

Slide 1 – Title Page

Neurodivergent language webinar: sharing learning from neurodivergent people and their families and carers

Presented by:

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Karen Scorer – Clinical Lead Occupational Therapist

Remie:

Welcome to this co-produced webinar on Neurodivergent language. Throughout this webinar we're going to be sharing what we've been learning about language from listening to many different people across Coventry and Warwickshire. We're also going to be sharing with you how this learning is helping us to develop and co-produce new resources. But before we start, Karen and I will introduce ourselves. So my name's Remie Colledge and I'm currently helping to co-lead the co-production work around Neurodivergent language. So I'm here today in my role as an Autistic expert by Experience. So as someone with lived experience as part of my involvement with Grapevine's Expert by Experience co-production service, what that means is that today I will be drawing on my own experience, sharing my own personal views rather than the views of Grapevine as an organization. But I will also be sharing some of that learning from listening to other people with lived experience as well. So I'll pass over to Karen.

Neurodivergent language webinar transcript

Karen:

My name is Karen Scorer. I'm a clinical lead occupational therapist within the Neurodevelopmental service and I also have lived experience of probable ADHD. So I'm sharing my experience from the perspective of someone with experts by training but also potentially expert by experience as well.

Remie:

Thanks Karen. So we're recording this webinar in August 2023. You may be watching this at a much later date, so we may have got further forward in coproducing the resources, so there may be other things available for you to tap into. Now you'll find a link in the description below for where you can go to find out more about this work. Updates of the resources so the way that this webinar will run, we've included some reflection questions. When we get to those questions, you might like to take some time pause the recording that might add to this learning experience. We understand as well that you may have different opinions and experiences to some of those that we're sharing today. Every person's experience of being Neurodivergent and the language we prefer to hear and to use is very different. And many people have been working together to understand more about Neurodivergent language and have been part of this project. So this includes many other people with lived experience, different organisations and professionals from across the Integrated Care System. So this is with a huge thank you as well to everyone else that has been involved in this work and has supported it so far. So we really hope that you find this webinar a helpful learning opportunity. So we'll move on to our first slide.

Slide 2 – Key Terms

Key terms

Co-production

Neurodiversity

Neurodivergent

Neurotypical

Karen:

Okay, so the purpose of this webinar isn't to share lots of terms and definitions because there are lots that you'll hear being said and language changes all the time and terminology changes all the time. But we're going to start by just explaining four key terms that you may hear us use within this webinar.

So the first one is Coproduction and in its simplest kind of definition. It describes working in partnership by sharing power between people who draw on care and support carers, families and citizens with the people that deliver those services. And it's all about involving people at all stages of service design and delivery, not just at the very endpoint saying, have we done okay? What's your opinion of that? It's at the very beginning of that designing and developing services.

Neurodiversity, so there's a lot of confusion around this one, really. And I guess it's just thinking about neurodiversity describes the diversity of variation in all of our human brains. So it's not just one singular group of people that are neurodiverse. We are all neurodiverse. And it describes how everyone in the

world has a unique brain and a group of people with diverse brains is neurodiverse. So you might have someone who's neurodivergent and someone who's neurotypical. They would be neurodiverse as a group of people.

Neurodivergent is the term then used to describe a person who has a brain that's built significantly different from most others. So they diverge from what you would call the norm or the majority is probably a better way of putting it. So that includes autism, ADHD, developmental coordination disorder Dyspraxia, Dysgraphia, Dyslexia, Dyscalculia and Tourette's. And some will take that definition much, much broader to include people with acquired brain injury and mental health conditions as well.

Neurotypical therefore is used to describe a person who does not have a diagnosis or don't self identify as being neurodivergent. So it's the opposite of neurodivergent. So your brain is more like the majority of others.

By neurodivergent language we simply mean the words we use to talk about being neurodivergent. So it's important to remember that, like I've said right at the beginning of this bit, is that language evolves over time. And looking back at some of the work we put together and produced, so some of the kind of booklets we put together as a service in 2017, when the adult service first started, our language use was very different from what it is today. And we are always constantly evolving and changing in response to the neurodivergent community and kind of what is being talked about and requested. So yeah, it's evolved massively.

Remie:

Definitely. And I've also seen that quite significantly since my own diagnosis, which was back in 2017. Thank you.

Slide 3 – Aims of today's webinar

Aims of today's webinar

- Why is it important to talk about neurodivergent language?
- Introducing the language resources being co-produced
- Sharing our learning from listening to lived experiences
- ~~Right or wrong~~

Remie:

Okay, so what will we be covering today? So, in this webinar we'll be introducing why neurodivergent language can feel very important to people. We'll share some of the work that's been happening so far to coproduce new resources to support people around language.

And then in the second half we'll introduce some key themes that we've identified within the feedback when we've been listening to Neurodivergent people and their families and carers.

And then towards the end we have some key messages and top tips from people with lived experience. So what can we do? How can we think differently around this topic?

So throughout the webinar. We won't be trying to say what is the right or wrong language to use, and we also won't be trying to speak on behalf of everyone. As I said earlier on, we're all very individual and may have different views. It's important to remember though, that not every neurodivergent person or their family or carers will have particularly strong views about language. However, the more, if I think back to the listening that we've been doing, what we've learned is that for many people it can feel really, really important that other people understand more about language and are respectful of their individual choices.

Slide 4 – Aims of the language project

Aims of the language project

Helping people to feel more comfortable and confident

Supporting people to understand jargon and acronyms

Encouraging conversations about inclusive language and individuality

Remie:

So those are our aims of today's webinar.

Karen:

Okay, so a little bit about the aims of the project overall. So we have a number of aims for our work around language that we've been working on. We've often heard people describe how they can have worries or fears around language. For example, a fear of saying the wrong thing. And I hear it from

Neurodivergent language webinar transcript

colleagues all the time, as well as people who are newly diagnosed fear of saying the wrong thing or offending. Lots of people say, oh, am I getting it right? I don't really know about this and can be really worried about that. And as we've said, kind of already throughout language evolves and changes. So what might have been right isn't when I'm doing training as well, it's about saying to people, it's okay that you have talked about in that way in the past. However, maybe we just need to reframe and change the way we're speaking about some things now. We aim to help people feel more comfortable and confident to talk about neurodivergence and to overcome some of the worries. So we're creating the resources for everyone, really professionals for individuals themselves. As a neurodivergent person, languages cause me some anxiety. Some of the neurodevelopmental conditions fit more neatly into identity first, language ADHD does not. And we'll talk a little bit about more about that later within the webinar. And as a professional, I don't say I'm the expert on neurodevelopmental conditions. People with lived experience have far more knowledge than I do of their own neurodivergence. And we're all still learning. We're all still learning together. And I think that's the really important thing to say. And we're learning from each other as well. We know that there's a lot of jargon acronyms and terminology related to neurodivergence but related to kind of health and social care services as well, which can add to that confusion. So when accessing services, there's just all these different things thrown around and which is the right one to use, which isn't, and sometimes it's a bit of a minefield.

So aside from developing new resources, we're also aiming to get more people thinking about championing this topic, about how we talk about neurodivergence. And it's very important part of making society more inclusive and welcoming for everyone. I don't know whether people have seen but very much the call out for Autism Awareness Week and things like that is, please, we don't need more awareness, we need some acceptance. So it's just changing some of that language. We need allies, we

need acceptance. We don't just need people to be aware, we need people to be doing something about it as well. So those nuances make a massive difference, definitely.

Remie:

And just to share, I guess. So I could relate, Karen, to when you talked about having some of those worries as well about language. So the reason it feels really important for me to be involved in this work is so I didn't come into this project as any kind of language expert. I'm definitely and I would never sort of class myself as a language expert. I was keen to keep learning more. I've experienced my own anxiety, worrying that I might say the wrong thing to peers, particularly early on in my own kind of diagnosis journey. But equally, the further I've gone along that journey, I've realised that language is such a key part for me of how I understand my identity, how I build my self-esteem. Makes sense for my experiences, I guess, and describe my experiences in a way that doesn't feel limiting, that is more empowering. So, yeah, feel passionately about this topic, but certainly not an expert on the topic.

Karen:

Just thinking about that as well when we describe something as a deficit and disorder, just how disempowering that can be on the flip side. So you were saying language can be really empowering, but it can. So that's one of the reasons, I guess, that drives me forward in this. And people will ask me all the time, and I get emails constantly kind of, am I saying the right thing? Is this the right way to and I'm kind of like, I'm not the expert either, or I don't feel like I always am. So that's exactly why we're coproducing this work, isn't it? Because if we all kind of come together and we're hearing lived experience, we're talking to other people that work in settings as well and just coming together with a shared understanding.

Slide 5 – Background to the project

Background to the project



- Starting point – a jargon buster
- Listened to many lived experiences
- Co-producing resources
- Working together - Experts by Experience and Experts by Training

Remie:

Absolutely. So what we'll do now is just give you a bit of background around that coproduction journey. So we began this work last year. Time has flown since that point. And at that point we identified the need to do more to help people to understand, as Karen said earlier, the huge amount of terminology, acronyms in and around neurodiversity and related services. So we set out originally to create a jargon buster and we started listening to people to understand, if we were to create this jargon buster, what would it be helpful for us to include within that? And after we started those initial discussions, it was at that point that we realised that there was so much work to be done in and around language. A lot of what people began to share with us goes beyond what we could include in that jargon buster. So the idea of developing other resources, including this webinar, was born, really.

So we continued that listening process to people from across Coventry and Warwickshire, for example. We facilitated focus groups, we had a questionnaire, but also listened to people at a couple of the Together with Autism conferences so late last year, early this year.

And this journey that we're on with coproducing, the resources is constantly being guided by people we are listening to. And that includes both people with lived experience, who we often call experts by experience, but also experts by training, people who are working within different services across the system, supporting neurodivergent people, as Karen shared at the beginning, who may also have their own lived experience themselves. So that's a brief overview of the coproduction so far.

Slide 6 – Gathering feedback

Gathering feedback

- Jargon/ acronyms
- Uncomfortable comments and the impact of these
- Key messages and advice
- Communicating language preferences

Karen:

And just a little bit about how we gathered feedback so the jargon terminology and acronyms people would find helpful to have explained. We talked to them about any words or comments related to neurodivergence that people hear are comfortable. And the impact of these how do these comments

make people feel? We asked about the messages and advice people would like us to share through these resources. And we also asked how easy or difficult it is to communicate to others about language preferences. And many people shared that actually it often isn't easy to have these type of conversations.

As a clinician. Very commonly, just immediately from after diagnosis, people ask a lot of questions about how do I share this with people? I don't know the right words, I haven't got a script for how I tell somebody. And it can feel really important to people to be able to communicate their own neurodivergence in a way that other people will understand and not to alienate others in their lives as well. Yeah, so that's how we kind of gathered some of that feedback as well.

Slide 7 – The power of language

The power of language

- Breaks down stereotypical ideas
- “Language is powerful, it can lift you up or bring you down, it can inspire...”
- Self-esteem, identity and embracing difference
- Feeling heard, forming connections, and building trust

Remie:

Okay, so we're going to think about the power of language. So why is it important to think about the language that we're using to talk about neurodivergence? So this work has been a reminder of just how powerful language can be. So with that in mind, how can we then use our language to best support

neurodivergent people and promote inclusivity, making our communities, our society more welcoming for people?

So the first thing I wanted to touch on is that we can use our language to break down stereotypical ideas about neurodivergence. And this is such a big part of the feedback that we've gathered. We'll come on to that on the next slide.

The second bullet point is a quote from the feedback that we received. So “language is powerful, it can lift you up or bring you down, it can inspire.” And this is one of the quotes that really stays with me because any of those impacts being lifted up, being brought down, being inspired could happen from just a handful of words. We're not talking about a long communication, just a handful of words could have that impact. So then, as that quote kind of described, the words that we use can support people to build their self-esteem and they can be also a really important part of a person's identity.

And again, that's something that we'll come back to, to bring to life a bit more so as well, the way we talk about neurodivergence can help people to feel safe, to express difference. And when people don't kind of feel safe to express difference, to be themselves when they don't feel accepted, often this can lead to masking, or what I mean by that is hiding, using different strategies to hide their differences. And I guess speaking from lived experience, this is exhausting, really exhausting. And it can feel almost impossible if you're in a space with so many stereotypical views about neurodivergence and surrounded by negative ways of talking about it. To be yourself and not to do that. Kind of like masking. Masking can lead to many different things, sort of burnout, mental health difficulties. So the impact can be huge. So with that in mind, language can really form one part of how we can support people in being themselves, in whether,

for example, that might be being able to bring our true selves into workplaces, into school, whatever environment it is, not feeling that need to mask.

We can also use our language to validate people's experiences by asking someone, how do you like to describe your experience? What does it mean to you? Rather than placing our own words, our own labels, onto somebody else's experience. Again, speaking from lived experience, feeling heard and feeling like my experiences are really being seen can be massively therapeutic. Particularly, I guess, when people go through life and receive a diagnosis much later on. Many of us can experience years of feeling like we've not really been truly heard, which can lead to lots of different difficult feelings, frustration. But validating people's experience can really help to counteract that. And then language can make people feel excluded, particularly if it's based on stereotypical ideas. So on the other hand, we can really think about carefully and use our words to build those connections between each other and to build that trust between each other as well. So language really can be powerful.

Slide 8 – Stereotypes

Language and stereotypes

- Many stereotypes still exist
- Example 1 - “you must have very mild autism”
- Example 2 – “you are too clever to have ADHD”

Reflection point: Can you think of any other comments that you've heard that reinforce stereotypes about neurodivergent conditions/ differences?

Karen:

And I guess just to then kind of really think about language and stereotypes a little bit more than so what are stereotypes? So it's an idea or a belief about something or groups of people which might be completely untrue or partly untrue, or an idea that's oversimplified or distorted.

And certainly with diagnoses such as ADHD, autism, dyspraxia, we hear all the time, oh, well, they must. And it's like, wow, no, not all autistic people or not all people with ADHD do that. So the language we use to talk about neurodivergence can reinforce or help to break down stereotypes. And the feedback we've received throughout this work suggests that a lot of people are still hearing comments that are based on stereotypical ideas of neurodivergence. The comments are keeping stereotypes alive.

So as a society, we're seeing some great progress and there's far more understanding about neurodiversity. But what our feedback suggests is there's still definitely still a lot of work to be done. And we're just going to really focus on two examples here to share with you to help demonstrate the impact of stereotypical comments. So let's just think about that phrase, you must have very mild autism.

Yeah. So I'm going to kind of pass it over to Remy to kind of think about the impact of that. Remie on you?

Remie:

Yeah. So there are parts of my life where people are less likely to see autism because I work incredibly hard to hide it comes back to that masking. A lot of the challenges I experience are not super visible all the time or exposed for people to see. And that might contribute people to labelling me as having mild autism, but that doesn't mean my autism is mild. And that can be an incredibly frustrating experience that

Neurodivergent language webinar transcript

feels like it belittles a lot of those struggles that I do that are there that are very real. And what we know is, I guess, that autism can't be kind of categorized in that way, in that black and white, mild, severe. That's not how it is. That itself is based on a huge stereotype. Yeah. So I'd say that it's frustrating because.

Karen:

It's very context specific, isn't it, Remie? I'd say in terms of where you find kind of something challenging or not can be very much about the environment and other people, rather than actually just yourself, I guess, as well.

Remie:

Yeah, definitely. And also on one date. So I have sensory difficulties and that is impacted on so many different factors. And yeah, I guess I'd encourage people to kind of look beyond that one snapshot of that one day and ask questions to kind of understand far beyond that. And I think the other impact is when hearing, and I have heard many times comments like this, that I then lose confidence to share my experience or to disclose my diagnosis with someone else. And then it feels like I'm very much keeping that to myself and I feel really isolated. So it shuts those conversations down further down the line.

Karen:

And then if we just move on to the next example. You're too clever to have ADHD. And I've heard this so many times for people kind of saying to me, I'm really thinking about seeking a diagnosis or just finding out a bit more about ADHD. But I've been to my GP and they're saying, you've got a really good job, you've got a PhD, you've been through education, you didn't fail at school, you're not stupid, la, la la. So therefore you can't have ADHD. So there's no point referring you myself, I hadn't really ever thought about ADHD until lots of the people I work with said, you are one of us, Karen. Because it didn't fit with my view of what ADHD was. So, yeah, people might be really struggling, they might have achieved these

things, but actually it can be really exhausting and to what expense of other things around them? You won't see that kind of swan flapping underneath and having to stay up till three in the morning to get things done, because they might have procrastinated all day long, because they just couldn't get started. And again, autism and ADHD both, and all the other neurodevelopmental conditions are not a measure of intelligence. I think this one's a real stigma. And I'm sure you heard more on this, Remie, didn't you, around when you were doing more of the conversations with people about they were told you're just lazy, or any of those things, you don't have ADHD, it's just that you don't try hard enough.

Remie:

Yeah, definitely. And as we move further through the webinar and the themes that we'll be sharing kind of really bring this to life a bit more as well. And there was many examples of these stereotypes, definitely.

Karen:

So I guess really, just to think and you might find it valuable to pause the recording for a short screen break anyway, but just to take some time to reflect on the question, which is, can you think of any of the comments that you've heard that reinforce stereotypes about neurodivergent conditions or differences? So if you want, you don't have to, but if you want, you can take a pause. It's always very good to have a movement break. I always absolutely kind of encourage that and just have a think about that. It might be that you've said some of these things yourself and we're not here to kind of say that was wrong and you shouldn't have done it. But it might be that we can reflect on what might be a helpful alternative. So, yeah, it might be just about asking people their individual experiences rather than assuming or putting labels onto something and really getting to know and understanding the person's situation and where they're coming from. So just not making that snapshot view of things.

Slide 9 – Identity: the gift of a diagnostic term

Identity: the gift of a diagnostic term

Shy

Geek

Disengaged

Socially
awkward



Remie:

Okay. So thank you for rejoining us. If you've taken a pause, what we're going to move on to now is just thinking about identity. And that was one of those things that when we were thinking about the power of language, that we started to talk about. So I'm going to share my own personal experience to bring this to life. So around the time of my autism diagnosis, I heard things like, why do you need that label? People around me were worried what impact the diagnosis and that term autism and all of the language kind of around that would have on me. But actually it's had a really positive impact. My self-esteem, for example, is in the strongest place it's ever been. My sense of self, my sense of identity. As I said, that worry. Initially people were discouraging me from seeking that diagnosis. But for me, because what I experience going through life similar to other people and what I've heard from talking to other people is I accumulated a lot of other words or labels connected to my autistic differences. And these are the words and labels that other people put onto me, particularly during my time at school, in education. So those words became really attached to my sense of self, my identity, and were really hard to kind of shake off.

They lived with me for a very long time. There's just four on the screen here, so shy, geek, socially awkward, disengaged.

There were others. And all of these words, labels felt very negative, felt very disempowering and very limiting. And they damage were very damaging to my self-esteem. So as I grew up, I had quite a low sense of self-worth.

But now with the understanding that I have and I guess the journey that I've been on, I would describe my autism diagnosis as a gift. But by that word gift, I'm not thinking or talking about neurodivergent, superpowers or anything like that. It's personally the word I choose to describe the impact that that's had on me being able to know now that I'm autistic to look through, I guess, that lens and develop a language that helps me to describe my experience, that helps me to communicate to other people, whether that's my family, my friends or any other people kind of around me. And a language that's allowed me to build my self-esteem and to counteract a lot of those words that you're seeing on screen there.

So this is why for me, and maybe if you're watching and you're neurodivergent yourself, you might be able to relate to this language, feels really important part of my identity.

Karen:

Thank you. I guess I'm looking at these words on the screen right now and if anyone knows me is watching this, then I probably wouldn't be described as any of those things. Shy, certainly not. But what I remember very much is some of the comments that were made or the feeling of myself and after people had kind of said to me you are one of us. Have you ever thought that you might have ADHD Karen? I was able to kind of work with my brain rather than against. And I always go back to the there's a brilliant Ted Talk which is called Failing at being normal. It's by Jessica McCabe, who has ADHD. And if you judge yourself all the time by neurotypical standards and you're failing at being that person, the mom who

always is chased up by the school for dinner money, or for forgetting that your child's had non uniform day or all those things. And just last minute.com everything and having to have almost that pressure to drive me forward. I actually went back and looked at some of my old school reports, and it was, if Karen could just if Karen stopped talking and did this and just got her head down and all of these kind of things.

And we're going to talk about some of those statements a little bit later on in the webinar. Equally. The memory that really stood out for me was being told I'd be far more suited to tap dancing than ballet dancing, which I think just describes me in a bit of a nutshell, that I was just a little bit too noisy and a little bit too much of a chatterbox to be in the ballet class because it didn't fit the stereotypical view of what a ballet dancer should be. And I'd be far more suited to being in a noisy classroom full of tap dancers. So I can laugh about it now, but I really wanted to be a ballet dancer, and I could see myself being really graceful and quiet. Couldn't actually ever do it. Okay, so, yeah, I think it's just about then being able to kind of identify and then working in a team with colleagues that really understood and really got it. I could be myself rather than trying to be something that I really wasn't. And I think that was really helpful for me and my mental health.

Remie:

Yeah. Could definitely relate to that. Finding a way to work with your brain, that would be my key takeaway from this. Thank you.

Slide 10 – Understanding different perspective

Understanding different perspectives

- 'You don't look autistic/ like you have ADHD... I'd never have known...'
- Comments can (sometimes) be well-meaning
- They can feel invalidating and frustrating
- Analytical skills and replaying conversations
- What is our intention? How can we communicate more clearly?

Karen:

Okay, so we're going to just spend a few minutes thinking about the approach we're taking throughout this work and how we're considering different sides of communication. So just thinking about the following examples to explain it. So you don't look like you have ADHD, or you don't look autistic. I'd never have known. So comments like these are usually accompanied by something else. For example, you don't look like you have ADHD because you have a job, or you're holding down a relationship, or you don't look autistic because you don't stim in a certain way, or you're married, or you can communicate. Again, these are comments based on stereotypes. So it's a helpful example here to try and understand both sides of communication and that it's a two way process.

What we recognize and have heard is that not all the time, but sometimes phrases such as these can come from a place of well meaning. What someone might be trying to say is, I'm so proud of what you're achieving or the way you're managing a certain situation. I wouldn't have known you were autistic,

because actually you're doing really well. But if you're someone who's really trying to mask and but you know, the kind of, I guess, challenge with that and the difficulty with that, it doesn't always come across as a positive thing.

So it can offend, it can belittle, and it can undermine a person's experience. There's a very real risk that these phrases can feel invalidating and frustration to the person at the receiving end. Neurodivergent people can also be really highly analytical, which is a massive strength because it means that we can think about things in great detail. However, it could also mean people may replay conversations like this for a very long time, trying to just work out what someone meant and taking up a lot of headspace time and effort. So what might be a very throwaway comment from someone. And I've had people saying to me what did they mean by that? And it can be replaying in their head for many, many days. And I've said sometimes they probably didn't mean anything and they probably didn't really think it through before they said it. And particularly for autistic people who really love language and hang on to language, but also maybe really study those kind of social interactions because they're analysing them beforehand, they're replaying it over and then they're analysing it again afterwards as well. So it can really stick with them that these comments that maybe others just made it as a very throwaway comment, they weren't ever thinking about it again.

The neurodivergent person might be replaying it over and over and over again for a very long time. So I guess our takeaway from this is that it can be helpful to just take a moment and ask ourselves what's our intention behind a comment or phrase or a question? How can we communicate more clearly? Is there a different way to say it? Just taking that time really to pause and reflect can really help avoid misunderstandings or causing offense.

Slide 11 – Themes across ages and experiences

Themes across ages and experiences



Remie:

Thanks Karen. So, coming on to the themes, we were able to categorize, as I said earlier, the feedback from lived experience into the six themes that you can see on the slide. So although we kind of categorise them into the six themes, there are overlaps between some of them. So some of the feedback might fit into more than one. And with the exception of blame, which was more specific to feedback from parents, carers and family members, for example, the other five themes were seen across feedback so from young people, adults, parents, carers and family members. And actually what we heard is that this experience of hearing comments which feel uncomfortable can almost follow people as they grow up, move through life, through different environments. It just might be that the type of comments change over time. For example, some of the words comments that I heard as a child, young person at school are very different to the type of comments that I now hear as an autistic adult. So what we're going to do is go through each of these themes in turn and just share some examples of the comments from the feedback.

So we'll start off with the just statements. It was surprising how many times that we heard the word just in the comments that people.

Karen:

Yeah, I think I've said a few of them already. If Karen just did a bit more work, worked a bit more slowly, more carefully. People talk about being told that they just want a label if they go to seek it, you know, seek a referral through for a diagnosis. One of the biggest ones at the moment is, oh, it's just a trend as well. Yeah, that's a big one. Everyone these days has got ADHD. It's just a trend. It's just anxiety. They're just naughty. It's just attention seeking. You just need to be more organised. Have you thought about a to do list? It's just an excuse. And they're all really powerful examples.

Remie:

Yeah. And the other words, as well as being powerful, the other word that comes into my head is it feels quite minimising. And again, it's that experience of feeling invalidated undermining.

Okay, so the next theme is assumptions and stereotypes. And we've mentioned this a number of times already, but this was loud and clear from the feedback and that message that came through that feedback. So we have some other examples. For instance, you can't be autistic because you can make eye contact. You don't look disabled or you look normal. They can't be neurodivergent because they talk or they have friends. They'll grow out of it being asked, what's your special talent? And there's many different examples, and I'm sure if you're watching this as well, that others will kind of be coming into your head as well.

Karen:

Yeah, and I think these assumptions and stereotypes are still very much out there, and some of the media hasn't been very helpful of late to feed into some of this as well.

Remie:

Neurodivergent language webinar transcript

Okay, so the next theme was overemphasis on deficits. So what we heard is that there can be still a real focus on what people can't do rather than what we can. So people can often still talk and talk about and view neurodivergent differences as deficits and kind of take that really deficit focused approach. But actually when we were talking and listening to people, what came through is this real need for balance. So it's important to highlight what people can do and what their strengths are, to kind of counteract that deficit kind of thinking, but at the same time still really validating these very real challenges that people might be facing on a daily basis. So it's important to recognise that to get that balance, but also really recognize that neurodivergent people, we can have many strengths that we're bringing into society and into organizations, for example.

Karen:

Yeah, absolutely. I think lots of people really worry disclosing their diagnoses and have said that when they have, people have said, oh, I'm really sorry to hear that, or yeah, it can feel incredibly difficult for people when they've probably taken a long time to think about that. And sometimes people might say, well, you can't be as well. So what could people say instead? I guess it might be helpful to say things like, thanks for sharing that with me, I'd like to understand a bit more. And then people sometimes will use the word suffering, which can be incredibly difficult for some. So suffering from autism or ADHD, some people will feel that actually there are some real, very real challenges and it can be very disabling in certain contexts and certain situations. However, they view very strongly their neurodivergence as part of their identity. To say they are suffering from might just not feel the right phrase or the right words to use. And then a lot of people would have talked about how there's a lot of negativity and it's almost like they're liabilities and they don't have any strength to share. The other kind of theme was around blame.

So parents and carers and family members spoke of feelings of judgment, inferiority, feeling quite patronized, maybe not believed as well, feeling helpless when they hear certain comments, all of which

Neurodivergent language webinar transcript

are understandably can have a huge impact on their self-esteem as parents and carers. So, examples of comments heard by parents and carers were if you spend more time interacting, you need to have firmer boundaries and it's just about parenting. So, parents will be working incredibly hard. I have been a foster carer as well and did her comments, but if mom had or why is it that you can and it's all these kinds of judgments of parents that they're not doing right by their children and they're working incredibly hard to understand their child, to do the best thing by their child. So to hear those comments can be incredibly difficult, disempowering, distressing. So yeah, there was a lot of those kind of attachments of blame.

The next theme was unhelpful and invalidating. So examples from this theme included the use of low and high functioning labels in relation to autism. People felt they were unnecessary and problematic. So if someone is described as being low functioning, it might mean a kind of lack of agency and a lack of actually, we might not ever try and work with the person to find out what they can do. However, if someone is described as being high functioning, it can absolutely invalidate their struggles and challenges and it might mean people don't get the support that they really need. It's important to remember that some people still choose to identify as having high or low functioning autism because that's maybe what the diagnosis they were given at the time was. And to respect people's individual preferences. Other unhelpful, invalidating kind of statements that you look normal neurodivergent. Adults shared that comments that talk about neurodivergent superpowers can also feel really patronising. So what are your superpowers? I'm not going to ask you that question, Remie. But they've seen Rain Man and he can count matchsticks. And there's other programs where someone's extremely good at maths and there's this image that everyone who's autistic might have a superpower. And whilst people might have what we would describe as an even profile of abilities, or sometimes referred to as a spiky profile, not everyone has savamped abilities in a particular subject. So then they feel like almost, oh, but I'm a bit

of a rubbish autistic person because I don't have these amazing superpowers. So again, it can feel incredibly invalidating.

People shared that when comments compare a neurodivergent person to a person of a different gender or someone a different age, oh, so you're not like my autistic nephew, or those kind of comments. Again, that can be really unhelpful. People shared that some comments ignore gender diversity and assume gender is quite binary rather than being inclusive. So there is a lot of work around, I suppose, autistic females and the lack of kind of awareness of diagnoses. However, we know that for our neurodivergent community, there is a lot of people that will identify as non binary gender fluid. So we just need to be really mindful of some of the language we're using and thinking about making sure we're thinking about gender diversity.

And finally, one of the other bits within this theme was that people can try and fit you into a box. So this is my view of autism. So you need to conform to that view of what I believe autism is, or this is what ADHD is, but oh, but you can ride a bike but you're dyspraxic. So when we've got these very kind of, I guess, stereotypical views or narrow and rigid views of what a certain diagnostic label will mean, we will then expect that person that maybe is a family member or friend or someone we're working with to absolutely fit into that version of what we know that diagnosis to be.

Remie:

Which I guess that links back to what we were saying earlier about how language is a real opportunity for someone to describe, be able to communicate, kind of build that picture, share that understanding about themselves. So yeah, some of these unhelpful invalidating kind of trying to put people in boxes kind of undoes that, definitely.

So the final theme that we have on here are the comments that we heard that we kind of fit into this category of being rude, disrespectful, hurtful, very outdated, and we won't kind of go into sharing those, but I'm sure you can imagine some of the things that kind of would fall into that category. So those are the six themes that we've found. The more that we continue to listen to people through this work, I'm sure that there'll be other themes that emerge and that there are many, many more examples of comments that people would share.

Slide 12 – Key messages

Key messages

- Every person is different
- Ask questions
- Listen
- Avoid assumptions and break down stereotypes
- Take time to reflect

Remie:

So we're moving into the final part of our webinar today and over the next three slides we're going to be sharing some of those kind of top tips, key messages from people with lived experience. So the first one that we have is so neurodivergent or not, every single person in the world is different and unique including the way that they like to talk about and describe their differences and experiences.

So thinking back to kind of neurodivergence, we're all different in how we describe our differences, the experiences that we have. So from that point, the second bullet point, ask questions. So we're really encouraging kind of this culture, this attitude of asking questions and being curious, but in a respectful way at the right time, in the right way. So for example,

ask questions so that you're clear what people's language kind of preferences are which may change over time.

Ask questions rather than going into a conversation, going into an interaction with an assumption in mind, trying to let those assumptions kind of go.

Ask questions rather than trying too hard not to offend. We all make mistakes.

So it's about learning I guess from those mistakes and to help you asking questions to help you to understand somebody beyond a diagnosis. So I'm autistic but yes, that's a big part of my identity but it's also only one part of who I am. There's so many other parts that make up kind of me, but not just asking questions.

So the next point listen. So really take the time to listen to what someone is sharing with you and they've trusted you I guess to kind of share that information about themselves.

So taking that time to listen carefully and recognise then that that person's experience is really unique. So trying not to then bring it back and relate it to somebody else's experience which could be very different. And Karen, when you described earlier how comparing it somebody's experience know when comments compare it to maybe somebody's grandson or I had that a lot, I'd share something and then somebody would kind of mention a young autistic boy or something like that and it wasn't matching up to what I was

trying to share. And then we also heard that conforming to the language that will make sense to other people can feel a pressure. So as we've said earlier, the language that we choose is a real opportunity to frame our experiences in a way that makes sense to us and then avoid and work together to break down assumptions and stereotypes. So thinking about what part do we each play in doing that because we can each play a part and together, I guess then the impact is much greater in breaking down those stereotypes. So what more can we do as individuals and within the different spaces of our life? So that might be our personal kind of home life, local communities, but also within our places of work as well and then taking time to reflect. So getting into the habit of checking in with ourselves. So are we being inclusive in the language that we use day to day and across our lives? So again, thinking about both our work personal lives, all the different aspects of our life. And I think, as Karen said earlier, this isn't about criticism or know, it's recognising. I guess we're encouraging this openness to reflection, to learning and to change.

Slide 13 – Key messages

Key messages

- Avoid blame
- Try to put yourself 'in the other person's shoes'
- Learn directly from lived experience
- Some people may prefer identity first, but others don't
- It isn't just the words you use, but how you say them

Karen:

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Yeah, thank you. And I guess just following on from that, it's about trying to avoid that blame. So we really heard how difficult this experience can be for people and the impact these type of comments can have. However, there's never any blame attached to that. We're all learning, as we said right at the beginning. So just trying to avoid that, trying to put yourselves in another person's shoes. So what we mean by this is asking ourselves, how would we like to be described and what would our reaction be if I heard this? And I think that can be really powerful way of reflecting, actually. If someone was referring to me as autism spectrum disorder, or if someone was referring to me as someone with deficits, would I like that? Communication deficits, attention deficits. So it's about thinking about it and just really trying to put yourself in those shoes. So how can we use more empowering and inclusive language? Learn directly from lived experience. So there's so many opportunities on social media, follow some neurodivergent influencers, there's some great neurodivergent comedians that will absolutely write brilliant comedy sketches around all of this that are about getting it wrong and getting it right. And yeah, they're brilliant. The best learning I have ever done is when they're written by neurodivergent authors. Ted talks. YouTube videos. Podcasts. There are so many more out there than there were even when I started working in this service back in 2017. It's just rocketed a lot. So there is no excuse not to go and find a book by a neurodivergent author because there's lots of them there's about people explaining their experiences and creating just brilliant resources and opportunities to learn. Really just bearing in mind, some people prefer identity first language, but some people don't. So just check in with people and ask. The best comment I've heard when kind of talking, doing some training on this was, but wouldn't we just call them by their name? And I said yes, exactly. So do we need to say autistic person or person with autism or do we need to say that person with ADHD? There might be times where we do need to kind of think about it in the way that we then offer support. However, it's best to just check in with the person. What is their preference? Some people will say they actually really don't mind, but it might come from a place of they've heard lots of awful things said about them, so they're kind of just used to it.

So it's about helping and supporting someone to develop that positive self-identity and whatever they decide is the right thing for them. That's what we should be respectful of. It isn't just the words we use, but how we say them as well. And things like body language, some of these terms can be really confusing and it can take a lot of effort to interpret. So when people's words don't match up, it just makes it really confusing. Remie, did you want to explain that one a little bit more as well.

Remie:

Yeah, absolutely. I think, yeah, I'd hate to imagine how much time I lose every week with this because sometimes what people are saying, it doesn't match up to their body language. And then it goes back to something that we said earlier about replaying conversations and being very analytical. So I guess it's just being very transparent, making that communication match. Otherwise the risk is that you're leaving. That my case. Autistic person or neurodivergent person really confused with what is your intention? So, yeah, I think that for me is hopefully it explains one, it's confusing, it's time consuming. I'm very frustrating then, because I don't want to be wasting my trying to make sense of what someone's trying to say. I've got other things to do.

Karen:

It's a bit about making your face match your words, isn't it, sometimes as well?

Slide 14 – Key messages

Key messages

- Different opinions and respect
- Be kind to people at different stages of the journey to you
- Be non-judgemental, respect people's preferences (these could change over time)
- Highlight the positive side of being neurodivergent

Remie:

Yeah, definitely. Okay, so we've got four more key messages on this slide within kind of if we say neurodivergent communities, different neurodivergent people can have different views. And what that means is that there can be disagreements or conflict between neurodivergent people as well around language. And when we listened to people, that felt really important to share. This isn't sort of a them and us situation. We are all in this kind of topic in this discussion together. We all experience difficulties around language, I think is the takeaway. And it's okay to have these different opinions, whether that's identity first person first kind of language, or I guess what we're trying to do through this webinar is encourage people to be respectful of people's individual preferences, choices and opinions.

And then from that point, I guess, being kind to people as well, we're all at different stages of a learning journey around language. I'm in a completely different place to where I was when I was first diagnosed with autism. And we're encouraging people to, I guess, gently educate other people on the topic rather

than approaching it from a place of kind of conflict. And again, I guess thinking about if you do make a mistake, which happened, we know that happens apologizing, and then using that as a real opportunity to learn and do differently next time. And again asking if you're not sure about something as well.

And the third one is about being non-judgmental, respecting people's preferences, remembering again that these can or could possibly change over time. Some of the language that I use now with more understanding, with more kind of self-reflection, is different to the language I use again when I was first diagnosed. So it's yeah, checking that out with someone and asking and.

Then finally, and this links back to that theme of deficit kind of thinking. Highlight the positive side of being neurodivergent. Because going from personal experience, there are some real positives for me about the way that my mind works that I can really tap into use, kind of embrace. But equally it comes back to that balance. And I also have challenges. People can face many challenges and it can be really difficult when those are overlooked. So it's this fine line between positive affirming language and avoiding, I guess toxic positivity, which by that we mean kind of having that overly positive mindset and ignoring those challenges. So really getting to know kind of somebody's experience, asking questions, remembering that balance.

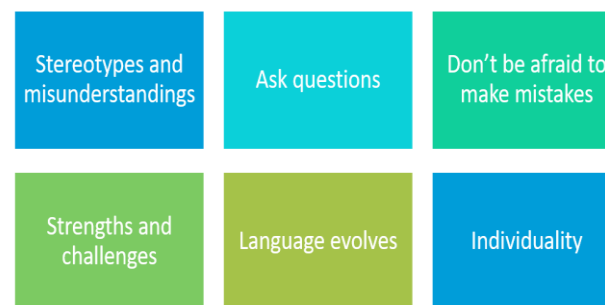
Karen:

And I think with all of this, what's really struck it's going to depend on where the person is at in their lives at that time as well. So if they're having a particularly difficult time with their mental health and well being, saying, oh, isn't it great to be neurodivergent, might not be the right time to do it. Or oh, do you know that chef who's amazing, that has ADHD, he's done incredibly well and you're kind of really struggling to just get up and dressed in the morning. Maybe those comparisons aren't helpful at that stage. It might be waiting for a different point. So yeah, I think it's just really thinking about that as well, that it will be context

and situational dependent on where that person is at. So yeah, we're now reaching the end of this webinar.

Slide 15 – Summary

Summary



Karen:

To summarize, our language coproduction work continues. A lot of what we've shared today is about stereotypes, about needing to work together and to keep breaking these down. Stereotypes can lead to misunderstandings and breakdowns in communication.

Ask questions, be curious, and listen to what people share. Don't be afraid to make mistakes. We all learn from experience and it's what we do with that learning that's really important. Find the balance between recognising strengths and validating changes, challenges, sorry. Language evolves. It can be really helpful to find ways to stay up to date and remember to see and support people as individuals. That's the main key messages we want you to take from this webinar.

Slide 16 - Reflection questions

Reflection questions:

- 1) After watching this webinar, what do you need to do next?
- 2) How can we be better allies to our neurodivergent colleagues, loved ones, friends, neighbours and patients?

Thank you for watching.

disabilitiescommissioning@warwickshire.gov.uk

Remie:

Thank you. So thank you to everyone that's watching this webinar for being curious about the topic and possibly the work that we're doing.

If you do have any questions about this work, please direct those, email those to the Warwickshire County Council Disabilities Commissioning inbox, which is disabilitiescommissioning@warwickshire.gov.uk. And you'll see that on the bottom of that slide there as well.

So before we close the webinar today, we'd like to leave you with two final reflection questions.

So the first one is on watching this webinar. What do you need to do next? For example, maybe you need to find new ways to stay up to date about language or new opportunities to learn from lived experience.

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As Karen kind of shared earlier. There's so many opportunities to do that. So what can you do next?

And then the second reflection question is, how can we be better allies to our neurodivergent? Colleagues, loved ones, friends, neighbours, patients? How can we be better allies? So you might like to spend a few moments reflecting on those two questions before moving on with the rest of your day. But other than that, that brings us to the end of today's webinar.

So thank you so much for watching. Thanks all.