



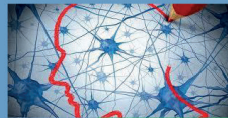
Working Together

Patient and public involvement in the Thames Valley

Working with the Seldom Heard



**The LGBTQ+
Community**



**People with
Learning Disabilities**

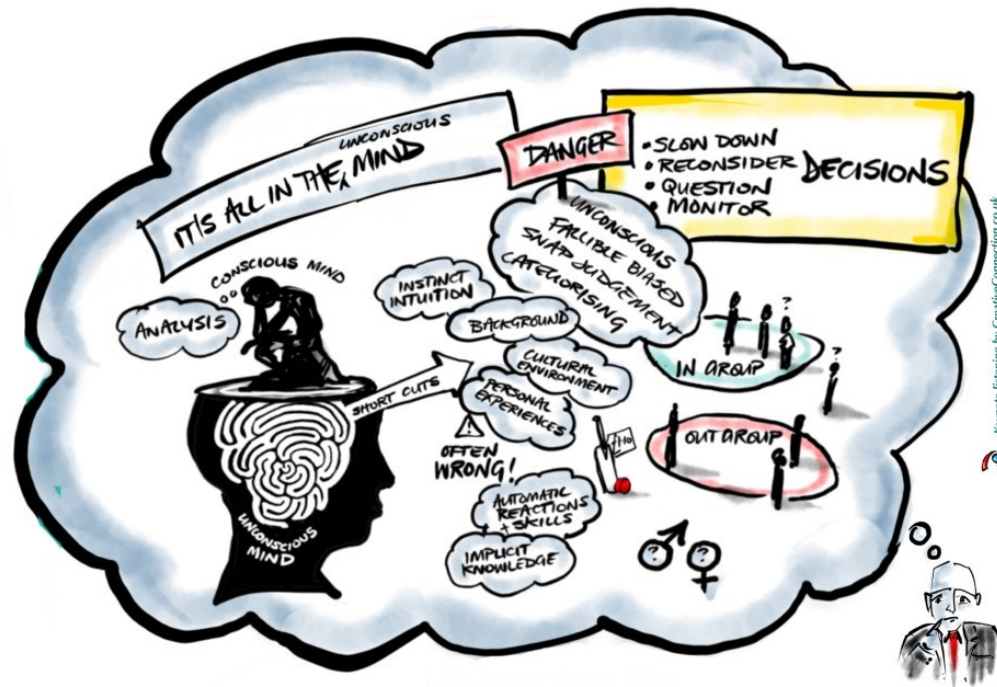


**People with Sensory
Impairments**

GETTING ON THE SAME PAGE

To provide some context to the discussions and speaker presentations that would take place during the events, we opened each of these webinars with a short clip from [The Royal Society](#) on unconscious bias. Professor Uta Frith, who wrote the introduction to the Royal Society clip says:

“Our unconscious brain is constantly processing and sifting vast amounts of information looking for patterns. When the unconscious brain experiences two things occurring together (e.g. many male senior managers or many female nurses), it begins to expect them to be seen together with the result that other patterns or combinations start to feel less ‘normal’ and more challenging to process. If left unchecked this can easily lead us into (at best) lazy stereotypes and (at worst) prejudicial or discriminatory behaviours”



Working with the seldom heard: Webinar report



The LGBTQ+ Community





INTRODUCTION

This webinar was the first in a series around the theme of *Inclusion for all? Working with the seldom heard* hosted by the [Working Together Partnership](#).

Hosts

Siân Rees – Director of Community Involvement & Workforce Innovation
Douglas Findlay – Lead Lay Partner
Laurie Kenny – Programme Coordinator

Speakers

Nicholas (Nic) Bray – Transgender Conduit
Georgia Pattison – Birmingham LGBT
Michael Farquhar – The Rainbow NHS Badge Scheme

Illustrations by [Creative Connection](#)

SPEAKERS

Nicholas (Nic) Bray – Transgender Conduit

Our first speaker was Nic Bray aka Transgender Conduit. Nic has worked with the Working Together group in the past and was introduced to the group through its Leading Together Programme¹.

Nic covered the subject of working with people who identify as Trans & Non-Binary. He began with a few helpful definitions and myth busters, presented population data but cautioned us, reporting that accurate prevalence data is not yet centrally collected.

He went on to talk about the prejudice (and sometimes persecution) faced by people who identify as Trans & Non-Binary. Nic finished his reflections by outlining some of the more important pieces of legislation that have changed the lives of people who identify as Trans & Non-Binary. These range from the 1970 Corbett vs Corbett (outlines the qualification to be recognised as their new sex in the UK), through the 2010 - Equality Act (The Gender Equality Duty) and right up to date with the shelving of the **2020 - Gender Recognition Act revisions** in our current Parliament.

¹ The Leading Together Programme is a coproduction leadership course for patients, public and professionals, more information can be found [here](#)



Georgia Pattison – Birmingham LGBT

Georgia is the Lesbian and Bisexual Women's Sexual Health Promotion Worker at Birmingham LGBT, grassroots, user-led organisation located within and accountable to, Birmingham's diverse Lesbian, Gay, Bisexual and Trans communities. More information on Birmingham LGBT can be found [here](#).

Georgia highlighted the importance of staff training within her talk, stating “knowledge is power” and that by ensuring staff are filled with the correct knowledge, it would hopefully give them the confidence to work collaboratively with the LGBTQ+ community. She also explained that unfortunately, too often, we only hear the bad experiences that LGBTQ+ people have with healthcare, but luckily within her work she does get to hear some positive stories in which the individual's life has been positively affected by the great healthcare service they have received.

Top Tips – Do

- Be mobile, use spaces where LGBTQ+ people feel safe, this will encourage them to engage with a service or piece of research. Go to the community that you are targeting/supporting.
- Amplify the voices of LGBTQ+ - ask local LGBTQ+ voices to be involved in the production of materials. Encourage social media takeovers on certain days of the year e.g. LBT Women's Health Week.
- Recognise the importance of pronouns - for some people this may be the only time they can truly be out and use their preferred pronoun. Use pronoun badges for staff, ask people what their pronouns are to avoid misgendering them. Pronouns such as they/them can feel very different at first but respecting an individual's pronouns is really important. Everyone gets it wrong sometimes but apologising and moving on is ok. If you are unsure of someone's pronouns, then use 'they' or address them by their name rather than using a pronoun.

Top Tips – Don't

- Start to shift around when the patient discloses their sexuality or gender identity.
- Asking questions out of personal curiosity, not professional need.

Michael Farquhar – The Rainbow NHS Badge Scheme

Dr Michael Farquhar is a Consultant in Sleep Medicine at Evelina London Children’s Hospital, and he led the rainbow NHS badge scheme. More information on the rainbow badge scheme can be found [here](#).

Michael said that despite improving social attitudes in the UK, LGBT+ people can still face significant barriers to accessing healthcare and this can have a detrimental impact on physical and mental health. There are high rates of negative experiences, and of mental ill health amongst children and young LGBTQ+ people.

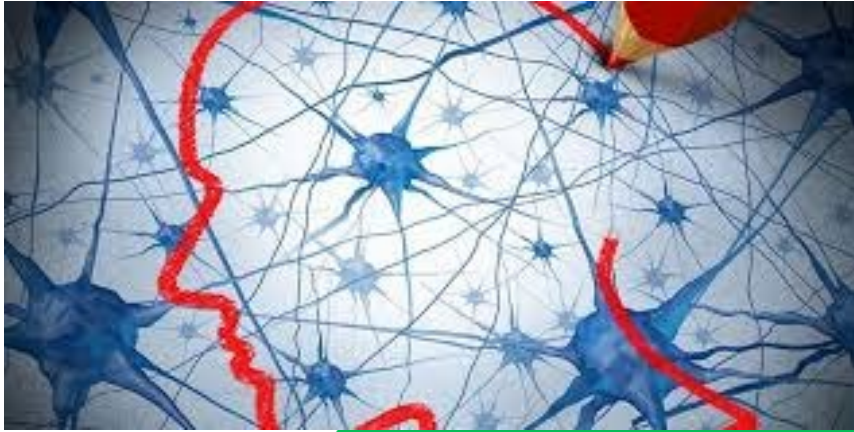
- 45% of LGBT+ children in school report being bullied for being LGBT+, 64% of trans pupils report bullying.
- High rates of attempted suicide in LGBT+ school children: 9% non-LGBT+ children, rising to 22% of LGB children and 45% of trans children. Rates of self-harm show a similar picture.
- 60% LGBT+ young people do not have an adult to confide in, in BAME groups this rises to 72%. Almost all found that having apposite role model made a major difference to them.

Wearing an NHS rainbow badge is a way for staff to show where they work is an open, non-judgemental and inclusive place for children, young people and their families who identify as LGBT+ and that we are here for them in every way. When staff sign up to wear one of the rainbow badges, they are provided with information about LGBT+ health inequalities and ways that they can help to tackle them, something Michael explained was very important. The initiative has already led to many extremely positive conversations and Michael went on to say that he really hoped that the toolkit they’ve designed will encourage other NHS organisations to introduce rainbow badges as they can play a valuable part in reducing stigma and inequality.

Michael finished his talk by saying that giving LGBTQ+ young people a simple, clear signal that healthcare professionals they may meet can be safe people to confide in can make a huge difference to them – the Rainbow Lanyard signifies this.



Working with the seldom heard: Webinar report



People with Learning Disabilities



**WORKING
TOGETHER**
Patients, professionals and
public working together

INTRODUCTION

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Hosts

Siân Rees - Director of Community Involvement & Workforce Innovation

Douglas Findlay - Lead Lay Partner

Laurie Kenny - Programme Coordinator

Speakers

Dawn Wiltshire and Jess Tilling – My Life My Choice

Angeli Vaid – Oxfordshire Family Support Network

Rachel Miller – Oxford Health NHS Foundation Trust, Learning Disability Services

Illustrations by [Creative Connection](#)

SPEAKERS

Dawn Wiltshire and Jess Tilling - My Life My Choice

Our first speakers, Dawn and Jess, were representatives from My Life My Choice, an Oxford based organisation working to help people with learning disabilities use their voices. They began by sharing the difficulties and barriers that people with learning disabilities face in their everyday lives. This included accessing services, making complaints and people making assumptions about them. Jess helpfully defined what constitutes a learning disability and these included:

- A significantly reduced ability to understand new or complex information
- Difficulty learning new skills
- A reduced ability to cope independently (impaired social functioning)
- Started before adulthood, with a lasting effect on development

Dawn followed Jess by giving some personal reflections on what having a learning disability meant to her and how being a part of My Life My Choice (MLMC) helped her and others with learning disabilities to have a voice. Jess picked up the theme of how The Law has developed to protect the rights of people with learning disabilities, citing **Article 10 of the 1998 Human Rights Act** and the **2006 Convention on the Rights of Persons with Disabilities**. These, as well as other laws have been passed to allow disabled people have the right to their own opinions and to make their own decisions. Both Jess and Dawn referred to 'Experts By Experience, as people who use their experiences to make changes for other people. An Expert By Experience is someone who understands what is it like and can speak up about it. Dawn concluded by pointing how she and her colleagues at MLMC have found working together with people who do not have learning disabilities has been really helpful in putting their views across and knowing that they had been heard. More can be found out [here](#).

Angeli Vaid - Oxfordshire Family Support Network

Angeli Vaid is a Family Advocate at the Oxfordshire Family Support Network (OXfSN), a charity set up in 2007 and run by family carers of people with learning disabilities – both children and adults. OXfSN provide information, advice, training and support to family carers of people with learning disabilities and cover all ages. They also support professionals in healthcare and social care to work better with families through training, co-production and partnership working. More can be found out [here](#).

Angeli then gave specific examples of the types of clients of all ages and from a variety of backgrounds that they work with, pointing out their 'family' situations and their preferred methods of communicating with others (including professionals).

Angeli also outlined what family carers often think about before signing up with OXfSN, which gave us a lot to think about, as it included – being seen as difficult or as a tick in a box, or that nothing would change – thankfully, she also gave us ways of addressing these hurdles.

Angeli's final slides gave us hints and tips on what to do and what to avoid.

Top Tips - Do

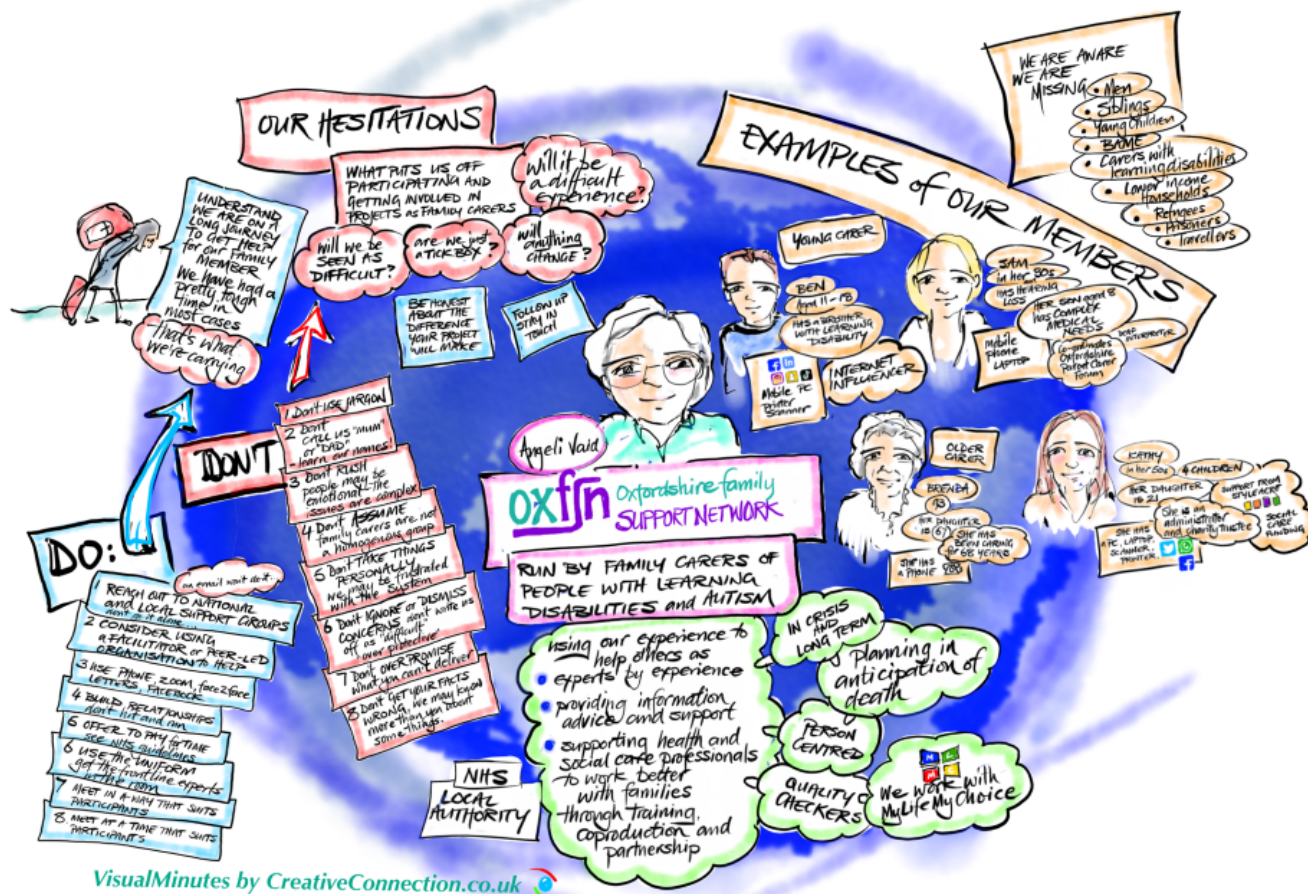
1. Reach out to national and local support groups – don't go it alone
2. Consider using a facilitator or peer-led organisation to help
3. Use the telephone, Zoom, face2face, letters, FB,
4. Build relationships – don't hit and run
5. Offer to pay for time – see NHS guidelines
6. Use the uniform- get your experts in the 'room'
7. Meet online, off-site, in the evening, at weekends, community centres, cafes, golf courses, wherever suits the participants
8. Timings – school run, holidays - not good

Top Tips – Don't

1. Jargon, acronyms - confusing and imbalance of power
2. 'Mum' or 'Dad' - learn names
3. Rush - people may be emotional, the issues are complex

Working with the seldom heard: People with learning disabilities

4. Assume - family carers are not a homogenous group
5. Take things personally - frustration and anger is with the system
6. Ignore or dismiss concerns – ‘difficult parent’ or ‘over-protective’
7. Over promise on what you can’t deliver
8. Get your facts wrong – family carers often know their onions



Rachel Miller - Oxford Health NHS Foundation Trust, Learning Disability Services

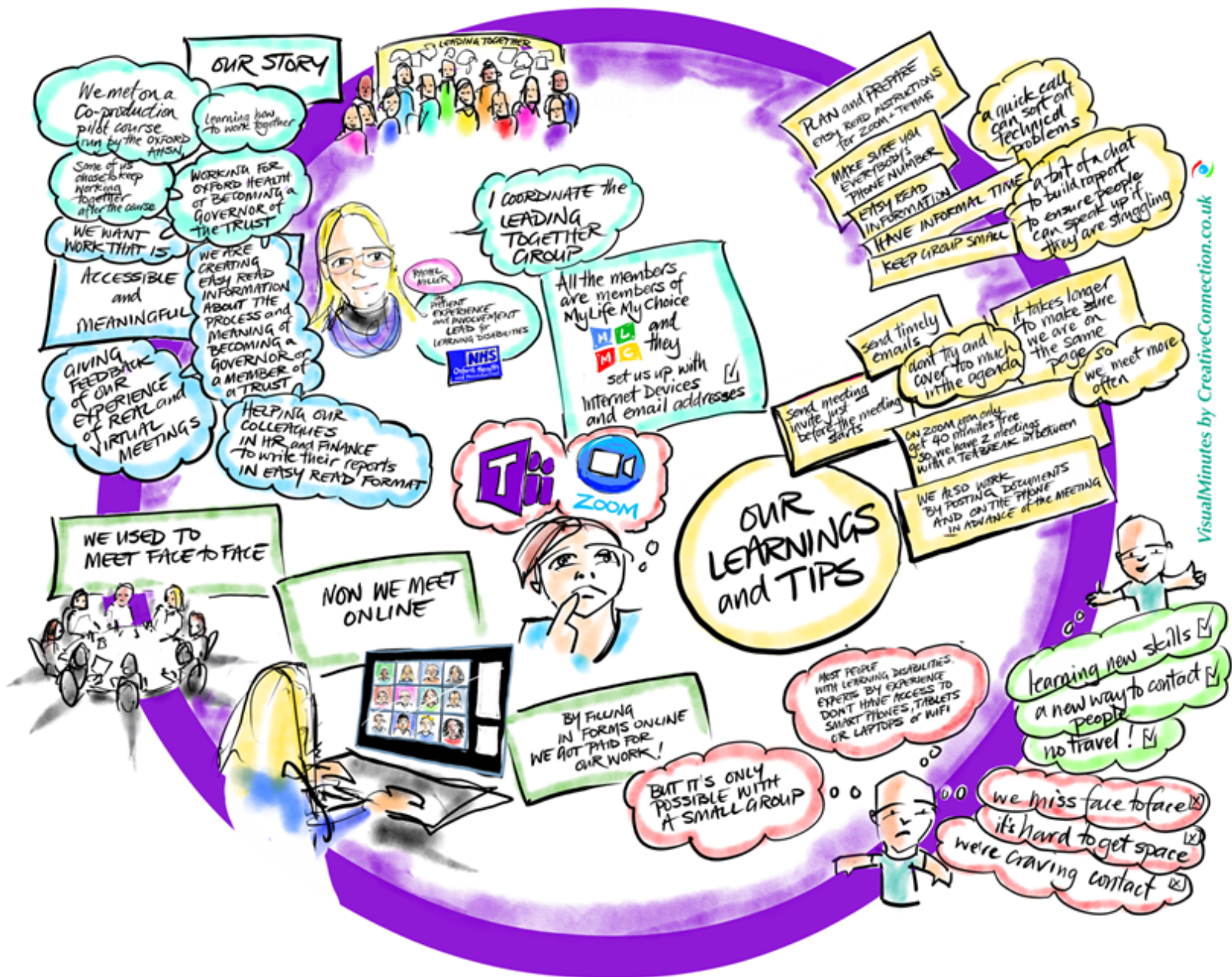
Rachel is the Patient Experience and Involvement Lead at Oxford Health NHS Foundation Trust that provides physical, mental health and social care for people of all ages across Oxfordshire, Buckinghamshire, Swindon, Wiltshire, Bath and North East Somerset. More can be found out [here](#).

Rachel told us about a project called the Leading Together programme – a co-production course run by Oxford Academic Health Science Network. The programme brought together pairs, consisting of a person with learning disabilities and a senior NHS professional, to support them to learn the principles of co-production. There were many things that everybody learnt about how to work together successfully.

Rachel then gave us an insight into how Covid-19 has changed the ways in which people in the Trust (both professionals and service users) have had to adapt working practices and the challenges that this has brought up. Mostly it was finding new ways to meet, that involved teaching service users how to use communication technologies (and sometimes providing the hardware). Rachel gave the following top tips:

Top Tips

1. Plan and prepare well in advance think broadly about what service users might need or struggle with.
2. Numbers – always have contact numbers, in case things don't go to plan or technology fails.
3. Easy read - provide easy read instructions and documents being used.
4. Informal time - build in informal time to touch base and make the experience as stress free as possible.
5. Contact Information- provide good and accurate contact information



Working with the seldom heard: Webinar report



People with Sensory Impairments



INTRODUCTION

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Speakers

Sally-Jane Davidge – Governor, Oxford University Hospitals NHS Foundation Trust

Chris Harrison – Action Deafness

Chrissi Kelly – AbScent

Illustrations by [Creative Connection](#)

SPEAKERS

Sally-Jane Davidge – Governor, Oxford University Hospitals NHS Foundation Trust

Sally-Jane Davidge describes herself as a “VIP” – a visually impaired person. She completed the Leading Together Programme in 2017 and is a governor at the Oxford University Hospitals Foundation Trust, representing patients and their carers in Buckinghamshire, Berkshire, Wiltshire and Gloucestershire. She is currently chair of the governors' committee for patient experience, membership and quality.

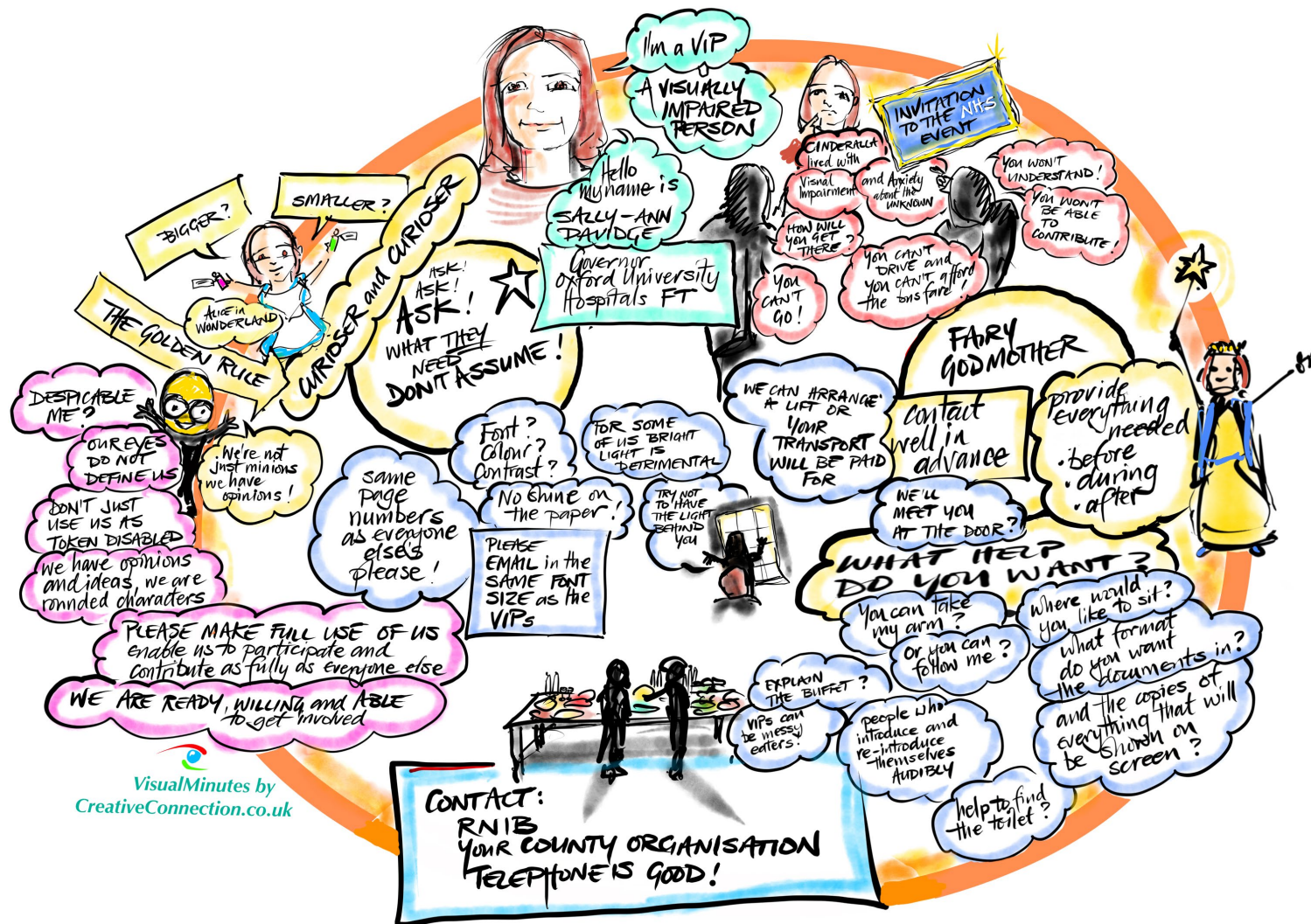
Throughout her humorous presentation, Sally-Jane endeavoured to attract attention to the many challenges a visually impaired person faces when trying to attend an NHS event. From the practicalities of getting to the event, to how the day might unfurl and what sort of assistance might make a difference.

Top tips – Do

- Ask people what they need and what would make their life easier
- Contact the person in advance with all practical information
- Make sure you make it as easy as possible for them to physically attend
- Adapt the material to visually impaired attendees and send everything in advance
- Ideally make sure somebody is available to accompany them during your event
- Make full use of your VIP – their disability does not impair their ability to think and contribute

Top tips – Don't

- Use them as your “token disabled person”
- Expect them to be able to read everything on a screen
- Assume they won't make as valuable a contribution as everyone else



Chris Harrison – Action Deafness

Chris is the Service Manager for deaf-led charity [Action Deafness](#). For over 120 years Action Deafness has been providing support for Deaf, Hard of Hearing, Deafened, Deafblind people and those with additional disabilities, with the strong belief that every person has the right to live with dignity, equality, comfort and independence. The charity provides interpreters, translators, equipment, support, personal assistance and other services adapted to every kind of hearing disability.

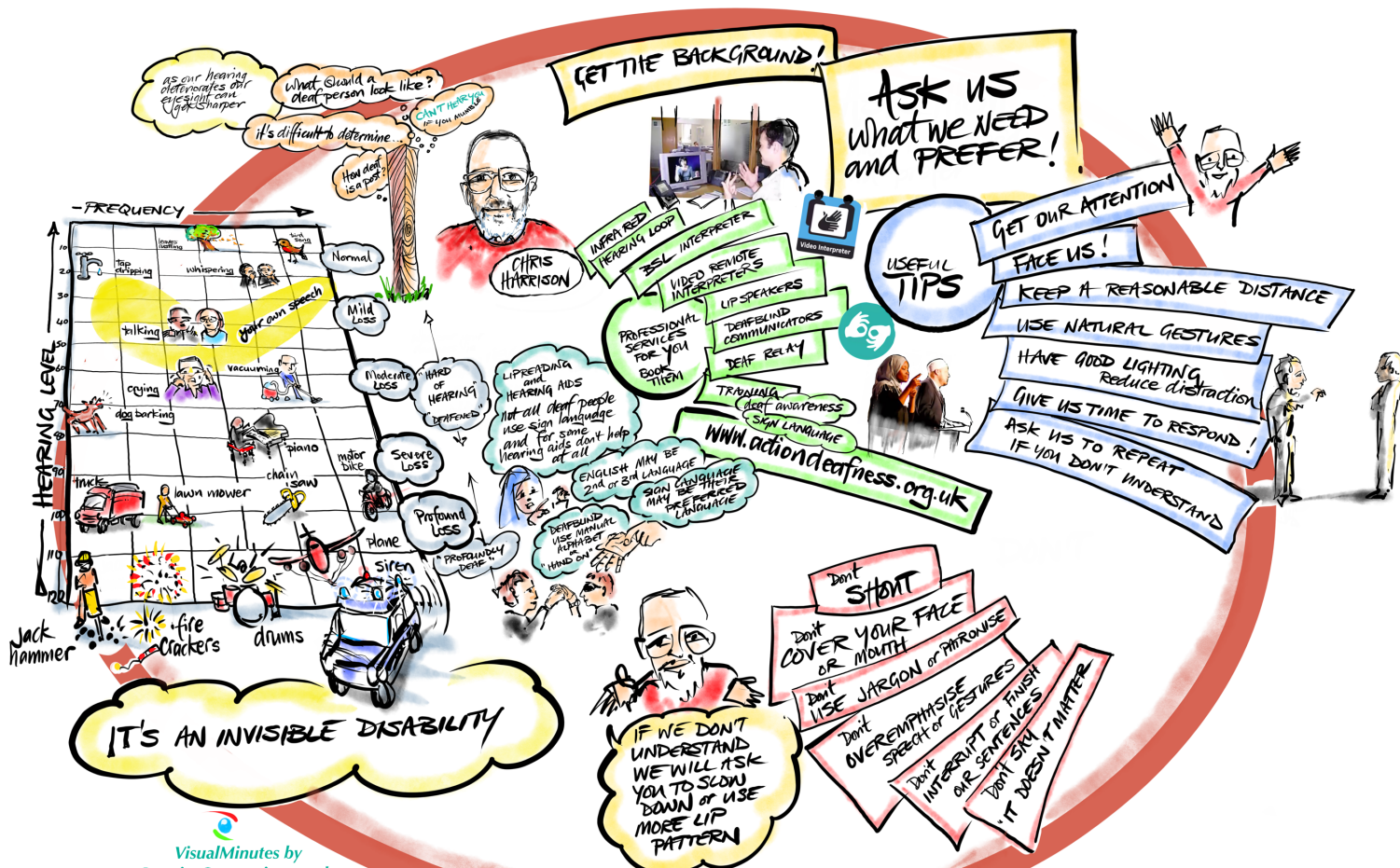
Chris is a qualified BSL Interpreter and trained Benefits Adviser. He has worked for educational establishments and in the voluntary sector as an employment adviser and employment manager.

Top tips – Do:

- Get the deaf person's attention
- Face the person
- Keep a reasonable distance
- Use natural gestures and body language
- Have good lighting and reduce distraction
- Give the person time to respond
- Ask them to repeat if you don't understand

Top tips – Don't

- SHOUT
- Cover your face or mouth
- Use jargon or patronise
- Over emphasise speech /gestures
- Interrupt or finish the person's sentences



Chrissi Kelly – AbScent

Chrissi lost her sense of smell in 2012. She is a founding member of the charity [AbScent](#).

AbScent is a charity registered in England and Wales, providing support and trusted information to anyone affected by anosmia or smell disorders. Supported by their advisory board and led by Trustees currently working in the fields of medicine and research, it makes a point of only sharing strategies and information based on peer-reviewed scientific evidence. They endeavour to create safe and supportive environments to enable their members to feel heard and enabled by shared experience. Information, current research updates, webinars, advice and support on their website and within their Facebook communities is provided free of charge and is open to everyone. Public interest in loss of smell and taste has grown immensely since the start of the Covid-19 pandemic, creating huge opportunities and challenges for the charity. In particular, research into the causes, consequences and possible treatments for anosmia has been given a huge boost.

Since losing her sense of smell Chrissi has supported thousands of other people with smell loss through smell training. She has taken courses with Professor Thomas Hummel, the author of the first research paper on smell training at the University of Dresden, Germany. Her techniques, used alongside smell training kits, have helped people to reconnect with their recovering sense of smell. Chrissi also speaks at conferences, runs workshops, online events and private sessions to support people with the condition.

Chrissi focused on her journey, successes and challenges founding AbScent and seeing it develop beyond anything she had imagined.

Top tips – Do:

- Acknowledge the fact that this is a distressing condition despite being invisible
- Listen to people's experience
- Only follow reliable information

Top Tips – Don't

- Minimise the condition – "At least you *only* lost your smell"
- Assume people's sense of smell will come back

