

This episode of Alliance Live Podcast is the first of four recordings being released to mark Coproduction Week 2019. Sally Shaw is the founder and director of Ideas for Ears, a third sector organisation supporting businesses and organisations to adopt best practices that are loved and wanted by people with hearing loss. Sally highlights the creation of the Hearing Access Protocol being developed making it possible for more people to more easily hear and follow the spoken word and other audible information. The initiative has coproduction at its core, having been developed with people with hearing loss across the UK, and by providing guidance to make any service design process more inclusive.

**Interviewer:** Could you provide a brief overview of the work of Ideas for Ears?

**Sally:** Ideas for Ears is a not-for-profit social enterprise. We support organisations and businesses to make their products, services, and facilities more accessible, more desirable, and more effective for people with hearing loss. We ourselves have hearing loss, and we involve others with hearing loss in what we do, so we open up our projects and invite as wide a range of people with hearing loss as we can to help us shape up our ideas, proposals, and plans. And by involving people with hearing loss in a range of constructive and progressive activity that we do, we help those individuals to become more knowledgeable and more aware of what's out there that can assist them, and we help them to become more confident and able at self-managing the challenges that hearing loss brings, and advocating for their needs and rights to be observed.

**I:** Thank you. So, we're here today to talk about the work of the organisation in relation to developing its services through coproduction, and more specifically the Hearing Access Protocol; can you give us some background around what that is?

**S:** The Hearing Access Protocol is a guidance document - actually it's more than that, it's a toolkit of resources that detail and show how to achieve hearing access. And the concept of hearing access is fairly new, and I can explain more about that in a bit, but what's important to recognise is that both hearing access and the Hearing Access Protocol are relevant to any situation where spoken communication or audible information is used. So, if you think about that for a moment, you realise that that means it's relevant everywhere and anywhere, because the most common way we communicate is by speaking. And communication happens all around us constantly, so there's relevance to lots of situations. For the moment, though, the situations that we're mostly focusing on are meetings, conferences, and events. We want the Hearing Access Protocol to become the practical bedrock for the way that any group gathering happens. It could be a work meeting or a public consultation event or a community council meeting, or maybe a group gathering for a club or a group that you're involved with. In all of these instances, the Hearing Access Protocol will help to make sure that everyone can participate and be included whatever their hearing is like. And I think what is also great about it is that so much of the guidance that's set out in the Hearing Access Protocol is just good practice generally. So, there is a lot in it that's beneficial and sensible no matter whether your hearing is excellent or you have no hearing at all.

**I:** So, can you actually tell us a little bit more about what hearing access is?

**S:** Hearing access is about making it more easy for more people to more easily hear and follow spoken language and other audible information, perhaps alerts or alarms or sound effects in videos. It is as essential as physical and mobility access, but it is poorly understood. And the coproduction work that we've been doing around the Hearing

Access Protocol has allowed us to define much more robustly what hearing access actually is, and there are five big themes that fall within the concept of hearing access. First, it's the environment where things are taking place, how hearing friendly is it? What are the noise levels like? What are the room acoustics like? Is there an echo? Does sound reverberate? Does noise build and spread? Second, it's about the audio equipment. So, what is provided in terms of the sound system, the loudspeakers, the microphones, the hearing loop, or any other assisted listening system? The third thing that falls under this concept of hearing access, and possibly it's the most challenging to get change with, even though in theory it costs absolutely nothing, is actually about the behaviour of people and the communication skills that they have, the way that they speak. So, their pace, their volume, and their diction. And then the fourth thing is around the details that need to be managed like the lighting, the room layout, making sure that faces and mouths can be seen as best and possible, those sorts of things. And finally, there is the use of additional communication support to assist. So, the use of notes, writing down information on flipcharts and having handouts and so on, so that key bits of information can be seen visibly as well as verbally given. And that can make a world of difference, even something simple like having name badges passed around a group, rather than relying on everybody hearing what somebody says when they verbally introduce themselves. Connected with that is the involvement of language and communication professionals such as electronic notetakers or sign language interpreters. And back to that whole mystery and surrounding confusion as to at what point do you involve language and communication support professionals? How many people need to be in a room before you make that standard practice? Or do you only do it when somebody requests it? Those sorts of things are all answered and addressed under this concept of hearing access, and set out within the Hearing Access Protocol.

- I:** So, if we go back to the development of the Hearing Access Protocol, planning with any endeavour is of course the utmost importance, but especially when beginning a coproduced initiative, what was the planning process like for you and the team? What advice would you give to projects or organisations before they set forth on a similar journey?
- S:** Yes, there's a lot of planning and organising. I think the development of any new resource is a big endeavour and a big undertaking, and a lot of time and attention has been given to the creation of the information and the detail within it, and making sure that it does a good job of articulating requirements, and crucially of course that by using and following the guidance within this Hearing Access Protocol, it will deliver a meaningful and genuine improvement for people with hearing loss. So, obviously that's the crux of things. However, all of that said, this was very much a grassroots-driven initiative, so it was never a top-down process, and it was never artificially concocted to kind of make check-boxes on access and equality forms easier to fill in. It emerged organically out of lots of conversations with people with hearing loss, so it wasn't imposed at all. It was a very fluid, organic response to commonly voiced problems and frustrations that people were experiencing. And it's been a way to capture and organise and share all of those difficulties and find sensible solutions that are felt to be sensible by lots of people who have hearing loss. So, it's a way to organise all of that information. So, in terms of setting out at the outset, thinking about how do we plan and move through this process? It wasn't done like that. The planning and the development processes actually happened and been thought about as we've moved through the emergence of the whole initiative and as it has grown and as it has expanded and as more people have come in and had a view on what's going on. And I think the advice that I would offer to others that are setting about a coproduction project is to just remember the importance of authenticity

and the importance of truly listening, because I think that's where you get the quality of output and you get something that genuinely is addressing and answering societal problems that are in existence.

**I:** During the actual coproduction process, how many different voices were involved?

**S:** Oh, gosh, a lot. Hundreds of people with hearing loss were involved in shaping the content, either through group discussion activity, survey input, or reviewing and giving feedback directly on the different versions and parts of the Hearing Access Protocol as it evolved. But I think in addition, we engage with people and organisations who provide services to those with hearing loss and deafness, and that's included audiologists, language and communication support professionals, deafness charities, and individuals and organisations involved in wider access and equality work, or who work in the disability sector. So, there's been a whole range of different sorts of voices that have been involved in this process. Specifically, I'd like to mention Deaf Scotland, which is the lead deafness organisation in Scotland, and the umbrella body, it's a membership organisation. And it's been particularly helpful in reviewing the resources that we've been developing, and helping to make sure that the work that we're doing dovetails and integrates with the wider push that's happening in Scotland to deliver this notion of communication for all. So, this notion of communication for all covers all forms of communication going beyond the part we're dealing with, which is access to spoken language and audible information, so it is looking beyond that. And it's important that everything, of course, dovetails, and that things are working together so that there is a clear picture and journey through different forms of access and inclusion and improvements that organisations are being asked to make, not just by the deafness sector but by other sectors as well.

**I:** How did you ensure that the voices of lived experience were especially valued? Especially considering those who have some form of hearing loss and need to communicate perhaps in other ways.

**S:** Well, I think for us, this actually wasn't that much of a challenge it may have been for others, because this has been very much a grassroots initiative. Then, actually, the voices of lived experience weren't just valued, they were actually fundamental and continue to be fundamental to the whole thing. So, very much central to the activity that we're engaged in. When it comes to people with hearing loss, then what we would suggest is that they follow the rules of the Hearing Access Protocol, so all we do is make sure that we're actually living the detail that we set out in the Hearing Access Protocol, and lo and behold that actually makes things quite easy. I mean, it is challenging in the sense that there are of course practical issues to be dealt with when you have groups of people with very varying levels of hearing and very different types of communication need. However, there's commonalities of requirement amongst them all, and certain things, as I said when I was talking through the five key themes underneath hearing access, that you can do. So, addressing those five key themes can help you to make sure that in actual fact, most people are going to have a pretty good experience. I think one of the really important things that people need to be aware of when they're thinking about people with hearing loss is the very vast majority of people who have hearing loss do have the capability to hear and follow what's said very well, or at least adequately, so long as you get the environment and you get the situation right. A core part of all of that is simple things like meeting with fairly small groups, because that then enables communication to happen well, to make sure that the room layout that we use means that everybody can see each other's faces. Depending on the number of people,

and depending on conversations that we'll have, electronic notetaking support might be there, so that there is a live transcript of what's being said as it's being said. If we've got people whose preference is British Sign Language, so they're first and foremost a British Sign Language user, which is a wholly different language to English so English could be their second language, then if it's somebody whose preference is to follow what's being said through British Sign Language, then arrangements are made to make sure there's an interpreter present that can help, so the English-BSL exchange. So, that happens quite fluidly. And I think the key thing, what we normally do at the beginning of group meetings, especially when we're getting people together face-to-face, is actually to spend five minutes or so, sometimes it goes on longer than this, asking people to have a little think about what they're actually hearing in that setting. And once they're comfortable or if they already know each other, it can be a bit easier because this can take a little bit of encouragement and confidence and them feeling relaxed enough to frankly discuss what they are personally experiencing as they try to hear and listen. In doing that what you recognise is actually how very varied and different experiences can be, even with a group that are clustered under a group of people who all have hearing loss, or all have mild hearing loss, or all have severe hearing loss. Their individual experiences can be markedly different.

**I:** So, what were some of the challenges that were highlighted during the actual coproduction process with individuals? And what were some of the unexpected successes?

**S:** In terms of the challenges, the key one is actually being to get recognition that what has been going on around awareness of hearing and deafness issues has been great. The stuff that's happened in the past has been great. We're not, in a sense, reinventing the wheel, we're trying to expand and frame things up differently so that it resonates with more people. What we're trying to do, in a sense, is we've been trying to swim upstream; we're talking about hearing rather than talking about deafness. So, we're turning things on its head in that sense, we are being a bit disruptive because we're trying to use language that people in the community will use when they're thinking and talking about their hearing, rather than using language that has been adopted and used by audiologists and other professionals and other service providers when they are looking to deliver support to people who do have hearing loss. So, categorising and theming people and discussions around hearing loss is a tricky one because there are some people who have just got a small amount of hearing loss, and there are people who have got no hearing whatsoever, and the experiences can be quite different with what's going on, and so therefore sometimes in a sense the language that is being used has been framed up to focus on the experiences at the most extreme end. But in actual fact, although we need to protect that and make sure that we never lose sight of how absolutely difficult it can be for people who have got very little hearing, and more than that, people who have lost virtually all their hearing in a very rapid timeframe, a truly difficult situation to get to grips with, and also we can't lose sight of the importance of making sure that the needs of sign language users are continuing to be focused on, we do need to recognise that the biggest number of people who have hearing loss sit at the kind of other end of the spectrum; people who have got some level of hearing loss, maybe a bit of substantial hearing loss, most of them are older and there's a lot that don't easily think of themselves as being deaf. And they certainly don't easily think of themselves as being disabled, because you don't wake up one day feeling "oh, that's me disabled by my hearing, by my deafness." At what point does that happen that you get to that point? So, I think that the fact we feel we've been swimming a bit upstream by trying to frame things up in a way that is more mainstream has been harder, because we've been going against what's convention and tradition, but I think looking at what the

unexpected successes of that have been has actually allowed us to engage with groups in a different way because we're talking about things that they suddenly go "oh, that's relevant to me", because we're talking about noise, we're talking about reverberation. These are issues that impact on people even if they fly through a hearing test and have got no obvious level of hearing loss, they may still have an issue with being able to process speech in a noisy space. And that's to do, actually, with the cognitive processing, so that's actually to do with the way your brain works rather than the way your ear is picking up the sound.

**I:** There's an obvious moral, ethical, and also legal case for inclusivity and accessibility, what legislation supports accessible communication, and what EU or domestic legal frameworks drive forward our thinking here?

**S:** Yeah, we've got the Equality Act that came out in 2010. And under that there is a duty to provide equal and fair treatment to all, and to be proactive in identifying potential barriers, so disabled people are not at a substantial disadvantage compared to non-disabled people. And there also needs to be a plan of action to reduce or eliminate these potential barriers. So, if you are deaf or if you have hearing loss, you might not think of yourself as disabled, but under the Equality Act you might be defined as being disabled, so that means you should have equal access and equality of opportunity without discrimination. What we do see, however, is that the Equality Act in a practical level isn't delivering great improvement at all, because very often when it comes to translating this reasonable adjustment for people with hearing loss or who are deaf, there are only a couple of things that are thought about: a hearing loop, or the other one is sign language interpreters. So, they can say "we'll be fully accessible, don't worry, it'll all be great", and you turn up and they've got a sign language interpreter. And 99% of people with hearing loss do not and cannot use sign. It would be wonderful if we all could, but we can't. There's a very, very small number of people relative to all of those with hearing loss who actually can use British Sign Language. The very, very vast majority of people who have hearing loss cannot. But the other point, and this bit about hearing loops, I am a huge hearing loop fan, they make the world of difference in lots of situations, but only if they're installed correctly, they're of the right specification, and they're used appropriately, otherwise they're just pointless. And, actually, sometimes a hearing loop isn't the solution that you need. So, for instance, you can be told "oh, yes, there's a hearing loop, it'll all be fine", and you'll go in, and if you go back and think about this workplace scenario, say, you'll go into that space and there might indeed be a hearing loop that's set up, but the way that the workshop or whatever it is that's happening is that you're going to be split into little groups and you're all going to be discussing things at tables. So, not only is that hearing loop that's set up round the full room utterly hopeless because it can't be used in a discussion situation with lots of tables, people discussing at lots of tables, it's not a solution for that, but there's also a huge amount of noise that then make that table discussion even harder. So, the Equality Act in terms of people's understanding, "that just means you need to have a hearing loop", or "that just means you need sign language interpreters", it's not there. And through what we've been doing with trying to make the understanding of hearing access more robust and setting out detail around the Hearing Access Protocols, what we're trying to do is actually frame up what 'reasonable', in terms of the Equality Act, might be deemed to mean when it comes to people with hearing loss and deafness. So, what we're hoping is that the work and all this coproduction effort that's gone on around the Hearing Access Protocols, that can actually be really helpful for defining where we're at with legal stuff. And it's not just the Equality Act that we need to think about, because there are other legal duties as well. The Human Rights Act that we've got has got really

big implications for what people with hearing loss should have a right to receive, and actually that's been an area of great focus and attention from Deaf Scotland, the umbrella and lead body in Scotland. And that's where they are really focusing on what these human rights are for people with deafness, because we see that might be where some gains are to be made because of this right to accessible information, this right to inclusive communication that's there, just simply because otherwise how can you take part in things? There are other things as well like public sector duties under the Patient Rights Act, and we've got the United Nation Convention on the Rights of People with Disabilities that recognises the requirement to ensure disabled people get support so they can enjoy the same rights as everybody else. So, there is quite a lot that's there, and what we just need is that people don't just tick a box with "oh, well, we're giving them a hearing loop." They actually think about "what does it mean for making sure that people actually can hear and follow and be included in these different situations?" And is it as simple as just put a hearing loop in, or for people who are sign language users, probably a sign language interpreter is the most critical and useful thing that they can have, but for some of them it might not be that. They might actually want something else, they might want a different form of support, maybe a lip speaker or something else. So, we really need to think these things through an awful lot more.

**I:** So, you're involved in a project with Dundee University in understanding the barriers and aids to access and inclusion and the use of table discussions and in the consultation process, which has elements of coproduction, how does the protocols inform or complement this work?

**S:** In actual fact, the project being done with Dundee University will actually form part of the content that is evolving and expanding within the Hearing Access Protocol. So, what we focused on with Dundee University was understanding what is going on when it comes to table discussions, group discussions, that are so often used within a consultation process. You'll bring people together into a room, you'll talk about a theme or have a presentation made to the group and then you'll be split into smaller groups and be asked to, in those smaller groups, discuss a topic or a subject, and then to feed back to the full group on what it is that you have concluded within your groups. That process is often very inaccessible for people with hearing loss because the volume of noise that's generated by all the groups simultaneously discussing things at different tables in the same space can make it really difficult to be able to hear and focus on what's going on in your own table. But it's not only difficult for people with hearing issues, it also can be quite hard for people who find it difficult to articulate or express their thoughts and feelings, or people who find it difficult to assert their point of view on something. So, it can be really hard. Or for people who are shy or who feel that they don't have enough subject knowledge to actually justify them having an opinion, especially when they're within a group of people who appear to be better informed or more confident or more articulate. So, there's quite a lot of people that can find those table discussions actually either inaccessible or not particularly fair. So, we were looking at that with Dundee University, and we focused on in particular the communication issues that arise for people with hearing loss, so we set up very small focus groups and video cameras were set up in the room by the researchers at Dundee University, and they then were able to train those cameras from all different angles to watch the verbal and non-verbal exchanges that were going on. And the actual situation and scenario that we set up was board games, family games, that we got the people in those groups to play, because those games were particularly chosen because they required different types of communication and exchange to go on between the people in that group. And what we had within some of the groups was sign language users, people who were relying on an

electronic notetaker, so essentially subtitles of what was going on and what was being said at the point it was being said. So, we had people who weren't able to look at the rest of the group or indeed at what it was they were looking at, the resources on the table that were being pointed to and referred to, because they were having to look at their language and communication support professional so they could actually follow what people were saying. So, if you stop and think about that, you can see immediately there's a whole load of practical issues that arise in that, and it was incredibly difficult, actually, for people to see and to be able to follow what was going on with some quite complex things that were happening with this board game. It was tremendous, tremendous fun, everybody involved had a wonderful time. It was a coproduction exercise with everybody being aware of why they were being brought together and what it was that was happening, what was really interesting was at the end of all of that, people were asked to keep a diary or to write down in a little diary what had gone on for each of the games that were played and what their feelings were, and what they thought about the experiences that other people in their group may have had. And although we were expecting all of them to have said "yeah, there were clear communication issues and challenges going on for either me or other members of the group", because they were so apparent, we didn't see this at all. We actually saw that in quite a lot of instances there were people who did not pick up the quite extreme challenges that some people were actually having. So, if you think about it, that was a group of people who knew that there was going to be communication challenges but they didn't actually pick up what they were within that group setting, even though we would have expected them to do that. So, if you translate that out across consultation activity that's happening throughout the public sector right across Scotland, right across transport, healthcare, education, anything else that's going on, you're going to have an awful lot of people who are taking part that you might think would pick up "oh, there's somebody finding this quite difficult", but they're not doing that. And that would be going also for people who are there to facilitate what's happening; they quite likely are not always seeing and spotting the difficulties that are there and are being experienced. Not unless they're really highly trained, but of course that's not always possible. Quite often, facilitators are lay people or volunteers or staff who have not actually had any specific training. So, the actual work done in this project with Dundee University has used these really innovative gameification techniques that Dundee University have used elsewhere to help us understand and be able to evidence the actual problems that are going on amongst people who have got communication disadvantage caused by the way that they hear.

- I:** So, the Hearing Access Protocols aim to enshrine best practice and inclusive service designed for those who may have hearing loss, are deafened, hard of hearing, or have become deaf-blind, however, maybe of the themes and advice within the protocols are incredibly relevant for other groups. How may the protocols also support other groups within meeting spaces, for example people living with autistic spectrum disorder or sight loss?
- S:** I think that because it's a communication issue, communications overlap between different groups of people, there are quite a lot of things set out in the Hearing Access Protocol and that get dealt with under this theme of hearing access that are highly relevant to people living with other types of communication needs. So, when we think about the key things, one of the key issues that we're trying to deal with under hearing access is around noise and acoustics. So, we're talking and thinking about how comfortable is that acoustic space for people? What noise levels, what volume of noise is being generated from conversational chatter or anything else that's going on? And it can become uncomfortable quite quickly for people with hearing loss, and it can become

uncomfortable for people with other sensitive hearing issues as well, and that can include people with autism, because sensory sensitivity can be one of the issues that they have. So, dealing and being able to deal better with noise levels, deal better with acoustic environments, and actually understand what you're working with so you can in advance let people know what the noise levels and what the acoustic nature of a particular space is going to be would be really helpful to more than just people with hearing loss. And I think the other group of people who can find noise levels and poor acoustics overwhelming are people with dementia. For the issues of it's kind of cognitive overload, there's a lot going on for them, they're trying to work a lot of different things out. Many of them also have got hearing loss, so there's that as well coupled with these other difficulties that they may have with cognitive processing. So, making sure that you've got an environment that is hearing-friendly plays to what they need also. You mentioned sight loss, and in actual fact, some of the good practices in Hearing Access Protocol deal with things like if you've got a visual display and you're using information, written notes and so on, if there are subtitles, it's just recognising that written stuff, which is really, really important to people with hearing loss because they want to be able to read stuff to make sure they've not lost the thread of things and can reassure themselves they are picking things up accurately, that written information needs to be big enough for them to actually be able to read it from the back of the room. So, if they're having to think about making sure the written information is big enough to be seen, that obviously is also helpful at a practical level for people who have got some kind of visual impairment as well.

**I:** That's really helpful insight, Sally. So, we're at the last question here: how can people, partner organisations, and other groups get involved? What is the best way to spread the word about Ideas for Ears going forward? And where can this information be found?

**S:** First off, where can it be found? Do go to the Ideas for Ears website and have a look there, and sign up for the newsletter, so you'll find links and things on the website that will allow you to do that, and periodically you'll get some updates on work that's going on. In terms of looking ahead and what's going on, there is an endeavour to make Scotland an inclusive communication nation, that's really important. So, we've got at the moment some legislation under the social securities which is around enshrining the need for inclusive communication, and the idea is to actually enforce that to possibly look at having more legislation or more need for compliance so that we protect the need for inclusive communication and accessible information at a wider level across our public services. But we also have got work that's going on through the work Deaf Scotland through human rights, and of course there is also the Equality Act that we can look at using to try to keep moving things forward and get momentum going. What Ideas for Ears is doing as part of all of that is focusing on things that need to be dealt with; first off we've got a raft of workshops now that are going to be available next year for organisations and individuals to sign up to, so we can run workshops on this notion of hearing access, helping people to understand audio equipment, acoustics, that kind of thing. For people who speak or present, workshops in helping them to speak with appropriate volume, speed, and diction, so that they can practice their techniques and make sure that they're aware of other important communication skills that they should have that maybe have not been something that's come to the foreground with them when they've maybe done other workshops on delivering presentations and so on. So, we can help them focus on the accessibility of the way that they speak and deliver things. So, I think what I would suggest right now is that organisations commit to this notion of hearing access and recognising that it's important for their own staff, for their customers, for their service users, for other stakeholders, especially as we've got this



aging population, but for anybody of any age with any hearing issue, really important. So, commit to that in the same way that you might have committed once to physical access and mobility access, and to recognise that it's cross-cutting. It's not just one thing, you can't just pop a hearing loop in and cross the box and go "job done." It's a lot more than that. It's not difficult to do, but it does require conscious thought, and it does require knowledge of making sure that you're moving through the steps properly and that you're actually checking back and getting the outcome that you think you're getting, and you're not just making assumptions about things working and things being okay because nobody is complaining so therefore everything's okay. Do not take that as being a measure at all. Just because people are not complaining, that does not mean anything; it just means that they're not complaining because maybe they don't have the confidence to complain or maybe there's no point because nothing can get done anyway. That's kind of where we're at at the moment, and that's the bit that completely needs to change.

**I:** That's great, Sally. That brings us to the end of our conversation and podcast here. Thank you so much for speaking with us and answering those questions.

**S:** Thank you very much indeed. It's been an absolute pleasure. And look forward to hearing access and the Hearing Access Protocol being something that more people know about and can use and get the benefit from.

**I:** Thanks very much.

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