are many examples of good care but frequently BAME people do not receive care that is appropriate for their needs, especially their cultural and language needs. Service providers should also provide dementia friendly services in general.

Information on dementia and dementia related services should be provided in a range of formats, not only digital, as many people do not have access to the internet or are not computer literate. Information provision should also take into consideration the cultural and language needs of BAME people.

There should be **more awareness raising and signposting around dementia and dementia services in BAME communities** and this would help to remove the stigma around dementia.

There is variation in the care provided for people with dementia. **Good practice and high quality care for people with dementia needs to be consistent across service providers.**

There must be **more support for carers**, particularly those caring for family members with dementia.



Appendix 1

Speakers Biographies

Councillor Daniel De'Ath

The Rt Hon The Lord Mayor of Cardiff

Municipal Year 2019 - 20 Personal Details

Dan De'Ath is the 115th Lord Mayor of the City and County of Cardiff and the first Lord Mayor of Black heritage of the Capital City of Wales.

Dan grew up in Warwickshire, where he worked in the museum and heritage sector and moved to Cardiff to work as a researcher at the National Assembly for Wales.

Dan lives in the Roath area of Cardiff, which he has represented as a County Councillor since 2012.

Dan's partner and Lady Mayoress, Rebecca, is a Criminal Defence Solicitor and lecturer in criminal law at Cardiff University. They have 4 children Ruby, Ella, Harry and Nancy aged 3 to 13.

Political Career

Dan was elected to Cardiff Council in 2012 representing the Plasnewydd (Roath) area of the city.


He has served as Chair of the council's Community & Adult Services Scrutiny Committee in 2013 which examines the local authority's delivery of Adult Social Services, Community Safety and issues like homelessness and welfare reform.

In 2014 Dan was asked to join the council's Cabinet serving as Cabinet Member for Early Years, Children and Families and then, following a reshuffle, the Cabinet Member for Safety, Engagement and Democracy.

After the 2017 elections, Dan left the Cabinet and became Deputy Lord Mayor of Cardiff for the Municipal Year 2017 / 18.

Lord Mayor's Charity

Dan has studied Social Work, which has involved him working in a refuge for male victims of human trafficking and modern day slavery and a placement working with male and female victims of domestic abuse. As a result Dan has chosen Welsh Woman's Aid and BAWSO as the Lord Mayor's charities for 2019 / 20.



Suzanne Duval has worked in the voluntary sector for over 30 years, representing, supporting and delivering much needed services to BAME individuals, agencies and support organisations throughout Wales. In 2018, Suzanne was awarded the British Empire Medal in the Queens Birthday Honours List for her BAME mental health work in Wales.

At Diverse Cymru she is BAME Mental Health Manager with responsibility for managing the BAME Dementia Project and a BAME young people's mental health project addressing inequality in mental health services within the BAME community.


She is currently working collaboratively with all 7 local health boards, the Welsh Government, local authorities, voluntary sector, Public Health Wales, Royal College of Psychiatrists and United Kingdom Investor in Equality and Diversity (UKIED) to represent the views and concerns of BAME people with mental health issues.

She has written a "Cultural Competency Toolkit for Wales" and is working with UKIED on an Accreditation for the Toolkit which will be the first of its kind in the UK.

Before joining Diverse Cymru, Suzanne was the Director of Awetu All Wales BME Mental Health Group (the only organisation of its kind in Wales) for over 10 years where she was responsible for managing the project and 7 staff.

Mohammed Akhlak Rauf is the Founder and Director of Meri Yaadain CiC, a community interest company, based in Bradford. The organisation aims to support BAME people living with dementia and carers looking after a relative or friend living with dementia. Meri Yaadain CiC also works with service providers to embed cultural competency into practice.

Mohammed has 20 years' experience of working with BAME communities with regard to engagement and access to information and services. He is currently completing his PhD studies looking at how South Asian family carers cope with the transitions associated with looking after a relative with dementia. He was awarded an MBE from the Queen in recognition of his efforts for "services to people with dementia and their carers".




Faith Walker is a co-founder of Women Stepping Out, which promotes education and self-confidence within the Welsh African Caribbean community and she managed it between 1994 — 2014. She has worked to help empower children, young people, families and communities in her many roles including community activist, life coach, mentor and community development consultant. She has 27 years' experience working with communities and is a qualified youth and community practitioner with a BA (Hons) in Community Education and a Master's in Education.

Faith is also a member of the Equality and Human Rights Commission Wales Committee and the managing director of F W Consultancy. She is a presenter on Radio Cardiff. Faith was appointed by the Police and Crime Commissioner for South Wales to conduct consultation work on his behalf with the African / Caribbean community in South Wales. She is a Llais member at Swansea University and is also a member of Friends of Cardiff Sickle Cell and Thalassaemia, which provides support to those affected with the condition and their families.

Humie Webbe was born in Cardiff to parents of Caribbean heritage who are part of the Windrush Generation and is one of 8 children. Humie has an MBA in Project Management and a BA Hons in Community Education. She has worked in the public and community sector for almost 30 years devoting her time to championing disadvantaged groups, in particular BAME and disabled people, to have an effective voice in improving services and opportunities.

Humie's roles have include Autism and Asperger's Lead for the charity All Youth Matters, National Diversity Co-ordinator for the mental health anti-stigma campaign Time to Change Wales, Operational Manager for the Cardiff Communities First programme, and advisory roles with Arts Council Wales and the Cultural Skills Sector.

Humie is employed as Work Based Learning Strategic Equality and Diversity Lead and works with Welsh Government to increase participation of disabled and BAME people into apprenticeships. She uses her personal experience of working with health and social care professionals to ensure strategies and policies work to effectively reduce barriers and reflect the individual's ability to access appropriate support.



As the mother of an autistic son and the main carer of her father who has Alzheimer's disease Humie is passionate that people with cognitive difficulties have an equal platform to communicate their wishes and concerns and she is a member of the National Autistic Society and Carers UK.

Humie's interests include politics, community arts and jazz music. She is a member of Wales TUC Equality Network, Unite the Union's BAME Committee and is founder member of Black History Month Wales and presenter / producer of a weekly jazz show for Radio Cardiff. In 2018, Humie was included in the "Western Mail" list of top 100 brilliant African Caribbean and African Welsh people who have helped shape Wales and in 2019 she received an Ethnic Minority Welsh Women Achievement Association Social and Humanitarian award.

Gaynor Legall is Chair of the Heritage & Cultural Exchange and was the Chair of the now defunct Butetown History & Arts Centre. She lives in Cardiff with her husband.

Gaynor was born and raised in Butetown, Cardiff and has been a nurse and a social worker, then moving into social policy and management, working with large (across Wales) and small third sector organisations. She was also a Cardiff City Councillor and a civil servant in the Welsh Government. She has combined her paid employment with extensive involvement in the third sector in Wales and is a founder member of many of the Black-led voluntary sector organisations in Wales. She has always been passionate about the area of Cardiff she grew up in and is very proud of her roots in Tiger Bay.

Gaynor became involved in politics as a member of the Black Alliance, an organisation that sought to raise the issues of racism and discrimination in Cardiff following the model of the Black Power movement in America. She has concentrated her voluntary activity on issues of racism and inequality.

Gaynor lives in Cardiff with her husband and is a carer for her brother, who lives nearby. Her experiences of caring for other people, directly and indirectly, has led to Gaynor becoming a member of Llais, a service user group attached to the School of Social Work in the University of Swansea.

Appendix 2

Further Information

“The Dementia Experiences of People from Caribbean, Chinese and South Asian Communities in Bristol 2017”

- The Bristol BME Dementia Research Group

This report is the product of an 8 month research project funded by Bristol City Council, which set out to establish the dementia experiences and needs of BME people. Below are highlights of some of the recommendations from the project. For full recommendations, please see:

<https://www.bristolhealthpartners.org.uk/uploads/documents/2017-02-23/1487859789-dementia-needs-of-people-from-bme-communities-in-bristol.pdf>

Recommendations from the Report

- **Raising awareness:** there is a need for clearer messages to be communicated in a range of ways about risk factors and prevention, including through public health campaigns. For instance, as many people from BME communities attend health services for treatment for other health conditions such as diabetes or asthma, these could be opportunities to pass on messages about reducing the risks of dementia. Consideration should be given to developing a co-ordinated public health campaign to help reduce the stigma of dementia within BME communities.
- **Data collection:** more accurate methods of establishing when diagnoses are made for different BME communities should be established. This could help to plan or commission relevant services for people at different stages of dementia.
- **Engagement:** flexible and pro-active methods of engagement with community organisations should be enhanced and developed.
- **Awareness:** although work to raise the awareness of GPs about the dementia needs of people from BME communities has taken place, this needs to be further developed. These sessions should include the perspectives of carers of BME origins so that GPs can more fully understand what carers experience when they try to get advice and support for the person with dementia.

- **Developing a toolkit of resources:** a toolkit of validated, translated and culturally-appropriate assessment resources should be developed. This toolkit should be made available electronically, and training in its use should be provided.
- **Commissioning culturally-appropriate residential care:** consideration should be given to ensuring that contracts with local care home providers meet the needs of different BME communities, with service providers working closely in collaboration with local BME-led voluntary groups.
- **Investing in partnerships with BME-led community organisations:** Consideration should be given for establishing viable mechanisms of financial support for the dementia work being carried out by BME-led VCSOs.
- **Supporting carers:** consideration should be given to meeting the needs of people who have previously cared for relatives, who have either now passed away, or entered residential care.
- **Enhancing the presence of people with dementia from BME communities in research:** people from BME communities need to be present within dementia research.
- **Increased diversity of staff:** recruitment should reflect the needs of BME communities, and it should be ensured that existing staff from BME communities are fully supported.

Other information

Diverse Cymru


Services include: Advocacy; BAME Dementia Project, BME Mental Health projects, Direct Payments Support and Financial Services; Policy, Training and Networking, Promoting the stories and experiences of people facing inequality and advocating on their behalf; volunteering opportunities.

307-315 Cowbridge Road East, Cardiff, CF5 1JD

Tel: 029 2036 8888

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www.diversesecymru.org.uk



Meri Yaadain CiC aims to support BAME people living with dementia and carers looking after a relative or friend living with dementia. Meri Yaadain CiC also works with service providers to embed cultural competency in practice.

Mohammed Akhlak Rauf MBE – Founder and Director

Tel: 07966 166665

info@meriyaadain.co.uk

www.meriyaadain.co.uk

Alzheimer's Disease International (ADI) believes that the key to winning the fight against dementia lies in a unique combination of global solutions and local knowledge.

www.alz.co.uk

Alzheimer's Society Cymru is the only UK charity that campaigns for change, funds research to find a cure and supports people living with dementia today. Find out more about Alzheimer's Society Cymru and get resources about dementia in Welsh.

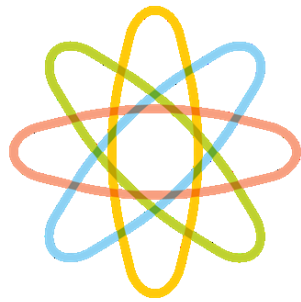
www.alzheimers.org.uk/about-us/wales

National Helpline: 0300 222 1122 (9 am - 5 pm)

Good Work: A Dementia Learning and Development Framework for Wales – Care Council for Wales 2016

This Framework is intended to support what matters most to the people of Wales as well as the spirit and requirements of Welsh policy, legislation and guidance regarding the care, support and empowerment of people with dementia, carers and the health and social care workforce.

www.socialcare.wales/cms_assets/file-uploads/Good-Work-Dementia-Learning-And-Development-Framework.pdf



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Promoting equality for all
Hyrwyddo cydraddoldeb i bawb

Diverse Cymru is a unique Welsh charity committed to supporting people faced with inequality and discrimination because of age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation.

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