

National Dementia Action Alliance

From Seldom Heard to Seen and Heard

Royal College of Nursing: 19 September 2017

Speaker Bios

Nuzhat Ali

Nuzhat Ali is the Lead for the Older Adults portfolio at Public Health England's National team. She has led the work on dementia and inequalities bringing to the fore the importance of targeted action for communities at high risk of dementia and seldom heard groups. She has 25 years of experience of managing and leading clinical, and public health services and strategy across the health sector in England and internationally as a clinician, commissioner, provider, and policy advisor at a local, regional and national level. Nuzhat is chair and founder of a voluntary Women's group, and she is passionate about engaging with and mobilising community stakeholders to tackle health inequalities in her paid and voluntary community roles. Nuzhat holds a Master's degree in Public Health from the London School of Hygiene and Tropical and is an Honorary Fellow with London Metropolitan University, teaching on their postgraduate and undergraduate programmes.

Shelagh Robinson

Shelagh Robinson who was diagnosed with Alzheimer's eight years ago has been a campaigner all her life; as a young mum she worked for improvements in Maternity Services and for the Welfare of Children in Hospital. She set up and eventually ran a Women's Refuge in her local community, and then trained as a counsellor. She taught counselling at University and at a College of FE. Since she was diagnosed she has campaigned in many different ways to raise awareness of Dementia and has spoken about the condition to many different from Local Scouting groups to the House of Lords. As a Quaker she has worked for the last three years on a project exploring end of life issues and this experience has enriched her awareness of the topic in relation to Dementia care. She is a member of an interfaith group looking at how Dementia is supported in different faith groups and has taken part in an international conference looking at the needs of countries that have no Dementia services at all. She still has lots of time for her ten grandchildren, for U3A literature and poetry groups, her motto being 'use it or lose it'.

Dr Stephanie Aiken

Dr Stephanie Aiken is Deputy Director of Nursing at the Royal College of Nursing (RCN). Her remit is to provide leadership to the RCN Nursing Department to shape and support the delivery of its professional work, focusing on developing nursing as a profession and enhancing nursing practice. Stephanie has a background in adult nursing prior to commencing her career in education and undertaking a Masters in Healthcare Ethics. She has extensive experience of working in nursing and healthcare education and more recent experience in regulation at the Nursing and Midwifery Council. She undertook her doctoral studies at the University of Brighton, exploring the image of nursing and how it is perceived from public, professional and policy perspectives.



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Kelly Kaye

Kelly Kaye is leading on the From Seldom Heard to Seen and Heard Campaign. She is also working together with hospitals to push forward the Dementia Friendly Hospital project. The target is to get hospitals to sign up to the Dementia Friendly Hospital Charter which provides principles of what a dementia friendly hospital should look like and recommended actions hospitals can take to fulfil these objectives. Kelly's first experience of working with people with dementia was a Sunday job in a Jewish Care day centre, whilst studying for her degree. Kelly loved the work and knew that was where she wanted her future to be. Kelly worked for a local authority for 12 years having the responsibility of running a day centre, managing an outreach team, managing a BAME team supporting members of the South East Asian community and dementia projects as a whole. Kelly indulged her love of football by working with local football clubs, and most notably Leyton Orient Football Club (where she is a season ticket holder!) to encourage them to become dementia friendly.

Toby Williamson

Toby is an independent consultant working in the fields of adult and older people's mental health, dementia, mental capacity, and safeguarding. He has many years' experience of working in and managing frontline mental health services, research, evaluation, practice and service development, and policy work, and for the last ten years has particularly focused on dementia. Toby worked for the Mental Health Foundation for 14 years where he led its policy work and its programme of work on mental health in later life, dementia and mental capacity. He worked in government for a time to assist with the implementation of the Mental Capacity Act and before joining the Foundation he worked in, managed and delivered training in a variety of community services for people with severe and enduring mental health problems. He helped established the Dementia Engagement and Empowerment Project (DEEP), and has been responsible for projects and reports on disability rights and dementia, dementia friendly communities, personalisation, and truth telling in dementia. He has co-authored a book on the Mental Capacity Act and is currently co-authoring a book on rights, values and dementia.

Rachael Litherland

Rachael Litherland has worked with people with dementia for the past 19 years, with a background in psychology and advocacy. Rachael is a director with Innovations in Dementia CIC, a national community interest company. We work with people with dementia, partner organisations and others to help people with dementia keep control of their lives and be happy. We achieve this through the delivery of innovative projects and a training and consultancy service, and by influencing dementia practice and policy. We promote a positive view of dementia, demonstrating that, although dementia is life changing, it does not have to be life ending. Our mission is to work on projects that Inspire Different Conversations about dementia. These focus on rights, accessibility, having a say, belonging and recovery and discovery. We work with and alongside people with dementia to shape practice, policy and attitudes. We also support DEEP - the national network of dementia voices. Prior to setting up Innovations in Dementia, Rachael developed and managed the national "Living with Dementia" programme for the Alzheimer's Society (2000-2006). This included providing leadership on issues relating to the involvement and support of people with dementia and supporting people with dementia in service and information development, campaigning and self-advocacy.



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Mike Parish

Michael Parish is a carer for his partner who has a diagnosis of HIV Associated Neurological Disorder (HaND). Michael is 62 years old and has lived with his partner Tom for over 41 years. Michael and Tom converted their 2006 Civil Partnership to a marriage in July 2016. Michael retired in late 2014 to care for his partner who has been medically retired since 2011. Michael has delivered a number of talks and presentations highlighting the particular issues surrounding a dementia diagnosis in someone who is LGBT and HIV+. Michael is particularly keen to see and take an active part in improving awareness of LGBT living with dementia among local authority, health and medical staff as well as when accessing home or long term nursing care. A priority for Michael is to see positive reflections of LGBT people in care and support organisations as well as nursing homes. One of these objectives is to ensure that care staff are provided with key knowledge, understanding and ways of delivering the best support to LGBT people being sensitive to their specific needs. Michael's career for the past 30 years has been with the London Fire Brigade in Disaster Management planning, training and response. Michael had a key role in the implementation of the London-wide strategic disaster response as well as multi-agency national and international coordination of planning, training and exercising. Michael also taught undergraduate students at Coventry University and led on integration of response arrangements with external organisations, private charities, agencies and other groups.

Shahid Mohammed

Shahid worked within the Learning, Skills and Community Development sector for over 24 years with organisations including the Training Enterprise Council, Learning and Skills Council, Oldham Council and the British Council. When his mother became ill he took early retirement from a long career in the public sector and he became a full-time carer. This led him to set about on a campaign to engage with the BME and South Asian community in Rochdale and became the founder of BME Health and Wellbeing; raising awareness of dementia, mental health and End of Life Care, and also providing help and advice to support services and other professionals. In 2016, Shahid was invited at the opening plenary of the UK Dementia Congress in Brighton on his work in Rochdale, he is also a member of the Public Health England's National BAME Dementia Task Force. Shahid has also authored a paper entitled 'A FRAGMENTED PATHWAY' Experiences of the South Asian Community and the Dementia Care Pathway: A Care Giver's Journey, and is working with Bradford University on a 'CareGiving Hope' project, and is an Expert by Experience to a PhD student. Shahid has been an important facilitator in promoting the awareness of dementia and other health issues within BME through his numerous TV and radio interviews, University lectures, public speaking, peer support work, as a Police trainer and his strong partnerships with key organisations. Separate to the health and wellbeing work, Shahid is an active campaigner on local issues - working with local councillors, Member of Parliament, council officers, the Police and the local community, and has organised community events. Shahid is the Chairperson of the local Area Forum and a committee member of several community organisations including PKCA. Shahid received a special award by the Mayor of Rochdale as part of the Queen's 90th Birthday celebrations in 2016 in recognition of his contribution to the community. He was a finalist in two categories at the 2016 Rochdale Diversity Awards; and in 2017 he was nominate in three categories.



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Sarah Lancaster

I am the frontline manager for one of Macintyre's registered care services which supports 40 individuals with various learning disabilities. I have worked for MacIntyre for 9 years. My main role is to ensure we are supporting those that live within the service with a life that makes sense to them whilst at the same time keeping them safe and ensuring their needs are been met. I have my Diploma level 5 in health and social care.

Patrick italo Johan Ettenes

I'm from Barbados, lived and worked in different parts of the world and currently reside in Manchester for the last 8 years. I'm a writer on HIV matters as have been positive for 14 years - I was the ambassador for HIV in Manchester, public speaking at a few World Aids Day events and doing as much media work as I could to bring down stigma and raise awareness of HIV. 4 years ago I had a nervous breakdown as a result of an abusive relationship. I suffered with homelessness, drug abuse and memory loss. A year ago after settling in I was told I had early onset dementia. Frontal Lobe Atrophy. The youngest in the UK with it. From there I campaigned to bring awareness to LGBT members, young people and single people living with dementia and those whom are neglected as a result of living on their own without family. I now publicly speak around the country, assist the NHS with training manuals and lecture at Manchester University about such topics. Raising again awareness for another disease that affects me.

Tracey Shorthouse

Hello, my name is Tracey Shorthouse, I am 47 and in December 2015 I was diagnosed with two types of dementia, Posterior Cortical Atrophy and Alzheimer's Disease. In a sense I was relieved as I had been fighting for a diagnosis for nearly two years but I was also devastated as well. But in life I have always been optimistic and I try and see the best of a situation because there is no point in being down about things all the time. Life is about living to the best of our ability and just because we have a condition, it shouldn't stop us doing things. We just have to pull on our strengths, for which we have plenty. Since having dementia I have 4 rules of thumb that I try to abide by: - Adapt, I can no longer do the things I used to be able to so I just adapt and do them in a different way. Try not to stress out about things I can't control, this is really hard. And there is always tomorrow so if I have a bad day then there is always tomorrow and the most important thing is to keep a sense of humour. Since being diagnosed with dementia, I have written a book of poetry called I Am Still Me. I like to walk and love gardening. I go out and give talks, to people who have been recently diagnosed with dementia and tell them they can live well, and to the general public to bring awareness that dementia affects all ages. I feel like I am embracing life rather than hiding away and because I live on my own it makes me push myself more which I think is important.

Sally Knocker

Sally has worked for over thirty years in dementia care and for the last five years with Dementia Care Matters as a consultant trainer on culture change projects in the UK, Ireland and most recently in Canada and Australia. Sally is the author of 'Loving, the essence of being a butterfly in dementia



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care', published with Hawker Publications and the seventh in the Feelings Matter Most series. She has also written a range of publications on the needs of older people who are lesbian, gay, bisexual or trans, including a Joseph Rowntree Perspectives on Ageing: lesbians, gay men and bisexuals paper and co-authored a new Age UK guide 'Safe to be me – meeting the needs of older lesbian, by, bisexual and transgender people using health and social care services'. She is currently working with Opening Doors London to set up a Rainbow Memory Café for LGBT* people living with dementia and LGBT* carers starting in October 2017.

Junaid Dowool

Hello, I am Junaid and I am currently the Lead for the Mental Health Services at HMP Pentonville. I have been in the Nursing arena for 17 years starting off my career in 2001 as a support worker. My role at HMP Pentonville is to provide Clinical Leadership to my colleagues under the MH Teams and to lead the team in delivering a mental health service that is equivalent to the wider community. We work with mentally unwell people, including learning disabilities, vulnerable adults and generally people who are at a point in their lives where they require utmost support and understanding from professionals like us for e.g. increased risk of suicide cases etc. We promote wellbeing by running a therapy led day care centre with the aim of engaging prisoners in therapeutic activities whilst maintaining their mental wellbeing. We have a 22 bedded inpatient unit which primarily focusses on providing mental health brief interventions, assessments as well as treatments for patients unable to be cared for in the main jail. In conjunction to this, we also provide tailored service to physical health clients in the unit. Our service also extends to providing support and maintenance of mental wellbeing to clients with severe and enduring mental illnesses through the In reach Team and the Enhanced Support service on the other hand offers an intensive service working closely with challenging and complex behaviours in the wider jail.

Dr Karen Dodd

Dr Karen Dodd is Co-Director of Services for People with Learning Disabilities, Associate Director, Therapies – Learning Disabilities Services and a Consultant Clinical Psychologist for Surrey and Borders Partnership NHS Foundation Trust. Karen has worked with people with learning disabilities for over 30 years. Throughout her career Karen has worked to develop new approaches, training materials, policies and guidance with regard to core issues for people with learning disabilities. These include: Sexuality and Personal relationships; health inequalities; treatment of psychological issues; health and pain; end of life and organ donation; CBT for staff working with people with learning disabilities and IAPT. Karen has had a longstanding interest in people with Down's and dementia. This has included undertaking a 24 year longitudinal study of adults with Down's Syndrome; developing work with peers of people with Down's Syndrome and dementia; developing resource packs and information for staff, families and people with learning disabilities; training and workshops. Karen recently chaired the joint group between the British Psychological Society and Royal College of Psychiatrists Learning Disability Faculties to update the national guidance on the Assessment, Diagnosis, Interventions and Support of people with Learning Disabilities and Dementia (BPS 2015). Karen is now using her knowledge to improve services for all people with dementia, including the implementation of a quality outcome measure. Karen is currently a committee member



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on the DCP Faculty for People with Intellectual Disabilities, and Co-Chair of the Learning Disabilities Professional Senate, and has been working very closely with NHS England on the Transforming Care Service model and role of the Community Learning Disabilities teams.

Akhlak Rauf MBE

Akhlak (also known by his first name Mohammed) has worked to support BME dementia over the last 11 years. His knowledge and expertise in this field cuts through community development, carer and Person with Dementia engagement and currently a part-time PhD at the University of Bradford looking at how South Asian carers manage to cope with the transitions associated with looking after a relative with dementia. Akhlak is involved in a number of organisations – working as a Manager in the local Council as well as roles with the Community Voluntary sector. He was a founder member in the setting up of Meri Yaadain (My Memories) which has had national recognition and the ‘thinking outside the box’ approach was acknowledged with an MBE in 2017 for ‘services to people with dementia and their carers.’ He has developed links nationally and internationally looking at BME dementia via Twitter and a vlog to try and move this area of work from ‘equality’ to ‘equity’.

Dr Mary Tilki

Dr Mary Tilki is a retired university lecturer and her professional qualifications are in nursing and nursing education. She has researched and published widely on cultural competence in health care, ethnic elders, health inequalities and the health of Irish people in Britain. Mary has more than twenty years’ experience in the voluntary sector and has participated in a number of strategic groups on health inequalities. She has a particular interest in dementia in minority ethnic, Gypsy and Traveller communities and what culturally and dementia sensitive care means for people with memory loss and their family carers.

David Truswell M.Sc. (Econ.), MBA

David has worked in community based mental health services in the UK for over thirty years developing services for people with complex care needs and enduring mental health problems in a career spanning the voluntary sector, local authority services, and the NHS at a senior level. From 2009 - 2011 he was the Dementia Implementation Lead for Commissioning Support for London, working with commissioners across London to improve dementia services. He is currently Chair the Dementia Alliance for Culture and Ethnicity (www.demace.com) a UK alliance of local and national voluntary organisations working with dementia and an independent writer and researcher on dementia support and services for Black, Asian and minority ethnic communities. Currently he is editing a book on dementia and BAME communities due for publication in late 2018. He is also the Director of somfreshthinking limited, a healthcare consultancy on service redesign and change management in health and social care.

Christine-Koulla Burke



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Christine heads up the Foundation's work on prevention and combating inequalities, as well as the Foundation for People with Learning Disabilities. She joined the Mental Health Foundation from the Institute of Applied Health and Social Policy at King's College London. Previously she worked as Deputy Chief Executive of Circles Network and as a senior manager in various organisations for over 35 years. She has developed and managed many service improvement programmes in both health and social care and supported them to change to inclusive, person-centred services for people with learning disabilities, nationally and internationally. Christine has promoted co-production and the involvement of self-advocates and families in all programmes. She holds a BA Hons in Psychology, MSc in Child Psychology and a Diploma in Psychotherapy

Pat Charlesworth

Pat Charlesworth is an expert by experience. She is a valued member of the team at the foundation for People with Learning Disabilities. Pat is an advocate, campaigner, researcher, trainer and contributes to many programmes both policy and guidance work. Pat works on the Palliative Care advisory group and developing guidance with NICE on growing older with a learning disability. She has chaired many conferences and meetings such as the DAA roundtable on Dementia and Learning Disability. Pat is an activist and is passionate campaigner on the rights of people with a learning disability.

Hilary Kinsler

I have worked as a consultant Old Age psychiatrist in many deprived inner city areas of East London for more years than I can easily calculate (or am prepared to admit to!). At present I work in a memory service in Dagenham in East London where much of my day is spent spending time with people being assessed for a diagnosis of dementia and some of my time in supporting people who already have a diagnosis who may need extra support. I worked as a consultant in nearby Redbridge for many years where my memory service won an award for being 'outstanding', one of only three memory services in the country to have given this rating. In Redbridge I worked with The Redbridge Dementia Partnership, a group of people from all sectors, health, social services and voluntary organisations, who worked together to try to improve and coordinate services for people with dementia. I trained all over East London and South East London so I have done a fair old circuit of socially deprived areas as well as some less deprived areas for comparison.

Donna Chadwick

I am the National Development Manager for YoungDementia UK. My role supports our Young Dementia Network which is collaboration, between individuals and organisations, with the aim of improving the experiences of those affected by young onset dementia. Before my recent move to Youngdementia UK I worked as a Dementia Support Manager for The Alzheimer's Society, in Derbyshire, where we developed a delirium awareness programme, delivered groups for people with young onset dementia and offered one to one support to aid individuals to live well. My role prior to that was Care Manager of a dementia specialist care home where we supported people under the age of 65 years old with dementia.



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