

Disability Transformation Project

What is the project?

The Disability Transformation Project is a project by the East of England Equality, Diversity and Inclusion team that aimed at amplifying the voice of colleagues with disabilities and to raise awareness of what disability is and how to get support.

The Committee

As part of the project, a Transformation Committee was formed. This consisted of representatives from each of the six Integrated Care Systems and the objective was to share lived experience stories of being disabled in the workplace to encourage people to learn more and normalise talking about disability.

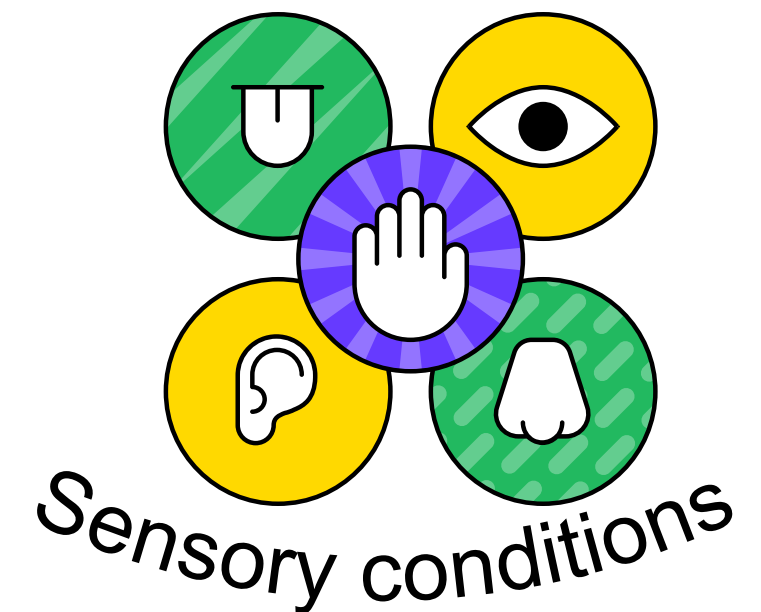
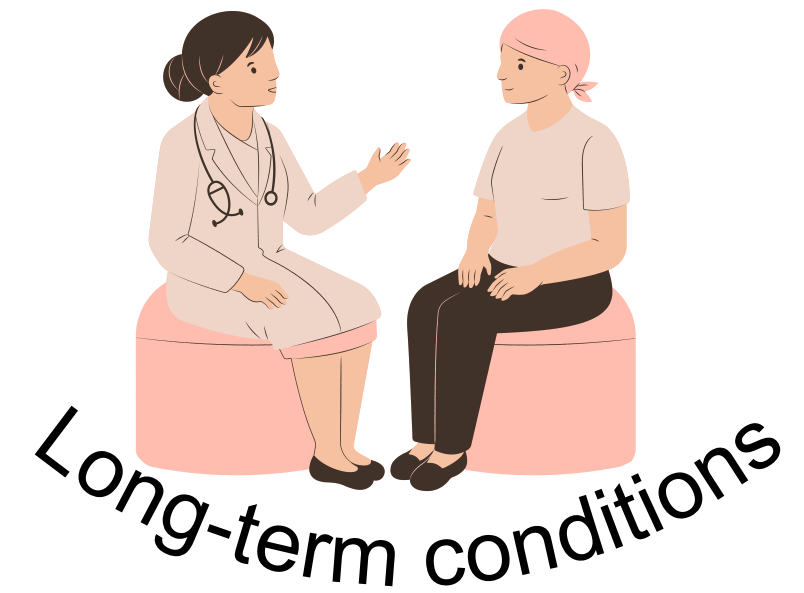


What is disability?

The Equality Act 2010 defines disability as a physical or mental impairment that has “substantial” and “long-term” negative effects on your ability to do normal daily tasks. With this in mind, a lot of people have incorrect perceptions of what disability is. There are people that may be classed as disabled and entitled to additional support that may not be aware of this. The intention of the Disability Transformation Project is to spread awareness and showcase stories.

How to get support?

There are different resources available that can be accessed at your organisation, ask your line manager about reasonable adjustments. For regional guidance, please contact england.equalityeoe@nhs.net



Understanding disability

There are a lot of misconceptions around disability that have been enforced by different stereotypes. There are stereotypes that all disabled people have wheelchairs, or that they cannot work. Neither is true, and this project will be showcasing real experiences of the Transformation Committee. Not everyone is born disabled. An individual can become disabled at any point of their lives, or could be diagnosed with a long-term condition.

Understanding long-term conditions

A long-term condition is a condition that has lasted or will last over 12 months and affects your ability to perform day to day activities. Some impairments are automatically classed as a disability even if it does not impact daily activities.

People with HIV infection, cancer or multiple sclerosis are covered by the Equality Act from the date they are diagnosed.

Long-term condition examples



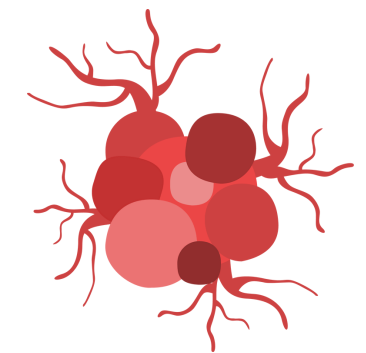
Heart disease



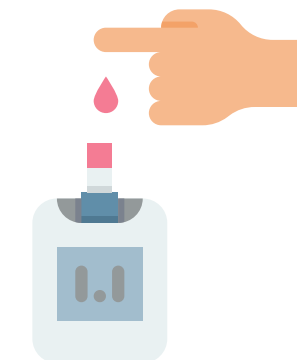
HIV



Mental health



Cancer



Diabetes



Musculoskeletal

Getting support in the workplace

There are different ways to get support in the workplace depending on your needs.

- **NHS Health Passports** allow people to record their health condition or disability.
- **Reasonable adjustments** are legal responsibilities for employers to make workplace adjustments for colleagues with long-term conditions or disabilities.
- **Access To Work** is a scheme that can provide financial or practical support for colleagues to stay in work.
- **ACAS** has up to date disability guidance on how line managers can support colleagues at work.
- If you feel comfortable, you should start with speaking to your line manager.
- **Staff networks** are a good way to meet people and to access organisational resources. You can find staff networks on your organisation's intranet pages.
- **Freedom to speak up (FTSU) guardians** can give you a safe place to voice concerns.

Understanding disability



Disability in the UK

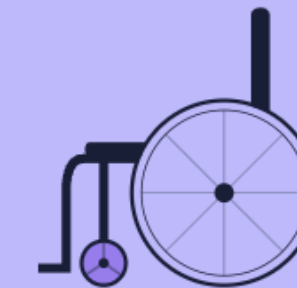


52%

of working age disabled people are in employment, compared to **81%** of working age non-disabled people.¹



Disabled people from BAME backgrounds report greater social inequalities compared to disabled people from white backgrounds.²



5-7%

of disabled people use a wheelchair.³



83%

of disabled people acquire their health condition during working age.⁴

Lived experience stories

The Disability Transformation Committee have written different stories about their lived experience to be showcased in this document. The objective of this is to:

- Support understanding of disability in the workforce
- Dispel beliefs
- Encourage others to seek support
- Shedding light on the reality of being disabled, the highs and lows

If you would like to speak to a member of the committee after reading their story, please contact england.equalityeoe@nhs.net



Dawn Poulson Whelan

Dawn is a dedicated Healthcare professional with over 20 years' experience, in Emergency Care and the Ambulance Sector. Dawn is a Fellow of the Society for Education and Training and has a passion for Education, Equity, Diversity and Inclusion. She is reading for a Professional Doctorate at Edge Hill University investigating the links between organisational culture and support for employees with disabilities. Dawn has lived experience of disability and caring for others and is a founder and Chair of the award-winning National Ambulance Disability Network and works with the Association of Ambulance Chief Executives National Ambulance Diversity & Inclusion Forum, responsible for shaping inclusive policies and practices across the NHS. Dawn joined the Disability Transformation Committee to actively contribute to improving the experiences of Disabled colleagues and patients. Through her research and lived experience she advocates for improved support systems and work towards creating a more inclusive and accessible environment for everyone.



Dawn's Story of Leadership



Dawn joined the Ambulance Service in 2004, to pursue her childhood dreams of becoming a Paramedic. Dawn initially worked in Ambulance Operations to build her knowledge and skills and found that she enjoyed supporting others and their development, so she became a mentor and trainer.

In 2012 Dawn was diagnosed with, Ankylosing Spondylitis, which affected her joints and resulted in widespread general symptoms. The condition is degenerative and there is no cure. Treatment is targeted to slow the disease progression. Medications are harsh and have significant side effects which impact on day-to-day life.

“In some respects, I was happy to have a diagnosis, I know that sounds strange, but it helped to have a name and a focus for treatment. Although longer term, this meant having to re-think everything I had set my heart on. My appearance changed and I had to use a mobility aid and recognise personal limitations. I had to find new ways of working with the condition rather than working against it”.

I realised how challenging it was to navigate work whilst trying to manage this life-changing situation. From access to buildings to helping colleagues understand the impact of the condition, there seemed to be so much to do.

Dawn's Story of Leadership

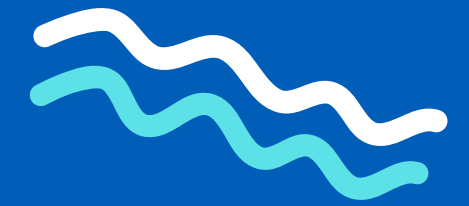
Despite these challenges, Dawn continued working and returned to University, she qualified as a teacher, and completed a Degree, an MSc in Healthcare Leadership and is a Fellow of the Society of Education and Training.

“Each day is different, and I navigate challenges as best as I can. when I was told that my condition was progressive and incurable, I saw that I had two choices, I could simply accept there was nothing that could be done and access sporadic support, or I could use my experience to help others understand disability and drive organisational change. So I committed to study and actively change the environment for everyone. I hope it has helped others and that Disabled staff can see the impact they can have too”. My qualifications have given me confidence in articulating my message and enabled me to effect positive change. I have undertaken various roles within the ambulance sector and feel this have given me a good understanding of the unique pressures this type of environment brings. It has been hard work and challenging at times, but I love that I can support colleagues and, with a better awareness of disability, we can be confident in supporting our service users with long term conditions too.”

In 2021, The National Ambulance Disability Network was formally launched following the backing of CEOs & Chairs of all UK ambulance trusts. When Dawn started her journey, she saw the potential to improve resources available to support Disabled staff in an ambulance environment. Now every Ambulance Trust in England has a staff network and the national network has been established to support progress and maturity, to share best practice and take an active part in ensuring the voices of Disabled staff are included in policy and practice development.



Introducing Greet



I graduated in Belgium with a BSC Physiotherapy in 1998. I then worked in private practice for 10 years, sharpening my interest and skills in respiratory physiotherapy with children and adults, alongside neuro development. Following my move to the UK in 2008, I followed my passion in children's physiotherapy.

In November 2019, I had a stroke in the medulla oblongata, affecting my mobility and causing chronic pain in the left side of my body. After returning to children's physiotherapy, I realised how important it is to empathise with patients and families, particularly where neurological events changed their lives at birth or throughout their young lives.

In the role as a Workplace Adjustments Development Lead and part of the to make a difference to the educational, access and application experience, seeking a balance with prospective employers towards reasonable adjustments.

Greet's Workplace Adjustment Passport

[Click here to watch](#)



The image shows a YouTube video player thumbnail. At the top left, there is an NHS logo and the text 'Workplace Adjustments Passport'. Below this, the main title 'Workplace Adjustments Passport (WAP)' is displayed in a large, bold, purple font. A smaller subtitle 'From a UK healthcare provider' is visible below the title. On the right side, there is a 'Share' button with a right-pointing arrow. The central part of the thumbnail features a circular portrait of Greet Janssens, a woman with long brown hair, wearing a patterned top. To the right of her portrait is a graphic with the text 'Together we can' in a curved font above several icons: a blue head with a heart, a green person, a blue ear with a slash, a purple head with gears, and a purple person in a wheelchair. A red YouTube play button icon is overlaid on the graphic. Below the graphic, the text 'HCT' is written in a bold, purple font. At the bottom left of the thumbnail, there is a 'Watch on YouTube' button with the YouTube logo.

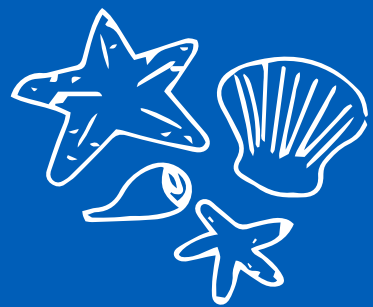
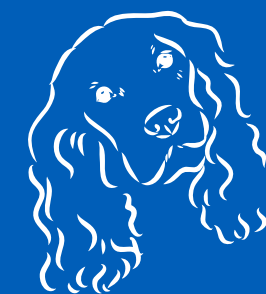
"I want to be my best at work, but due to my health conditions, I need to make a few changes to how I work"

Introducing Sarah

My name is Sarah Johnson and I work for Norfolk and Waveney Integrated Care Board. I'm 46 years old, I live in West Runton, Norfolk and have the most amazing Blue Flag beach basically on my doorstep (or at least at the end of my road). I have 2 spaniels Poppy (12yrs) and Lottie (1yr!), 2 step-children Martha and Austin, a wonderfully supportive partner and I happen to have multiple hidden disabilities.

My hidden disabilities are the reason I am passionate about work around disabilities. It took me quite some time to accept the 'Disability' badge and I still don't really feel that it fits me. I have Long Term Conditions, not disabilities. However, the long term conditions that I have are probably the ones that no one wants to think about, let alone talk about them. I have Ulcerative Colitis (no one wants to talk about poo!), I have depression (no one wants to talk about mental health) and I have HIV (no one ever wants to talk about sexually transmitted disease!).

My experiences of living with these conditions and continuously trying to function at work, without falling into the presenteeism box is really challenging. That's why I think it is important to be part of the EoE Disability Transformation Committee. We need to ensure that all NHS workplaces across the EoE allow their staff to be as productive as possible, whilst balancing the needs of the organisation with the needs of the individuals. Staff should be encouraged to discuss their needs in a way that feels comfortable for them, they should feel supported to be at work, but also understood if this is not always possible. Policies and procedures need to be adaptable and flexible enough to meet both the needs of the organisation and individuals, recognising that one size does not fit all.



Sarah's story - Am I Disabled?

My name is Sarah Johnson, otherwise known as SJ, I live with 2 long term physical health conditions and a long-term mental health condition. According to the Equality Act 2010 which measures the impact of these conditions without medication I am disabled because without my medication they would have a severe impact on my ability to do day to day activities.

However, even with these conditions, and thanks to modern medicine, I have been able to achieve so much that I am incredibly proud of. I have undertaken 5 overseas treks for charity in The Sahara, Costa Rica, Vietnam, South Africa and Nepal (to Everest Base Camp), I have completed numerous 1-day walks in the UK ranging from half marathon length to full marathon length and across the Yorkshire 3 Peaks, I have abseiled 220ft down Canonteign Falls. Does this mean I am less disabled?

I am able to work full-time with limited adjustments needed to my work environment. I have been able to raise awareness around my physical and mental health conditions, Ulcerative Colitis (UC), HIV and Depression. I have overcome discriminatory behaviours directed towards me and proved my ability to do my job. I have chosen not to declare myself as disabled on job applications as I want to be interviewed based on my achievements. I have managed to gain a Foundation Degree, A BA Hons Degree and a Master's Degree whilst working full-time. Does this make me less disabled?

I also have times, where my joints are swollen and painful, I have nerve pain from surgery linked to the HIV, I have times when my UC is flaring that I have diarrhoea and bleeding due to ulceration in my colon, I have to have my cervical screening annual because of my HIV status, colonoscopies or sigmoidoscopies every 3 years because of my UC and have to have annual Flu and biannual covid vaccinations due to the immunosuppressive medications I take for my UC. Is this what makes me more disabled?

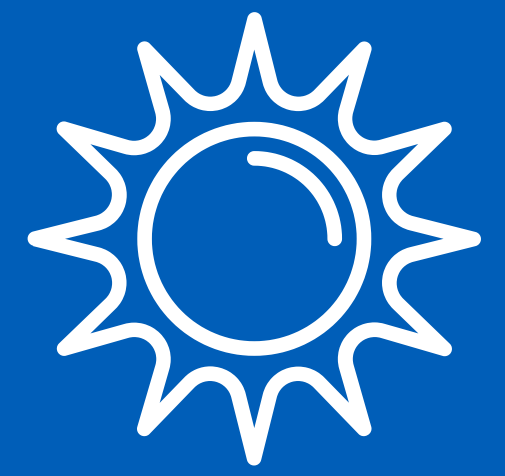
Many people are disabled but probably wouldn't identify as such, they are successful and full of achievements and just like me they face challenges that they probably don't even recognise as challenges as they have lived with them for so long. This is the reason I am part of the East of England Disability Transformation Committee, not all disabilities are visible, not all disabilities have noticeable affects every day, but they are disabilities non the less.

Thanks for reading

SJ



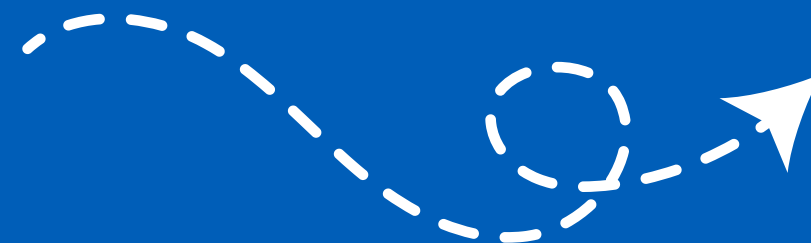
Meet Joshua



I am Joshua, A team player. I am a hard –working and driven individual, who is not afraid to face challenges I am passionate about my work and I know how to get the job done. I would describe myself as an open and honest person who doesn't believe in misleading other people and tries to be fair in everything I do.

I am passionate about providing care to those in need in my community. And that motivates me, and makes me excited to do my best work.

I am interested in working around disability because I am passionate about helping people live more independent lives it is extremely rewarding to watch service users fulfilling their goals.



Meet Geraldine

I'm Geraldine, an inclusion professional with a background in programme management and legal compliance. I've worked in the public sector for 19 years in various strategic and operational roles and always been really interested in the people aspect. I love to see people thrive so working to create an environment where everyone has access to opportunities, feels valued and is able to maintain their own best standard of health is really important to me. I also have personal experience of various disabilities, both hidden and visible.

I currently work for the James Paget University Hospitals Trust as Equity, Diversity and Inclusion Manager, providing leadership on effective and informed equality initiatives.



Meet James



I am the Project Lead for the Disability Transformation Project and the Committee, I am extremely passionate about disability in general, but more specifically making sure that disabled colleagues have a positive experience at work and that the workforce has an accurate representation of the diverse population.

I personally consider myself to be disabled with a hidden long-term condition in the form of an auto-immune disease, and I also struggle with mental health. My diagnosis came as a complete shock to me, I had been unwell for a while but didn't think too much of it, I had been to the GP a couple of times who initially just said I had IBS caused from stress and sent me on my way but it didn't get better. I went back and had a blood test and was told that I had a positive indicator of the disease, then I had a camera down my throat (very unpleasant) and was diagnosed on the spot. Suddenly I went from being a fairly healthy guy to being told that I had an uncurable disease overnight and it really affected my mental health, it took me the better part of the year to really come to terms with it. I'm almost two years post-diagnosis and a lot better at handling it, but I do have to be really careful with how I live and I am not fond of the necessary evil of having regular covid, flu and phenomina injections (I hate needles!) but I have to do it.

Having said that, when I do have a flare up I feel like I'm being stabbed from the inside, and there is nothing that I can do apart from ride it out and it really sucks. I dislike that there isn't much understanding about the disease so people can't relate to how I'm feeling, or that the sudden onset of flare ups are out of my control, or that the flare ups are real, and they hurt.

So that is why I am passionate about improving experience for other disabled colleagues. If I can help just one person get a better experience at work because of the Disability Transformation Project, then that will be a massive victory in my eyes.

Meet Jamais

My name is Jamais Webb-Small (she/her) and I am the Organisational Development Manager- Equality, Diversity and Inclusion (EDI) at West Suffolk Foundation Trust. I lead the strategic and operational EDI work for staff within the Trust.

I was diagnosed with Myalgic Encephalomyelitis (ME/CFS) in May 2020 after 7 years of debilitating fatigue and other symptoms, starting after I caught Pneumonia when I started University in the Autumn of 2013. I also have ADHD.

I am a member of the EoE Disability Transformation Committee as this is an area of both professional and personal interest to me. From my own experience, I have often found it challenging and confusing navigating through working environments due to the intersections of my identity. It would therefore mean a lot to me to be able to work together with others to make impactful changes around disability within our workplaces, and to enhance equity for disabled colleagues across the region and beyond.



Meet Heidi



Hello! My name is Heidi Buckell and I work for West Herts NHS Hospitals Trust as a Disability Champion. A job which I am very proud to have. I have been in this role since November 2018 but I started working for the Trust in March 2003 so I have been in the NHS for over 20 years!

I was born with Cerebral Palsy which has left me with a passion to create greater awareness of disability as well as wanting to come alongside others with disabilities/long term health conditions. One of my biggest achievements within my role as Disability Champion has been to set up the staff network, Diversability.

This group provides a Safe Space for staff to come and share problems which they may be having in the work place, I then escalate them accordingly. One such example was liaising with the Estates team and securing a Car Parking Permit for one of our network members. Introducing the Sunflower scheme, as well as the Reasonable Adjustment Passport are also initiatives which I have been pleased to work on. In my spare time, I like to work on my own Disability Awareness project www.beawarebeclear.org

My manager forwarded me an email about the EofE Disability Transformation Committee which was starting with the aim of helping to influence change around disability within the NHS and as soon as I received the email, I knew I wanted to get on board.

Heidi's story



[Click here to watch](#)

The screenshot shows a video player interface. At the top left, there is a logo for 'MS Society' and the text 'Heidi Buckell - My story'. To the right of this is the NHS logo and 'West Hertfordshire Teaching Hospitals NHS Trust'. A 'Share' button with a right-pointing arrow is in the top right corner. Below the title, there is a navigation bar with 'From a UK healthcare provider >'. The main content area has the title 'Managing my disability in the workplace' in blue. Below the title, there are three text blocks: 'Speech (Due to working in a team, all my colleagues have tuned into my speech. MS Teams has assisted me greatly – the 'chat' function)', 'Mobility (Being able to do hybrid working - brilliant)', and 'Co-ordination (poor co-ordination means I can't drive so I use the brilliant Access to Work Scheme)'. A red play button is overlaid on the text. In the bottom right corner, there is a circular video thumbnail showing a woman with glasses. At the bottom left, there is a 'Watch on YouTube' button.

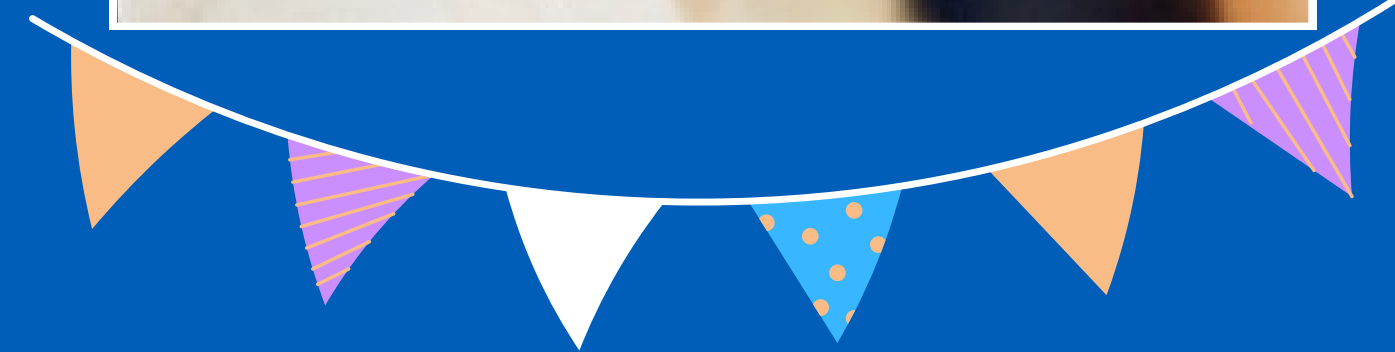
“Life can be summed up by needing lots of determination.”

Meet Zoë

I'm Zoë May, Head of Business Relationships part of a small Infrastructure Transformation Team working in Operations Support within the Operations Directorate at EEAST. I have a varied role, liaising with ICS and Blue Light colleagues mainly in relation to estate matters, Nationally Significant Infrastructure Projects (NSIPs) (which might be new roads or Sizewell C) and respond to applications for planned housing developments. In November 2023, Sustainability was added to my remit in November 2023 and have a small team dedicated to deliver our ambitious plans.

I have always been enthusiastic in supporting those who have disabilities or feel disadvantaged – especially those with conditions that are hidden. This became even more important following my own diagnosis of Multiple Sclerosis in 2019 – being open about my diagnosis and how it can affect me, how and when I work, helps provide a foundation for others to speak up about their needs too.

Early on in my (nearly 40-year) career, I undertook a course with someone who worked with young people and he used the phrase “alternatively abled”. This deeply resonated with me as it recognises diversity and differences in how individuals and organisations should approach what and how we do things. I have always been involved in delivering change to make continuously improvements – not keeping the status quo just because this is how it has been done previously but to making things better for everyone.

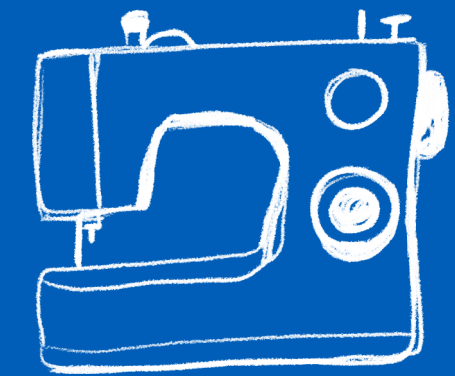


Meet Fiona

Hi I'm Fiona! I'm in my 30s and I live in the East of England. I was born and raised in Essex and moved back to the East of England over 10 years ago after studying in Scotland.

I'm married and live with my husband, and our very spoilt dog and two cats. I'm protective of my family, especially as I'm the older sibling, and I have a very close group of friends who I've known for 20+ years. I love to learn, and always have, but I'm also creative and love crafting, sewing and doing glass work in my free time.

Professionally I'm a Consultant in Public Health, working for NHS England on Specialised Services for the North West region of England and nationally. I also enjoy teaching healthcare professionals, and I'm a course tutor on the PGCert in Medical Education at the University of Cambridge.



I have a personal interest in work around disability and supporting professionals with disabilities as I live with an acute long term complex mental health condition which I have had since my teens. I've had lots of different diagnoses over the years, and variable experiences with how people have treated me in my personal and professional life. While I'm much more than the labels I've accumulated because of my disability, my condition, and my symptoms have an impact and to a certain extent have shaped some of my life.

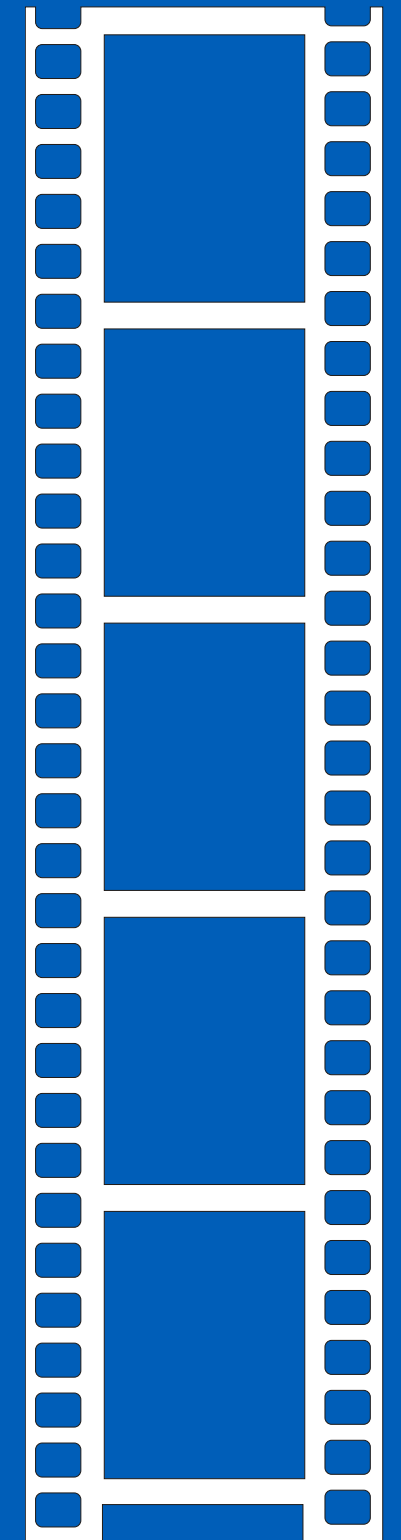
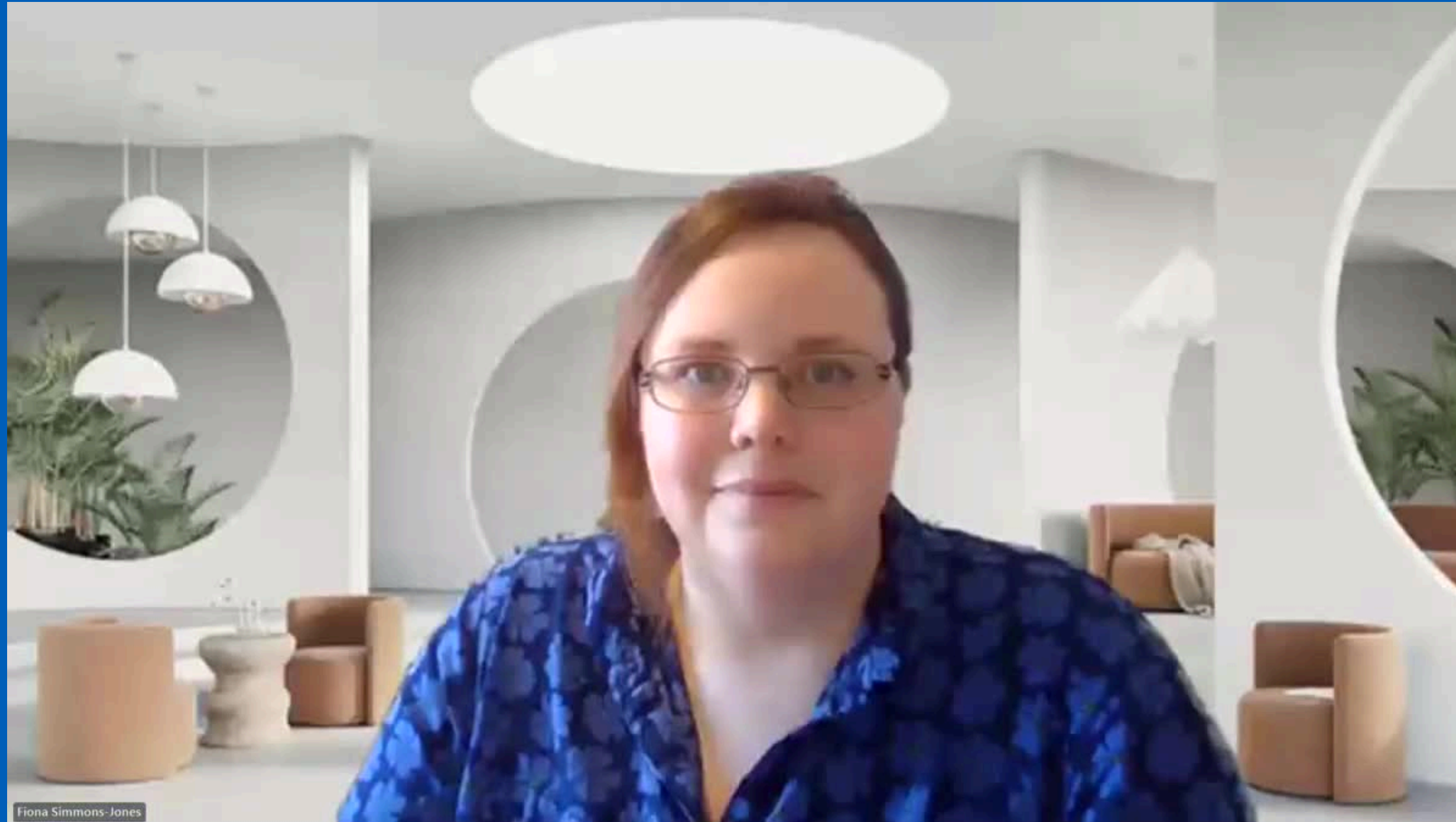
It is these experiences that have driven me to try to understand and improve the experiences of healthcare professional with disabilities and additional needs. I believe it is really important for us to have a fair, diverse and representative healthcare workforce in order for us to collectively best look after the interests of our patients and population.



Fiona's story



[Click here to watch](#)



"I have reasonable adjustments enabled and they allow me to bring my best self to my role and my team"

Meet Angie

I work for Bedfordshire Hospitals Trust, as Head of Health Inequalities and Inclusion. I've had a varied career in healthcare, this began in clinical dental nursing, - general dentistry and oral maxillofacial and orthodontics. Due to health reasons, I moved into education & training and dental workforce development. Prior to my current role I worked in the Trust's Integration & Transformation Team on various projects around service improvement.

Since returning to work after having my children, I opted for a portfolio career and continue to work in this way. I currently divide my working time across the following post.

- Head of Health Inequalities and Inclusion, Bedfordshire Hospitals Trust (Job share)
- Director of Dental Nurse Education, Antwerp Dental Academy (Part of Antwerp Dental Group, Cambridge)
- Registrant Council member of the General Dental Council

Me time, consists of riding my motorbike, live music (my husband is a musician) and spending as much time as I can with my family, especially my granddaughter. I am fortunate that the medication and treatment I receive is currently working well, allowing me to continue to ride my motorbike. That I know is a gift.

In 2016 I was diagnosed with a long term condition, this brings various challenges in my work and personal life. I want to help make a difference for disabled people, my lived experience is not life-long; nevertheless, it has provided insight, that drives my commitment to make a difference.

Not only is this work key to my role at Bedfordshire Hospitals NHS Foundation Trust, it is an opportunity to work with likeminded colleagues to share best practice and standardise process to make working in the NHS in our region more inclusive for disabled colleagues. Let's make the NHS in our region the employer of choice.



Meet Deb

Deborah O'Hara is a dedicated advocate for disability rights and equality, drawing from personal experiences that have shaped her profound commitment to this cause. With a deeply rooted allegiance to the disability community, Deborah's journey is influenced by her upbringing alongside a sister grappling with complex health conditions, ultimately losing her sight at the age of 21. This intimate experience has fuelled Deborah's unwavering determination to be a primary voice for equality and fairness for individuals with disabilities.

In addition to her familial ties, Deborah's personal journey encompasses her role as a supportive parent to a daughter with mild learning difficulties. Through her steadfast encouragement and assistance, her daughter has achieved full-time employment, underscoring Deborah's dedication to facilitating opportunities and empowerment for those with disabilities.

Furthermore, Deborah extends her advocacy to her son-in-law, who lives with autism. By providing unwavering support and guidance, she has enabled him to realise his dream of homeownership and to lead a life of complete independence.

With a profound understanding of the challenges faced by individuals with disabilities and their families, Deborah brings a unique blend of empathy, experience, and determination to her work on disability committees. Her advocacy is not only informed by personal experience but also driven by a resolute commitment to fostering inclusivity, accessibility, and dignity for all.



Helpful links

- [Disability and why it is important](#) - NHS Digital
- [Supporting disabled staff](#) - NHS Employers
- [Understanding disability](#) - NHS Employers
- [Definition of Disability under the Equality Act 2010](#) - Gov
- [Disability at work](#) - ACAS
- [Check if you are disabled](#) - Citizen's advice
- [Building disability inclusive workplaces](#) - NHS Employers
- <https://hdsunflower.com/uk/>