SKILL SESSIONS

September 2024 **The Realities of Missed Diagnoses and Misdiagnosis** with Hannah Butcher

[Claire]:

Hello everyone, and welcome to Skill Sessions. It's lovely to see all of you arriving onto the webinar. Please say hello in the chat, and let us know where you're joining from. I am hosting today from Bristol. It's quite grey and drizzly outside, actually. I'd love to know what the weather is like where you are. So we've got Australia, I'm sure you'll have better weather than we do in Bristol. "Hello," from people in Coventry, Nottinghamshire, sunny Oxford, very nice, Stafford. Welcome, everyone, onto the session today. And also, let us know if this is your first time at Skill Sessions, or have you been with us before? Drop a message in the chat.

Today you're here for our incredible guest speaker, Hannah Butcher. In 2022, Hannah was named as an Autism and Learning Disability Leader and was shortlisted for the Women for the Future Awards in 2023. And this was for her work as an agency managing director, where she brought in three neurodivergent team members and set about advocating for more understanding and accommodations in the industry. So I am incredibly excited for you to hear Hannah's personal story and learn lessons from her journey today.

And if you're brand new to Skill Sessions, thank you for joining us, and welcome. We've been running these free online events for over a year, and there's now a community of over 1,700 of you, which is incredible. The objective of these events is to bring you experts and speakers on a range of topics around inclusion and neurodiversity in the workplace. So you can always find the latest events on the CareScribe website or by following CareScribe on LinkedIn. And we also have all of our past event recordings for you to watch back at your leisure on our website. And we've got summaries and additional information for you to explore on there as well. So I would encourage you to go and look through the back catalogue because we've explored lots of brilliant topics over the last year.

So, who are we? Who is hosting this event? Well, my name's Claire and I work for a company called CareScribe. And we're the organisation which makes these events happen. We're an award-winning software company based in Bristol, and we create assistive technology to help people who are neurodivergent or who have disabilities to be more productive and confident in their work and in their studies. So we have two products, Caption.Ed which is a note-taking and captioning software which helps people capture and comprehend the piles of information which gets thrown at them either at



work or in education, and we have TalkType, which is an incredibly accurate, lightning fast dictation software which works with Mac, Windows, Chromebook, on mobile and in your browser as well. So if you want to know any more about those products and what they can do for your workforce, just drop a message in the chat and the team will happily reach out to you.

So if you were in the waiting room for the webinar, you should have noticed our new video with a little bit of housekeeping in it. We'll send a survey out after the webinar to get your feedback on the event. Please let us know if you found that new video helpful. You can also request a certificate of attendance through this survey as well. Now, before I hand over to Hannah, I just want to remind you of some of those key points from the video, just to make sure that you're getting the absolute most from Skill Sessions today. So to join in the chat, which I know some of you have been doing already, all you need to do is – there is a button at the bottom of the screen, pointing down, I would encourage you to talk with other people on the call. Make sure you've changed your chat setting from Panellist to Everyone. That means that everyone can see your comments.

And something that I'm really proud of that we've created on these Skill Session events is the sense of community and interaction through the chat, so I would encourage you to use it. Also, you can turn off the chat if you find it distracting during the session. You can hide notifications by hovering over the chat icon at the bottom of your screen and just ticking Hide Chat Previews. And you can also enable Captions by Zoom if you'd like to as well. If you have any questions, please use the Q&A section at the bottom of your screen. It means that any questions that you have don't get lost in the chat. It does get quite busy. So put your question in the Q&A section at the bottom of the screen. And what it also means is that people can upvote questions so we know which ones to tackle as a priority on the call.

The biggest thing to remind you of today is that this session is being recorded, so you'll be sent a follow-up email tomorrow with links to the slides, transcript, and recording, and any other useful resources which Hannah signposts us to during the session. That's enough for me. I'm going to hand over now to Hannah, who is going to share the impact that misdiagnoses and misdiagnosis could be having on individuals in your team. So without further ado, Hannah, I'm handing over to you.

[Hannah]:

Hi, thanks. Thanks so much, Claire. I'm just going to share my screen for everyone. Just bear with me. It's always lovely. So thank you so much for everyone joining today. That was a great introduction as well. I don't think I could have done it better myself. I will save my little intro for a few slides' time, but I just want to kick off and get started because I know that all of your time is really valuable and precious. So let's get started. Today, we're gonna be covering a few topics which are important to me. So I'll be covering my own personal story of diagnosis for both autism and ADHD. I'm gonna be showing a couple of scenarios showing the impact of underdiagnosis and misdiagnosis, the reality of occurring conditions, and finally, some practical takeaways so you can better support others in your workplace. The reasons that we're talking about this, I have three. So not every neurodivergent individual gets a diagnosis, a full diagnosis, or the correct diagnosis. Some neurodivergent individuals are stuck in waiting lists. They can't face the waiting lists, or they simply don't know they're neurodivergent. And No. 3, not every neurodivergent individual wants to disclose their diagnosis to anyone in their life, particularly in this aspect at work. So that means that you may have people on your team that fall into these groups. So we have undiagnosed individuals, misdiagnosed individuals, undisclosed individuals, potentially unmedicated, those who are partially diagnosed, those who are self-diagnosed, those who are unaware, and those who are awaiting diagnosis as well. And every single person in all of these groups is someone that you need to consider that you may have in your team. Because if you're simply just relying on the facts of a diagnosis, it could actually be impacting your staff and overall, your company.

I want to go into my personal story of diagnosis for both autism and ADHD. And before I begin, obviously just a small disclaimer, I can't speak on behalf of every type of neurodivergence. These are the ones that so far have been identified for myself. But in this presentation, we will be covering some other types of neurodivergence as well. So I do encourage anyone who has more lived experience than me to hop into the chat and share some of your stories as well. So a little about me. My name's Hannah. I'm a 35-year-old freelance digital marketer who regularly speaks about neurodiversity. I received separate – and I'm highlighting that here – diagnoses as an adult for autism, ADHD, anxiety and depression, and PTSD as well. And I want to highlight here that they were separate diagnoses, and none of these have ever been delivered in one appointment. So they've all been treated very separately from each other.

Yeah, I just had to apply a little [inaudible - 00:10:04] too. So you noted the weather earlier, it's a little bit sunnier in Spain so sorry about that. But the important thing for me is that my neurodivergent traits weren't noticed as a child. I don't know whether it's because I'm female and obviously there's a higher proportion of potentially females that are masking, not showing their symptoms as much. I did very well in school but I did have some quirky interests and traits that obviously weren't identified. It was just like, "Oh, Hannah's a little bit different. She's, you know, just like a unique child." And that often happens. But it did mean that it basically impacted my ability to excel in university and my early career until I actually received my diagnoses and I was able to get accommodations for these.

So I want to take you through some of the struggles in university, because I think it's an important step. Obviously, a lot of people go through education before they become employed. And I guess I noticed that a lot of my struggles started at that level. I kind of made my way through high school. I had a few odd comments on my report cards, like "Hannah never puts her hand up in class," and things that were quite specific to me as an individual. But certainly, some of these areas of university then have a knock-on effect when you go into the workplace. So things that I particularly struggled with, not having any clue at this point about neurodivergence was like timetabling and scheduling. So obviously, classes happen at all times of the day in totally different buildings across

campus. At my university, some of them were outside of the usual campus as well so you had to travel across the city to get there. All of these things were like chaos for me. So I never really knew where I was, where I was going, how long I had to get between classes and just quite bad with the time-keeping, from that perspective as well.

I would say in terms of handing in reports and things, they were slightly easier for me because they were like concrete in my diary, but certainly getting to and from classes I found very, very chaotic. I had a fear of public speaking, and I know that sounds totally ironic considering I'm speaking to you today, but this is something that I sort of learned to do over time. As I said, I never put my hand up when I was in school. I refused to answer questions in class. Even though I knew literally every single answer that the teacher was asking, I just would refuse. I didn't want any attention on me whatsoever, to the point that when I was in high school in grade 11, we were supposed to do a presentation to the class and I pre-recorded a video of me to play to the class rather than just getting up in front of the class and speaking to people. So this was a big thing for me. And in a couple of my classes, I did have to do presentations and that gave me the fear, it would be the only thing I'd be thinking about all the time.

And then another thing was unclear expectations from tutors surrounding my dissertation. So I actually wrote a whole dissertation. And then because I misunderstood the feedback that I had from one of my tutors about my topic, she basically said, "Nope, that topic isn't valid for this dissertation." I was doing journalism and she told me that my dissertation was more media. So for me, I was like, okay, fine, whatever. So I submitted it anyway. And she was like, "No, we're not going to accept it. You need to write one that's specifically journalism-related." So that left me 48 hours to write an entire dissertation from scratch. And as you can imagine, quite a lot of burnout happening in that scenario. So, the communication and unclear expectations definitely started at this age.

And it's probably a struggle for quite a lot of people, but particularly for those who are neurodivergent, living in a house share or university halls – and I did both of these – I found halls incredibly isolating, noisy, like, so many different sensory things going on. And then living in a house share, having to see those same individuals every day with their annoying habits, I found really difficult as well. Like, I just wanted my own space, never really felt like I was at peace or at rest. So yeah, I found that really challenging. And obviously, your living environment then impacts your ability to excel in your course as well.

Budgeting. Another thing, I'm sure a lot of those with ADHD recognize that budgeting can be quite difficult. You know, you get your student loan at the beginning of the year and then how you're supposed to use that over the term, I found quite difficult. And I would admit in my first year, I got my student loan and I brought flights to Canada to go and see some of my friends. Incredibly bad decision. I thought it was an amazing decision at the time because I was like, "Yay, look at all this money." And then I realised that actually I needed money to survive. So it meant having to, you know, have the tinned beans and all those classic university cliches. So I found this one really tricky and I didn't really find anyone to help me with this.

Lecturers who didn't share slides. So I actually, when I started my degree, I was doing journalism combined with photography. Photography was one of my amazing hobbies. When I was in high school, I had my photographs displayed in online magazines, and it was just something I was really into. I found it very peaceful and like a nice solo activity. I could go out into the city and take amazing shots. But yeah, I had to give up photography after the first year because I simply had a lecturer who would not share her slides. She would keep the slide on the screen for about five seconds before flipping to the other one. And my brain was still trying to catch up being like, "What's she said?" "What's the information that I need to retain from this?" And I was like paralyzed almost in the way that she would say something and I leave with nothing. And I just had no notes because I was so stressed with the fact that she was just moving on so quickly. So I requested the slides to be sent to me and it was a blanket, "No." They just wouldn't do it. So again, it's a real shame that I had to give up that element of my degree, because that was the area that I was actually most passionate about. But yeah, that really impacted me too.

And then a big life change. So I moved continents. I was living in Canada when I was in high school and then I moved to the UK with my family. Obviously, I'm originally from the UK as well, so that was huge. And I didn't really know how to process it at the time. And particularly as a neurodivergent individual, I didn't really find the words to be able to explain it to anyone. And I kept a lot of those struggles internally as well. So yeah, it was a big change, moving country, and then immediately starting university about a month later. And the pressure to fit in, as I'm sure that a lot of you kind of feel this in all areas of life, but there were so many new people in different classes and different halls, and it was just feeling like I needed to be a certain way to be accepted by people, which ultimately meant maybe drinking more alcohol and things like that, which I didn't really like doing anyway, but I just kind of wanted to be accepted, having always kind of felt a little bit different. So, these are some of the things that I'd already started being impacted by in my life.

And then you finish university and then suddenly you're in the workplace. So, you know, it's a very interesting time going from, like, education into work. So some of the things that I struggled with when I moved into the workplace, aside from having to get up every day and go to the office and public transport and all of those lovely things, was things like work night outs or team events. So some of these should be quite enjoyable for people, but I always felt a pressure to say yes to everything because I felt like if I said no people were gonna judge me in some sort of way. But then I'd pretty much always find an excuse to not show up anyway after the fact, but it just meant a lot of mental gymnastics of having to think of excuses. And then like, it was just really exhausting.

But I did find that when I went to specific times and nights out, like it would take me a lot longer to recover than other people would be very keen to get back to the office and be like, "Yeah, we had so much fun." And I'd be like, "I am so burnt out and I don't want to see people for three days." So I didn't not go to things, but it certainly had more of an impact on me. And, you know, if there were reasons like I didn't want to go or I couldn't get out the door to go, I definitely found excuses to not attend all of them. So yeah, I think this is just something, like team events. I would prefer things without alcohol and potentially activities where I don't have to talk to people as much in that way.

Tea Rounds, this is quite specific, but the office that I've worked in in my first like proper job, there were like eight, nine of us on the team. And it was the thing that you had to take everyone's mugs, bring them into the kitchen, make a tea for everyone, and then give them out. And I just found that whole dynamic very stressful. Like, I'm a little bit of a germaphobe so thinking about someone doing my tea and mixing it with their spoon when they've got a cold. All of these things worried me more than they worried anyone else. No one seemed to care. They were all like, "Yeah, yeah, make me a tea." And I'd be like, "Mmmn, no. I'm fine. I don't want a tea." And then 15 minutes later being like, "You know what? Now I really fancy a tea. I'll just go and make my own." And I'm sure that at some point they figured out that I just didn't really want to be part of the Tea Rounds. But another social expectation. I just felt like I didn't really fit in.

Again, It's very specific to the office that I worked in, but I had one member of my team who played Oasis every day, all day – from the minute you got into the office until you left. And I'm sure that a lot of you are like, "Yay, Oasis," cause they're touring again, but for me, it was just like, "Ugh, if I have to listen to Oasis any more times, then I'm gonna scream." So it was like, you know, putting your own headphones on and then again, looking kind of isolated and just standing out. And yeah, I'm hoping he's moved on, music wise, since then, but probably not.

And then dealing with feedback as well. So as I said, it was on a team with eight, nine people and I had one person who was line managing me. They weren't very good with feedback, and we were very busy as a team as well. But, you know, sometimes things weren't necessarily communicated very clearly. And I do remember a couple of examples where I sort of got quite overwhelmed with feedback and so went to the toilet and cried for a bit and felt really ashamed. And I don't think these things should happen in the workplace, so it's just about having that really open and clear communication. Because I wouldn't want to think of other people struggling with that now too.

Phone call courtesies is another thing as well. So luckily, a lot of the comms that we do these days is by email or video chat, which is nice. But when you're having the kind of like old school video conference calls where you're all in the meeting room and you have a little conference centre in the middle and you're kind of taking turns, all the time clients will be like, "Hannah's interrupting me...Hannah's really rude." And for me, it was just like, "I already know what you're gonna say so I'm just preempting it by jumping onto the next point." But that isn't the social thing to do. So yeah, I got in trouble quite a few times, just from my way of dealing with that kind of comms. And so yeah, again, made me stand out a little.

Office sensory overload, and the lights, the noise, the oasis, all of those things going on. I just found it really exhausting. And, you know, when you get home in the evening, rather than doing anything, you just want to get on the sofa and just slob out and watch TV and just decompress from the day. And so it did mean that it was basically work and nothing else because that's all I could really manage to do. I did have the ability to hyper-focus, which ultimately led to too much workload, because I basically would just be like, "Yeah, I'm done. I'm finished. What next?" It just meant that I had too much on my plate. So at one time I was working on maybe like 19 clients at the same time in my marketing position, which is just too many. It means that you can't really give your attention to any one person at a time, any client. And it just means that you're always working on something different. So, hyper focus for me is a blessing and it's also evil. Sometimes it's great because I can get lots of things done, but sometimes I've done too much and then I can't really do anything else after that either.

And just feeling a little misunderstood, as I said. People just didn't really get me as a person. Sometimes I was called rude or bolshy or things like that. Direct, I'd get a lot as well. And again, this is – I was undiagnosed at this stage so I didn't really know why I was that way, kind of thought something was wrong with me. So yeah, there was like, obviously an impact in my early career as well. But luckily for me, one day, one of my industry peers shared her own autism diagnosis in a social media post or a blog post, and basically, the penny dropped. So I went overnight from unaware to anything to do with neurodivergence. I hadn't really understood anything about this previously or been exposed to it. So I went from kind of unaware to suddenly self-diagnosed, undiagnosed, and awaiting diagnosis.

And sadly, I waited three years for my NHS autism assessment, which left me as selfdiagnosed, undiagnosed, and awaiting diagnosis. In that time, and I had a bit of it, I realised that I also had ADHD traits as well. So again, I was still unaware at this point. And then I became self diagnosed, undiagnosed, awaiting diagnosis, and also unmedicated, just like another one to add to the club. Because I just didn't want to wait that long again, I decided to go private for my ADHD diagnosis. So I became partially diagnosed, but still also undiagnosed, awaiting diagnosis, and also unmedicated. And then finally, finally I got my autism diagnosis, which I mean, I knew I was autistic before I got my diagnosis but at that point, I guess it became undisclosed. And I was still unmedicated from the ADHD diagnosis as well.

I chose to disclose my diagnoses at work and also in my industry, hoping to help out others. And as Claire mentioned, obviously this led to me being able to recruit a couple of neurodivergent individuals in one of the agencies that I worked at as MD as well. So I do feel like it kind of came full circle, and hopefully some of the struggles that I went through eventually kind of helped me in my role as well. But as you can see, I actually ended up in seven of those eight groups that I shared earlier, all the different colours down the side. And so, as I said, the facts are you can't presume that people fit like one box. It's not just like neurodivergent or not neurodivergent because there's that middle ground, and I sat in that middle ground for a good amount of time. So even though I was neurodivergent, one, I didn't know I was. And then obviously, I had to wait to be confirmed that I indeed was. So it's kind of why neurodivergence in the workplace needs attention.

I want to show you some of the impacts of un-diagnosis and misdiagnosis as well. So first we look at misdiagnosis, which may be missed by individuals, teachers, caregivers, and employers. They may also be missed by medical professionals who are assessing for neurodivergence as well. Research shows that 80% of autistic females remain undiagnosed or misdiagnosed at the age of 18. So obviously, I fell into this group. And you have my own kind of case study about how it actually impacted me in university and in my early career as well. And then misdiagnoses. So this is where a person has a particular illness or condition, decisions made on that when in fact they have a different one. So it can have a really long-lasting impact because it means that appropriate support, medication, and accommodations aren't being provided to the individual.

I want to talk about Miriam. Names have been changed, but it's a story that I told a few months ago based on a case study and I want to take you through, like what happened with them. So originally, the doctor said that Miriam was stressed with their school, which I'm sure a lot of people will relate to. At that point, she kind of got a diagnosis of Seasonal Affective Disorder, which you may know as SAD. But it didn't quite fit. So later on, General Anxiety Disorder and depression were added as diagnoses as well. And as you can see, these things tend to come individually. But again, it didn't quite fit. So later they added bipolar and PTSD (Post-Traumatic Stress Disorder). Medication for this basically became a coping mechanism for this individual. And again, it didn't quite fit. So her doctor then suspected borderline personality disorder. But they didn't believe it. They didn't feel like that was the right diagnosis. So ultimately, they stopped all the medication, and all they ended up with at this point was just a handful of misdiagnoses and the individual then self-diagnoses themselves with RSD.

You'll see that through this story, they've been diagnosed, misdiagnosed, self-diagnosed, a handful more of those groups that are shared. We really shouldn't underestimate the toll that this can have on individuals. So the impact of these misdiagnoses, well, firstly, they're unable to disclose their neurodivergence because they just don't know, they don't have the answers. It means they're lacking suitable accommodations for the diagnosis. They might not be having the right medication or dosage. They might be taking the complete wrong thing or nothing at all. And feelings of shame or embarrassment, like "Why can't someone not figure me out?" Like, "What is wrong with me? Why can no one feel what I'm feeling?" Not understanding one's own self too. So, doubting their symptoms. Are they making them up? All of these things are going on in your mind. Feeling tired mentally and physically from all of the stress of having to self-advocate, all of the appointments that you go to, everything that you're reading online, all the conflicting information.

All of those things can really stack up. And potentially, leading to a mistrust of those in a decision-making position as well. Because if you're going to someone that you should be trusting to give you a diagnosis and it's just not fitting and they keep changing their mind and changing things around, it can ultimately have an impact on other decision-making positions or feeling like people of power in that person's life as well. Which again, can be say, a line manager or a boss in a business as well. So they may just have feelings of distrust generally. And then a worsening of symptoms in science as well. So if they're not getting the right support and medication potentially, then that can only just get worse over time as it's not being treated.

And there are a number of co-occurring conditions, and I haven't even gone into all of them in my presentation here. For any specific type of neurodivergence, you can go online and have a look at some of the co-occurring conditions as well. And actually, I've been doing a lot of reading this week, and some of it has really opened my eyes, particularly into autism. Because neurodiverse conditions do co-occur at very high rates. And I want to go back to the single diagnosis pathways. So as I said, I've gone through this myself where I've had to have individual diagnosis for every single kind of thing that I've seen a medical professional for. And because of this pathway, individuals may not be aware that they have more than one type of neurodivergence. So for me, it was people around me that made me more aware of myself, that I wasn't seeing it myself. Because I didn't know that the traits fell into a certain pattern or a group or anything like that.

I'd seen myself as an autistic person based on something that my friend in my industry shared. But it took maybe even over a year, two years, for me to recognise the ADHD side of that as well. And that was just because, again, someone was talking about some of the ways that they work and I was like, "But I always thought that ADHD was like this..." but then you look into it and I am actually a combined type of ADHD. So I thought, "I'm not running around all the time. I'm not shouting, I'm not loud, I'm not boisterous." So I didn't really feel like I fit that profile, but it was actually a lot wider than I expected. So obviously, if you're seeing a medical professional for an autism diagnosis, they're not immediately harping into, "Hey, you might also have ADHD." You really do have to self-advocate for that as an individual.

I'm going to go through some of the core neurodivergent conditions and some of the cooccurrences that they do have. So, ADHD first. Obviously, it's characterised by hyperactivity, impulsivity, and inattentiveness. But it can often overlap with autism, dyslexia, dyspraxia, anxiety, sensory processing disorder, and learning disabilities as well. Autism Spectrum Disorder, so it involves challenges with social communication, repetitive behaviours, and sensory sensitivities, and it overlaps with ADHD, anxiety, OCD, sensory processing disorder, dyspraxia, learning disabilities, and Tourette's. Dyslexia is the learning disability that affects reading and language processing. And it commonly overlaps with, again, a lot of the very similar things like ADHD, dysgraphia, dyspraxia, and all the ones that you've heard already. Dyspraxia affects motor coordination, speech, and movement. And again, it overlaps a lot with ADHD, autism, dyslexia, sensory processing disorders, and learning disabilities. Sensory processing disorders, when you have difficulty processing sensory input, leading to kind of like over or under-sensitivity to stimuli. So in this example, flavours and textures of food. And again, common overlaps, autism, ADHD, dyspraxia, dyslexia, anxiety, Tourette's. And an important one with this as well is, I think with autism, this is something that's quite common, but it can actually be diagnosed as its own diagnosis as well. So again, it commonly overlaps, but it can actually be separate to that too.

Tourette's syndrome, which involves involuntary tics, whether that's motor or vocal. And again, it commonly overlaps ADHD, OCD, autism, anxiety, sensory processing disorder. Dysgraphia, which affects writing ability and fine motor skills. So commonly overlaps with dyslexia, ADHD, dyspraxia, sensory processing disorder, and learning difficulties. And then dyscalculia, which is a disability that affects mathematical skills and number processing, which again commonly overlaps with dyslexia, ADHD, anxiety and learning disabilities as well. And then there are additional related conditions. And again, as I said, I haven't gotten into all of them because there are a lot of chronic medical conditions as well. For example, with autism, epilepsy is a really common co-occurrence. But again, if you want to go and do your own research, then there's plenty of information out there.

But just in terms of some of the co-occurring with current conditions, a lot of them you'll have seen, anxiety listed. As mentioned, I got a diagnosis of general anxiety disorder from my own GP. And again, this has never been even looked at in regards to or with any other condition that I have, so it's always been treated separately. So I have taken medication for anxiety previously, I'm not taking it anymore. But yeah, I've obviously had a couple of times where I've had medication and there's never been any kind of consideration about autism or ADHD in regards to that medication. Learning disabilities as well. Again, they're not always co-occurring, but they definitely can be. Obsessive compulsive disorder (OCD), again, commonly co-occurs. And again, depression, which as I said, sometimes kind of goes hand in hand with anxiety too. So these are all things to consider. So if someone comes to you with a type of neurodivergence, I think it's 8 in 10 autistic people have an associated mental health condition as well. And that statistic is quite high. So if you do have someone on your team who is autistic, it's wise to think that there may be something else that they haven't specified on their HR file, for example, that may fit into this group.

There are some practical takeaways that you can use to better support others in your workplace. So we'll just go through these now. The first is to recognize neurodivergence beyond the diagnosis, which ultimately is kind of the theme of what I've been talking about today. So just because someone is undiagnosed, it doesn't mean that they're not – it doesn't mean that they're neurodivergent. So you need to stay open-minded to the possibility that colleagues may not have an official diagnosis but still experience neurodivergent traits. And then not relying solely on those HR records, we've touched on this as well. So don't just use these for neurodiversity awareness in your organisation. So

just having that culture of openness without making people feel pressured to disclose. Regularly communicate that support is available for everyone, regardless of formal diagnosis in the workplace. Having that safe and open culture. So encouraging open conversations about neurodiversity. So however you want to do this. Optional discussion forums, lunch and learns, anonymous feedback mechanisms where they can share challenges and request adjustments without fear of judgement.

Again, when you're doing forms and surveys and things, you need to have that neurodivergent view in mind. So, never making things overly complicated. Don't have like a 20-page form because as an ADHD person, I'd be like, "I'm not filling that in. There's no chance." So again, just thinking about the format in which you do those things as well. And remember that neurodivergent employees aren't there to advocate for all other neurodivergent employees in the organisation. It should be up to an employer to actually do this on behalf of their employees and not use people for that purpose. It is really important to train leadership on neurodivergent support as well, so providing managers with specific training on neurodiverse communication styles, work preferences, and ways to give feedback constructively. Again, within this, recognizing that every neuro diversion individual has different needs, and that it's not just like a cookie cutter, it's not one size fits all. Having that flexible work environment, particularly in terms of work arrangements. So it might be flexible working hours, remote work options. I mentioned I really struggled with that kind of workplace environment, the tea, the Oasis, the lights - everything that was going on in that office. So for me, being able to work remotely, having my own peace and quiet, being able to get up when I want to, taking breaks, maybe even a nap, these are all things that I find really helpful.

And then creating sensory-friendly spaces as well. So if you do have an in-work office environment and remote working is just not possible, it may be that you can provide some other spaces in the work environment that are slightly less stressful to neurodivergent people. So just reducing that sensory overload, maybe letting people wear noisecancelling headphones, having quiet work zones, softer lighting. Because I would often find myself in one office, getting to a point in the day where I was like, "I just can't take any more people at this point." So I would take my laptop and I would go into a meeting room and it would be, like, so quiet. And then someone would come and be like, "Oh, are you on a call?" "Oh no." "Why are you sat in here then?" And it was just not accepted to be separate to the rest of the office. And that always made me feel quite uncomfortable, like someone was judging me for being away from my physical desk, even though I was still doing my work in the office, just in a different room. So again, just being open to the fact that people may not want to sit at a bank of desks all day, every day.

And practising clear communication as well. So being really clear with expectations. I gave you the story of my university dissertation, where it wasn't clear to me that the feedback was, "This topic isn't acceptable." It was, "This is more media." Like for me, I was like, "Okay, cool. Journalism, media, same thing." No, she needed to say, "You cannot submit this dissertation because it is not the correct topic," or whatever it was. It was just not clear to me so I just went ahead and did that dissertation. And as I said, I had to redo it from scratch. And to be super clear with expectations, direct, unambiguous language, written and verbal communications. For me, I prefer to have things in writing so I can read them, process them in my own time. It takes me slightly longer with verbal presentations. For example, where I have to really think about what's being said before I kind of catch up. So I'm always slightly a sentence behind everyone else. So, written, for me, is much easier to process. And then breaking those complex tasks into smaller, manageable steps as well. Offering multiple ways to communicate. As I said, I prefer written communication. So maybe rather than a phone call, someone wanted to use Slack, video conferencing, email, whatever it is. So, just making sure that you understand everyone's ways to communicate just in terms of their own personal preferences and how they best retain information.

And then looking at the performance of feedback methods that you use at work as well. So regular feedback is helpful, you know, a lot of people will do a yearly review, and this can be quite unhelpful. Obviously, it's not as if you're gonna get a pay rise, but maybe in that time, you haven't been getting the feedback that you need for your performance. And if it's kind of all held up for this one meeting. It can be quite overwhelming to suddenly get a load of feedback that you need to do something with and feeling like maybe you failed or you're not good enough. And then obviously, that having a knock-on our back in terms of performance. So, just keep feedback more in real time, rather than saving everything for formal reviews, even though obviously you need to sort of note things down on a formal basis regularly. It just helps neurodivergent employees to make adjustments or maybe even request them without feeling overwhelmed by that one big meeting that they're going to have.

And then this may be something you can look at as well. It won't work for every type of role, but looking at a strengths-based approach where you're looking at what that employee excels at and finding ways to align their tasks or their strengths, like reducing their focus on their challenges. And again, there's always going to be challenges for every job or whatever it is. But I'm just looking at the ways you can take away some of those bits that they struggle with. So just thinking about myself, for example, like when I learn a new piece of software, for me, it's really overwhelming at the beginning. So if someone immediately said, "Oh, Hannah, you need to just crack on with this program and just produce this thing," I would be like, "Oh my gosh." Or taking someone else's template as well. Say someone's done an audit and they're like, "Here's one I've done earlier, use this and just replicate it." I'll be like, "Ugh, now I have to learn how someone's thought about this and how they've done it before I can just do it." So for me, I would rather just go in and do my own thing. So yeah, for me, doing my own template is much better. So maybe that's something that someone would just take off my plate and let me do my own thing and then maybe put it into a different template later on. So there's lots of ways that you can work around this.

And then looking at workspaces and tools as well. So offering those accommodations to individuals, but to everyone. So allowing personalised workspace adjustments, which is

like standing desks, alternative seating, screen magnifiers, and then accessible tools and technology as well. Obviously, you're hosted by CareScribe today, who have their Alpowered captioning and note-taking software and Al-powered dictation software as well, which can be really helpful for individuals. And then looking at your existing policies. So reviewing those policies and accommodations, how current policies are affecting neurodivergent employees. So try really simple – and I urge, really simple – surveys of one-to-one meetings so you can find how those are working. And then making the adjustments based on that feedback. So be open to evolving your policies as you get that new information or that feedback. So it might be things like adjusting sick leave policies, mental health days, or flexible working hours. So once you have a policy, it's not stuck in stone. It's something that needs to be iterated, particularly as you get a wider and more diverse workforce.

So that's everything from me today. I've gone speedy quick through those, but I welcome any questions. And yeah, I'll hand back over to the chat.

[Claire]:

Hi, Hannah. Thank you so much. That was wonderful. And a side note, your slides were fantastically designed. You wouldn't have seen the chat, but there were so many comments, a lot of people resonating with the experiences that you described. There were loads of comments around that section in particular. Everyone found it very relatable. We have had a few questions as well, and we've got about 15 minutes left on this call. So I will just refer through to the Q&A section and find some questions over to you, if that's okay.

[Hannah]:

Perfect.

[Claire]:

So the first one is from Jamie and their question is, "Would you tell your employer that you have requested to be put forward for an ASD assessment through a GP or wait until actually having an assessment?"

[Hannah]:

Yeah, so this is again, totally personal preference. And I would never tell anyone to do something that they were uncomfortable with. Everyone's position in their company is different, their relationship with their employer, and the ways that the team is set up. So for me, because I'm just so open about everything anyway, it wasn't really like a concern for me. I didn't really think it through so I just kind of did it. But there may be consequences, obviously. I know that I'm in a couple of networks with people who don't feel like they can disclose it to their employer because they just know that there's no one else in the organisation that has disclosed neurodivergence and they just don't want to be the first person to do that because accommodations haven't really been set up for the team. So again, totally personal preference on what you feel comfortable with and how

you feel like that may affect your kind of employment. And I hate to say that because it shouldn't, but it is a reality that, you know, it can happen.

[Claire]:

Yeah, so much of that rests in the culture of the organisation that you're within as well, which I feel very strongly that that should be spoken about and advocated for at a leadership level as well. But yeah, totally agree with your point, Hannah. It's personal preference, but yeah, a lot to do with the culture of the business, sadly. So thank you for that one, Jamie. The next one is from Andrea who is asking, "Are there any specific tools or techniques or places to go for managers so that they can provide the best support for neurodivergent team members diagnosed or undiagnosed?"

[Hannah]:

I mean, obviously there's lots of different types of neurodivergence. So my kind of experience comes more particularly on the autism side. And there are a number of charities in the UK who campaign around that. So there are free workshops you can take. So as one of the outcomes of this, I will track down some of those links for you and we'll send them across in the newsletter.

[Claire]:

Wonderful, thank you. Also, Andrea, you might be interested to know that CareScribe, we have a newsletter called These Great Minds, which is designed and written for neurodivergent professionals, which may be useful for your team. So we'll include a link to that in the email tomorrow. We also have a LinkedIn newsletter, which is for managers of neurodivergent teams or managers who want to create neuro inclusive workplaces. So we'll include a link to that as well for you, Andrea, so hopefully that's helpful.

And then tools, obviously Hannah mentioned the tools which CareScribe produces, which is Caption.Ed and TalkType, which are designed to alleviate the stress and anxiety for neurodivergent individuals in a team. So, just wanted to remind you that those exist, should you find them useful and want to explore them a bit more. Right. Oh, we've got questions coming in thick and fast, Hannah. Right, so the next one we have is from Eva, which is, "What is the difference between high-performance autism –" Oh, it's disappeared...here we go. "What is the difference between high-performance autism and Asperger's syndrome? There's often a lot of confusion about the possible differences between the two." I don't know if you can answer that one.

[Hannah]:

Yes. So I did a bit of research for myself. I mean, obviously, this is just my own research so please go and do your own. But I had heard of Asperger's when I was growing up and I honestly thought that was totally different to autism because I knew someone who had been diagnosed with Asperger's. And basically, now, that is just absorbed into the same condition, so it's just the autism spectrum. So it's one of the same things, and I know that there's a lot of people out there campaigning for more clarity in the way that diagnosis is provided, particularly because of co-occurring conditions, as I talked about before.

So if someone is autistic and has a learning disability, for example, they may need more support than an autistic individual without the learning disabilities. So again, it's a bit of a grey area, but Asperger's, as a name, isn't used anymore. And that's just because of some of the problematic backstory behind it, basically.

[Claire]:

Thank you. And we have another one here from Isabel, which is related to the discussion that you had with your GP, Hannah. So, "How did you approach the discussion?" They've said, "I feel my GP wouldn't even believe me, but my sister has ODHT and other autistic family members, but I feel chronically tired and burnout." So, yeah, could you share your experience with that?

[Hannah]:

Absolutely. So, because I'm a researcher and I like to have my facts, as soon as I read this post from my friend, I was like, "This is me. You can't convince me otherwise, I know I'm autistic." So I was like, "I need to do everything that I can do in order to get this diagnosis, because I know it but I want it to be valid." So I went online and I started looking up all of the autism diagnosis criteria, and I read through them. So I knew exactly what to expect from the GP experience before I even spoke to them. And so my GP gave me a 10-question quiz, which they used as a barrier for entry in terms of referral. So I already knew what those questions were gonna be before she asked them to me, because I had it right in front of me when I was speaking to her on the phone.

And they basically used that as, "Either this person is someone that we should just let go and just be like, "There, there. You're not autistic." Or move me on to the assessment criteria where you could actually speak to someone who is obviously a lot more qualified on that topic. So I made it through the GP's test and then from that point, I got a lot of forms in the post and waited that three-year period to actually speak to someone. When I got my diagnosis, I cried. Not because I was like, "I'm really sad." It was just like, "All of this time and energy that I've put into this has been worth it." So yeah, it's not an easy process. As you say, some GPs are easier to speak to than others. I just kind of bulldozed my way through the process, I guess.

[Claire]:

And yeah, what you mentioned there, Hannah, about sort of crying after the diagnosis, I think, you know, from what I've heard from listening to other people's lived experiences, it's a very emotional journey. And when you hear that diagnosis, it's like that validation for all of these experiences that you've had.

So just a reminder that if you have any other questions for Hannah, we've got about five more minutes in terms of time for questions. So just do drop them in the Q&A section, not in the chat, so we've got visibility of them. A question here, Hannah, from an anonymous attendee. They've said, "I understand you can't directly approach the subject, but how do you advise supporting a member of your team if you felt like they might be neurodivergent while remaining as sensitive as possible?"

[Hannah]:

Yeah, so I've definitely had that in my own employment. So people knew I was neurodivergent, but I had other people in the team who weren't quite ready to let me know. So I kind of suspected it myself, but that's why I often say, try and make sure that you accommodate everyone with the individual accommodations that you can provide rather than just doing it specifically for neurodivergent or not neurodivergent people. Because as I said, there's like eight different groups that I shared that are not neurodivergent, if that makes sense. So anyone could fit into any of those groups at any time. So just, yeah, being really clear with the communication, the working environment, and all of those things that we discussed. They apply to everyone, whether they're neurodivergent or not.

[Claire]:

Yeah, that is a tricky one to navigate. So that was a really good question, whoever popped that one in there. Stevie has a question, which is, "How do you tackle changing long-standing procedures and processes and being met with the comment, "It's not in the budget," when you're trying to access reasonable adjustments?" Do you have any experience of that, Hannah?

[Hannah]:

I don't, personally, from the kind of workplaces that I've been in, because we've always put a budget aside for that. But I know that can be really challenging. I think it's just, you know, I can't necessarily give full advice on this or the way it's being done, but it could just be a lack of understanding at a senior level in terms of the diversity and inclusion and how important that is. I don't know whether it's worth pulling some statistics because when you start digging into the numbers, the world of, particularly neurodivergence, is much bigger than a lot of people would think in terms of the number of people, particularly in the UK, with different conditions.

So if you're able to provide data, sometimes that's helpful. We know that leadership love data. If they're talking numbers, can you just throw something back at them?

So again, that might not be the most helpful advice, but it's just maybe somewhere I would start.

[Claire]:

I totally agree with that response, Hannah. We've had speakers in the past and this question has been posed to them as well. And a lot of it comes back to getting buy-in from the leadership team and sort of speaking their language. So to your point, often that comes back to data or staff retention. You know, if you are supporting your staff who are neurodivergent, you can retain them. And we know that that has business benefit.

So yeah, a really, really wonderful answer there. I did see-I think I saw a question pop into the chat, so just bear with me whilst I scroll back. Right. So there was a question.

So someone has asked, "What's the best way, Hannah, to bring this up to your manager? So if you are undiagnosed, but you have a very strong sense that you might be neurodivergent, do you have any advice for how someone might approach that conversation with their manager of work?"

[Hannah]:

Yeah, so I think it's kind of similar to the question we had before about whether to disclose prior to a diagnosis or not. It could be rather than, you know, if you didn't feel comfortable necessarily saying, like, "I think I am neurodivergent." It could be just maybe some of the ways that you're struggling, that are kind of traits of that rather than going in with that big topic, if that's something that you're not prepared to do.

So, you know, I think mental health, generally. I know we have a long way to go, but that's maybe a little bit more known in some workplaces. And I feel like maybe it's a couple years ahead of where we are with neurodivergence in terms of mental health awareness and acceptance.

So if there are things that you're struggling with that are potentially to do with your neurodivergence but they are having a knock-on effect in terms of anxiety or stress or anything like that, these may be softer ins where you can start having that conversation about some of your accommodations that you need, which will ultimately help your neurodivergence or suspected neurodivergence. But again, in the meantime, could be accommodations that are made for you.

[Claire]:

So we are coming up to the close of the webinar. So what I will do is say thank you once again, Hannah, for your time this afternoon. Super valuable. And like I said, it resonated with so many people on the call, so thank you for sharing your personal story.

Just a couple of bits from me before we end the session. So if you enjoyed the session and you found it valuable, please help us spread the word and tell people about these events, whether that's mentioning it to a colleague, sharing it on LinkedIn, every bit of word-of-mouth helps. And we're so eager to grow this community and create just a truly valuable network for everyone on the call. So whether you're neurodivergent yourself or you manage a team of people in an organisation and you want to better understand how to support your team or your colleagues, please help us spread the word and grow out this community.

Next month's event is Menopause and Autism in the Workplace, and we'll be joined by Dr. Deborah Leveroy from Neurobox. And we'll drop a link to register for that in the chat now, but we'll also share it in the follow-up email tomorrow, which will have a link to the recording from today, the transcript, Hannah's slides, and of course those resources that Hannah mentioned during the Q&A as well. My team are also about to post a link to the survey, which I mentioned at the start, where you can request a certificate of attendance if you'd like one. We love hearing your feedback. Honestly, it directly shapes the events. And the survey will also appear as you exit the webinar as well. So, please let us know your thoughts and your feedback.

Once again, emoji round of applause for Hannah in the chat. Thank you, Hannah, so much for your time. I really enjoyed the conversation. And thank you for everyone on the call for joining us. And we will see you next month where we will discuss Menopause and Autism in the Workplace.