

A4D Disability Arts for Brain Health webinar - Tuesday 4 October 2022

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[with Involve BSL interpreters]

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VERONICA FRANKLIN GOULD FRSA AMRSPH founded Arts 4 Dementia in 2011 to develop weekly programmes for early-stage dementia at arts venues, training, best practice conferences and reports, with a website to coordinate arts opportunities for dementia in the community. Her inaugural programme, *Reawakening the Mind* (2012-13), won the London 2012 Inspire Mark and Positive Breakthrough in Mental Health Dementia Award 2013. Veronica was named finalist in The Sunday Times Changemaker competition and on publication of *Music Reawakening* (2015), she was appointed A4D president. Her regional guide, *Reawakening Integrated: Arts & Heritage* (2017), maps arts opportunities for dementia and aligns arts within NHS England's Well Pathway for Dementia. Veronica's social prescribing programme (2019-21) opened with a conference *Towards Social Prescribing* (Arts & Heritage) for the Dementias (May 2019, Wellcome Collection). To address cross-sector issues raised, she piloted dance and drama social prescribing programmes to test the process and ran a series of 15 cross-sector conferences around the UK. Findings were disseminated in a two-day conference and report '*Arts for Brain Health: Social Prescribing as Peri-Diagnostic Practice for Dementia*' (2021).

DR RASHMI BECKER MBE, (CHAIR) is the founder of Step Change Studios, which provides opportunities for D/deaf and disabled people to dance. Over 20 years, she has developed expertise in the arts, sport, social affairs, and disability advocacy. She is a Board Member of Sport England, also serving as the Board Champion for Equality, Diversity and Inclusion. She holds a PhD from the University of Cambridge where her research focused on Intellectual Disability. Accolades include the One Dance UK Innovation Award, London Sport Award for Health and Wellbeing and National Learning Disabilities and Autism Award for Outstanding Contribution to Innovation. In 2021 Rashmi was recognised with an MBE for services to disabled people.

DR MICHELLE HOWARTH, Senior Lecturer in Nursing at the University of Salford, is due to commence a post as a Senior Engagement Fellow at Edge Hill University. Michelle has a specialist interest in social prescribing and the use of nature based, person-centred approaches that are used to support health and wellbeing. Michelle is a Trustee on the Board for Social Farms & Gardens and a Trustee on the National Self-Care Forum through which she works towards supporting innovative and creative ways to improve self-management using personalised approaches. Michelle is a member of the National Social Prescribing Network and chairs the National PerCIE group which uses research, curriculum development and placement opportunities to raise awareness of social prescribing, personalised approaches across health & social care practitioners.

DR LUCY BURKE, Principal Lecturer, Centre for Culture & Disability Studies at Manchester Metropolitan University. She specialises in the areas of critical medical humanities, literary and cultural disability studies and critical and cultural theory. Her research considers representations of dementia and cognitive disability in contemporary literature, life writing and film. Lucy is also interested in cultural representations of disability more generally and in the impact of new medical technologies on the ways in which we think about ourselves and others. The units I teach combine the analysis of theoretical texts with a close reading of literary and cinematic works — She is interested in thinking about the ways that novels and films shape our responses to a range of contemporary political and ethical dilemmas.

NABIL SHABAN, co-founder of Graeae Theatre Company of Disabled Artists in 1980. Actor, writer, film-maker spanning three and half decades. Various performing roles including Sil, alien villain of "Doctor Who", Jesus (Godspell), Hamlet, Ayatollah Khomeini, Haillie Selassie, Marquis De Sade (Marat / Sade), Mack the Knife (Threepenny Opera), Azdak (The Caucasian Chalk Circle). Probably the first genuine wheelchair-user to play a "romantic lead" in British television as George in "Deptford Graffiti" (1991). Made many attempts to introduce disabled people's love and sex lives in

TV drama and documentaries, beginning with “Skin Horse” (C4 documentary 1983), “Telephone Dummies” (BBC Drama 1984).

FLEUR DERBYSHIRE-FOX is Director of Engagement, English National Ballet. Fleur joined ENB in 2007, establishing the Company’s Engagement offer and building its reputation as a leader in creative learning and outreach engagement. Leads the strategy for Engagement, founding Dance for Parkinson’s - the first UK dance company to offer a specific dance and cultural programme for people living with Parkinson’s, which celebrated its 10-year anniversary in 2020. She has designed and delivered international projects in Vietnam and China through the British Council and for Portugal-UK 650. Fleur holds an MA in Choreography from Middlesex University. Currently a Trustee at DanceEast and Russell Maliphant Dance Company, and an RSA Fellow.

WILLIAM OGDEN, Trustee Director of Decibels, Music for the deaf. William Ogden was born profoundly deaf and partially blind. William’s working portfolio is set out to make a positive difference to the lives of many people. William currently works at Kingston University supporting and advising students with various backgrounds relating to disabilities, learning differences and mental health to ensure they have equal accessibility and opportunities. William is also a Trustee Director for Decibels Charity and both William and the charity believes all people have opportunities to develop their creativity and discover their talents through music. In his spare time, William collaborates with Performance Interpreting, attending music festivals, shows and gigs on a regular basis to ensure they have accessibility provisions in place for the D/deaf community. William was recently given a British Empire Medal (BEM) as recommended from our late Her Majesty The Queen for his work for the accessibility and education sector. William Ogden BEM | LinkedIn

REBECCA MCGINNIS is the Mary Jaharis Senior Managing Educator for Accessibility at the Metropolitan Museum of Art in New York, where she and her team are responsible for Access programs tailored to the needs of disabled people. They also partner with disability and other organizations and advise on accessibility and inclusion for all education and public programs and throughout The Met, for example on exhibition design, digital access and staff training. Access programs include regularly scheduled tours and workshops for people with dementia and their care partners; blind and partially sighted people; those with developmental and learning disabilities and autism; and the Deaf community. Blind and partially sighted people can request tours with detailed description and touch, and groups with disabilities can schedule tours and art making experiences at the museum, at their sites throughout the city, or online. Touch, movement, and other multisensory strategies are a hallmark of these long-established programs, connecting visitors with and without disabilities with art and each other. Through ongoing partnerships and outreach, the Access team continues to identify new audiences for Met Escapes (for people with dementia and their care partners). Although social prescription for the arts is not yet widespread in the US, this practice has developed naturally with Met Escapes as the Access team has developed ongoing relationships with the medical community. Doctors and social workers regularly recommend Met Escapes and some even contact the Museum directly to register their patients for the program monthly.

FURRAH SYED FRSA, Artist, Educator and Colour Energy Specialist based in London, is a strong advocate for making art accessible to all. Her inclusive approach to sharing art led her to design and develop her Art Appreciation Workshop for the Blind and Partially Sighted in 2009, which she has delivered globally to organisations. Furrah’s bespoke workshops also highlight the unique insights that can be gained if we temporarily stop using one of our senses. We can then be more aware of how to produce an inclusive environment, a range of products and services for all, including those with additional needs.

DR BEVERLEY DUGUID is a writer and researcher who has worked widely in the not-for-profit and academic sectors on projects which highlight inequalities. She is also a business owner, in 2020 she created InsightMind, creative courses for mind, body and soul, teaching workshops in mindfulness, mindful movement and poetry. She offers courses online and in person to

underrepresented and marginalised group, but chiefly those with visual impairments. In 2021 and 2022 she was awarded grants from the from the Royal Borough of Kensington and Chelsea to teach ‘Mindful poetry’ in the community settings in West London such as the Tabernacle.

JAN-BERT VAN DEN BERG has been Director at Artlink for the last 30 years. Originally trained as visual artist, he found that collaborating with communities and other artists was his real calling. In the early days he set about making sure that the opportunities the organisation created were long term and progressive - where people with complex disabilities could extend their influence and voice within contemporary arts practice. Recent highlights include the highly acclaimed Human Threads exhibition at Tramway, Glasgow and post lockdown tri-cycle rides through the Meadows in Edinburgh where service users could enjoy company and impromptu music and poetry recitals.

RUTH FABBY MBE, DL, FRSA, CF & JMU fellow. Ruth Fabby, (formerly Gould) has been Director of Disability Arts Cymru (DAC) since August 2019. Now residing in Wales, Ruth is leading the organisation to support a creative and equal Cymru where disabled and deaf people are pivotal to the arts of the nation. Previously she was the founder and Artistic Director of DaDaFest, one of the most successful disability arts festivals in the world. Trained in performance arts, speech and drama at Liverpool Theatre School, Ruth has worked in the arts / disability arts all her professional life. She sees disability rights as human rights and is a passionate and knowledgeable speaker.

TALKS

Veronica, President, Arts 4 Dementia

Good morning to you all – joining us from around the UK, Australia, Austria, Ireland, Italy, Malaysia, Mexico, Taiwan and the United States of America. Welcome to our first Disability Arts social prescribing webinar to preserve our health and wellbeing – our brain health.

It is everyone’s human right to participate in arts in the community, but for people living with a disability and experiencing early symptoms of a dementia, this can be a challenge.

CHAT:

Anna Briggs, You right. It's everyone's right

Rona Topaz: HEAR, here, it is society that disables us.

Anna Briggs I sometimes wonder whether the fact that dementia isn't often considered a disability is influenced by the often poorly prepared elder care sector in which many MANY nursing homes are not remotely fully accessible or dementia-friendly, and a lot of people are kept in restrictive and punishing environments. People without capacity in those settings have very few supporters to advocate for their rights.

So it is truly splendid on this tenth anniversary of Disability Rights UK to be opening the conversation on a compelling range of disability arts that can help to preserve our brain health. Our webinar chair Kamran Mallick, Disability Rights UK’s chief executive, has just been rushed to hospital – we do wish him the very best and most comfortable recovery – and are immensely grateful to **Dr Rashmi Becker MBE**, Founder of Step Change Studios and Sport England Board Champion for Equality, Diversity & Inclusion, for stepping into the breach.

Some ten million people around the world are expected to be diagnosed with a dementia this year, their natural fears compounded by stigma. Creating and being seen to participate in artistic endeavour can transform their despair to desire.

I speak on behalf of Arts 4 Dementia, the UK charity specialising in arts workshop practice to help re-energise and inspire individuals and carers to override symptoms of early-stage dementia, with a website to which you can signpost your arts opportunities for all stages of dementia in the community, by art form, virtual accessibility, dementia need, and postcode.

The growing understanding we share today is that thanks to social prescribing – GPs referring patients for personal appointments with link workers for much valued non-clinical support – their patients with and without disabilities can now be empowered from the onset of symptoms of a potential dementia – to take-up inclusive disability arts to re-invigorate their lives

Social prescribing connects patients to local arts programmes of individual and exciting interest – and in choosing to participate, whether peri- or post-diagnosis, they are taking enjoyably constructive action to preserve their brain health.

Joining social arts groups of personal cultural interest, through social prescribing, empowers people to preserve their sense of wellbeing, their cultural identity, achievement and resilience in the community for years longer. Sharing imaginative ideas, making music, performing dancing, creating together helps modify risk factors for dementia and nurture resilience for person and carer living with both dementia and disability.

Our aim through these webinars is to raise awareness of the linkability of patients to the brilliant practice such as we shall hear today from our speakers.

- **Dr Michelle Howarth**, the National Social Prescribing Network lead on Nursing,
- **Dr Lucy Burke**, Principal Lecturer at the Centre for Culture & Disability Studies at Liverpool Hope University.
- **Dr Rashmi Becker MBE**, Founder of Step-Change Studios, London.
- **Nabil Shaban**, Actor, activist, co-founder of **Graeae Theatre** for disabled people.
- **Fleur Derbyshire-Fox**, Director of Engagement, English National Ballet presents 'Dance for Parkinson's'
- **William Ogden**, Trustee Director of Decibels, inspiring and enabling deaf people to make music.
- **Rebecca McGinnis**, Senior Managing Educator for Accessibility, Metropolitan Museum of Art, New York, presents a range of programmes for the disabled.
- **Furrah Syed FRSA**, Artist, Educator and Colour Energy Specialist, astonished me at the Royal Society of Arts by her Visual arts approach enabling the blind and visually impaired to feel and sense colour.
- **Dr. Beverley Duguid**, founder of InsightMind. Poetry for the visually impaired, shares her approach to mindful poetry for the visually impaired, touching also on cultural diversity.
- **Jan-Bert van den Berg**, Director, Artlink Edinburgh and the Lothians, explains Artlink's thoughtful multi-sensual, multi-engaging approach to disability arts
- **Ruth Fabby MBE**, Director of Disability Arts Cymru, trained in drama and founded the disability arts festival, DaDaFest.
- **Veronica Franklin Gould FRSA** (President, Arts 4 Dementia)

I should like to express thanks to the three speakers, who could not in the event make the date, yet kindly recorded contributions – and to our Involve BSL interpreters and to Nigel Franklin of Arts 4 Dementia, who is leading our technical support..

Each speaker will talk for five minutes on their specialism or approach to Disability arts, after which Dr Rashmi Becker will chair the speaker debate, looking at issues arising from their talks.

One thought I should like to share with surrounds stigma – some people with early symptoms of dementia, as well as natural fears, can feel a sense of shame. In preparation for this webinar, I sense

that Disabled people are proud to identify as such – look at the Paralympic Games – I wonder whether with the additional challenge of potential dementia, stigma may be less of a worry, than actually coping with symptoms – still a challenge. Interesting to know.

Message from KAMRAN MALLICK, Chief Executive, Disability Rights UK (sent from hospital)



I am really sorry not to be there today, I was looking forward to listening to all the wonderful speakers lined up today and take part in the conversation. Disability Rights UK is a Disabled people led organisation.

Our work is rights and justice based and we are working with other organisations and individuals to bring about a truly inclusive society – one where Disabled people are supported, listened to and valued. Our rich diversity as a community is our strength as we bring unique perspective through our lived experience.

We talk about Disabled people and those with long term health conditions because everyone does not identify themselves as a Disabled person. However, often the experience is the same. Someone with a condition such as Dementia may not think that they are a Disabled person, they may see it as an illness or perhaps age related. What matters is that all of us, experience barriers because. These barriers are part of the social construct - the way we structure our communities, places of education and work, social activities to the narratives written about us. If we can start to remove the barriers that I would ask, are we still Disabled people. Yes we have various conditions, illnesses, disabilities but those in themselves don't make us Disabled, the barriers do.

The arts have a significant role to play in changing narratives, in creating inclusive practises and environments that values our human difference, by doing so we are better as a society. Inclusive thinking, planning and performing is the world I want to see. I certainly don't have the answers but working together we can move in that direction. The saying in our Disabled community of *Nothing About Us Without Us* is something we should always remember.

I hope you enjoy the rest of the session today.

VFG Here is a link to the [Social Model of Disability](#), to which he was planning to refer. We are very grateful to Kamran, and wish him all the best for his health.

Our Disability Arts for Brain Health webinar today is now in the fine hands of our chair, Dr Rashmi Becker - Rashmi, thank you very much!

CHAIR: Dr Rashmi Becker MBE, Founder of Step Change Studios, London. Board Member of Sport England, the Board Champion for Equality, Diversity and Inclusion.

Good morning, or good afternoon, depending on where you are in the world. I am Dr. Rashmi Becker. I am the founder of Step Change Studios, and I also have over 25 years' experience, working in government, social policy, disability, policy. The care sector educational, and the arts amongst other things. So I'm, looking forward to hosting today.

Thank you very much for joining us and really excited about the discussion, and am looking forward to hearing everyone's views and to having an exchange and debate after everyone has spoken, so I will introduce our first speaker who is Dr Michelle Howarth, who is the lead in national social prescribing that works special interest group in nursing.



Dr Michelle Howarth, Lead: National Social Prescribing Network Special Interest Group: Nursing



Thank you for the introduction I've been asked to set and seen a bit, and talk about social prescribing (SP), and what that means and particularly what it means for people with disabilities, so I am hoping to put some context around today.

What is social prescribing?

SP is a means of enabling GPs and other front-line health professionals to refer patients to a link worker, (SPLW) to provide them with a well-being conversation about what matters to them, not what's the matter with them. So it turns this medical model on its head, during which they can learn about the possibilities for themselves and design their own personalized solutions.

Link worker (SPLW)

The important thing here is that that SPLW has a very personalized conversation, a wellbeing conversation with that individual. Not everybody is referred, that people are only referred if it's for a non-clinical reason. It's estimated that about 30% of GP appointments now are made unnecessarily for a non-clinical reason.

You can self-refer to different organizations, but for a social prescription to work that has to be that referral pathway.

The SPLW or Community Connector works alongside a number of different other roles, such as the Health and Wellbeing Coach and Care-Coordinators and is embedded within that multidisciplinary team. They work alongside the GP, advanced practitioners, the voluntary services, etc.

Typically, SPLW might originate from the area that they are prescribing to, and they will have asset-mapped all the different opportunities within that particular area.

The organization that I've worked with in Salford, for example, started off a number of years ago with five Community Connectors. They were all born and raised in Salford. They knew that area like the back of their hand, and they could refer very quickly somebody to an intervention. I think there's now sixteen of them. That demonstrates the explosion of link workers and Community Connectors that we've had over the past couple of years.

CHAT Kate White: With Dementia, are the link workers accessible via the Memory Services? This is very often the first step in the pathway to access support

The social prescription

The things that they might send them for are arts-based movements, drama, exercise, yoga, gardening groups, Knit and Knatter groups, all of the lovely assets that are there in the community, that build on somebody's strengths, rather than their deficits.

We know there's a lot of SP ongoing across the United Kingdom. It has tried to be mapped, but because of the uniqueness of the interventions. it's really difficult to pinpoint where everything is taking place.

If we take, for example, Greater Manchester, there are over 17,000 VCSE organizations operating in Greater Manchester alone, of which 72% or thereabouts are very small organizations with less than a £1,000 a year income, right the way through to larger organizations, such as Macmillan, Age UK, 42nd Street, and all of those amazing organizations.

SP process



The referral pathway often originates through the GP, through the SPLW, out into the one of those assets within the community, such as arts. There are different models of SP - the Social Prescribing lights. This is based on Richard Kimberley's work (2015) where somebody might recognize that someone's going to a GP a lot, and it might be somebody in the reception area, who notices a patient coming in a lot for social isolation and says: *Have you thought about going to this local group* and that's just a simple signposting.

Wellbeing conversation

There's a medium prescription where a GP or health professional may have a wellbeing conversation and that might be around a medical reason that's related to a condition – for example, weight management as part of management of the long term Type 2 diabetes, and they might refer to Weightwatchers or to a physical activity supporter; and then the holistic approach, which is what we all try and aim towards is where the SPLW has a well-being conversation with the individual.

Individual SPLW support

They follow that individual what they need so it's like eight times with that individual. They literally take them to the intervention and hold their hand. It's been very effective. There's quite a lot of evidence about the referral processes about the impact. We now have specialist pathways emerging: we have a National Academy of Social Prescribing (NASP) that was launched in October 2019 or 2020. We have specialist pathways for children, young people, people with mental health.



SP support for people with learning difficulties

There are emerging pathways specific for people with learning disabilities, and those are SP services to patients who have a learning disability. That might mean helping them to find things in the local area that can help their physical, mental health and wellbeing to help them feel happier and healthier.

Green prescriptions

We even have Green SP now, where nature-based intentions are promoted, being outdoors, getting involved allotment groups, etc.

How a social prescription can help you

To recap then, how a social prescription can help you: It's used for non-clinical reasons. It's never used for a clinical issue – the GP or health professional always support clinical issue.

It's about helping you to find things to do in your local area that can affect your impact, your physical mental health and wellbeing, making you feel happier, healthier, more connected with the with the community.

They can support annual health checks; they can help complete goals, health action plans, etc.

They have questions. If you're worried or concerned and can help to join groups, volunteer organizations, prepare for employment and enabling people to meet others in a safe and encouraging way.

So I would encourage everyone if they're interested to find out more about the SP schemes. There are many across the country. They are all very different. But they all follow the same referral pathway.

CHAT Claire Stevens, Voluntary Health Scotland: My organisation, Voluntary Health Scotland runs the Scottish Community Link Worker Network, sponsored by the Scottish Government, a community of practice and peer support for the nearly 300 link workers embedded in primary care across Scotland: (typically these link workers are commissioned via the Health and Social Care Partnerships):

<https://vhscotland.org.uk/what-we-do/scottish-community-link-worker-network/> Additionally in Scotland Spring runs the Social Prescribing Network Scotland, which is an open access network for anyone in Scotland involved in SP.

Ruth Fabby, Disability Arts Cymru: Lovely to be in the zoom with you -

RB, chair: Thank you, Michelle, and really I think that the point about community and local is very interesting, and something we might pick up on later.

RB, Chair:

I'm going to go straight onto our introducing our next speaker, Dr Lucy Burke, who is a Principal Lecturer at the Centre for Culture and Disability Studies at Liverpool Hope University



Dr Lucy Burke, Principal Lecturer at the Centre for Culture & Disability Studies at Manchester Metropolitan University

I am very grateful to Veronica for extending an invitation to me and inviting me to speak about the arts, disability and dementia. My research explores the ways in which we think about and portray forms of cognitive difference for instance, learning disability, autism and dementia in life-writing, literature and film and I have also worked with people with dementia and learning disabled and autistic young people and artists and performers on a range of projects, including, most recently, the Arts Council England project Transforming Leadership with Access All Areas Theatre Company and Disability Arts Online.

There is a paucity of research on the role of the arts in the early stages of a dementia diagnosis in relation to the experiences of people living with specific impairments.

Learning disability and dementia

I'm going to focus here on learning disability. We know, for instance, that people with Down's Syndrome are at particular risk of early onset Alzheimer's and that the prevalence of dementia across in people over 60 is two to three times greater in learning disabled people. However, there is very little sustained research currently that focus on the ways in which arts-based interventions might be utilised in this specific context.

New ways of evaluating arts interventions needed to assess true impact for learning disability

There's a pressing need to do this work, although I feel strongly that we need new ways of evaluating arts-based interventions that avoid reducing outcomes to measurements and to ways of measuring that often exclude or fail to capture disabled peoples' experiences. However, I would argue that insights from critical and cultural disability studies and creative projects with and by learning disabled people have a very significant role to play in reorienting some of the ways in which we tend to think about dementia and what it means to have a diagnosis and indeed in a broader sense, what it means to be human.

Creative and critical work that explores the experiences of people whose differences are strong, in other words, whose difference is marked by atypical forms of communication and different ways of interacting socially and some different sensory experiences, all of which we see in autistic people learning disabled people often. Often there's a very important insight into the very diverse ways in which people exist in the world, and about what matters and what we think makes a meaningful life.

Expressions of selfhood – poetic rather than narrative, beautiful fragments of language

For example, conventionally in dementia studies much is made of the centrality of memory to identity, and to the importance of Telling a Story. However, for lots of learning-disabled people and particularly those who may not use language in a typical way, they might not express a narrative identity according to the traditions of autobiography, or express a sense of self via memory work.

However, one of the things that emerges very strongly in the kind of work I've done is that expressions of selfhood can be poetic rather than narrative, captured in moments or exchanges, in beautiful fragments of language, in the movement of bodies and the rhythms of our daily rituals.

Interdependence

For people who require other people to live and to thrive, recognition of our interdependence, mutuality and interconnection of shared meaning-making is essential, and at its very best, there is a creativity at the heart of care and caring, and of creative, imaginative interaction with the world.

Creativity and connection

Everyday creativity is expressed in the songs we might sing together, the rhymes we make up, the rhythms we beat, the value we place on these moments of connection and problem solving, working together, to create spaces in a world which is fundamentally inhospitable to particular groups of people.

What is important is that this insight dislodges the highly individuated models of personhood that are deeply entangled with the fear of dementia and the fear of the losses that it might bring; and they point to other ways of understanding selfhood and human value.

Understanding of dementia – valuing different ways of being

The understanding of dementia as a disability or via the lens of disability activism is therefore not simply about bringing social-model thinking to our identification of environmental, physical, attitudinal and communication barriers – though this is obviously very important - it is also about appreciating and valuing different ways of being in the world and the new knowledges that they provide us with.

I need to emphasise that in saying all this, it is not an attempt or an endeavour to elide learning disability and dementia – I think we are talking about very different conditions and experiences – but to argue that a recognition of the value difference and drawing on the creative and collaborative nature of care and life, with living with various differences in its very best sense is something we need to hold onto and extend to our thinking about dementia today and the ways shared practices like the arts might be used to enhance people's lives and to enable people to flourish, particularly through a difficult diagnosis. Thank you. [Recording]

RB, chair Thank you. That was really interesting from Lucy, some really interesting points around the Social Model and interdependence.

RB, chair I'm wearing two hats at the moment, firstly as chair – I now speak as the founder of Step-Change studios. They follow on from each other.



Dr Rashmi Becker MBE, Founder, Step-Change Studios, London.
Board Member of Sport England and Board Champion for Equality, Diversity and Inclusion

Step-Change Studios, is an inclusive dance company that supports disabled people to dance. We support people from all ages and abilities from aged two to 102, people with physical, mental and sensory impairments. I am currently in the US. doing a little bit of research. I'm in New York, but normally I am based in London.



Terminology

Just a bit of framing, in case there are people taking part that may not know some of the terminology, and things like the Social Model. It's funny because disability is often talked about in minority terms.

One in five people in the UK is disabled, and the figure is similar in the US, where there are 61 million people who have a disability. Again, we use different terminology: in the UK we tend to say 'disabled people' and in the States, we tend to say 'people with a disability'.

Understanding and thinking around disability – the Social Model

In my background I have a PhD which focused on intellectual disabilities, and I did a lot of work around the Social Model and over our history, our understanding of disability has changed.

We are less likely now to think of it in terms of just the medical impact of having a disability. We have the term Social Model and that thinking is that it's not just the condition of having a disability, it's our environment. It's social conditions around us that actually are disabling. Whether that's housing, whether that's transport. whether that's our working environment that can be physical challenges, it can be social attitudes, and so on.

CHAT Rona Topaz: Disabled people are disabled by society, people with disabilities are defined by their impairments... That's my interpretation of the difference between the two terms. **Ruth DAC:**I agree Rona

The thinking around the Social Model is changing – interdependence vs stigma



Also, as Lucy referenced, our thinking is changing as well, because there is a stigma around dependence. Yet most of us will have dependencies at some point in our lives. Most of us will be carers or be cared for at some point in our life.

Even the thinking around this Social Model is changing because there is greater recognition that this idea, what we valued in life is focused on independence. But, actually, there's growing recognition of the importance of

interdependence, and that actually we're all reliant on each other.

Disabled people's rights and better self-advocacy

The last point I make before I mention a little bit about Step Change Studios is also greater recognition of disabled people's rights, but also seeing much better self-advocacy. So not just seeing disabled people as vulnerable or at risk and using the sort of language that we have in the past and seeing much more leadership and representation.

But at the same time there are still challenges and there are still lots of lots of issues concerning people that may lack mental capacity.



Benefits of dance and movement for people with dementia and verbal challenges

We're talking about dementia today and people who might be non-verbal or not able to self-advocate; and at Step Change Studios we work a lot with people with complex disabilities and who are nonverbal and who lack mental capacity.

The role of the arts is absolutely amazing in terms of people's quality of life, and I think we'll be preaching a little bit to the choir here today with some of the speakers that we have. There's so much research out there, so much evidence showing the positive impact of the arts and also physical activity on health and wellbeing, on physical health and mental health. You'll hear about those from colleagues I'm sure, and it's everything from the obvious physical benefits, but also the importance of connection, helping tackle social isolation, helping with things like concentration. We work with people with behavioural challenges in terms of severe Autism.. It can help manage people's behaviours and anxiety, self-injurious behaviour - the list goes on. Our work at Step Change Studios.

Founding Step Change Studios: Lived experience and the need to improve connectivity through dance

I founded Step Change for a lot of reasons: I have a brother and I am guardian to my older brother who has severe Autism. He is nonverbal. He lacks mental capacity and growing up music and movement has been a really important way for us to connect, and in helping manage his self-injurious behaviour and his anxieties. I felt there weren't enough opportunities where I was for disabled people to participate in dance.

So I set up Step Change Studios.



Range of dance genres

We provide a whole range of dance, lots of different genres, and we work in a wide variety of settings. We look at very grassroots level in the community, but we also create professional work, creating a platform for professional artists that don't often have an opportunity to have their talent showcased. We have delivered and continue to deliver a whole range

of innovative programmes. Blind ballroom, for example

Race and disability – Dance Dosti

We've started also to look at intersection so as well as disability - the intersection, for example, between race and disability.

During COVID we ran a really innovative programme, supporting people with

disabilities from a South Asian background, because both disabled people and people from black and Asian backgrounds were disproportionately impacted. So we developed all sorts of online dance programmes, and in person programmes when we could emerge from Covid.



Influencing care providers to integrate arts and physical activity integral into care provision

But the third point which is really important, that as well as the delivery is the advocacy side, in trying to improve better practice in the sectors that we engage with, for example, the care sector. Trying to work with care providers to recognize the value of the arts and physical activity in the lives of people they support, working with the dance and the sports sectors to recognize and improve the support that they can give, both to participants, but also in improving inclusive practice amongst professionals, and also influencing policy, and making sure that policy when it comes to inclusive practice again and creating opportunities isn't a tick box and it isn't an add-on. But it's integral to formulating policy.

Enabling disabled people to feel empowered through dance – and behavioural change

Lastly, we work and again, you we've already heard this and I'm sure you'll hear it more, for a lot of disabled people and the adults we meet, they've spent their lives being told what they can't do rather than what they can. This can impact a lot of psychological barriers when it comes to feeling like they belong, that they can contribute, and that they have a place in dance, and there's a whole world of dance when it comes to the body, and how you should look etc, which again is almost a separate conversation. But, in trying to enter that space they can feel stigmatized. A lot of our work focuses on empowering and supporting disabled people, both as artists, but also to represent what they want and the sort of environment that they want to see, and the behavioural change they want to see when it comes to feeling like they can be in that space, and that they can benefit from everything that the arts has to offer.

CHAT: Rashmi Becker: If anyone would like to know more about Step Change Studios please visit: <https://www.stepchangestudios.com/> and this video about the dance programme focused on disabled people of South Asian heritage (with audio description) is available [here](#):

Anna Twells, freelance print designer: Could anyone advise or point me in the right direction to starting up an arts group for people who would benefit in my area [South=east London]?]Just wondered how these types of classes are funded

Anna Briggs: Anna local libraries and the local Arts Council officer would be good starting points.

RB, chair

I am going to move on to our next speaker, who is it's my pleasure to introduce, Nabill Shaman, who is an actor activist and co-founder of Graeae Theatre for Disabled People



Nabil Shaman, Actor, activist, co-founder, Graeae Theatre for disabled people.

Hello! First thing I'm not Nabil Shaman - Shaman is a joke on my part in creating my email address, which doesn't have my real name. It's Shaman Nahagwe which is to do with my heritage. My name is Nabil Shaban

Mythological foundation – to destroy myths surrounding disability – Solidarity!

Also Graeae is pronounced as 'grey eye'. But we don't speak Greek. I've never met any Greek who could enlighten me as to how you say the name of the Three Sisters who were the inspiration for the name 'Graeae'. They were cousins of the Gorgons and why we chose them as the name for the theatre company, partly because we were interested in mythology, and the purpose of the founding of the company was to break up the myths, destroy the myths surrounding disability in every respect. So we focus on the misconceptions and the mythologies regarding handicap, cripples, disabled people. The *behindert*, as described in Germany. We toyed with various ideas for Greek names for the theatre company. One was Cyclopes - we didn't think that would quite work. Another was Centaur – half horse, half human.

The Graeae – analogy of the disabled gorgons, their solidarity, sharing in order to advance



The one that I felt was perfect, though I didn't know their name at the time, I just knew that as there were three sisters who had one eye between them, that was a very good analogy of being quite disabled by having only one eye between them, and that it also represented the idea of co-operating, solidarity, being together, sharing what we've got in order to advance our situation.

Anyway, the story of the Gorgons and the Graeae was such that Perseus who was out to kill the Gorgons, out to kill Medusa, could only get information about where they were, how to do it by approaching their cousins, the Graeae. He double-crossed them in the end and didn't help the Graeae at all, but that's another story.

Graeae Theatre founded to provide opportunities for disabled actors to act

Now, why did Graeae come into being? Why did we, Richard Tomlinson, my co-founder – who sadly is dead - and I create Graeae. From my point of view it was because I wanted to be an actor, pure and simple. Back in the '60s and '70s, the opportunities for disabled people to be actors didn't exist unless you were in an amateur dramatic group maybe or at school, but even then as a disabled person, it was very hard, almost impossible, to get a local AmDram to consider you to be part of their group.

At the age of 16, in 1969, I wrote to nearly every drama school I could think of and said *I'm in a wheelchair and I want to be an actor*. They basically told me to get stuffed, or maybe 'form your own group', or run play-reading sessions. One suggested that I got in touch with the only person in Britain that we knew of who was a disabled performer -

Michael Flanders advised

He was a singer, comic writer called Michael Flanders. They said: write to him and ask him how he got going and get advice from him. I did and his best advice was the only way you are going to do it is to create your own opportunities. Write your own material, write stuff that the public would be interested in hearing about or seeing, and make sure you give yourself the best roles. So that's basically how Graeae was created from this very good advice.

Now I'm someone with a very vivid imagination. I've always been accused of that. That is often an excuse for telling me I'm a liar because of my vivid imagination. But I thought of television back in the '50s and '60s, because I was in a hospital for disabled children for six years, and the television and the radio was my mother and father in many ways, and I wanted to be like those people I saw on television. When I saw Roy Rogers or Richard the Lionheart, or William Tell, Robin Hood, etc. I that ah, that's how I can escape from my condition. I can become what they are. Now I knew that they weren't real. I knew that they were people who were pretending, and that was a great excuse for me to think that I can live in a pretend world and be something that I know I'm not. But at least I can pretend that and that in a way was what inspired me to try to become an actor. But, of course, it wasn't easy, as I've just explained, and we had to create our own opportunities to do that.



Art as therapy for all

The thing about art as a therapy is that I think that art is a therapy for everyone. Because everyone is searching for themselves, searching to find out who they are, where is their position in the world. where is that position with themselves? Many of our problems are created because we don't know enough about ourselves. I was thinking about that the other day and thought,

Know thyself – heal thyself

This is what the Greeks were talking about, the Socratic maxim which people quote, although actually it didn't belong to Socrates. It's just a phrase found in the Delphic oracle. *Know thyself*. This is the thing about the arts. That's the means by which a person can discover themselves, find out what their worth is, know how they can present themselves to the world, express themselves. Now along with that idea of Know thyself, there's also what Jesus is allegedly said to have said *Physician know thyself*, or, I should say, *Physician Health thyself*, and you can put the two together by saying: Artists, with your work you can know thyself and thus heal yourself.

That is how I regard the whole idea of art therapy, because it's not a specialist area. It's something that affects every single person who wants to be creative, who wants to find out who they are. Every artist is struggling to find out who they are, why they are, whether it happens to be Van Gogh, or Dali, or Frieda Carlo or Beethoven, they are all struggling human beings. They are all people with some kind of soul hurt in many ways, partly perhaps because they don't feel like they belong in this world, that they are perhaps alienated from themselves and from the universe. So they need to find a way in which they can find themselves, so that they can then heal themselves.

Dementia

This is pertinent obviously with regard to anyone at the onset of dementia, because that's when you're starting to forget who you are. That's when you are getting lost in a world where your memory is fading; and it's our memory that enables us to know who we are. Without the memory, we don't know who we are, and memory can be one of the first casualties of the onset of brain damage which then brings about dementia, so it's important that we try to be artists when we feel we are using ourselves so that we know, so we can rediscover who we are.

RB, chair Thank you, Nabil. I'm very particularly interesting reflections around sense of self and again I hope we can get to that in the discussion.

CHAT: Sarah Barbee: All so interesting, thank you

Anna Twells: Wow thank you Nabil, such an inspiring talk! **Ruth DAC:**thank you Nabil - brilliantly put.

Martyn Gardener: Fantastic thank you

Sue Johns- Battling On:Excellent Nabil, thank you

RB, chair I'm going to move on to our next speaker Fleur Derbyshire-Fox from the English National Ballet. Nice to see you, Fleur.

Fleur Derbyshire-Fox, Director of Engagement, English National Ballet 'Dance for Parkinson's'

That was wonderful, Nabil. I was really touched by those words, so meaningful, and although I have written some things I wanted to talk about, you've made me think about why Dance for Parkinson's?



I felt very passionate about, starting Dance for Parkinson's for English National Ballet, because my uncle was living with Parkinson's and his world was getting a lot smaller and he was feeling very isolated.

Parkinson's affects a 145,000 people in the UK. Many people develop the symptoms after the age of 65, but thousands of people living with Parkinson's are still of working age.

Dance for Parkinson is a dance and cultural programme that supports people to manage their symptoms. But fundamentally it's about being in the moment when you enter English National Ballet, you are a dancer. You leave Mr. Parkinson's outside, and you express yourself and the beauty of your movement, and everything is about what you can do in that moment, and that's very special connectivity with others that group motivation in the class. We have very beautiful musicians, so the music and the movement together is a driving force for people living with Parkinson's to be expressive dancers and to feel empowered, and we challenge the public perception of Parkinson's and about living well with Parkinson's into a more expressive part of your life and what you can contribute and co-create.

Social Prescribing

I am going to talk a bit about SP. We scaled up Dance for Parkinson's over four years, and it's delivered through affiliated hub partners. We've got a dance Agency, [Dance East](#), [National Dance Company of Wales](#), [Oxford City Council](#) and [Merseyside Dance Initiative](#), and to supplement in-person and to widen our reach, we also have a [National Online Dance for Parkinson's Offer](#).

University of Roehampton – Dance for Parkinson's (DfP) A report on a three-year mixed-methods research study

The programme was underpinned by research from the [University of Roehampton](#). [Dr Sara Houston](#) The findings of this three-year mixed methods research suggested positive outcomes, such as helping people with Parkinson's to stay motivated and to maintain an active lifestyle physically and socially. When you're living with Parkinson's at whatever stage, it is that social connection that is so important, and if you're living with [Parkinson's at stage three](#) - that is when there is a slow cognitive decline with memory, mood, behavioural problems, processing information – that's when dementias may set in. So we need to provide this very caring and nurturing environment, while also challenging, fun and joyous.

Dance provides a meaningful and stimulating activity in that supported environment, enabling our dancers to feel more certain about the future, despite their symptoms, and reduce the interference of symptoms in daily living.

West London Clinical Commissioning Group (CCG)

The West London CCG commissioned Dance for Parkinson's, under their older people's portfolio in 2016-17, when the company was based in West London. (We have since moved to East London). They commissioned the programme because of the opportunities it provided for personal expression, recognizing social interaction and peer support the people living with Parkinson's might otherwise lack. They also felt that the project helped fill a gap in provision for post diagnosis support, especially for older adults in stage two and three, as clinically described symptoms.

Scaling-up Health Arts Programmes: Implementation and Effectiveness Research (SHAPER) with King's College London – 12 weekly sessions on diagnosis

Following the CCG Commissioning, we are now part of a major study with Kings College, London, funded by the Wellcome Trust, under the acronym SHAPER. This study will assess the effectiveness and implementation of known arts in health interventions by scaling up and embedding them across King's Health partners, making the case for NHS CCGs to socially prescribe and fund these programs.

The study aims also to evidence how the arts can enhance health and well-being for larger cohorts than has previously been possible. So the end game would be that everyone at the point of diagnosis may be offered a twelve-weekly sessions of dance for Parkinson's, and in twelve weeks there's a real journey – it's not just the dancing and the music. it's also about attending cultural activities, having other artists coming in and having a performance at the end of those twelve weeks; and it would be provided for people of all ages, with all groups 1, 2 and 3 of mild, moderate, and severe symptoms.

Ambassador Alan Ferrett

Going to English National Ballet classes has changed my life. The atmosphere is more like a club where everyone is upbeat and happy. I couldn't do without it. When I'm at English National Ballet I am a dancer and I leave Mr. Parkinson's outside the door

That's what we're about – it is about our dancers and our ambassadors with lived experience shaping our programme and evolving this programme. I'd like to finish with a little extract of a film, *Momenta, 10th Anniversary of Dance for Parkinson's.*



Fleur adds two further resources:

Patterns of Perception – Central St. Martin's, UCL
More Than Movement: Exploring Motor Simulation, Creativity, and Function in Co-developed Dance for Parkinson's - BEAM Lab, University of Manchester

CHAT: Pernille Charrington: Thank you so much ! Best Wishes Pernille

Kate White: Transport is often a difficulty is this covered by the project at ENB?

Belinda McLean: Thank you SO much for this webinar speaking about so much that lights up my heart. I am an Occupational Therapist and I've worked with all sorts of beautiful humans for over 35 years. I have a partner who runs an art group through The Silverlining Charity for people living with the effects after brain injury. I work in a care home in Oxford city with a very diverse group including those who have accessed the ENB's programme. I'm passionate about making art and getting art on the walls (donations welcome!). I continue to change/check and challenge my own language around disability and I'd LOVE to stay in touch and be part of this conversation. Please get in touch with me. bmcleanot@gmail.com

RB, chair Thank you so much, Fleur. I am going to introduce our next speaker, who is William Oden, who is a trustee director of Decibels. Welcome William



William Ogden, Trustee Director of Decibels, Music for the deaf.

First of all, I should introduce myself. (Signing) My name is William Ogden, and because I know that some of you have come from abroad as well, I know the American sign language, which is my name is Will. I am profoundly deaf and I'm partly blind as well in my right eye.

A big thank you to Veronica for allowing me to be part of this fantastic webinar today, and I must say that all the speakers here have been so inspirational and fantastic to be able to hear what they did as well, and it's obviously inspired me even more to continue with the work that I'm doing at the moment.

As someone who is profoundly deaf, I have always used my personal experience to make a positive difference to the lives of the deaf community in the UK. We have always had love for the arts in general, whether it's theatre comedy, music, festivals, or exhibitions.

Inclusivity and Diversity

The word 'inclusivity and diversity' is being thrown around a lot these days. The rapper Stormzy said *It's not a buzz word* and even though that was such a short sentence, it was really impactful because it isn't a buzz word - it's always going to be around. We are continually having to fight sometimes for that to be provided or implemented with the deaf community.

CHAT:
Anna Briggs Riz Ahmed MC and actor said on the Trevor Noah show that diversity is often used as a cop-out to just add a 'sprinkle' of something different from the dominant group and say 'We've done it! We're not discriminatory'. He advocated instead for representation, a word that means a lot more, ie. all people must have a voice, rights and agency.
Rona Topaz: Hear, here Anna!

With that in mind, I am advising a variety of different organizations, recommending positive working practices to be put in place, because they need to be able to embrace the diverse and inclusive world that we live in today, in the UK.

In my work with the Performance Interpreting and they provide interpreters to be provided at music festivals, gigs, Wembley Arena. I know has a permanent contract with them to have every show to be interpreted, and we were part of that to be able to fight with many different organizations to be able to get them to get the resources to be able to put them in place because deaf people love music just like they would do with any anyone else.

Just on that note, I am a musician myself, and I was fortunate to have learnt to play the electric guitar, because I have a cochlear implant and enhancers for me to be able to pick up on and the musical notes and I had the opportunity to support Mr. Paul Weller who used to be a guy from The Jam, who I am sure you may have heard of, who was also trying to get more awareness that deaf people can be able to do anything, and you'll probably think him.

Decibels,

Decibels is a charity that I feel strong about because we are currently, for example, overseeing a project where we're going to Barbados in line with American as well as British musicians, to be able to give an opportunity for deaf young adults, older adults, adults living with dementia, and as well as young children who are all profoundly deaf to be able to use music as a tool to communicate to one another. Music is such a is such a powerful tool. like Nabil was saying, - I feel really strongly about what he said - it connects all of us together. We are all artists in our own right.

You may be asking, Does it take extra specialist knowledge to include people who are deaf, to be able to make music? The answer is, No, because it doesn't take much of an adjustment.

Adjustments for deaf musicians

Simple steps, such as tapping deaf people on the shoulder to get their attention, or flicking the lights on and off. you can't touch them, demonstrates just how important it is visually, as well as connectively, that they can be able to learn how to play a music instrument. Even learning some basic sign language as well, such as playing notes from A to G also engages deaf people to be able to memorize as well as play a musical instrument.

Memory

Now talking about memory: The reason why that's also such a keyword for the deaf community is because I have a very lovely friend who's called Rose Ayling Ellis who is deaf herself and she's been on a show called *Strictly Come Dancing*.

Deaf dancer Rose Ayling Ellis felt the music to win *Strictly Come Dancing* 2021

For our American viewers, *Strictly* is a bit like dancing with the stars. It's a show about demonstrating your dancing skills. Rose Ayling Ellis famously won it, and she has said that she memorizes all the feel of the beat and to be able to feel the music through how she expresses herself. through the arts of music.



It just comes to show that we can do anything, the deaf community, but it is the society that disables us from stopping ourselves in being given these opportunities.

I hope that I have shown you a range of what we can do as individuals, and what we try and do to get ourselves out there, but sometimes we just have to just keep fighting, to be able to hope that people will start to accept that deaf people can do anything.

Thank you very much.

CHAT:

Furrah Syed FRSA: Here here Will! Thank you!

RB, chair Thank you Will. That was very good, thank you so much. I'm really interested in words around advocacy and empowerment.

RB, chair

Our next speaker is Rebecca McGinnis, who is the Senior Managing Educator for Accessibility at the Met the Metropolitan Museum of Art in New York. Ah, you are down the road from me. Welcome.



Rebecca McGinnis, Senior Managing Educator for Accessibility, Metropolitan Museum of Art, New York

Good afternoon, everyone. It's such an honour to be here with this this amazing group of people. I want to talk to all of you after the webinar today, and some on an ongoing basis. I thought I would first, just to set the scene:

Access – Accessibility at The Met. What we Do

My team is based in the Education Department at The Met, but we have a remit that crosses the museum. We develop programmes that are tailored for people with specific disabilities and partner with organizations – disability and community organizations. We collaborate with others on designing programmes that are inclusive for all audiences; and we act as internal advisors on accessibility and inclusion throughout the museum. We also work to centre, to make more visible representation of disability throughout the museum, and disability justice in the arts, in terms of staff and interpretation.

Access Programmes

Our programmes take many forms. Some are scheduled, they happen on a regular basis, people sign up for them, or some people just drop in. There are partnerships and we also develop tours and programmes throughout the city, at different sites for groups and individuals with disabilities.



Offering choice

Some of the principles that we consider. When we are designing our programmes, we are very conscious of offering choice, different ways for people to participate – whether within a programme or across the options. People might just want to visit the museum independently or participate in a particular programme for particular audiences.



Challenging perceptions and expectations

Another thing that's very important is the idea of challenging perceptions and expectations - Fleur mentioned that in relation to Parkinson's – challenging what people might expect to do or want to do in a particular context.

Connectivity and co-creativity with disabled people to foster belonging

We also want to connect people to art and to each other through the experiences that we offer and create. Those experiences are really co-created and become a community with the programmes that we devise. We value and centre disability perspectives and the experience of disabled people. I think that's a really important justification for programmes that are tailored for particular audiences to have this co-created space where the disability experience is central. Others have mentioned how that co-creation and interdependence, mutual meaning collective meaning-making fosters belonging.

Multi-sensory arts engagement

Multi-sensory experiences that centre on art is a hallmark of our programming. So I want to focus on that, and how that affects accessibility, inclusion for all audiences with and without disabilities and why is this important

Why create opportunities for engaging with art through different senses in any type of experience in the Museum.

Every sense offers different types of information. Some senses are good at some things and not so good at others. We get different types of information from, for example, when we look versus when we touch, so one sense isn't a substitute for another. They all give us different information.



Learning through the senses other than vision and hearing, which are the predominant senses that we think of using in a museum are that is essential for some people.

Redundancy of information through different senses, reinforcing information through different senses can help people with, for example, learning disabilities or cognitive impairments, dementia, as long as we don't overload with too much sensory stimulation all at once.

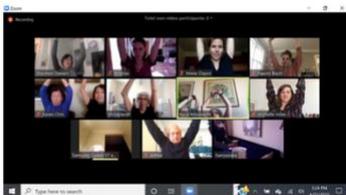
And, of course, multi-sensory experiences can help everybody to connect, to engage. Programming is really more inclusive when designed with this type of sensory engagement in mind, and also offers those important options for different ways to participate So if you want to identify as someone with a disability that's fine. If you don't, that's fine. We're doing these things anyway. people can choose preferences based on preferences or access needs.



Movement

Activities inviting movement help participants to understand

- Spatial relationships
- Narratives
- Emotions, body language, gesture
- Artistic processes



Movement

For example, movement is good at helping people understand spatial relationships stories, emotions, and even artistic processes.

Here are examples from different programmes for different audiences. In these images: (top) for kids who are blind or partially sighted, acting out characters in a [Miro painting](#); (centre) in our [Seeing Through Drawing](#) workshop using one's body to conceptualize the size of a painting. In our [Discoveries](#) programme for people

with developmental and learning disabilities and autism (bottom right), using movement to understand this sculpture by [Umberto Boccioni](#), that is very much about movement through space.

In the screenshot (bottom left) from our [Virtual Met Memory Café](#) for people with dementia, we are stretching – physical movement is a component of those online activities as well, to get the blood flowing, help people connect with others. You see that others are doing the same activity.

Movement can also be really integral into different ways.

Drawing from a verbal description that focuses on movement



William Merritt Chase, "Carmencita", oil on canvas, 1890

Here our drawing class for people who are blind or partially sighted, Seeing Through Drawing where we're drawing from a verbal description that focuses on movements at the top, or drawing movement from touch – so touching a sculpture, and then responding to that with mark making that represents movement.

Drawing movement from touch



Edgar Degas, Dancer, bonded bronze replica from original bronze cast, original cast, 1919



Touch

The sense of touch is central in many of our programmes too. I mentioned how designing the tactile experience with those differences in mind, so touch is immediate, requires physical contact. It is sequential. You can't get this global view that you get when you look at something it's active. You're active, so it can help to focus attention, for example, if you're touching and looking at the same time. You're moving your hand across a tactile diagram, for example, or across a sculpture.

Smell

We also use smell in a number of programmes. Smell is a sense that is sometimes compromised for people with dementia. But it's an option, to imagine smell in a programme, to create smell or sense by combining different senses to create a fragrance, to think about an object, how smell fits into the narrative, the history of an object. For example, an incense burner in our Islamic collection is a work of art, where we talk about smell, and maybe even how an opportunity to smell what might have been burned in that incense burner.



Sensory Experiments



Wine-tasting, multi-sensory pairing with works of art

We like to combine these sensory experiences for different audiences. This was a drop-in Friday evening event when the museum is open late. We brought in a sommelier for a wine tasting. People were invited to note the smells and the taste that they experience, what words would they use to describe those smells and tastes of the wine. Then we paired those with works of art. They followed up with a tour in the

galleries and used their place mats with their notes to see if they could connect, using that cross-sensory vocabulary to connect to the works of art in tours.

Programs and accommodations for visitors who are blind or partially sighted

- Scheduled programs
 - Picture This!
 - Seeing Through Drawing
- Partnerships and by-request programs
 - Guided Touch tours
 - Verbal Imaging tours
 - Touch Collection
 - Offsite programs
 - Art-making
- Handling materials, tactile pictures, and other multisensory activities
- Large print labels booklets
- Accessible digital media



Programmes for people who are blind or partially sighted.

Here are different ways of using touch. I show here a tactile graphic. We had an artist in residence from the Pacific Islands - we did a tactile graphic of tattoos on her arms (top left) and she was explaining the significance of each. This is a programme that took place in our Arts of Oceania Galleries.

Then we touch original works of art, and sometimes reproductions in the galleries and in more intimate classroom settings, sometimes with gloves, sometimes without gloves, but always really focusing on what touch can tell us about an object. So regardless of disability. we can get new information through touch.



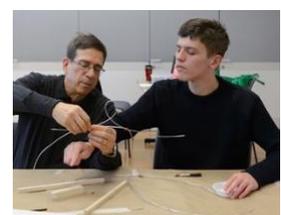
Seeing Through Drawing

In our drawing class for people who are blind or partially sighted, we're also considering things that might be adaptations or design elements for participants who might also have some cognitive impairment, dementia. So I'm thinking again about that idea of redundancy of information, giving instructions in a way that's not overwhelming, that's one step at a time, offering those choices and different ways to connect a physical, sensory and cognitive stimulus that that others have mentioned.



Discoveries

Similarly, in workshops for kids, teams, and adults, with learning, disabilities, developmental disabilities, and autism. I know the terminology is different in the UK.



But these are really multi- or intergenerational workshops, where everyone participates together. so that multi-multi-sensory engagement and flexibility of strategies that are used to engage people are crucial here. It's very much a community, a co-created community of participants and educators teaching artists that's evolved over time. We are making thinking, meaning together – Rashmi was talking about that – and also creating an experience that's going to be hopefully accessible to everyone, which involves a lot of experimentation. Some things don't work. Let us know and we'll try something else.

Programs and accommodations for Deaf people

Scheduled programs

- Met Signs Tours
- Met Signs in the Studio
- An Evening of Art & ASL

Partnerships and by-request tours in ASL

Accommodations

- ASL interpretation
- Tactile interpretation
- Captioned digital features
- Audio guide transcripts

Videos in ASL

Training for Deaf educators



Programmes for Deaf people - training

We have programs in American sign language which are also engaging multiple senses. Art making touch

We have a training program for deaf educators so we're also looking at when we're training people to become museum educators, incorporating teaching with smell, with touch, how to incorporate those in a setting which is American Sign Language-(ASL) led .

Met Escapes for people with dementia and their care partners



We have Met Escapes in person in the Museum, and the Met Memory cafe, which is currently virtual. The goals of those programmes are very much in line with what others have talked about: this idea of creating a space where everyone is comfortable.

We have a lot of opportunity for social engagement for making new friends, sharing experiences. hopefully having a positive impact on caregiver burden and isolation, giving that opportunity to just be in

the moment and to focus on what's in front of us. Moving around the museum, we get that physical exercise and cognitive and social stimulation that hopefully contributes to improved quality of life for everyone and including the educators

Met Escapes



Riffing together, creating graphic art scores – inspired by live jazz music

Here's some examples this was a on the top left an art-making workshop for Met Escapes where we had a jazz trio and we're looking at works of art inspired by jazz. The musicians were playing as people were making. They played music that was familiar to people, and then they also they actually improvised by using the works of art that people were making. They use them as a graphic score and played their artworks. The two art forms were riffing off each other, which was great fun.

RB, chair Thank you so much. That was so interesting. I can see from the exchange in the chat. that people have found, particularly the multi-sensory descriptions and the work that you do really fascinating. I hope we get a chance to explore that.

CHAT Furrarh Syed: Art transcends many boundaries and empowers people collectively and individually. Great to hear what the Met are offering in NY! Absolutely Rebecca - multi-sensory experience for all.
Rona Topaz: Yup. Here we are transitioning from “autism spectrum disorders” to “neurodiverse” and “neurotypical” for non-autistic people..
Fleur Derbyshire-Fox English National Ballet: Wonderful programming
Kate White: Co creating!!

RB, chair Our next speaker is Furrarh Syed. Furrarh is an artist, an educator, and a colour energy specialist, working in the visual arts. Welcome.



Furrarh Syed FRSA, Artist, Educator, Colour Energy Specialist, Visual arts for the blind and visually impaired

I am Furrarh Syed,, an artist and educator, based in London. I am passionate about making art accessible to all, and always focus on making art inclusive, as we all need to be able to experience the enrichment that art can offer us. Art transcends barriers of language, culture, disabilities. age gender. Art connects us immediately. I offer a multi-sensory art experience. I have seen

results in many formats as to its benefits in a therapy sense, in an empowering sense, improving our mental and physical health,

Experiencing life – and art - without one sense

I have worked with many organizations globally the Royal National Institute for the Blind, Vision Australia, the Singapore Association for the Visually Handicapped, Visions in New York and organizations in the UK.

Recently, I did an interesting workshop with the multi-national technology company Atos, which showed a different perspective, offering an opportunity to experience the effect of shutting down one of your senses. You learn a lot more about the experiences of people who don't have those senses in their day-to-day life, how things can be designed to be more accessible to them. Working with Atos was quite enlightening, how you can share with people a different perspective.



I gathered valuable data from workshops I delivered globally. Learning at the workshops was educational for both e educational for both the participants, and people delivering the workshops.

CHAT Rona Topaz: ATOS and Maximus, and Capita, should have undergone this experience in 2010. It might have saved a few lives. Sigh.

Rebecca McGinnis (Met Museum):'Yup. Here we are transitioning from “autism spectrum disorders” to “neurodiverse” and “neurotypical” for non-autistic people..' - Thanks for sharing this - we are transitioning to neurodiverse and neurotypical, too - a bit behind you!
Ruth DAC: We are all neurodiverse - what we need to say is neurodivergent

Workshops for the blind or partially sighted

My workshop format for people who are blind or partially sighted – tailored for people with varying needs – consists of three separate parts.

Feeling textures and movement

The first is feeling textures and movement on the canvas. I have created many canvases for workshop with specific that varying amount of textures that are interesting for people to experience using the sense of touch.

In each workshop I have a variety of people with needs in terms of sight. Some are completely blind, some are partially sighted, so it's an interesting perspective to hear what different people experience on the canvases.



Feeling Colour Energy

I then show people how to feel colour energy without the need for sight. We can actually all do that. I'll mention more about that in a moment. But it's wonderful to share that technique with people where we can actually physically feel colour energy without the need for sight. It's been wonderful, hearing the empowering responses from people when they realize that they can actually do it. We can all do it.



Creating abstract art

The third section of my workshop is where we create textured art together. So I provide a range of textures for people to choose what they want to put onto a canvas, with a variety of colours, which they could also go in depth if they want to have warm colours and cool colours. The purpose of this is to empower people to know even that if they can't see what they're doing, that they can absolutely create art, and then they can have the pleasure of being able to share that art with their family and friends.

I cannot explain in words the emotional feeling that I get when I see people feel so happy that they can do this, that they've been given the opportunity to do this. During many of my workshops is in various countries, I have had feedback from people where they have said, and coming from the perspective

of somebody who's blind they've said to me, *Nobody has ever bothered to ask us about art, let alone give us the opportunity to experience art using the sense of touch.* They have felt very grateful and empowered and enriched to have these experiences. I have had a lot of feedback about the aspect of showing people how to feel colour energies without the need for sight.

Feeling Colour Energies – technique

Colours have a varying wavelength of frequency, depending on the colour and the shade of the colour. Dark colours absorb a lot more energy. Therefore, they emit a higher frequency of heat and energy that we can physically feel, in comparison to a light blue or a white. Light colours absorb a lower frequency of energy which means that they emit a lower frequency of heat. It's more of a cooler energy. We can differentiate between these two energy emissions with

Colour	Wavelength Interval	Frequency Interval
Red	- 700-635 nm	- 430-480 THz
Orange	- 635-590 nm	- 480-510 THz
Yellow	- 590-560 nm	- 510-540 THz
Green	- 560-490 nm	- 540-610 THz
Blue	- 490-450 nm	- 610-670 THz
Violet	- 450-400 nm	- 670-750 THz

our eyes closed, or if somebody who is blind. Then going deeper I can show people how to feel shades of colour depending on the frequencies displayed on to the canvases.

So, each canvas I create for the workshops has cool areas and warm areas. Those are easy to differentiate. I show people how to feel shades of colour depending on the frequencies that we have or displayed onto the canvas.

Dementia inclusive

I deliver workshops for people of all ages and needs including the older generation, where there are aspects of dementia and other conditions.

Impact testimonials from international workshop participants

My workshop findings have been fascinating to me and to organisations I work with, seeing the responses of participants at able to physically feel the difference between colours and between shades of colour and how excited they are that they can actually do this. I have data showing correlations between people's reactions to different aspects of the workshops. Interactions with art can makes such an impact on people, not just their mental and emotional health, but their physical health; how to utilise the power of colour in everyday life, how colour can improve our mood and how art breaks down the barriers of culture, language, age and disabilities. I have seen the power of art making positive impacts on people in many countries.

For an idea of the impact of these workshops in encouraging people to create, here are sample testimonials.

The workshop was exciting and exhilarating. I didn't think I would be able to 'feel' the colours on the canvas, but to my surprise, I could easily feel the warm and cold areas. (VISIONS, New York)

I learned that blind people can also paint using their own creativity and found that colour has energy too. (Malaysian Association for the Blind)

Really felt the energies and colours, and appreciated the chance to create art for the first time. (Hong Kong Association for the Blind).

Participants feel empowered by their art experiences, which leave a lasting impression and encourage them to continue to create art.

Spreading the practice

Programmes exploring colour energies for people who are blind should be available in museums and galleries and institutions where people can access art in all formats. I should like to see visual arts for them and those with other disabilities available on a wider scale in all countries where people do need accessibility to art.

RB, chair Thank you, Furrah.

CHAT maggie chessher: Thank you so much to the wide and informative range of speakers. So interesting and much food for thought!!

Norwood Creech, Memphis: Furrah, speaking as a visual artist, I so totally appreciate the opportunities and experience you provide/facilitate.

POSTSCRIPT Veronica, A4D

I should like to add a reference to the [Blind Braille Artist Clarke Reynolds – Seeing without Seeing](#) – who I met the following day through the [Royal Society of Arts](#).

RB, chair Now we hear from Dr. Beverly Duguid, who is the founder of InsightMind. This is about poetry for the visually impaired



Dr. Beverley Duguid, founder of InsightMind.

Poetry for the visually impaired.

Hello! I am here today to talk to you about InsightMind, which is an initiative I started two years ago, to teach creative courses for mind, body, and soul.

What I mean by that is courses that will help you relax, and learn meditation, and also learn mindful movement.

A big part of this is Mindful Poetry, courses which I developed and am still developing, to help you write poetry, and also just have fun with words. I teach predominantly marginalised and underrepresented groups. This is so because these are the most marginalized people in our society.

I also teach from my own lived experience of having glaucoma, which means I have collateral sight (Mindful Poetry booklet)

Mindful poetry for visually impaired people

Two years ago I developed and continue to run an eight-week course, as well as a four-week course, on Mindful Poetry for visually impaired people, which have been very successful. The feedback has been very positive and my class has produced an ebook of illustrated poems. The course is really how I teach is very adaptive, but inclusive., which is my main aim. So I talk to people particularly my visually impaired students.

Discussion 1: How participants want to write

We talk about how they want to write first of all, because we talk about journaling and how do you want to do that as a visually impaired person. Some people will use braille. Some people will want to write digitally. Some people still write with Pen, but not everybody can do that.

Time and space

We talk about the issues they've had in other classes, where they weren't given the time to explore those different issues. First of all, I give people the space to do that.

Accessible formats

What are the access and format? How do they want to write? and what's the easiest for them to write in the class, It's really a big discussion we have at the beginning. We get rid of that, and then people want to come along to the next session and learn poetry from that. What they feel comfortable about and writing in their own format.

Voiceover, dictating, typing

People sometimes use voiceover, as well – that's an example where voiceover is something you might have on your smartphone or your apple phone, and it reads out the screen. It can also read out your own work for you, so you'll dictate it, or type it.

Hearing your poetry

Then you can listen to it back to make sure that it sounds okay. You can get a mechanical voice to reading it back - that is better than nothing to some people, because it helps them to hear what their poetry sounds like, and then they can 'read' it themselves.

Exercising memory

It calls for a lot of memorization of their work and that's another skill that visually impaired people have quite good memories to be able to remember their work without having it in front of them.

Discussion 2: Writing poetry

The second bit of the course is when we go on to write poetry. We talk about all the things that you would talk about in a mainstream class and try to foster all of that. But we just do it in slightly different ways sometimes and have to be inventive.

Metaphor imagery similes

I teach about metaphor, imagery simile, all those different things you use to write poetry. Then I ask people who haven't seen before, or maybe haven't written poetry before, how they how they get in touch with imagery. If you haven't been able to visualize in your mind before, or see around you, it's a bit difficult how you want to write things down.

Sound, touch, smell

I use sound. We then go into the senses; and this is where my second course came in about developing the senses to write poetry. I would then give people a series of prompts to help them write. Normally prompts are quite visual but in my course the prompts are sound, or touch or smell, and so we use different things to help people to write that poetry which are very different. It adds to having a quite a dynamic class where I give people find an object to write about, and it can invoke memory as well. It leads to quite exciting work where people think *Oh, I didn't think I could do this before, because I couldn't imagine before I can't think about what something looks like*. So they can they think about it.

Thinking about colour

Then some people begin to think about colour and they've never seen colour before, and they think about how they can write about colour.

It lends to a very interesting and dynamic class. [recording]



Veronica, A4D, adds Beverley is a committee member of **BAME VISION**, providing workshops for culturally diverse blind and partially sighted people.

RB, chair I am now going to introduce Jan-Bert Van den Berg Director of Artlink

Jan-Bert van den Berg, Director, Artlink Edinburgh and the Lothians



Hello! I'm going to briefly talk about the ways in which we support disabled people to access the arts in Edinburgh and surrounding areas.

What you can see behind me is the Red Note Ensemble performing, and they are performing on a large

blue wedge, which also transmits the sound as/vibration. What happens is that sound is transposed into vibrations, and people can experience that music in a completely different way.

The blue wedge was inspired by work that we were doing in a day centre for people with complex disabilities, where we looked at different ways in which we could engage people, where their perceptions were as important as the ones that the artists brought, and where the collaborations developed in a way where equality was achieved. It took a long time. It took us about 20 years to get to this point.

Multi-dimensional and multi-sensory engagement

The blue wedge was situated at the Tramway in Glasgow, a large exhibition space, where we also had a huge tower that blew bubbles in smoke. We had a massive silk which blew in the wind, and then also transmitted sound. It was a multi-dimensional and multi-sensory way of engaging with people.



All that work was inspired by the people that we'd worked with, that we'd worked with over a long period of time, and where we had made real efforts to understand different sensibilities, different ways of thinking and different ways of being.

Thinking differently

I think that's an incredible level achievement. It's also an incredible way of thinking about the arts in a slightly different way, from a slightly different direction, from a slightly different perspective. Really really important for us, but I think for all of us, this thing about how people not only access the arts,

but also how they engage with it, and how they direct us to achieve different things, to achieve different ways of experiencing what is around us, different ways of thinking.

Health and social care

What's been interesting in this particular example is that actually those who worked in health and social care got it very quickly. They knew it was a contemporary art space. They knew they were occupying an exhibition as such, but they also understood where the exhibition had come from.



Variety of interactive artistic experiences

What was more interesting for us is then how we make sure that people would engage with it, how we make sure that they had the time to really experience this. We did this not only by having exhibition there, but also by performances, performances of contemporary classical music, dance, but also of different types of experiences, things that we knew would appeal to people; and that included an

impersonator, an opera singer and the Contemporary dance company that's based at the Tranway. So, a whole load of different ways of getting people to respond, to engage and to participate.

What we created was something quite special, [he created something] where everybody could enjoy and engage with the exhibition on their terms – not something that I've seen that often, but also not something that should be unique, and I think with that thought I'll leave here because actually this should be what we should all be able to experience. From my point of view, it is something that after twenty, thirty years we have finally achieved.

Thank you for listening. If you want to find out more, please visit our website [Artlink Edinburgh](#) and get in touch with us. Thank you. [recording]

RB, chair We arrive at our last speaker before our panel debate. I would like to introduce Ruth Fabby, who is the Director of Disability Arts Cymru.



Ruth Fabby MBE, Director, Disability Arts Cymru

Hello everyone, it's so lovely to be here. Thank you for asking me to come. Fascinating to hear the talks and lovely to see some people I've known for quite some time in the room as well. I'm the Director of Disability Arts Cymru. 'Cymru' is the Welsh name for Wales. We have our own language and our own culture here. We are supporting artists to really make it in the sector.

When I started this job just three years ago, I was the Director of DaDaFest, formerly Northwest Disability Arts Forum, and before that Full Circle Arts in Manchester, so I've been around a long time in disability arts.



Political activism – our weapon to challenge the ableism

What's been great is how we've seen the sector change. Our work actually was formed through the movement to get our voices heard in society, and the arts were the vehicle that was our weapon, our weapon for change, our weapon for activism, our weapon to challenge the ableism.

Sorry I'll slow down. I've got a signer working with me. I get very excited about the work I do. It's been exciting, because that political start to our work became quite active and quite demonstrative in very political ways. It's why we've got these conversations today, because disabled people were fed up being talked about or done to.

Changing the narrative around disability – callout inequalities around Ablism

We have to change the narrative around disability and call out the inequalities round Ableism, and the fact that, particularly in the art sector, very few of us are in positions of leadership. Hearing Nabil talking about that earlier, setting up Graeae, that's very much the same model we had with setting up DaDaFest, because we just didn't see artists getting a break into the spaces where we all need to be seen, where we can affect change by having ourselves seen. One of the great quotes we've had in DaDaFest was *This festival reflects my reality*, and it's so important our reality is seen throughout society, so DaDafest has done its thing and it continues in Liverpool

I'm now in Wales, working with a membership organisation to bring change, supporting those members who are self-disclosing as disabled, or deaf, or neurodivergent artists across Wales. It's a free service we offer them. If people want to join us from outside, they can for £10 a year and we do a lot of activities to support them.

Strategic change in Wales

But the big thing we do is really institute that strategic change, both delivering the quality training, but also initiatives in arts programmes that will make more and more opportunities for the artist to work in the sector. In Wales, when I first started in 2019, the Arts Council of Wales showed only about 2% of artists self-disclosed as disabled people. It's gone up to 8%. But if we're going to reflect the fact that 25% of the population of Wales are disabled and deaf people, we need to actually be seen more in those places.

CHAT Ruth adds: Wellbeing of Future Generations (Wales) Act (2015)] is a Game changer

Impairments rare from birth – usually acquired

Now one of the big things that is a myth about our lives is to say as disabled people is that we're all born with them. Most of us acquire our impairments. Only about 14% of us actually are born with our impairments.

Disability is normal

So, disability is normal, it's every day. it's going to be you're disabled, or you're not disabled yet if you live long enough. so we need to have a narrative and a discussion about bringing that into the full.

Gawad

One of the big things we've just finished last week was a programme called Gawad, where we used radical inclusion principles to embed actors and writers and technicians and young people who were disabled people in that work.

Dewch â'n Hawliau Creadigol

Bring us our Creative Rights: **Disabled people's Cultural and International Manifesto**

One of the big things we did last year was develop a Manifesto to present to the Welsh government called *Bring us our creative rights* and That's where I see the conversation is changed for us is disabled artists across the country.

It's about our rights to be included, our rights to be in the places where we're often ignored or left out and forgotten about, and we put nine demands there and the Welsh government have accepted them following the United Nations Convention for the rights to disabled people, the Social Model of Disability that we are subject to an ableist society, and we need to call that out alongside racism and sexism and the other isms which affect our intersectionality, because we're never tidy in one place.



Art as Platform

Art is a platform that can challenge negative perceptions of disabled people, highlight inequalities, and support socially progressive alternative futures.

At DAC art is used to educate and remove the barriers that restrict disabled people, their life choices, and right to live independently and equally within society.

All of our work and activities aim to be accessible and barrier-free. We embrace diversity and are proud to promote and celebrate the language and culture of Cymru in this context.

I hope I've given you enough of our work. But don't forget to get in touch with us if you need to find out a bit more. Thank you for letting me be part of this important conversation today.

RB, chair Thank you so much Ruth, and again, there's a whole subject in there around intersectionality as well.

CHAT: Furrah Syed Thank you Ruth. I can feel your passion and will definitely be in touch.

Rona Topaz: I love the Welsh government. Along with Scotland, they are much more progressive on disabled people's rights than England!

SPEAKER DEBATE, chaired by Dr Rashmi Becker

Could I open discussion and invite people's reflections on anything that particularly stood out, or that you wanted to highlight that you've taken from the discussion, or from the speakers that we've had so far, so reflections or anything that particularly stands out as critical in the discussions we've had,

Veronica, A4D I should like to ask speakers about the stigma issue:

Proud to identify as disabled vs prominence of dementia stigma

This arises from our preparatory discussions for this webinar, learning that disabled people are proud to identify as disabled, whereas many people new to the disability of dementia, deny even to themselves that they have the condition, partly due to anxiety about their degenerating brain, but also to the stigma that surrounds the condition.

My question is do people already living with a disability challenge, mindful that they will have internalised while publicly declaring pride as a disability artist, think of dementia as another challenge to be coped with, thinking less of the stigma than people who are not living with a disability and are new to the sense of being 'other' with the sudden realisation that their brain is degenerating. It is because of this fear of stigma that I promote the idea of preserving brain health.

I just wondered what speakers think about stigma of a dementia diagnosis when you're disabled?

Ruth Fabby, Director, Disability Arts, Cymru

Can I answer that because it has been really interesting for me. I started wearing hearing Aids at six years old, after being labelled as Educationally Sub Normal, then, realizing it was actually a hearing thing I was dealing with, and that my engagement from that point on really impacted the rest of my life, and I found the arts was the first time I got to find a voice, something I could do and feel proud of. Then I found the Social Model and the disability movement, and it radically changed. how I saw myself. I was no longer that burden.

Language – deafness gain, rather than hearing loss

I realized a lot of the language about the stigmatization of being deaf, and *I Can't* is always from a deficit. So it has been something that really interests me.. As I've got older and acquired more impairments. It is interesting how you change and shift the narrative around your life, but actually I challenge, I say, I've got a deafness gain not hearing loss, and as I can't move as much because of my lung condition and my mobility impairment it's giving me a new way to be liberated in a wheelchair when I need to use that. So, changing that conversation is really important.

In Liverpool we did an intergenerational project in shelter accommodation where many people becoming disabled with young disabled kids to do writing, and they were discovering new ways to see themselves as disabled people acquired impairments later.

It's not exactly the context of dementia, but actually the conversation doesn't always have to be about tragedy, suffering, *We can't*. It needs to change and challenge that. Words are important that we use words that can do that.

RB, chair

Thank you, Ruth. Is there anyone else who would like to comment on the difference in in acquiring a disability or developing dementia later in life?

My own reflection is that most people don't have just one disability. People tend to have more than one disability and different impairments and each one has its own opportunities and its own

challenges, and I think it very much depends on the type of disability you have, the type of environment that You're in and the type of support that you have.

One of my worries as guardian to my brother who is nonverbal and severely disabled. I have a massive fear around ageing and disability because he won't be able to communicate what is happening, or how his feeling, and so on. I do think there's a whole subject of study and that we need to better understand around aging and disability, particularly people with complex needs.

Furrah Syed, Visual Art for the Blind – culturally diverse approach and stigma

Can I just add to that Rashmi. I totally agree with what you're saying and coming from a perspective of the Asian background, there are a lot of cultural aspects to address as well, because I've seen it myself where there are stigmas, people are embarrassed to talk about it, and they don't have the support. A lot of people from various ethnic backgrounds don't have the support network, where somebody can be open and honest about their additional needs. Definitely in the older generation in the Asian community there is a big issue of admitting, or of anybody feeling comfortable to say they have dementia, or they have Alzheimer's etc. I'm coming from a perspective where my mother has early-stage dementia, and there are a lot of complex issues going on right now. So I think, cultural backgrounds, especially with the Asian community that I have experienced, there are issues that do need to be addressed. If there's more support. that would be really helpful.

Rebecca McGinnis

I think it depends. People's own changes to the way they see themselves and their own personal identities are not held in a vacuum. An important variable there is going to be the way in which one society or culture perceives dementia, and the experience of dementia. It's all very wound up together also with ageing in general, and the way we perceive ageing and the acquisition of disability. I don't think you can separate them, but I love what Ruth said about having discovered the Social Model and being able to have a way to recontextualize your own experience as a disabled person, and possibly apply that to the changes that one experiences when they have dementia. Very interesting.

CHAT Ruth DAC: Thank you for saying that. We have to be sensitive to context and cultural nuances - Always important to use labels that empower and that you choose - not the labels are imposed on us. Everyone's experiences of dementia is different so it hard to make a generalisation - people all respond differently no matter what happens to them. We are not tidy people

RB, chair

I think Veronica, putting it more delicately, putting it crudely, no personally, I don't think just because you have a disability it's easier to deal with another type of disability and they're all very different, and I think we all experience stigma. If you look at our protective characteristics. people experience stigma and unequal treatment in very different aspects of their lives. It's not something people have talked about intersection as well going back to Furrah's point, but that can be gender. It can be sexuality, it can be all sorts of things, and then there are social inequalities that also impact.

Veronica, A4D

Actually, my question, mindful that those who have not experienced disability are rarely proud of living with dementia and speakers having explained to me how proud people often are to identify as living with a disability, how do speakers about disabled people's response on being faced with symptoms of a dementia, might their focus be more on the new challenge, than concern about stigma.

Veronica adds Awareness of stigma with dementia, whether it's cultural diversity or the awful general stigma associated with dementia, was Arts 4 Dementia 's raison d'être – inspirational arts activity io override the stigma and preserve wellbeing.

So my question was, is it easier for people who already live with a disability whether stigma was lower down the their agenda for them when dementia hits or whether just the same where they still feel that awful worry about dementia.

RB, chair Three colleagues have experience they want to share around stigma.

RB, chair **Kate White**, a delegate, has her hand up

Kate White, It's been an amazing event. I wanted to speak to the stigma issue because I think it is about the feeling of empowerment, and that comes from so many different factors in a person's life. So, the being able to face a diagnosis - perhaps it might be. dementia in this case – comes from so many different factors in your background and in the culture and community that you live in.

I think that the narrative, as people have been talking about narratives around disability, are also so stigmatizing around the narratives of dementia.

We're out and proud with dementia - Dementia as an asset

When my partner and I, John, who had dementia he said, *We're out and proud with Dementia*, and that's made a big stir in not only in our family, but in the community – how can you be out and proud with a disability of that kind? So I think we need to really be speaking out about the ways in which dementia can be an asset to the community, and not a deficit.

RB, chair

I think one of the interesting things that that's a sort of thread that's run through a lot of speakers has been this sense of community and the role of the arts in connecting people and bringing people together versus the isolation one might feel whether living with dementia or someone with a disability.

Thank you all very much.

CHAIR'S SUMMARY, Dr Rashmi Becker

There are a lot of speakers and I hope people have found what each other have shared valuable. I'll just flag a couple of things that grab me from the speakers.

Just a very brief summary of the things that stood out for me:

The value and role of arts in the community

The idea of community and the value, the role of the arts, both in terms of the practical obvious benefits when it comes to physical health, but also the social benefits,

Philosophical, existential understanding

An almost philosophical, existential in terms of understanding, the arts helping us understand ourselves and understanding the world around us, or ourselves in the world .

Social Model of Disability – dependence, independence, interdependence

When we were talking about systems and the Social Model of Disability, quite a few people talked about dependence, independence, interdependence, and that that seems really critical.

Arts transcending barriers

People talked about the value of the arts also just in terms of transcending boundaries, so transcending boundaries of language.

Learning, multi-sensory experience, empowering

We talked about different ways of learning and experiencing the arts - the multi-sensory experience, the power of stories and narrative. I think that was really striking and interesting ways that colleagues were shared around learning and developing.

Advocacy around disability, justice, challenging perceptions

There was a lot of talk around advocacy, disability, justice, challenging perceptions, both external perceptions, but our own perceptions in what we think is possible, and how we adapt and transpose the work that we do when it comes to delivering the arts.

Social Prescribing

When we were talking about social prescribing and the different elements of delivering the arts and artistic practice is around a whole system change. So this isn't just about doing art better or doing it more inclusively, it's about all the other factors around us - it's about social attitude, about our environment, it's about transport. it's about the support that we have, it's about stigma.

But there are so many aspects, particularly because a lot of practitioners here may not have direct influence over, but are critical to the effectiveness of how we deliver and present its happening.

Veronica, Arts 4 Dementia

It has been such a privilege to have you Rashmi as our chair. Your informed, wise guidance all the way through has shone so strongly in every aspect, that thank you very much for coming to a chair at the last minute, after Kamran was rushed to hospital. We were just so lucky and honoured to have you. Thank you to our Involve signers. You really have done wonderful things for us all. And our speakers – my goodness, what a lot of experience you've shared, guidance, calls for action. You are hugely inspirational. We shall never forget today. Thank you very, very much.

(Please note that contact with speakers and their websites can be accessed at the head of and within each talk.)

CHAT

ParveenKhan	Brilliant talks thank you everyone, very interesting topics.
maggie chessher:	Thank you so much to the wide and informative range of speakers. So interesting and much food for thought!!
Furrah Syed	Thank you all for such inspiring approaches to empower those who are dealing with additional needs!
Jessica Ryan-Ndegwa:	Thank you for organising this talk and will catch up on minutes after!
Norwood Creech, Memphis:	Thank you, all, so much! - Might you have tips for documenting results to appease researchers looking for “proof” as to how the arts can transform “limitations” of the human experience?
cheryl.hamilton2:	Thank you , very interesting
Sue Johns- Battling On:	Thank you to all speakers.
Tracey Lilley:	Thank you so much, this has been really interesting,
Ruth DAC:	Been fascinating to hear from you all - <i>diolch yn fawr</i> / thank you for including me. Keep on being creative & connective. I will leave you with this - https://gov.wales/well-being-of-future-generations-wales-equality-and-the-social-model-of-disability-embedded-into-it
Rebecca McGinnis (Met Museum):	Thank you everyone!
Nicky Tann:	Thank you for organising this impressive line up
Claire Street (Link Age Southwark):	Many thanks indeed
Will Ogden (Trustee Director for Decibels):	Thank you all.
Furrah Syed	Thank you all for an incredible event.
Vivienne Daly:	Thanks everyone. Excellent.