STAMMA with Kirsten Howells

Speaker 1:

Welcome to The Sunflower Conversations where we explore the Hidden Disability Sunflower and its

role in supporting people with hidden disabilities.

Chantal Boyle:

Kirsten is the program lead for adults at STAMMA UK and she is also speech and language therapist. Kirsten has a stammer and joins us today to discuss the condition. Hello Kirsten, how are you?

Kirsten Howells:

Hi, thank you for welcoming me to come on to talk today, Chantal. I really appreciate it.

Chantal Boyle:

Oh, thank you. So in the UK I've heard that people use the term stammer and stutter. Are they the same thing and can you tell me about the condition?

Kirsten Howells:

Yeah, so stammering and stuttering definitely both mean the same thing. Historically, the word stutter is more commonly used in American English, and stammer more commonly used in British English. In the UK now, you tend to hear people using both words sometimes in the same sentence, but it means the same thing. So stammering, at its core, is a different way of talking. It's an aspect of neurodiversity. So we know that the brains of people who stammer are wired up just a little bit differently. They're working just a little bit differently. And what it means is that a person who stammers might experience disruptions in the flow of their talking. So you might get moments when sounds or words are repeated, or when they're prolonged or extended, and you might hear what's often called blocks, and that's when no sound comes out at all for a little while. But the key thing with stammering is that the person knows exactly what they want to say. It's just a challenging physically saying that word or sound in that moment.

Chantal Boyle:

Is it tiring?

Kirsten Howells:

It can be really tiring. So, for different people they stammer in different ways and it's also very characteristic of stammering that it fluctuates over time. So people who stammer might get days when they're stammering more or less, or they might stammer more or less in the mornings or evenings or even have months or years where they're stammering more or less is a real pattern of fluctuating the fluctuation. But it can be particularly if

experiencing blocks and working very hard to get through those and to push the sounds out, it can be really, really tiring for some people at some times.

Chantal Boyle:

I read on your website that there's roughly, is it 2% of the population identifies having a stammer? Do you think that this is an accurate number?

Kirsten Howells:

It's a really interesting question. So, the published research historically suggests that... So we know that in children, in young children, it's about 8% of children will stammer for at least a while. So there are a lot of children who stammer. For many of those children, it will pass over time. The published research suggests that amongst adults, it's about 1%. But Stammer, the charity that I work for, we do YouGov polling every year and one of the questions we asked to this representative cross section of the UK population is, do you have a stammer? And for example, last year we polled 6,000 adults and 2% of them said they stammered. So it is just really interesting to consider what might be leading to that difference and who's made those judgements about the previous research. Is that people from the outside counting and does that differ from that internal experience of whether you have a stammer or not? But that's our latest figure suggests that 2% of the UK population feel that they stammer.

Chantal Boyle:

Okay. And your stammer became apparent at age nine, I believe. Is that usual? When does it usually present in a person?

Kirsten Howells:

So the vast majority of people who stammer start between the ages of two and five. That's very much the most common age range for it to start. Often around the time when children are naturally experiencing these bursts of language development. But there are children who begin later, and I was one of those. Wasn't aware of it before I was nine at all and it can sometimes occur in adults for the first time. So some people experience this much later onset of stammering and that can happen from a range of reasons

Chantal Boyle:

Between the ages of two and five is when it usually presents. So you were quite late in that sense with it being age of nine, that must have been quite a surprise for you?

Kirsten Howells:

Yeah, I think it was a real surprise. As well as stammering looking and sounding different for different people, how we respond to it is individuals really varies and kind of varies depending on who we are and how we deal with these disruptions to our talking. And will also depend on the responses of people around us and what messages we are drawing from that. But certainly, and for me that I've found it a really uncomfortable experience, both personally, found it very hard sitting in those moments with that sensation of being stuck and moved quite quickly at that time to try and mask that, to try and not to let other people see it. And that was very much how I dealt with it when I was younger and how some

people as adults would also deal with it. Whereas other people feel able to be much more open about that.

Chantal Boyle:

So you mentioned some strategies. What are the strategies that people use to avoid or hide their stutter, and what do you think about that? You just mentioned it's a very personal decision.

Kirsten Howells:

Yeah, I think so for starters, not everybody can hide or mask it. So I think you know you will have people who can hide or mask it and those who can't do that. For people who can hide or mask it, there's then that choice point, is this something I want to do or not? So I think you know get lots and lots of these subdivisions of people dealing with it in a different way, and for the people who are able to mask it and choose to do so, they might not be doing that in all situations because it might depend to some extent on those reactions around you. But for people who aren't choosing to mask it either some of the time or all of the time, some of the most sort of common masking techniques people might be using, one is swapping words.

Kirsten Howells:

So, finding a different way to say the same thing. That way may or may not be as elegant as the words you didn't originally intended to say. For some people this might involve saying less than they would've done. And for some people, it might involve avoiding whole situations or not speaking at all when they do have something to say. And for some people they find that masking really works for them. It's a tool to achieve what they want to. And for other people, that begins to be really restrictive and to be a real challenge in itself. Some people who mask talk about the frustrations of being at a restaurant or a coffee bar and ordering something that you didn't want.

Chantal Boyle:

Oh, really?

Kirsten Howells:

Okay. Yeah, so ordering what you can say, not what you want and that might then translate into meetings saying what you can say rather than what it is you actually want to say. So some people who stand that quite challenging over time, it can begin to be a really restrictive strategy for some people and to really work against them in terms of what they want to do.

Chantal Boyle:

So speech and language, how does that support people that stammer?

Kirsten Howells:

Yes, there are for people who stammer, again there are some people who are super comfortable stammering who won't looking for therapy or to change anything about their relationship with their stammering and the way that they talk. For those people who are

looking to change that there's a range of support and therapy options, and speech and language therapy is one of those options. One of the most helpful things that many people find is just that connecting with the wider stammering community, connecting with other people who stammer, it can often feel quite isolating and perhaps because there are some considerable numbers of people masking, there's actually lots of us out there, that you might not always realize that either as a person who stems or a person who doesn't.

Kirsten Howells:

And there's lots of research that really demonstrates the benefits in terms of a whole range of areas of quality of life, like having connection with other people who stammer and being able to share your own experiences, and learn from other people's experiences too. So that those ideas around peer support and networking are often some of the most important ones. In terms of speech and language therapy as a profession it can help in lots of different ways. One can be in making those introductions to those networks in providing doors in therapy can also help in terms of addressing specific challenges. For example, if you are wanting to change jobs and are concerned about what interviewing is going to be like as a person who stammers, therapy can be very, very directed towards specific challenges and opportunities.

Kirsten Howells:

Also in tackling the reactions of others, if that's a challenge in someone's life is actually not your own response to it, but dealing with unhelpful responses from others, therapy can help people work out how they're going to navigate other people being, frankly, idiots and being unhelpful, how to navigate that so that that impact can be reduced. And some people will want to just work on their own feelings about the way that they talk and their experiences as a communicator. And some people will want to work on techniques to change the way they talk, to have a sort of overlay of control to manage those moments of stammering and all those things, again, it's really individual, and one of the benefits is speech therapy is being able to individualize that so the therapy matches the goal.

Chantal Boyle:

Yeah, yeah. That's really interesting because I remember watching a documentary with Gareth Gates.

Kirsten Howells:

Yeah, so the approach which Gareth Gates does is very much a speech control approach. So it's about speaking in a different and deliberate way every time you talk, perhaps so that it reduces some of that physical struggle involved in speaking. And lots of these approaches that everything has pros and cons in life, doesn't it? Nothing is ever straightforward, and there are conversations and discussions around people using their authentic voice, speaking spontaneously and using a different voice and having perhaps a greater sense of control. And different people will choose different routes through that. But that route which the therapy approach which Gareth Gates has used is one of those about this having a different way of speaking to reduce that struggle.

Chantal Boyle:

I have had a couple of questions about stuttering, stammering, and if I can ask you... So I think you've already covered it, really, and it just goes to show about maybe where the statistics about people that stutter might not be accurate. There's a friend of mine who has a stutter and his question was, is it something to do with the brain or is it something to do that's not correct with my voice? And you've said it's neurological, so it's the brain transmitter. Correct? And he also, his brothers stutter. I don't think it's all of them, but it's certainly, I know at least two of his brothers also have a stutter, so I think he was just wanting to understand why.

Kirsten Howells:

And I think it's a hard question to give a pithy answer to because, because it's complicated. I think we don't know all the whys and wherefores of it yet. But what we do notice is thinking about his brother's stammering, we do know that it's really likely that there's a genetic component to it. And whether that arises spontaneously in some people that you are just the person in your family, you are the first one with this slight genetic difference and that leads to your brain working in a slightly different way. But we know that it does run in families. So there is something like about 60% of people who stammer have family members who stammer or stammered when they were younger. So there's quite a strong pattern of hereditary-ness. I think I might have just made up the word, hereditary-ness. But there's definitely quite a strong pattern of it.

Kirsten Howells:

And there are twin studies. You know when twins are separated at birth and things and you can follow their pattern, they can see it in the twin studies too that, if one twin stammers, it's much more likely that the other twin will also stammer regardless of the environment that they're brought up in. So yeah, there's something innate. And how I often conceptualize stammering for myself is that... So we know that there are lots of different speech centers in the brain and there're all connected by nerves in these pathways. And I kind of think of those pathways like roads. So we've got motorways and A-roads and country lanes. And that for people who stammer, sometimes the motorways are like traffic jams on the motorways. So we might be using the less efficient roads and they're a bit more prone to disruption. If a tractor comes along or something. There's only one lane, it takes longer to get past it.

Kirsten Howells:

So it seems that some of those, it's not that the connections are broken, it's not that there's brain damage or anything like that, but that some of these connections are working a bit less efficiently and it makes us vulnerable to that disruption. So for some people, they might be always working on the back roads and there's lots of tractors for them. And for some other people who stammer, maybe they're mostly using the motorways but just occasionally they're taking a detour off onto an A-road and that sort of in my mind helped me to conceptualize some of these differences between people who stammer. So some people who stammer are stammering multiple times in a sentence. Another people who stammer might just be doing it a couple of times in a conversation. And then those

fluctuations over time too that maybe sometimes there's just more or less efficiency in the system.

Chantal Boyle:

And does it hurt? Is it tiring on facial muscles and your body?

Kirsten Howells:

If you're stammering a lot or if your moments of stammering are lasting a long time, it can be really, really tiring. And for some people, if they're using a lot of tension to really push through those moments, then some people report having headaches at the end of the day or if their jaw has been clenched because they're working to get through the moment of stammering. So often that's not necessarily the stammer itself, but it's those that physical effort to say the words you want to say that pushing through the moment for some people can be really effortful and can then be physically either comfortable or just exhausting.

Speaker 4:

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Chantal Boyle:

I can see what the importance of the speech and language therapies and the multi approach way, not one size fits all, can be really beneficial. Because not being heard, feeling like you're not being heard makes you feel invisible, doesn't it?

Kirsten Howells:

It does, and feeling that your voice isn't good enough. We have this, perhaps particularly in this modern internet age, these ideas around speed and time. If you think about, I don't know, I'm born in the '70s and in the '80s computer games were just coming in, and they would take four minutes to load off a little cassette.

Chantal Boyle:

Commodore 64.

Kirsten Howells:

Exactly, with that little sort of noise that they used to make. And we were all really used to waiting for that length of time. And nowadays if a webpage doesn't load up in two seconds, we're tapping our feet and frustrated. And I think for people who stammer, there's a dynamic there about unreasonable expectations of society for speed. And what's so good about speed anyway? Might there not the opportunities in taking the time in those interactions? So I think there's often an external pressure to change the way you talk. That's really devaluing, this is the way talk I talk, this is my voice. And if I was going to change something about it, that might not necessarily be my voice. It's some sort of overlay voice. Yes, I think there's some really interesting discussions about how we make space for stammering because this is the way some of us talk, and that's okay.

Chantal Boyle:

Yeah it is okay. And it's really important to know that, isn't it? And for everybody else to know that.

Kirsten Howells:

Yeah, absolutely.

Chantal Boyle:

I used to work with somebody and he had a stutter and he didn't hide it, and as far as I can tell, he didn't change words. And he stuttered a lot, but he also spoke a lot as well. It was part of who he was and he was very comfortable with it. I always remembered that, it didn't put him off often talking in any ways whatsoever. And highly intelligent. He's like a scientist, highly intelligent. So it's not a sign of... Well, this is actually brings me on to my next question, in fact, do you think there's a stigma associated with stuttering and what challenges and barriers do people face?

Kirsten Howells:

Yes, there definitely a stigma. So there's lots of research that demonstrates that there is stigma and lots of false stereotypes around stammering, which is probably why some people who can mask it choose to because they're protecting themselves from the consequences of some of those negative stereotypes. So, one of the most common ones is being nervous, assuming that stammering equates with nervousness. You see it in literature all the time, children's books were a nightmare for this. It crops up a lot in the stories. And when I'm reading to my son, I'm always editing out because the characters, it'll be blah blah blah, he stammers. But it's when the characters are nervous and it's just being drip fed to them all the time that stammering equals nervousness and definitely there are challenges around that in job interviews about being misperceived.

Kirsten Howells:

Most people are a bit nervous in a job interview, that's normal, but if the interviewer is misinterpreting stammering as being this sign of nervousness that this is a nervous person and, can a nervous person do this role. So nervousness is probably one of the most common ones. Definitely sometimes it's misperceived as being related to intelligence in some way and almost either being super intelligent or being not very intelligent at all. These sort of outliers. Of course, some of us are. Some people who stammer are complete brain boxes and some people who stammer are not at all, but most of us just sit somewhere in between those two extremes.

Chantal Boyle:

Yeah, it's not the stammer that makes that the reason.

Kirsten Howells:

Those two things are separate. So there's a lot around intelligence and nervousness. And occasionally, and this is particularly unfortunate, being misperceived as being drunk. So that happens sometimes is people are just working through some moments of stammering being

misperceived as being drunk. Or people are just often interactions in shops and service environments. Sometimes, you'll see staff members who are clearly uncomfortable because they don't really recognize what it is and are then uncomfortable and might smirk or laugh, which is obviously not remotely helpful when you're just using your voice. It's like, this is the way it's coming out in this interaction, this is what I got.

Chantal Boyle:

Yeah. And do you have any suggestions in ways that schools and workplaces can remove barriers? You just used the example of being in a shop and being met by, I know customer service representative of that particular shop. So do you have any suggestions in which ways?

Kirsten Howells:

Yeah, I think the first and most important ones of these ideas around welcoming stammer speech and those expectations around that around time about just giving time for the way people talk so that they can say what it is they need to say. So that as a pupil in a school, that you can contribute to those lessons and you can give the answer you want to the question, so that as an employee you can contribute in meetings and say the words that you plan to say, not avoid saying them or say something different. And that, as a customer, you can order what you want. So I think that the big thing is this recognition of the idea that this is how some people talk, get over it and just allow time for it. I think that's the biggest one. And then I think ideas around flexible communication methods.

Kirsten Howells:

So it's up to us how we choose to deal with our stammering. So removing those expectations from society that we should find some new way of talking or we should overcome this in some way or we should spend the rest of our lives two hours a day practicing some new way of talking just so that we can make other people more comfortable. I think these ideas around... So in meetings as an example, in online meetings, valuing spoken and written contributions to the same extent, those things having equal value. And that can benefit lots of people. That's not specific to stammering. We know in society there'll be some people who are more willing to speak in front of groups than others. Having flexible ways of communicating can be really helpful.

Kirsten Howells:

Lots of skills. Skills make use of things like whiteboards for when the teacher asks a question, pupils can speak or they can write their answer on whiteboards. It's like allowing that flexibility that it's about the participation more than the form in which you participate. So I think there's lots of things that, in education and in the workplace and in customer environments, that people can do to really make space for that and make space for people participating in the work ways that work best for them. And then, the person receiving that also actually benefits from that interaction because you are getting better quality participation.

Chantal Boyle:

Of course. I like that expression, taking up space. I've heard that recently and it really works doesn't it, for the message you're trying to get across, and the different learning styles and communication styles for everyone. We don't all do that in the same way and we need to kind of work towards that social model, like you said, and let people use the approach that best suits them because you are going to get so much more from that because you are allowing that person to contribute. And their contribution is valuable. Just might not be in the way that I contribute or how I receive information might be very different to how somebody next to me receives information. So, I think definitely removing those barriers is crucial.

Kirsten Howells:

Yeah, absolutely. We see it in lots of... Any sort of system which has automated voice recognition on the telephone, for example, some systems are really good and they allow almost you can signal early that this route isn't working very well for me today. Can I go on a different route? But some of them will force people to stay in that route. And if you need to say your post code or your name or your phone number and the system doesn't recognize you, or it cuts you off before you finish saying it. And ultimately what you're trying to do is to pay a bill or report a problem.

Kirsten Howells:

And the company on the receiving end wants this information or wants this money, but the system is preventing you from being able to do that thing. That's not in anybody's interest. It's certainly, from the individual perspective, it's an awful experience and one that extends beyond that moment. You carry that with you the rest of the day. You carry that into your next telephone interaction and the one after that, and your feelings around that company. But also, you might never have actually got through and paid the bill. So those things are really challenging and having those flexible options is a huge reduction in barriers to involvement and participation and interacting between individuals and organizations.

Chantal Boyle:

Absolutely. So what do you think about the Sunflower as a tool to remove barriers or...

Kirsten Howells:

Yeah, I think Sunflower is... So we have some people, some of our volunteers at STAMMA who are actually already using the Sunflower as a tool. And they've reported that has been really useful because often it just helps to create that space. That the person who they're interacting with in a particular organization doesn't necessarily know what the difference is, but knows that there is some difference. And what that seems to do is to create that space. It slows down time. And that's actually really, really helpful for people who stammer in just creating that space for that interaction to really occur and for that rapport to happen. So I think, for people who are comfortable using that tool and having that subtle but visible signal, it can be a real positive.

Chantal Boyle:

And I've seen this amazing video that's been produced by STAMMA UK featuring many people from diverse ethnicities and ages who are all stuttering. Can you explain about the video?

Kirsten Howells:

Yes. So we wanted to make a short video, so it was really accessible that we're not asking people to sit down and devote like an hour of their life, which sort of two minutes long around there. But what we wanted to do was two things. We wanted to give some key information about stammering in a really fast and accessible format, but we also wanted to show some of this range that stammering, how it looks and how it sounds and when it happens, is different for different people. So knowing that someone stammers doesn't mean the details of that. So in this video with lots of different people, it we're able to show some of that range in what stammering looks and sounds like. And also to show some of that range in how people deal with those moments of stammering too.

Kirsten Howells:

That again, it's not the same. So you can't make assumptions based on knowing someone stammers. The only assumption you can make is creating space for conversation. But beyond that, you need to find out and understand and having this range of people just visible in the video and giving some of this key information about stammering in their own relationships with it, was a really effective way of doing it. And lots of people seem to really like the video, it really makes sense to people saying, oh, I think it brings that bit of an oh moment for people. Yes, so we love it. It's a great little video and we're really grateful to the people who participated in it and step forward to show themselves and their stammering in such a public way.

Chantal Boyle:

Yeah, it's fantastic. We will definitely be sharing it as well. For anyone who is listening who has a stutter and feels alone, what advice would you give to them?

Kirsten Howells:

Yeah, again, it's really hard, isn't it? Because you're trying to come up with one message that hits everyone. But some of the things that I'd like to share that, you're not alone. There are actually loads of us. So do come and seek us out. And there are lots of different ways to do that. If you want to meet people in groups, if you want to have email interactions, if you just want to look at an online forum, there are routes to suit different people. If you just want to listen to podcasts in the privacy of your own home, there's all these different routes, but you're not alone. And research tells us that experiencing these networks can make a difference, a really practical difference, to people's lives. And that your voice matters and it's beautiful. It is enough. We know that it can be hard, but that your voice with all its stammers, it matters.

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Chantal Boyle:

Thank you so much. And STAMMA UK presumably has lots of advice and resources.

Kirsten Howells:

Yes. So it's stamma.org. We have lots of resources for people who stammer. We have resources for employers and recruiters. We have resources for parents with children who stammer. So there's lots of information and guidance available. And we also, for example, have a specific service around employment and you can reach that employment support at stamma.org. And that's for individuals and organizations with questions around stammering related to the workplace. So come and find us, and we have a helpline in the web chat. There's lots of stuff, just come find us.

Chantal Boyle:

They're ready and waiting to hear from you in written or text format, or whatever. Thank you so much for your time today, Kirsten. This is really going to help raise awareness. And also, I think it will help to educate people that we just need to take time in our communication. We don't need to run at a million miles an hour. And in my case, if I took a bit more time, I'd probably make less mistakes. So yeah, just allow people the space to be who they are and you will have a much better interaction and rapport, as you already mentioned. Thank you.

Speaker 1:

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