

Inclusive and Insightful Events

Research into people's lived experiences



#SocialCareFuture

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Thanks go to Angela Catley who was commissioned to undertake this research project on behalf of TLAP. Angela is the main author of this report.

Background

The perspectives and experiences of people who draw on care and support are often missing from conferences and events. Think Local Act Personal (TLAP) is working with Social Care Future and their members and partners to change this.

Ensuring people contribute to events is crucial in shaping policies and practices that reflect people's wishes and aspirations, so that everyone can have the care and support they need to be able to live their life their way. The aim of this project is to make this easier for event organisers. In phase 1, we explored what helps and hinders people's participation in events, both from the perspective of speakers and event planners. We also collected ideas and examples of good practice and useful resources.

“We need it to become unacceptable to talk about social care without the voice of lived experience”

Project brief

- Engagement with a diverse selection of older and working-age adults who draw on social care with experience of social care events or of challenges in being included.
- Parallel engagement with a good diverse range of organisers of various types of event to discover the key areas that challenge their inclusion of people and identify areas of advice and guidance and what would help.

Project started 1st May with a completion date of 8th July. The results of phase 1 will help inform phase 2 of the project, the development of a guide for event organisers, led by Social Care Future.



1. What we did

The project was a partnership with the National Co-production Advisory Group (NCAG). We developed a project narrative – which we used on social media, as a blog and in direct emails – inviting people to share their experiences and ideas, individually or in groups. We developed an online survey to enable us to hear from more people. We used established networks to engage a diverse range of people with very different experiences and perspectives. We invited people who responded to the request to meet, face-to-face or online or to complete a survey.

People we heard from



Events represented

Very large, large, medium, and smaller events with both commercial and non-profit perspectives were considered. Events represented ranged from very large national conferences attracting 5000+ delegates, to conferences for hundreds, and smaller events for lower numbers of people. Some events were face-to-face, some hybrid and others online. Some were planned and organised directly by the titular organisation e.g. the Learning Disability England annual conferences, while others were planned and organised by an intermediary 'event organiser' person or organisation. Some events had a focus on generating income and others sought only to cover their costs. All had a focus on health, social care, or wellbeing. Events and conference organisations interviewed included:

- NHS England
- Learning Disability England
- Local Government Association and ADASS for the NCASC conferences
- People's Voice Media
- Community Care Live
- Kings Fund
- Technology Enabled Care Service Association (TSA)
- Commissioners Conferences
- National Association of Equipment Providers
- National Care Forum
- Broadway Events
- In Control
- Skills for Care

We also interviewed the representative of one specialist conference venue recommended by one of the event organisers.

Resources and information produced

See Appendix A for case study stories of three event organisations and their approach to including people with lived experience.

See Appendix B for a list of reference tools and resources.

2. Lived experience

Definitions of lived experience:

*'The experience of people, on whom a social issue, or combination of issues, has had a direct personal impact'*¹

*'Lived experience' recognises the personal knowledge and impact of people who access health and care services such as those living with a long-term condition, disabled people or family carers'*²

Positive impact of lived experience on events and conferences

Most of the people we heard from, representing both sides of the event process, were clear about the insights gained and/or positive impact of working with and hearing from people with lived experience of social care or support.

'It means we can shift the power dynamic and demonstrate who is important' – Organiser, medium-sized events

'A few years ago, we sat down and reviewed our objectives. For us it's all about the citizen or the person. It fits with our ethos to have people with lived experience feature strongly at our events. We get someone to talk early in the first day, and that really helps reinforce the ethos. We really see the value in this way of working' – Organiser, large events

'I'm a childhood abuse and rape survivor. Having childhood in care from my teens, a 30-year career in the sector, and now drawing upon care myself as an adult, it's that whole 360-degree experience that informs why I want to share my lived experience...' – Person with lived experience

'The Care Act has been a real driver of co-production for us' – Organiser, large events

"My lived experience could be valuable to others because it provides first-hand insight and perspective on navigating challenges, coping strategies, resilience, and overcoming adversity. Sharing my story can inspire, educate, and empower others facing similar situations...."

– Person with lived experience

¹National Voices: <https://s42139.pcdn.co/wp-content/uploads/Valuing-Lived-Experience-Learning-Report.pdf>

²NHSE: <https://www.england.nhs.uk/long-read/case-study-how-peoples-lived-experience-is-improving-health-and-care-services-in-the-north-east-and-north-cumbria/>

3. Event organisers – what they told us

Perception of the value of lived experience

- Most event organisers can see the value of contributions and/or wider co-production with people with lived experience.
- Many see this as a process of continuous development and know that they have work still to do.

'We are on a journey of co-design, co-production and involvement... we are open to change'

'They brought a different element'

'We're really clear that getting better at co-production is a priority for us, and we are ambitious about where we want to get to on our journey'

- Those organising events aimed at managers and professionals who are a long way from service delivery tend to see less value in including lived experience perspectives.

'We need to always consider: who is organising the event and what do they need to get out of it?'

Establishing principles and standards

- Some organisations have developed principles that underpin the way their events are run, and some of these include things like accessibility, inclusion, and contributions from people with lived experience.

'We set principles for all our (event-organising) teams to follow. For example, ensuring that the voices of people speaking from personal experience are heard'

- Event organisers can also place expectations on contributors and exhibitors, and these expectations can influence how they act and involve people.

'We are developing a co-production expectation on contributors. We want more and more sessions to be co-presented'

"People do have more of a voice now, but there is still a way to go"

"We have a rule that all adult social care sessions must have at least one person with lived experience involved"

Planning and time

- Large events take a long time to plan and organise, with lots of moving parts.
- Events are time-pressured.

'We start planning the conference nine months in advance'

'Events are time-pressured - time can be tight'

"It can be a real challenge finding good people. It would be great to have people who are recommended"

- Working effectively with people with lived experience can also take time and resources. This is sometimes seen by event organisers as an additional challenge.

'Sometimes the biggest barrier is the time it takes to do it right and to give people enough time and the support they need to share their experience well'

Finding strong, fresh voices in the right places can be a challenge

- Organisers need people with different perspectives, and it can be a challenge to find the right individuals.

'It's important to us that some people with lived experience speak at the event, but it can be hard to find new voices'

'It can be easy to rely on the same people, and that can become a problem. There is always a drive for us to increase the pool of people we can draw on'

- Some groups can be particularly challenging for event organisers to engage – for example, older people who live in care homes and/or live with dementia.
- Some events have a strong local focus. They look for speakers from the local area and this can be difficult.

'I contacted ten different groups within an hour of the venue and wasn't able to find anyone. Sometimes we might contact fifty people before we can find one'

- Some organisers put out a call for speakers or develop a list. Some work through their members or forge strong VSCE or similar networks to find good, new people to speak.
- Some events forge strong, ongoing connections with people whose voices they value.

"Finding those other stories is the difficult bit... we need to get creative"

'We have ongoing relationships with people, doing a lot through our networks and drawing on links and relationships some of our colleagues have'

'We are looking for people who really understand the audience and the environment they are working in. People who know how to have the most impact'

"Communicating with people can be difficult. They might not have phone or access to emails"

It can be difficult for organisers to communicate with some people

- Some older people may not have phones or access to email.
- Care settings may contribute to digital exclusion due to poor access to Wi-Fi and technology.

Some event organisations work through others

- Some event organisers go to another organisation with more expertise in engaging and hearing the voice of people with lived experience.
- This 'middle' organisation is paid to enable the event organisers to do co-production well and/or source and support good speakers.

'We help Integrated Care Boards set up events. We insist on involving people with lived experience'



Getting creative

- Some people may find it difficult to travel, be present at, and contribute in-person at a physical event. These people may have strong opinions and perspectives.
- Some event organisers recognise that they may have to get creative to ensure these voices are heard.

'We tried hard to get some people (who live in a care home) to join our panel, but we couldn't make it happen. So, we did some work to ask people the questions beforehand and then shared their contributions on the day'

"Is it rude to ask people what they need? I worry about what is appropriate to ask but I would be disappointed not to be able to get it right"

Event organisers and event commissioners can be different people

- Some events commission another person or organisation to organise their events.
- Some of these 'middle' event organisers have strong experience in health, social care, inclusion, and accessibility. Some have strong experience in events but less experience of inclusion than the organisation that commissioned them.

Knowing what is respectful and right

- Some event organisers do not have knowledge of disability or access to disabled people
- Many have a genuine commitment to better access and greater inclusivity but don't know how to get that right.

Sponsors

- Sponsors can control elements of the event, and this might impact the inclusion of people with lived experience

'In the sponsored sessions, the sponsors choose their own content and speakers'

"Getting the terminology right can be a challenge"

Selecting, checking and preparing a venue carefully

- Choosing a venue can be a challenge.
- There are a limited number of larger venues.

'For large events, there are a really limited number of venues nationally'

- Not all venues understand or are fully engaged in accessibility issues.
- Many organisers undertake a site visit in advance to check things directly themselves.

'When we organise an event, we have criteria that we use for all venues. It includes accessible rooms and stage, a hearing loop, good lighting, a clear table plan, good flow for people. We consider things like wet rooms, changing places, quiet spaces and dietary issues. We make sure we check everything, personally in advance'

'When we find a new venue, we go around and video it in advance. We ask a wheelchair user to check it out. We ask about accessible loos. etc.'

"Venues say they are accessible, but then we turn up and find the way in for wheelchair users is round the back, or you have to hold the lift button to operate it'

'We can't always trust the venue to get that right'

- When considering access issues, most venue organisers rely on personal knowledge rather than checklists.

'Checklists can be constraining and don't always work. We need to take a personal approach when we organise events'

- Event organisers have a role to educate, influence, and guide venues.

'We help venue organisers get into the right (accessibility) mindset. If needed, we educate them. We might ask for extra catering staff on the day if we know our delegates might need a bit more help'

'As event organisers, we need to get venues to think much more about accessibility and inclusion issues. We are a huge market, so we could have influence... venue options can be really limited'

- Setting up the venue well is seen by event organisers as really important.

'We always put in a low-level lectern. Some venues have one, but others don't and have to source one. Why should a speaker who uses a wheelchair have to sit on the stage on their own when other speakers get a lectern!?'

- Organisers recognise that things like the way rooms and chairs are configured may need to change.

"We need to consider a range of people and their needs"

- Changing places are not always available, and this can be a challenge for event organisers.
- Venues are aware that some people need equipment to be able to participate well. Many have arrangements with venues and equipment companies.

"We tend to avoid booking venues in London because it just gets too expensive"

"Most venues nowadays will be wheelchair accessible. We do a site visit to every venue that we use and really consider accessibility implications carefully"

'We can source equipment if people need it. We have a local company that can bring a hoist. We bought a particular type of bed that a person needed. We pass the costs onto the conference organiser'

'Sometimes we buy pieces of equipment rather than keeping on hiring. It can be cheaper, and it means it can be personalised and immediately available to the person who is going to be using it'

'In Pembroke, they rented hoists and even beds for people to use during a conference, making it more accessible for people to attend'

- Some event organisers hire the services of other organisations who have particular expertise in key issues such as audio, visuals or wheelchair access.
- One fixed venue can make inclusion easier - events that stay in one venue forge a strong relationship with that venue. They get to know the venue well and can influence it. Actions needed to increase accessibility and inclusivity can be easier. The downside of one fixed venue is that it makes it less inclusive and accessible to people who live in distant areas e.g. people outside London.

"We think about how rooms are laid out and request cabaret rather than rows of chairs. This is an example of our general direction of travel"

Accommodation and catering

- Most venues have a limited number of accessible bedrooms. This presents a challenge for event organisers when many people need accessible rooms at the same time.
- Event organisers are aware of food and catering issues, such as special dietary requirements and allergies

Payment and reward

- Many events pay people for their time and expertise, but some events struggle to find ways to pay people that are equitable and sustainable.
- Some events offer free tickets to the event, either as well as or instead of offering payment to people.
- Some events offer bursaries or free places for a limited number of people who are unwaged or have lived experience.

'Getting a balance between paid professionals (who are salaried for their time) and people with lived experience can be difficult'

'We pay all our speakers equally. They are so valuable to our events. If people need a PA to support them, we pay the PA's expenses...but not their time'

"If we need a large number of accessible bedrooms, it can be difficult. You can be limited to 4- and 5-star venues and they can be very expensive"

- Some event organisers are concerned about benefits and tax implications for people.

Bureaucratic or time-consuming processes

- Many events cover the costs of people and any PA or supporter. Some organisers concede that the process for people to reclaim these costs and/or other expenses can be time-consuming and difficult.

'We cover people's expenses, but our process needs improving – it's time-consuming and complex and takes real effort to claim'

'We are working on a new expenses policy to reduce the barriers to people attending and contributing'

"The people we engage are in a position to invoice us. Organisations need to be aware of the possible benefits issues and other implications of paying people"

Costs

- Some events are designed to make money, while others are not. Most events are very conscious of costs.
- Where income is lower or resources are an issue, making reasonable adjustments or incurring additional costs can be a financial challenge.
- Where the benefit of co-production and/or hearing the voices of people with lived experience is less understood or valued by event organisers, the extra cost of doing so is harder to justify.

'We need to consider who is paying to attend the event and what they want to hear'

"We need to keep costs down. The costs of bigger spaces, special catering, BSL interpreters, etc., add up. We will spend the money so that people can come, but the funds aren't unlimited"

Preparing, informing and supporting people

- Event organisers recognise the need to prepare and support people well.

'We need to make sure that people are prepared – meet them beforehand, be clear about expectations and everything in advance'

'We had one lady who was extremely nervous – it was her first event. We invited her to visit in advance and reassured her. We talked to her and put in place what she needed. It was a big thing for her to attend, and we needed to make sure she was comfortable and happy'

- Some people may be sharing very personal information – this could be very difficult for them. People may need time and good support.

'People at our event have shared their horrendous, traumatic care experiences'

- Larger events may have lots of people involved – from lots of different organisations. This creates a communication chain, e.g. from the lead organisation, to the event organiser, to the workshop lead's organisation, to the person with lived experience, to the venue. Key elements of information, communication and connection can get lost in this chain.

'This time there was too much of a communication chain and I am not sure we all knew who was in that chain. We weren't always clear who was talking to who about what. We need to be much clearer about that in the future'

"We started to do proper co-chairing last year and we now have an ongoing commitment to that. We want co-production to underpin everything"

Chairing

- Some events have worked with people with lived experience to chair events and panels. They feel this sets the tone and ethos of the whole event.

Some larger events don't have big presentations

- Very large events can't have all delegates in one room and don't tend to have keynote speakers or big presentations. Instead, they have a pick-and-mix programme with lots of smaller sessions taking place at the same time.
- Smaller sessions tend to be more practice- or technical-focussed (e.g. legal) – potentially offering less opportunity for people with lived experience.

Online events

- Event organisers know they need to make reasonable adjustments for online events – things like font sizes, avoiding flashing screens, offering subtitles or text.

"We had two older men speaking virtually at our face-to-face event. One was using a laptop and couldn't hear properly – it didn't work well. The other had support from family, and it went really well – their contribution was really powerful and valued"

"People need to be able to get online and use the technology, or have competent supporters that can help them"

4. What people with lived experience say is needed

Involve people in the planning process

- If you co-produce your event – or key elements of it – from the start, you will get it right first time.
- Contact the right people early and ask them to help.
- Think about who is in the audience and how people with lived experience can be directed to tailor what they do and say to have the most impact.

“Sometimes it’s just one person with lived experience – and then we are shoehorned in at the last minute”

Avoid being tokenistic

- Look for diversity of experience – one person can’t represent everyone with lived experience.
- Be clear about the anticipated expectations or value to be added.

‘I sometimes feel like I am ticking a box ‘cos I am in a wheelchair’

‘More involvement of people with lived experience results in authenticity’

Forge strong relationships

- Strong relationships result in real trust and create the conditions for people to work in true partnership – making mistakes and growing things together.

‘There is a massive thing about connections and relationships. People are very forgiving if they feel well supported’

Be clear about the ‘ask’

- Be clear about payment, terms, and expectations upfront.
- Be clear about the expectations on the speaker – the topic you would like them to speak about and what you hope they might add to the programme.

‘Lay out all the information, then people can choose if they want to get involved or not’

“There is fear on both sides. Get alongside people... carry the load together”

Offer payment or reward

- Pay or reward people – or at least offer to.

'They want you to do it for a cup of tea and a biscuit'

- Be clear about fees – in advance, without people having to ask.

'They rely on the fact that asking about payment is an uncomfortable conversation'

- Fees should respect expertise as equal to that of professionals – recognising that employed people will be receiving a wage from their employer. Some people with lived experience may be employees, while others may be unwaged, so equal doesn't always mean the same.

'Professionals are often paid more. There is a lot of shadiness!'

- Low pay doesn't take account of preparation time. If people are getting a higher/equitable day rate, this is less important as that anticipates and covers the cost of preparation and/or early arrival. But if the rates are much lower, then the cost of preparation time should be covered in addition.
- For some people, this is their only source of income.
- People know that some events are smaller or don't have resources – and often they are happy to give their time for free to support these kinds of events.
- People know that some events are larger, with high ticket prices and aim to make a profit. People feel strongly that these larger events should not expect to get lived experience for free.
- Sometimes people are contacted by consultants who have been paid a high day rate to organise an event or session. People feel strongly that these consultants should pay people with lived experience, share their day rate, or secure a similar rate from the organisers for others.

'I don't always expect fees... unless it's a consultancy firm that is being paid themselves!'

- Some people don't want to be paid – respect that and find other ways to reward their contribution.
- Understand that some people are motivated by an opportunity to influence change, want to contribute to events for altruistic reasons, or just want to make a difference.

'I give my time and expertise in order to make a difference. I need to see that my story will have an impact on the audience'

'I would do stuff on spinal injuries for free if I knew it was making a difference'

"How would they feel if they had to do it for nothing? They wouldn't do it, would they?"

"I feel guilty sometimes asking for payment. A lot of times they assume you are employed and already getting paid"

Expenses

- Pay expenses and be clear about them – for the speaker and any support – in advance, without people having to ask. Cover people's support costs, including expenses for their supporter or Personal Assistant (PA).
- Have a process for paying expenses that isn't complicated and doesn't expect people to pay out lots in advance or stay out of pocket for weeks.

"If they are not able to pay me, they need to ask themselves what else would be in it for me"

'I am still waiting to get my train tickets paid. It's a lot of money'

'I used to pay my own travel expenses as I didn't know any better'

Bursary or free places

- People don't always need to have a role as a speaker or workshop leader. Sometimes having a place at the event as a delegate, with an opportunity to ask questions can be really powerful. It can send a message in itself.
- Some people struggle financially but still really want to be involved.

"One organisation took from November to March to reimburse me"

'Personally, I struggle because I would like to go to these things, but there is an economic barrier to do it or get there. If you are part of an organisation, it's better but for us sitting at home, it's much harder to even get a ticket or place.'

'I ask for bursary or free places at the event if I think different perspectives are missing or really needed'



Value the person for who they are and what they bring

- People want to share their real experience and ideas, and sometimes this is at odds with or a challenge to the event organisation or to delegates.
- Don't try to sanitise and control what people say. Create an environment that allows people to disagree respectfully.

'You are expected to toe the party line, and if you don't, you are not invited back. I don't know why they invite autistic people if they don't want us to be honest!'

'They can't expect people to always be shiny, nice, and friendly'

'We are not allowed to be frustrated or angry'

"If events can't find a way to get lived experience on the programme, they should at least get lived experience in the room"

Becoming a speaker can play a personal development role for people

- Speaking can play a development role for some people – helping them develop skills and believe more in themselves and what they can achieve. Speaking can also help people raise the profile of the activity they have been involved with and its impact.

'The more confident I get, the better I speak in front of people'

Ask what adjustments and support people need

- The onus is on conference organiser to ask – not the person to volunteer.
- Have questions to ask people to help them consider what they might need.
- Understand and accommodate that some people need help to travel and contribute.

'They will ask you if you need anything, but you might not think about it at the time. If someone is new to events and speaking, they won't know what they need until they have done it a few times'

'I have throat problems, so speaking can sometimes be a problem for me'

Clear information well in advance

- Avoid jargon.
- Clear direction and expectations.
- Information about things like the venue, other speakers, food, travel,

"The only reason I bring a PA is because I am disabled and can't do things for myself"

delegates, and what the person needs to bring with them. Floor plans of the venue available on request.

- Information in formats that are accessible for people, e.g. easy read or photos.
- Details of the programme and times.

'It can sometimes feel like an episode of Dr Who, with all the jargon and physics. Then you feel stupid and don't want to participate'

'I have autism, and I need to know what to bring with me. Things like cash, food, my speech written down. I need to know what food and drinks there are. I need to know what I need to pack. It's the knowing that is important...so I can prepare'

- Give people time to plan and orientate – offer a pre-meeting to learn and ask questions, perhaps online.

"I was once speaking at a big event. When I arrived, the hall was full, and all the other speakers were sitting up on a high stage. They indicated I should wheel onto a platform at the side of the stage. Then in front of everyone a man cranked me up to stage level. It was awful"

Work hard to make the experience equitable for all speakers

- Respect the speaker in the same way as you respect all other speakers.
- Allocate a named contact that the person can easily ask for information or help.
- Set up the space for chairs and wheelchairs – don't be quickly moving furniture and people around the room as the wheelchair user arrives.
- Enable people to sit at the same level – for example, don't have a wheelchair user sitting down while everyone else is standing.
- Don't use venues that expect people to use a back entrance or other inferior route.

'Disabled people are often told they have to enter by the back 'Tradesman' entrance, ring a bell, or use a service lift. Then there is no one there to greet me. I want to come in the same door and be part of things like everyone else' 'I was once asked if it was OK for my PA to carry me onto the stage!'

'I was told the disabled toilets were kept locked... to stop taxi drivers from using them!'

'Stages are often too small for wheelchairs. Ramps up to them have been unstable with the projector too high, not accommodating people who are seated'

- Manage panels well. Make sure people know who else will be on the panel with them – names and roles. Introduce people beforehand.

"Evacuation forms are not personalised. Often what they ask doesn't work for me or isn't practical"

Plans in an emergency

- Have a plan for the event of an emergency. Inform people how they get out of the building – especially if they use a wheelchair or have a physical disability.

'Evacuation forms are not personalised. Often what they ask doesn't work for me or isn't practical'

"I prefer online events. Then, if I am not well enough on the day, I can just ask for the recording or notes"

Timing and timetables

- People may need more time to get ready for the day.
- Give people time to get to the venue.
- Recognise that if you start early or end late then people will be less likely to be able to contribute and/or their expenses and need for support will be higher.

'They have to realise we need to get from where we live. Trains where I live stop running at 9pm'

'They set the times assuming everyone lives in London...or Birmingham'

- Make adjustments to the timetable if people need it.

'I would much rather speak at the beginning than the end – waiting makes me anxious'



Understand personal circumstances

- Some people have conditions that have an unpredictable and inconsistent impact on them. People may be able to do certain things when they are making plans, but not able to do them on the day. People worry about not being able to plan for the unknown.
- Recognise that people might have caring responsibilities.
- Offer to cover the costs a person incurs in getting someone else to support the person they care for.
- Recognise that early starts, late finishes, long days, extensive travel, or overnight stays may not be possible for carers.

"I can't guarantee that that on the week, day, or hour I will be well enough to do it"

'Overnights are a challenge as I need to pay someone to support my son if I am not there'

Understand the personal impact

- Speaking can be daunting, and speaking about personal experience can be difficult or even traumatising.
- This is personal to each individual, and reasonable adjustments can sometimes make it easier. Some people value things like detailed information, calm music, and strong support.
- Some people or circumstances might benefit from time to discuss and debrief.
- Greet people on arrival – make them feel welcome and valued.

'The first time, I was scared I was going to mess things up... anxiety'

- Some people might find it hard to contribute to an event on their own.
- Offering opportunities to groups of speakers or contributors can provide peer support that is highly valued.

'There is something about doing stuff in a small team. People value the peer support in the moment'

"If they ask at the last minute, I might not be able to get someone who can support me"

Pay for or offer practical support

- Most people want help from someone they know and who knows them well.
- Sometimes family, friends, Pas, or Shared Lives carers are not available to accompany and support the person. This may mean the person cannot attend and contribute. Last-minute bookings make finding good support less likely.

'I have a relationship with [person]. I trust him'

- Some people need support to accept bookings, make arrangements, plan and prepare.

'A few days before, P helps me write flashcards with bullet points on. Then I know I have things written down; in case I get stuck on the day'

- PAs and assistance animals can offer a valued support role for the speaker.
- Understand that the role that PAs and assistance animals play is very personal to each individual – ask the person how they want their PA supported and what role they want them to play. Ask if animals need anything too.

'My PA is not contributing professionally to the event themselves'

"They say they have an accessible toilet, and then when you get there, it is full of stuff or can't be used"

Accessibility

- Check the facilities – don't just trust the assurances of the venue without checking and probing.
- Visit the venue in advance and make sure all facilities exist and work – ramps, toilets, changing places, etc.

'I turned up to one event having been told there was a changing place in the building next door. Then I discovered it had been vandalised and wasn't usable. No one from the event knew, and no one had let me know'

- Conferences with exhibitors can be really inaccessible – with high stands, bar stools, etc.
- Make sure venues work for more than one wheelchair user. Avoid things like small lifts that only fit one chair, only one accessible toilet, or toilets or other facilities on a different floor.

'If there is more than one wheelchair user, we have to do everything one at a time... it can take ages, and we end up being late or embarrassed... or both!'

- Remember, physical disability doesn't just mean a wheelchair – some people have impaired mobility but don't use a wheelchair.
- What is accessible for a wheelchair user might be harder for someone who does not use a wheelchair. Consider trip hazards, stairs without bannisters, and steep ramps, which can be a challenge. Long corridors or long distances between rooms or event areas can be very difficult for some people.
- Consider people who can't fully use their hands.

"They think about wheelchairs, but not about people who can't use their hands"

'When people are thinking about accessible buildings, they need to think about people who don't walk well and don't use a wheelchair. Long or steep ramps, lots of stairs without bannisters, and long corridors are all hazardous, exhausting... or both!'

'They had tiny steps which were not marked'

- Take account of larger modern wheelchairs and scooters. Ensure lifts and toilets are big enough for the disabled person, with space for a supporter and/or assistance animal, and provide toilets with turning space.

"Sometimes I feel the stage moving and I think I might fall in front of all the people"

'I need space on stage for my actual chair (not the small chair someone thinks I might have!)'

'Sometimes with accessible toilets I can go in forward, but then there is no room for me to turn my chair to the side and transfer to the toilet. No way for me to turn round to come out either!'

Make reasonable, practical adjustments

This is very personal and only people themselves can tell you what they need. Examples shared by people included:

- Give people more time to speak – especially if they speak slower or need extra time to get their point across well.
- A firm, secure, ramp up to the stage, and space to manoeuvre once there.
- A lectern to hold on to and place papers on – at the right height for wheelchair users and/or people who need to sit to present.

'I need a table I can put my notes on that is not too high'

- Mic arrangements that work for everyone – some people can hold a mic, while others need a lapel mic.

'I need a plinth because I have hand tremors and can't hold my papers. I can't hold a mic either'

- Hearing loop.
- BSL signer.
- Screen reader.
- Circulation space around the room for wheelchair users and others – especially in a room with lots of people or furniture.
- Lifts.
- Accessible toilets and changing spaces.
- Quiet spaces.

"It can sometimes feel like I am trapped. I am squashed in with no obvious way to get across or out of the room... it's a horrible feeling"

'I need to [be able to] take five minutes if needed and have a sensory and quiet space for afterward and being able to use my sensory aids.'

- Speech written down so someone can step in, if needed.
- Tech support where needed – to set up, click slides, etc.

'I have no sensitivity in my fingers so I can't do touch screens. So, no texts, smartphone, or QR codes'

- Signage at the venue.
- Large text documents for people with a visual impairment. Word documents sent in advance can be adapted to larger print or voice by the person at home. PDF documents cannot.

'If it comes in PDF, I can't do anything with it'

- Teleprompter or text option for people who can lose focus.
- Minimise loud noise.
- Noise-cancelling headphones.

"I can't move my chair and use my white stick at the same time. So, people don't make allowances for my visual impairment because it's not obvious to them"

Names badges and contact details

- Lanyards dangle and often turn the wrong way.
- Names and organisations are often printed small.
- Events should have badges that are easy to read at all times.
- Provide a way to get people's contact details without having to write them down.

'They recognise you, but you have forgotten who they are and can't read their badge. Panic sets in'

'One event had QR codes on people's name badges – if you clicked, it took you to their contact details'

The power of stories

- Using stories can have a strong and positive impact.
- Video and audio stories can be captured in advance.
- Using video or audio stories can be better for some people than speaking live.

"I was going to an event and my second train was cancelled. It was early and I had no way to contact the event organiser to tell them I would be late. I got myself into a right flap"

Travel

- Have disabled parking spaces.
- Recognise that some people can't use public transport.
- Public transport is very unreliable, and recent strikes have made that even worse – which can be very stressful for the person. People who live in rural areas may have a very poor train service.
- Recognise that people might be more likely to need to use taxis. Some places do not have many wheelchair-accessible taxis – organisers need to consider this when booking locations and venues.
- People may need support to travel. Make sure people feel safe to get to and from the venue. If people are travelling alone have a way for them to contact you for help outside office hours, e.g. when travelling early morning to your event.
- Offer to book travel for people if that would help.

"I have an app that tells me what train to catch and the platform, I don't have to look at the boards.

After I need transport back to the station"

'I have only spoken at events in places near my home. I would like to go to places further away, but I would need support to travel there'

'I need someone to meet me at the station and make sure I am safe'

Accommodation

- Many people need accessible bedrooms.
- Some people will need a mobile hoist. If they do, they will need a bed that can be used with a hoist – with space underneath or 'elephant feet' raisers.
- Some people need a hospital profiling bed, and most hotels do not have one.
- Twin and double bed options including 'next door' room options for people supported by a PA.
- Think about people who struggle to walk but don't use a wheelchair – rooms with less distance to walk are key.
- People may need other reasonable adjustments. These are personal to individuals, but examples given were things like: extra pillows for leg elevation, sockets near beds for equipment, information about parking at the hotel, and somewhere to eat at or near the hotel.

"Don't assume that if a person is coming with a supporter, that the supporter won't be their partner"

'It is a real performance for me to stay overnight because I need a hospital profiling bed. I was asked to speak at a big event in a big city this year. Then I discovered there is no hotel locally that has or can get the bed I need. I was offered a place in a 'respite unit'...I declined to speak!'

Breaks, food and mealtimes

- At bigger events there can be nowhere to sit with a drink or food – don't assume everyone can stand to eat and chat.
- Avoid paper cups that are too flimsy or full or hot. Provide an option for a ceramic cup.
- Some people need clear information in advance on what food and drink will be provided and when.
- Food serving stations can be high – so people can't see what's on offer to make a choice.

"I always take my own mug to conferences and events just in case"

'Food service stations are often at wrong height meaning I have to rely on strangers to support me'

Online and hybrid options

- Some people like online meetings, while others don't.
- Some people struggle to log in and navigate online meetings.
- Not everyone can travel – hybrid options enable people to engage and contribute from home.
- Events need to handle hybrid options well – with clear info on how to join etc – otherwise else it feels excluding.
- Some people prefer Zoom to Teams.

'Zoom is a much more accessible platform...it's friendlier'

Use feedback and reflect on experience

- Invite feedback, and then act on it.
- Give people feedback as well – enable them to develop as a speaker or contributor.
- Gather feedback from online events as well as face-to-face events.
- Take a 'you said, we did' approach.

'I give feedback, but I never see it being implemented'

'I can understand it if they get it wrong once, but not more than once'

'Feedback afterwards would be really helpful – from both sides. Everyone would be developing together as a result'

"If it's a virtual event and I'm struggling to talk, I will often type in the chat facility"

5. What would help event organisers?

Finding speakers and contributors with lived experience	<ul style="list-style-type: none">• Guidelines for conference organisers on how to find and engage people• Knowing good people to contact• A database or website of speakers
Working well with people	<ul style="list-style-type: none">• Guidelines for conference organisers on how to involve people well• Guidance on etiquette when working with disabled people
Venues	<ul style="list-style-type: none">• Information on how you can make your event environment work for everyone• Template checklist to assess accessibility of venues
Paying people	<ul style="list-style-type: none">• Information on the 'going rate' to pay people• Best practice around payment processes and protocols
Practical guidance	<ul style="list-style-type: none">• Advice on how to address particular challenges or answer specific questions. For example: <i>'Advice on supporting a speaker or questioner who uses a voice machine – how to achieve amplification if they ask a question in the main hall'</i>
Good practice examples	<ul style="list-style-type: none">• Stories and examples of good practice

"It would be good to be clear about what we should consider; for example, inviting people to co-design or co-produce sessions, how to make the experience inclusive and accessible, and how to make the whole experience comfortable"

6. Key issues that need to be addressed

6.1 Clear, sector-accepted, definition of lived experience

There is a need to have a clear definition of lived experience accepted within the events sector. The definition needs to have a clear focus on people who draw on health or social care services in the longer term. Since most people use health services, without a strong definition there is a danger that co-production is undermined or diluted by this ubiquity.

"I do want to be paid, but often say that I don't. I know it can mess with my benefits and it's just too complicated to work this out"

6.2 Clarity on payments for people who are neither employed nor self employed

No one really knows what is allowed. There is an issue with payment for people who are not self-employed or are not employed. Some people who are on benefits find it too complicated to navigate the existing guidance. People who support people do not have the expertise and/or confidence to help people navigate it either.

'I say I don't want to be paid for speaking. I wouldn't mind getting paid, but I am in a full-time job, and it might mess with my wages. It's just too complicated and no one really knows what is allowed'

'I know someone who is on Personal Independence Payment (PIP). They got paid as a speaker, and it caused big issues with their PIP. It had an awful impact on their finances and the finances of their parents. They say they don't want to get paid now!'

6.3 Assured quality of contribution

The quality and impact of speakers are key to increasing the influence of people with lived experience. People need to understand the event, the role of the people there, and the scope of their power to change things. If they are getting paid, they need to prepare well and do a good job. If they don't, they risk undermining the whole movement for challenge and change.

"We only need one or two events where people don't add value to quash this movement for positive change"

'I get uncomfortable when people with lived experience slag people off or ask questions from the floor that are just not relevant to the event or audience. It gives a bad name to people with lived experience'

'I want them to go away with a message that is positive and possible, not with a moan'

'We need clear tactics!'

6.4 Hearing the voice of older people who use social care services

Older people who use social care services are even less present than other people who draw on social care, even though they are the biggest demographic. This is particularly true of people living in care homes and/or living with dementia. They can be invisible, and their voices unheard. Sometimes the experience of younger people with an emerging voice can be very different from that of older people. Getting creative about ways to hear voices, that are not reliant on people travelling and attending in person, is essential to address this issue.

'We do hear less from the elderly. We use carers or carer groups'

'Older people use social care the most, but they are the least represented at events and conferences. We have involved people with dementia in the past but maybe not those who draw on social care'

Technology can help and hinder increased involvement of older people.

"Technology has given us more creative ways to involve older people. We have heard from older people who live in a care home and couldn't be in the room in person"

6.5 Address knowledge gaps

People with lived experience say there is a lack of understanding of disability, equality, and reasonable adjustments within some conference organisations or venues. There is a need for more training and awareness-raising – relating not only to disability but also to wider protected characteristics such as race, sexuality, and gender identity. Sometimes the organisation that is leading the event understands the issues well, but the 'middleman' organising organisation and/or the venue's events team have less awareness.



7. Ideas

Find more ways to take the initiative

Speakers shared that they sometimes approach events to challenge the fact that they do not have anyone with lived experience prominent on their published speaker list or wider timetable. They offer their services or the expertise of someone they know to help the event address this issue. People have had some success with this approach.

Create more and better ways to link event organisers with high-quality speakers with lived experience

Use existing structures, such as speaker agencies, and/or create new ways to find, support and promote speakers with lived experience. Broaden smaller, existing groups to include more people.

'Create a pool of lived experience ambassadors'

Maximise the influence potential of senior leaders

Larger or more influential organisations could play a stronger role in defining expectations and setting parameters. An expectation that hearing from or involving people with 'lived experience' is required can help to influence wider sector change.³ ⁴

Develop a liaison role

A named contact person or team who can act as a liaison between event organisers and people with lived experience who can contribute or speak.

Develop peer support structures

If it's a big event with more than one speaker with lived experience, set up a peer support group so that people can talk to each other beforehand. This way, they can share tips and information and support each other.

"I used to wait for people to invite me, then I saw events I thought I could make a difference to. I contacted them and offered to speak or run a workshop. I get a good response"

"Conferences should give 10% free tickets to people with lived experience (PAs are extra to that, like they would be at the theatre, for example) subsidised by other sales"

³<https://patientsincluded.org/>

⁴<https://socialcarefuture.org.uk/noticeboard/building-people-power/>

Find more effective ways to support carers

If carers have to leave the person they support to go events, they might have to find someone to cover the caring role in their absence. This could be a paid worker or a family member or friend. Giving carers a bursary or allowance in advance of the event would enable them to pay for someone to care for the person they support in whatever way works for them. This is preferable to asking carers to submit receipts for reimbursement, which could leave them out of pocket in the meantime.

"We are going to be asking other organisations about their involvement of people with lived experience before accepting requests... Would be great if we could do it sector wide, I think"

Training for event organisers and venues

Offer workshops for event organisers and/or venues, with people with lived experience leading the design and delivery.

Find ways to make it easier for people to be in the room

Work with conference and event organisers to explore ways to make no-cost or low-cost tickets available. Explore opportunities for sponsorship and similar initiatives to support this cost.

Find more ways to amplify the voice of people with lived experience

Get creative, share ideas, organise, and mobilise.

'To amplify voices and make a change, consider organising rallies, starting online campaigns or petitions, reaching out to media outlets for coverage, collaborating with advocacy groups, hosting community forums or town hall meetings, and utilising social media platforms to raise awareness and mobilise support. Additionally, forming alliances with like-minded individuals or organisations can strengthen advocacy efforts and increase collective impact.'

"...broaden the number of places at national events, increase places, provide financial support for accommodation and travel, change the same voices and get more voices of those who have care heard"

Intentional work on accessibility and inclusion in a locality or city

Venues, hotels, and transport providers in one place don't seem to talk to each other or work together to ensure that the place is accessible to all. Is there potential for local work in a city or place, with a Metro Mayor or Council, to ensure that there are accessibility standards and joined up working that can be trusted and built upon? Examples of locations developing a local guide for event planners could be a good place to start conversations.⁵

'We would like to be able to locate all our conferences in places that support accessibility of things like transport and hotels'

⁵<https://www.visitliverpool.com/liverpool-convention-bureau/about-liverpool-convention-bureau-our-services/liverpool-event-planners-guide/>

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Everyone who shared their experience and ideas

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Social Care Future

MacIntyre

Shared Lives Plus

Learning Disability England

“...we still have a long way to go before the culture has fully changed and shifted. We just need to elevate the worth and value of lived experience steadily and ensure that at all events that the percentage of people with lived experiences who draw on care and support attending increases”



Appendix A – Case Study Stories

Learning Disability England (LDE)

Learning Disability England is a membership organisation which represents people with a learning disability, family carers and paid supporters. They run three big events each year – a conference in the north, one in south and one online.

LDE aims to model the kind of real partnership, equality and collaboration that underpins its ethos as an organisation. Events are always cochaired by people with a learning disability and/or family members.

'The conferences are co-production in action. They demonstrate what is important to us and intentionally shift the power dynamic in favour of people with personal experience of learning disability'

The programme is designed to have workshops and sessions that will appeal to all three membership groups

'We design the day to have something of interest to all the people who will be attending'

All workshops or smaller sessions at the event are run by members or people from LDE. Workshop leaders are encouraged to co-present with a person or people with a learning disability and/or families.

The events aim only to cover their costs. Members are offered some free places and there is a lottery of free places for unwaged people with a learning disability or family carers. People who need support to attend can bring a Personal Assistant (PA) free of charge.

'We aim only to break even'

LDE asks all speakers and contributors what reasonable adjustments they need to be able to get to and around the venue and to deliver their speech or workshop.

'We ask explicitly what people need and have a tick list to help the process'

LDE has clear criteria which it uses to choose the event venues including level access, near to public transport and with accessible toilets and other facilities. They always have a quiet room so that autistic and neurodiverse people can get away from the buzz of the event if they need to. LDE is a small organisation, and delegates pay a low amount to attend so venue cost is also key.

'We choose the venues very carefully. We can struggle to find a place with a Changing Place so we sometimes have to settle for one very near to the venue that our delegates can use'

LDE think carefully about people's dietary requirements, asking everyone in advance what they need.

They produce an accessible information pack in advance for both delegates and speakers. They use large font, symbols and clear text so the information is easy read. The information aims to pre-empt everything that people might want to know about travelling to, navigating around and attending sessions on the day.

'We try and remove barriers for people, so they feel welcome and well informed. We see this as our responsibility and not theirs'

LDE pay speakers who are unwaged. They also pay expenses and can book people's travel and other arrangements for them if this is needed.

The King's Fund

The King's Fund is an independent charitable organisation working to improve health and care in England. We aim to be a catalyst for change and to inspire improvements in health and care by:

- generating and sharing ideas and evidence
- offering rigorous analysis and independent challenge
- bringing people together to discuss, share and learn
- supporting and developing people, teams and organisations
- helping people to make sense of the health and care system.

Our work involves understanding developments, challenges and opportunities across health and care. We use this understanding to influence policy and practice and to help people navigate the complexity of the systems in which they operate.

The King's Fund runs many events and conferences each year all of which have a health and care focus. They run in-person conferences including their large annual conference, leadership summit and integrated care summit. They also run guest lectures, smaller events and webinars. They have 3 current priority areas:

- drive improvements in health and wellbeing across places and communities
- improve health and care for people with the worst health outcomes
- support people and leaders working in health and care

All face-to-face events are run at their own venue in central London. They work hard to make the venue as inclusive and accessible as possible

but acknowledge areas such as toilets, quiet spaces and prayer rooms that could be better. They have a policy of continuous development and improvement of their facilities.

Their events are run on a mixed economy with some seeking to generate revenue used to financially support other activity. Some events are free for people who participate. Ticket sales and sponsorship are used to generate income. They use sponsorship to offer bursary places where possible.

The King's Fund event team is split into two different focus areas with one sub team leading the practical aspects of events and their delivery and a separate team leading on event programmes and content.

The King's Fund have a strong commitment to working with, hearing from and giving a voice to people with lived experience. They actively seek people to contribute to programme development; meet people in advance to prepare; take time to make sure people are comfortable and support people throughout.

'We believe strongly in warm greetings, full introductions, regular check backs, ensuring people are safe and comfortable, thanking people properly and seeking and using their feedback to improve future events'

Organisers know from delegate feedback that learning from lived experience is highly valued.

'The stories of the experts by experience were very moving and powerful and helped to focus us to understand why we do the job we do and the need to improve our healthcare services'

'The sessions with lived experiences were so powerful that they have reinvigorated my motivation to make quality improvements and ensure we have a patient safety learning culture.'

They run some virtual events and try hard to make these as inclusive and accessible as possible using things like live captioning.

'We plan and prepare in advance when it comes to technology'

They use recognised and valued approaches such as 'listening with fascination' to inform the way they work with people.

They have a varied approach to sourcing new speakers or participants including links through other Kings Fund projects, working through their extensive networks or asking partner organisations who know specific community groups or people well. If people are strong at the event the Kings Fund will work to stay connected with them.

'We sometimes work with experts who can help us find the right people with the right experience to share'

They intentionally try to ensure that a person with lived experience plays a strong role early in the timing of the event.

'We know that hearing from amazing people with lived experience sets the tone early'

They have a strong commitment to staff training and development to enable them to be able to support a diverse range of people well. For example, they have signed up Action on Learning Loss' Louder than Words charter and offered Sight Guide training to their staff.

'We work hard to make everyone feel comfortable and welcome'

People's Voice Media (PVM)

People's Voice Media is a civil society organisation established in 1995, that uses storytelling as a tool for social change in the UK and across Europe. They are on a mission to use lived experience to inform services, research, and policy, and to change institutions, systems, and society for the better. They want to create a just world in which people's lived experience is heard, valued, and has influence.

In 2007 they launched the Community Reporting methodology and began to build the Community Reporter Network.

Community Reporting is a digital storytelling approach that supports people's participation in research, policymaking, service development, and decision-making processes.

Each year, they run an annual conference (usually held in-person) and run many Conversation of Change events throughout the year with the stories the Network gathers and deliver launch events linked to project reports or toolkits. As an organisation they have a strong commitment to collaboration and equity.

PVM believes that there is a need to rethink events and how they are done. Their events and conferences always centre lived experience and work alongside Community Reporters, storytellers and partners to design and deliver events that promote social justice. They have a commitment to finding ways for people to contribute well, offering the right structure, planning, support and back up. They recognise that this will not always result in an equal division of labour and see this as a positive.

'You need to ensure that the ways you are asking people to contribute is good for them. We need to create an environment for them to do what they do best, to be who they are and also have grace with each other'

'We create a scaffold that is like a safety net. We are not going to let people fail.'



They are clear that the approach they take has real challenges but even stronger benefits.

'It's not always easy and it takes time, effort and money. We need to be honest about that...but it is really worth it'

They see real positives for other events taking a similar path and for wider society.

'Event organisers have to want that...it has to come from the right place. But it's the only way we get to a socially just world'



Appendix B – Resources and Tools

Venues and accessibility

Name	Produced by	Link	Notes
Access passport	AXS	Click for link	<p><i>"You may be an individual looking for a way to share your access and inclusion needs without losing control of your personal data. You may be an organisation searching for a way to create an inclusive, welcoming and productive environment for everyone. Either way, AXS Passport is the answer."</i></p>
Venues and accessibility	Seeds for Change	Click for link	<p><i>"Many of us are involved in organising events as part of our campaigning and community activities. A crucial part of this process is finding a venue that's accessible for everyone who wants to attend. Venue accessibility can influence how easily people can participate—whether it's about moving freely around the building, having baby-changing facilities accessible to all carers, adjustable lighting, gender-neutral toilets, or catering for specific dietary needs. This guide addresses a wide range of access issues, though it's not exhaustive."</i></p>
Checking the accessibility of an event or venue	SCOPE	Click for link	<p>Designed for disabled people, this resource offers valuable information, checklists, and links to additional resources—covering key considerations and essential questions to ask.</p>
AccessAble		Click for link	<p><i>"AccessAble is here to take the chance out of going out. To give you the detailed information you need to work out if a place is going to be accessible to you.</i></p> <p><i>Our Detailed Access Guides tell you all about a venue's access. They are 100% facts, figures and photographs."</i></p>
Venue Accessibility checklist	Shaping our Lives	Click for link	<p>Contains link to an accessibility checklist for venues and event organisers that can be downloaded.</p>

Dementia and accessibility

Name	Produced by	Link	Notes
Accessibility and dementia	UK Network of Dementia Voices (DEEP)	Click for link	<p>A suite of checklists and guidance for venues and services serving people who live with dementia. Tools include:</p> <ul style="list-style-type: none"> • Is this INSIDE public space dementia-inclusive? A checklist for use by dementia groups • Is this OUTSIDE public space dementia-inclusive? A checklist for use by dementia groups • Dementia words matter: Guidelines on language about dementia • Writing dementia-friendly information • DEEP guide for conference presenters and speakers

Guidance for organisers on accessible and inclusive events (continues on next page)

Name	Produced by	Link	Notes
Making your event accessible	Leeds University	Click for link	<p><i>"When organising meetings, training sessions, conferences and other events it is important to ensure that they are accessible to people with a range of different circumstances and needs. Anybody who is involved in organising events should be aware of this and ensure that the event is accessible to all potential participants. The checklists below should act as a reminder of the things that should be taken into account at the different stages of organising and delivering an event and help to ensure that events are accessible to as many people as possible. These can be tailored to the individual event ... Checklists include:</i></p> <ul style="list-style-type: none"> • Pre-event administration • Considerations relating to the timing of the event • Considerations relating to the venue • Considerations relating to refreshments • Considerations relating to event materials • Social Events"

Guidance for organisers on accessible and inclusive events (cont)

Name	Produced by	Link	Notes
Accessibility Guide to Meetings and Events – a Toolkit	Sisters of Frida	Click for link	<p><i>“Sisters of Frida CIC is a collective of disabled women, bringing disabled women together, mobilising and sharing through lived experiences. This guide has been produced as a practical tool to help groups to support and ensure that disabled women will be included and participate when planning meetings and events. There are other accessibility toolkits, but we have included specific mentions to disabled women’s needs. The guide is based upon the Social Model of Disability. The guide covers:</i></p> <ul style="list-style-type: none"> • <i>Access considerations when publicising meetings</i> • <i>Access considerations when choosing a venue</i> • <i>Access considerations during meetings.”</i>
Organising an inclusive and accessible event – top tips	Shaping our Lives	Click for link	Top tips for organising inclusive and accessible events, including links to checklists and additional information.
Making events accessible	SCIE (2019)	Click for link	<p><i>“This web resource is split into three main sections:</i></p> <ul style="list-style-type: none"> • <u>Choosing a venue</u> • <u>Planning the event</u> • <u>The event</u> <p><i>The web resource also gives checklists for organisers to work through to ensure they are making their event as inclusive and accessible as they can”</i></p>
Top 10 tips for accessible events	Unltd	Click for link	Top 10 tips with links to additional tools and resources.
Accessible Event Planning	Autistic Advocacy	Click for link	Guidance and checklist with a focus on accessibility for autistic people
Engaging with Disabled People – event planning guide	EHRC	Click for link	A series of detailed checklists

Information and accessibility

Name	Produced by	Link	Notes
Accessibility standards	Ulster University	Click for link	<p><i>"Accessible content is easier for everyone to access. It's the right thing to do, it benefits everyone, and it's the law. When you create any content (including documents, presentation slides, meeting notes, images, blog posts, web pages, videos), you're legally obliged to make it accessible for people with disabilities. It's important that accessibility is not treated as an afterthought but built into your content from the start. The following guidance will help you to create accessible content."</i></p>

Technology and accessibility

Name	Produced by	Link	Notes
AbilityNet	N/A	Click for link	<p><i>"AbilityNet is a pioneering UK charity with a global perspective. Established more than 25 years ago, we believe the power of digital technology should be available to everyone, regardless of ability or age. Our free online resources and a network of over 450 community-based volunteers help individuals with any disability, of any age, to use all kinds of digital technology. Our vision is a digital world accessible to all."</i></p>

Guidance for individuals on sharing their lived experience (continues on next page)

Name	Produced by	Link	Notes
My Voice Matters - A guide for people who want to share their lived experience	Shaping our Lives	Click for link	<p><i>"The My Voice Matters guide is designed to help you understand the power and benefits of sharing your lived experience. The free guide contains an overview of what involvement means, who can do it, and where you can go to find opportunities. The guide also contains links to tools such as our My Involvement Profile and our Involvement Pledge, to help you to have a positive and inclusive experience."</i></p>

Guidance for individuals on sharing their lived experience (cont)

Name	Produced by	Link	Notes
Inclusive Conferences	MCPIN	Click for link	<i>"The McPin team and a lived experience group member recently attended and co-presented at academic conferences – here are their thoughts on how to make conferences inclusive for people with lived experience of mental health issues and/or neurodivergence."</i>

Co-production

Name	Produced by	Link	Notes
Top tips for co-production	Shaping our Lives	Click for link	<i>"This document provides simple, practical guidelines on what people can do to provide inclusive and accessible co-production and involvement activities."</i>
Co-production impact tool	SCIElink	Click for link	<i>"This resource is designed to provide insights into how to identify the difference that co-production is making in your work."</i>
Engaging people with lived experience: best practice, challenges, and opportunities	Health and Social Care Alliance Scotland	Click for link	<i>"This research has been commissioned by the ALLIANCE with the aim to identify and share best practice and evidence on including people's lived experience in health and social care policy and practice."</i>

Finding speakers (continues on next page)

Name	Link	Notes
In Control 'People Power' Speaker Finder Service	Click for link	<i>"This is a people finder page for event organisers, publication editors, news media and others to connect with a diverse range of people who draw on long term health and social care to live their lives."</i>
UK Network of Dementia Voices (DEEP)	Tool to enable people to find a 'dementia voice' group in their area Click for link	<i>"DEEP brings the network of individual groups together to share experiences, learn from and to support each other. Some groups are formed for support and friendship in the beginning. Many groups go on to become involved in campaigning and awareness raising about dementia. They all matter and they all aim to enable people to have a voice about what matters to them.</i> <i>On this website you can find out more about the DEEP network, and about the groups that are DEEP."</i>

Finding speakers (cont)

Name	Link
Gordon Poole	Click for link
Celebrating Disability	Click for link
Disability and Inclusion Speakers Agency	Click for link
Disability Positive	Click for link
Speakers Corner	Click for link
London Speaker Bureau	Click for link

Paying people (continues on next page)

Name	Produced by	Link	Notes
Our Co-producer Payment Policy	Co-production Collective	Click for link	<i>"This payment policy has been co-created by the Co-Production Collective community and is for anyone who co-produces with Co-Production Collective. It sets out who we can offer payment to, in what circumstances; rates and methods of payment; and information about expenses. It also signposts to further resources and support."</i>
Payments and Benefits Information	Co-production Collective	Click for link	<i>"This information sheet will help you understand:</i> <ul style="list-style-type: none"> • <i>What counts as permitted work</i> • <i>Who/when/how you may need to declare any work you do"</i>
Statement on involvement payments	Shaping Our Lives	Click for link	<i>"Shaping Our Lives supports and promotes making involvement payments to people who share their experiences of using health and social care services; or who share their experiences of discrimination, oppression, and exclusion. We think that these experiences are invaluable in improving services, systems, and societal structures and should be valued in the same way as someone who is usually engaged through work to provide or influence them. Here is our statement on involvement payments detailing our position on this."</i>

Paying people (cont)

(continues on next page)

Name	Produced by	Link	Notes
Paying people with lived experience	Scottish Human Rights Commission	Click for link	<p><i>"A review of legislation, literature, and practice</i> <i>The Commission is pleased to publish this important research into the benefits and challenges of paying people with lived experience of human rights issues to participate in research, policy making, and other processes that affect them."</i></p>
Research volunteers, lay participants and participants in clinical trials	HMRC EIM71105	Click for link	
Payment for public involvement of health and care research	NIHR	Click for link	<p><i>"This guidance document is aimed at organisations that pay public contributors as part of their involvement in research. In developing this guidance document, the authors have consulted with His Majesty's Revenue and Customs (HMRC)...</i></p> <p><i>The aim of this document is to:</i></p> <ul style="list-style-type: none"> <i>• Give direction to those managing and administering payment arrangements to navigate employment status and tax regulations in an appropriate way so they feel more confident</i> <i>• Provide information and links to the most appropriate HMRC guidance in order to inform decisions on payments to public contributors based on involvement activities, especially around employment status</i> <p><i>The National Institute for Health and Care Research (NIHR) has developed a separate guidance document aimed at public contributors."</i></p>

Paying people (cont)

Name	Produced by	Link	Notes
Payment for public involvement of health and care research	NIHR	Click for link	<i>"This payment policy sets out how NIHR supports members of the public to be involved by rewarding and recognising them through payment and reimbursement of expenses. It sets out principles and methodology for a consistent and coordinated approach to the payment of public contributors within NIHR. This policy outlines payment rates..."</i>
Experience Pays - How to make money from your lived experience	Peter Bates	Click for link	<i>"Personal lived experience of mental health difficulties, disability or a significant caring role is often viewed as an impairment or a problem... This short paper aims to show how, in small ways and large, people can use their lived experience as an asset and earn money from it."</i>

