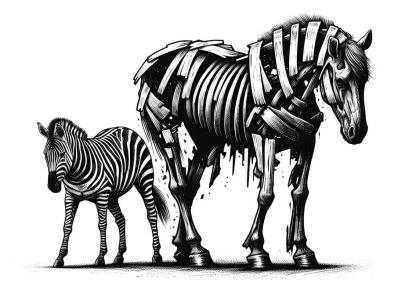
# What's going on inside that head? Embracing the wonders of neurodiversity in our sector



By Glenn Lyons, 20 November 2024

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On 14 November 2024 the 19<sup>th</sup> event in the PTRC Fireside Chat series took place. You can find recordings of all the events in the series on <u>YouTube</u>. Each event has touched upon an important topic of relevance to the transport sector. A feature of all of them has been the human touch – heartfelt and sometimes vulnerable conversations sharing expertise, experiences and feelings. Those topics that have addressed different facets of equality, diversity and inclusion have, for me, been particularly important. I have had the privilege of chairing panels in which our participants have shared their own stories, opened our minds to the lived experiences of others and given us all a chance to learn lessons of our own.

The 19<sup>th</sup> event has considered neurodiversity. It brought together a panel of neurodivergent people, all of whom have received a formal diagnosis, to help shine a light on how different people's brains work in different ways and to give a glimpse of what it is like to live in a neurotypically-designed society. If you are ready to engage with what follows, I hope you will find some affirmations and new insights about yourself.

This writeup (including at the end a list of further resources) is provided in the interests of helping as many people as possible to benefit from the event in the format that best suits them. I would nevertheless encourage you to watch the <u>recording</u> of the event and hear directly from the people involved. Any misrepresentation in the text that follows here is my own.

# Insights on a page

I hope you'll find value in reading the whole document and/or watching the recording, but if you're really in a hurry, here is your 'grab and go' set of insights:

- 1. *Neurodiversity* encompasses us all, but society has been constructed to favour of *neurotypical* brain types, even though approximately 1in 7 or 1 in 5 people are *neurodivergent* and can face challenges in a neurotypical society, while offering great opportunity to society.
- 2. Clues pointing to possible neurodivergence include: being unlikely to be pulled into group think; challenging assumptions; the ability to assimilate and process information and ideas; being innovative; and being strongly justice-oriented.
- 3. Engaging in understanding neurodivergence and learning from others' experiences can help us illuminate new understanding about ourselves. Watershed moments can follow, especially after formal diagnosis.
- 4. Neurodivergent people can appear very capable but this may demand considerable energy while they also harbour a crippling sense of inner shame when they fall short in a neurotypical society.
- 5. Neurodivergent people can exhibit super-empathy yet there can be considerable vulnerability and mental health pressures associated with being neurodivergent.
- 6. Linking professionalism to outward appearance can be short-sighted and risk the brilliance of the pyjama-wearing neurodivergent being missed out on.
- 7. Being neurodivergent in a neurotypical society can prompt unhealthy coping mechanisms to fit in with what is expected. This includes masking, which can lead to one losing sight of where your 'presentable' self ends and your authentic self begins. Coping strategies might also include addictions or risk-taking behaviours.
- 8. Workplace adjustments are important and yet can be poorly understood or handled addressing them also benefits from mutual understanding and compromise.
- 9. Look up 'Spoon Theory' to appreciate how once we wake up, tasks we perform can deplete our energy levels this is especially true of navigating the transport system, which risks compromising the ability to function at the destination.
- 10. Spare a thought for the sensory torture neurodivergent people can suffer, including sensory overload through heightened response to light, noise, touch or smell leading to possible extreme emotional reactions. Eating crisps on the train anyone? Noisy conferences/exhibitions?
- 11. Paying closer attention to the strengths of, and challenges for, neurodivergent people can help ensure human talent is not wasted, and make life and work more rewarding for everyone. Almost 80% of Autistic people in the UK are currently unemployed.
- 12. A strong sense of justice combined with the superpowers that can be associated with neurodivergent brains offers great potential to help in the onward evolution of society.
- 13. While neurodiversity is often expressed as everyone being on a spectrum, it might helpfully be seen as 'tapas' a whole table of different things that can be drawn upon in particular ways makes up the experience of the meal each of us have.
- 14. Up until the realisation that you are or might be neurodivergent you may have been feeling like a broken horse, until you meet another zebra and realise you are one too and finding another zebra and being honest about your zebra stripes is amazing.
- 15. If you see someone with a sunflower lanyard they are visually signalling hidden disability.
- 16. The journey through, to, and beyond formal diagnosis is non-linear and can be spikey and there can be great value in finding your tribe of people you can relate to and learn from in terms of brain wiring.
- 17. In some indigenous cultures there is no word for disability. Ask yourself, what is normal and who gets to decide what it is?

# **Setting the scene**

This Fireside Chat was an important opportunity to look inside our minds and at how our brains work, and at what this means for a diverse society in which we each have different talents, and experience different opportunities and challenges.

One of my climate heroes, Greta Thurberg, is autistic or 'living with autism'. **Many well-known people are neurodivergent**. Take a look online for yourself. While never diagnosed, Albert Einstein is one. Elon Musk is another. Greta has referred to her neurodivergence as her superpower.

It seems **there are many neurodivergent people out there making a big impact on society**. There may also be much untapped potential from neurodivergence in a neurotypical society where those who don't fit the typical 'mould' face struggles and discrimination.

I'm on my own personal learning journey with a lot of things and with diagnoses of neurodivergence of family members, I am on a learning journey about neurodiversity.

## Coming to terms with terms

For those who need a primer, let's consider what the difference is between being neurotypical, neurodivergent and neurodiverse.

**Neurodiversity** encompasses us all, its about how our brains work differently affecting how we process information and behave. However, society has not been constructed to adequately accommodate neurodiversity but instead favours certain brain types that have come to be called **neurotypical**.

Social, educational and employment environments tend to favour people who are neurotypical. Some people meanwhile have conditions such as autism, attention deficit hyperactivity disorder (ADHD), dyspraxia, dyslexia and many others and, if diagnosed with one or more of these, they are considered **neurodivergent**.

And there are a lot of neurodivergent people out there - perhaps 1 in 7 or 1 in 5 of us. In a neurotypical-oriented society, neurodivergence can be a strength and/or a weakness.

## **Coming to terms with ourselves**

As I've taken a closer interest in neurodiversity and talked more about it (particularly in the build up to this Fireside Chat and immediately following it), I have begun to wonder about myself. If you watch the Fireside Chat recording or as you read on in this document, particularly if you don't have a diagnosis for neurodivergence, you may find a mental checklist starts to form. **Yep – that sounds familiar. Yep, I do that. Yep, that's me**.

Let me illustrate by drawing upon a <u>blog</u> from Jenny on our Panel in which she lists characterising features of neurodivergent people:

- unlikely to be pulled into group think Yep
- may challenge assumptions; often wants to understand the building blocks to create the bigger picture Yep
- able to assimilate a range of data and process it in a way that communicates a narrative or vision for the rest of the team to get behind and deliver Yep
- creative, resilient, curious, innovative, and strongly justice orientated Yep

Neurodivergence can affect the need for sensory stimulation. Hmmm – heavy metal provides lots of that. Yep. A picture starts to form! Indeed someone I met only a few days ago, who's a

kindred spirit in being a heavy metal fan and who told me he had ADHD, said to me as we got onto discussing neurodiversity "Glenn, after that speech you just gave, there's no way you are not neurodivergent". Likewise Craig on our Panel, following my invitation, very kindly offered an assessment of my traits, ending with "**let's be honest, there's no way you are bog standard neurotypical**". Maybe lots of you knew that already?! His suspicion was AuDHD - he suggested traits of ADHD, tempered by a bit of Autism Spectrum Disorder (ASD).

Boom! Learning about yourself – thanks to the generosity of others in sharing their experiences and insights. **It's good to talk**. But you also need to be prepared for processing what you discover. I had a moment of worry that perhaps the only reason I love Heavy Metal is because of my brain wiring! Emma Woods on our Panel had some simple but important advice for going on a journey of discovery and realisation – "**just be kind to yourself**". My son Robin subsequently gave me the reassurance that **even if knowing some of the magic we think we enjoy is down to brain wiring and so seemingly less magical, if it is hard-wired in it won't be going away**. So my love of Heavy Metal is not in jeopardy - phew!

## **Origins of this Fireside Chat**

Strictly speaking, this Fireside Chat series is about Transport, and the many topics that intersect with it or which are part of it. Our Panel was chosen because they have background in or work in the transport sector. However, as you'll see, **the substance of the discussion in this Fireside Chat was not really about transport**, but it may be helpful to you to appreciate that it has been a discussion amongst people from the sector.

Nevertheless, I have no doubt at all that the transport sector would benefit from paying closer, open-minded, attention to being more inclusive of the diversity of brain wiring that exists. We really need people who can make a big impact on a sector that is all too familiar with doing what it has always done and getting what it has always got.

It was <u>Michael Whittaker</u>, the CILT Cymru Chair - who refers to himself as a "proud dyslexic and dyspraxic" – who, in a conversation with me, gave rise to the idea for this Fireside Chat. In response to my musings over transport futures, Michael said "wouldn't it be good to get a collection of neurodivergents in a room and let them loose on the task!". Well, here we are Michael!

## A couple of quotes

I'll just end these introductory remarks with two quotes.

The first is from Audre Lorde, a civil rights activist, who said "It is not our differences that divide us. It is our inability to recognize, accept, and celebrate those differences."

The second is from Greta Thurberg: "No, autism is not a 'gift'. For most, it is an endless fight against schools, workplaces, and bullies. But, under the right circumstances, given the right adjustments, it CAN be a superpower."

## Hearing from our Panel members



Jenny McLaughlin Inclusion Lead – Solutions at Heathrow

Jenny has worked within the airport industry for over 20 years. She is dyslexic and has ADHD and believes that "the way that my brain is wired differently is an asset". Jenny speaks at industry events on 'systematic inclusion', bringing to life the criticality of accessibility if we are serious about a more equitable society. Jenny advocates that each person should have an equitable seat at the table and creating a safe environment to challenge and improve the way we interreact and build the world around us.

Jenny was diagnosed with dyslexia at primary school and put her subsequent life challenges purely down to the dyslexia. In her 40s, as a result of her son's ADHD diagnosis and her involvement in the post-diagnosis course, **she started to pick out traits she saw in herself**. "It was the facilitator of the course who took me aside at one point and suggested that maybe I want to look into a diagnosis for myself" - which she then got.

She notes staying at Heathrow for so long because of the variety of different roles and challenges she has access to, pointing out that **many with ADHD find that they jump from company to company to find engagement and stimulation**.

Jenny reflected after her ADHD diagnosis on how she would like her children's experience in the workplace to be different to her own. "I can't deny that the beginning of my career and the difficulties I had trying to fit into a box I didn't fit into left me with **some quite considerable unhealthy coping strategies and some areas where my heavy masking caused significant burnout**". She started to look at what things made her feel broken and what things she was excelling at. With a new increased hyperfocus on inclusive design, she is playing a part in addressing how to "meet the needs of the many rather than meeting the needs of the few". She emphasised that everyone has access needs, "it's just that some of us are lucky enough to not have to worry about whether those access needs are met or not and others of us are forced into a scenario where we have to request them". Jenny is working to help **create a more equitable, safe environment that has the bonus of reducing error, increasing performance, and meeting everybody's well-being needs**.

I was keen to hear more about masking from Jenny. She noted that it would be different for different people and experienced differently. Jenny's masking arose, within education and employment, from "being told that I wasn't quite good enough in certain areas, that I needed to speak less, that I needed to be less emotional, that I needed to be able to remember things". Getting better at those things seemed necessary to fit into the box expected of her and so **she masked her challenges to try and offer up the image expected of her**. Meanwhile she wanted to be at her best rather than feeling like she was trying to be someone else and wasting energy doing so. She would go home having been so overwhelmed by sensory activity that she had nothing else to give and could barely prepare a bowl of cornflakes. She had been masking for so long that **it took time and coaching to be able to realise where the mask ended and where she began**.



#### **Craig Drury** *Head of Strategic Forecasting, Department for Transport*

Craig leads a team dedicated to informing the future of transportation through innovative analytical work. He has worked in consultancy, local government, armslength bodies and now central government. Recently, as an unusual 50th birthday present, Craig received an ADHD diagnosis. This revelation has brought new insights into his professional and personal life and has empowered him to embrace his unique strengths and be more transparent about the challenges, fostering a culture of innovation and inclusivity within his team.

Building upon Jenny talking about needing different roles and challenges, Craig pointed to his CV reflecting several different employers and roles. He was diagnosed with ADHD nearly 2 years ago. "I guess I'm still working out what that means for me, because actually it's a complicated journey". He now has a committee role in the DfT which helps to ensure greater diversity and inclusion thinking in the organisation.

Craig wanted to share some of his lived experience and the bumpy ride that can be involved. The first help he got from his employer was to be referred to a dyslexia (not ADHD) specialist. **"I was given good old-fashioned project management and time management training** to do the urgent, important things first", as if his 25 years of experience might not have meant that he already understood well the challenges for himself. **Workplace adjustments are important. Yet they may not be properly understood by those offering them up**. He referred to the importance for him of having a desk to work at in a hotdesking office environment (a point also made later by Emma Woods) and the challenge of having to remember to make desk bookings. His employers, as a workplace adjustment, gave him a desk booked by default for him, to take that task away, but he was then expected to unbook the desk when not needed – one task replaced by another.

Craig recalled massive watershed moments that come once you have been diagnosed that help explain all kinds of things. One example was Craig's struggle as a university student with writing up his final year thesis. He had done all the clever work of the project itself and impressed his professor. He had no motivation to write it up. Thanks to an extension being provided he got it finished, so he thought, by the skin of his teeth. "I've just bound this lovely document in leather with a gold edge down the side. I open the front page and it says 'Abstract' and then it's blank. I mean if I was studying philosophy that might have been okay, but as an engineering graduate probably they were expecting something else!".

Workplace adjustments are hard for those who put them in place who may not themselves properly understand, especially where the person affected may themselves still be struggling to understand and make sense of themselves. **It is about mutual understanding and compromise** in Craig's view. And there are grey areas where systems and protocols may struggle – such as a person with ADHD who really likes to talk and has a slight problem with butting in. On this example Craig went on to explain that "I love writing things in the chat so if you ever get on a Teams meeting with me you will definitely see me chucking my thoughts in the chat because **if you get me to wait my turn I will almost certainly have forgotten**, because you'll have said something really clever that has triggered a thought". He pointed out that the label 'ADHD' (Attention Deficit Hyperactivity Disorder) can be misleading because he is not very hyperactive and has **an excess of, rather than a deficit of, attention**. "The problem is controlling or channelling it. It should be Attention Channelling Disorder".

#### Dr Emma Langman-Maher Associate Director, AECOM



Emma has had multiple roles in different sectors and countries. Perhaps it shouldn't have been such a big a shock to her when she was diagnosed with ADHD last year, as her crazy-paving career path is typical of this brain-wiring. As part of that diagnosis, her autism also became clear. This explained a lot of her struggles, and her strengths. Emma now uses her ADHD to develop big picture, vision work, and her autistic traits to empathise with and support people through change. She is mum and step-mum to 6 youngsters aged 18-12. You can learn more about her from her recent interview with the Women in Transport podcast (here).

As Emma was listening to the panellists before her, she was spotting patterns and drawing threads together, as is her neurodivergent talent. **"My favourite thing in the world to do is to do closing keynote speeches at conferences**". But she went on to explain that this was weird "because according to my autism assessment, **my social anxiety is a score of eight out of 12**". So, while she enjoys applying this talent, the outer character and performance can be accompanied by an inner lack of self-esteem and self-belief.

Emma highlighted that "for many neurodivergent people, we can have quite a crippling sense of shame". She referred back to Craig's desk-booking story and how being told off for not unbooking the desk might be a case in point.

Following her diagnosis came the experience of trying medication. She suddenly discovered she was able to be more organised, which was wonderful. However, "it also made me very angry because **neurotypical people have been playing on cheat mode their whole lives**, as far as I can see". Her medication also helped with Rejection Sensitivity Dysphoria (RSD) – which is like being on the edge of paranoia at times. Imagine then being bullied at school for wearing nappies as a teenager (Emma was born with exstrophy of the bladder) and how that might affect you.

As part of Emma's ADHD assessment last year, aged 47, she was diagnosed with combined ADHD, meaning that she is hyperactive and her **apparent inattention is a product of paying attention to lots of things that she doesn't perhaps need to**. She referred to a Chris Packham documentary and the realisation that "I just thought that's how everyone experienced the world, I just assumed everyone sees every leaf on the tree and I feel kind of a little bit sad that many people miss out on some of that beauty in nature and the patterns that are out there. And **what must it be like to go to a friend's bathroom and not see faces in the bathroom tiles?** - You know so I just thought those were things that happen for everyone".

Her special interest and fascination now concerns how systems, places and processes can be created that allow people to be at their best. "I think it's criminal that human talent gets wasted doing stupid things and I do believe that **joy in work** should be an absolute human right". Emma then further illustrated "I was on a call with a colleague yesterday who said we shouldn't be having this much fun at work, because we were really having a great time; and I believe that we should absolutely be having lots of fun at work and doing our best work".

Emma pointed out how different forms of neurodiversity can mean she finds her brain connects more easily with some forms than with others, which presumably speaks to how across society each of us have a more natural affinity with some people compared to others.

There is a need to recognise the makeup of our talents and our strengths and weaknesses to in turn work with others in a way that we complement one another, rather than being expected to necessarily work on our own weaknesses. This needs to be understood by managers. "One of my colleagues and I were reflecting that quite often I feel like I'm cheating and he's working harder because I'll say some stuff and then he puts it into beautiful PowerPoint slides; and he shared with me that he had felt that he was cheating because all he was doing was taking my stuff and putting it into beautiful PowerPoint slides". The challenge, as Emma went on to explain, was for neurodivergent people to articulate what adjustments they need to maximise their strengths and accommodate their weaknesses. Sometimes, said Emma, "I've tried to explain but trying to explain why it's difficult is in itself difficult and quite often I feel like I spend my whole life in like a second or third language and I'm constantly translating for other people".

Emma spoke in a very moving way about vulnerability. She indicated that about 72% of autistic people in the UK are unemployed and autistic women have about a 13 times higher rate of suicide than other people. "Certainly I have struggled an awful lot with mental illness and things throughout my life, and I stay because I have children and they need me to be their mum; that's the main thing. But also, because I feel like if I can be me then other people can be them, then that's better for everybody so that's very important.

Emma pointed out how over time she has found herself in a space she is really good at. "It's a bit like someone with a stutter becoming a phenomenal keynote speaker". She has become really good at observing groups, understanding interactions and creating safe places for people to be. "So, my buzz is doing transformational work". **One of her autistic traits is super empathy**. She has a great sense of how people are feeling in a room and is able to identify what to put in place to make things work better for them. "So, in my change projects I don't have resistance to change – I don't think that creating resistance to change is a necessary step". **The culmination of Emma's own struggles and strengths is that she can deliver elegant, very human transformational change in organisations**.

Emma's touching insights helped me join a couple of dots in my own head about something we used to say to describe my wonderful son Robin when he was at infant school staring out the window in class – "he's got stars in his eyes and frogs in his pockets". The power of listening to others and their willingness to share and how that can unlock things in our own minds.

I was struck by Emma's ability to make sense of herself and of others around her. I'm not sure all of us are so good at that, and some seem distinctly lacking in this respect. She responded with the following. "One of the reasons I find eye contact quite demanding is because you can see in a person's eyes quite a lot of what they've been through and what they're going through now". She pointed to this experience when coming out of the Underground on the escalator: "I'll just look at some people's eyes as they go past and I can like, I can fall into their eyes by mistake". Demonstrating her super empathy she said, "I have had bullies and things like that and I don't hold anything against any of those people because I think that they must have just been going through their own stuff". "The other thing is I spent a lot of time in hospital and if you spend time in hospital there's always somebody a lot worse off than you are and somebody who's not as badly off as you are so I learned not to compare, and that's really important, but just to be just to be kind and just be present and hold space for people, that's very important." It struck me that Emma's superpowers come with a huge amount of weight to bear.



Emma Woods Founder of Flourish Economics

Former Government economist turned renegade, Emma stepped off the traditional career ladder 18 months ago to set up Flourish Economics, seeking to democratise economic thinking through radical economics education. This comes after a period of unlearning mainstream economics, unmasking after a mid-life ADHD diagnosis, and seeing the world through a different lens since becoming a parent. Emma's blog explores a series of ideas and deep and sometimes uncomfortable questions.

By the time we got to Emma, she had filled an A3 piece of paper with a mind-map of notes. Emma highlighted how in her last 'formal' job people were wowed by these, yet she just thought that was a normal thing to do. She also highlighted to the audience her **lovely fidget toy to help keep her on task**.

Following her diagnosis at the age of 34 **she feels she is still unravelling herself, reflecting on the slow process of understanding**. She was reminded of a book on neurodiversity she read a few years ago that left her thinking "this sort of sounds a bit like me", before such thinking going away. It came back when she started working with someone who was neurodiverse and who kept sharing memes on Instagram.

Emma gave an example of "just classic ADHD stuff" describing how she has episodes of feeling manic when she takes on too much. "I've taken on so much the past few weeks and I just feel kind of overwhelmed because **I'd not prepared for this [Fireside Chat], you know** rather than preparing for this I was making a dress last night until 1:00 in the morning", which her husband understood was part of who she is and how her brain works.

She described her move from a full-time salary job into self-employment as "simultaneously very liberating but also terrifying". Part of the liberation is not feeling constrained by an organisation. "I have a very strong sense of justice and if we were doing things at work that didn't fit quite, you know didn't sit well with me, I would find it really hard to bite my tongue and be like, 'do I have to do this, do I have to toe the party line?'". Emma noted also that she always had a reputation in the transport sector for asking the hard, challenging questions. In her current business she is finding it liberating to cast a critical lens over different facets of our economic system and society.

At this point I was moved again by the sense of learning from each other by sharing our understandings of ourselves. I was also minded to share the example of my resident troll on LinkedIn who, true to form, when I'd put up a promotional post about this Fireside Chat had replied "it's called LIFE, get over it". Maybe lacking in empathy or just trying to get a rise, who knows? But a reminder too perhaps of **the need for much more progress still to be made to bring our differences into the light and to better understand, support and celebrate them**.

I wanted to revisit a point Emma had made in conversation with me about the frustration with job interviews. She was reminded, she then said, of how people can be referred to as very professional according to their online profile and yet be someone who wears their pyjamas most of the time when working might not be seen as professional. (Emma had found the

meme shown to the right online). Jenny had earlier referred to part of the conformity challenge being to dress appropriately for work when she had no natural sense of how. "Professionalism being linked to outward appearance, it sort of just makes me cringe a bit because it's like you know I could be brilliant for the job but I'm just not fitting that mould that society is kind of demanding" said Emma. Naturally I was thinking of the liberating feeling I'm currently having of wearing a metal tshirt and jeans for most of my professional appearances!

This linked to how Emma saw interviews as a kind of game. Candidates are asked to jump through particular



Me reading the email:



hoops that can automatically exclude people with disabilities. The sorts of hoops designed to put people under pressure. "Is this real? Is this necessary for the job? Why do we want to stress people out? Surely we want the best out of them?". When Emma is on the interview panel, she takes a different approach. "When I start these interviews, often online, I say my job actually is to get the best out of you, I don't want you to fall apart and feel stressed, I don't want this to be a horrible experience". Surely this is part of reflecting the type of organisation on offer to the interviewee?

I also reflected on the alarming notion of artificial intelligence being tasked with doing the initial sifting of applications for a job with – perhaps – a strong bias towards neurotypical based upon its training data. As Emma Langman-Maher put it, "**My CV is too wobbly for AI to sift**".



#### Bonnie Price CEO, Young Rail Professionals

Bonnie has dedicated her career to empowering the next generation of rail professionals and promoting the importance of neurodiversity within the workplace. In her late 20s, Bonnie received a diagnosis of ADHD, a pivotal moment that reshaped her understanding of herself and her professional journey. Under her leadership, YRP has launched programs aimed at raising awareness about neurodiversity, providing resources, and fostering a culture of understanding and acceptance among peers.

Unfortunately, our Panel discussion on the day missed the opportunity to have the wonderful Bonnie as part of it due to technical problems. However, you can look up Bonnie on <u>LinkedIn</u> or read up on a series of articles about diversity and inclusion from <u>Young Rail Professionals</u>.

# **Continuing the conversation**

## **Chillies or tapas?**

The phrase 'we're all on a spectrum' is often used in relation to neurodiversity. Sometimes the term neuro-spicy is used in relation to someone's neurodivergence. In our Fireside Chat audience, mention was made of the distinction between a spectrum and a constellation. Meanwhile, Craig wanted to make **the distinction between chillies and tapas**.

The notion of a spectrum wrongly gave Craig a sense previously of a continuous line image of something ranging from really bad to not so bad – lots of chillies to few or no chillies. Now he has moved on to tapas. **"This is a tapas. You've got a whole table full of different things...it's a series of different traits that are at different levels**". I loved this notion of tapas because it's typically something that is diverse and to be shared in an inclusive way. It is also important to note comorbidity – the simultaneous presence of two or more conditions.

#### Broken horse or zebra?

Wondering what that image at the front of the document is all about? Well, it is what I got when I asked Co-pilot to create a black and white sketch based on something Jenny mentioned in the Fireside Chat.

She explained one of the best metaphors she had come across when being on that journey of finding out that you're neurodivergent. "  ${\bf Up}$ 



until that point you feel like you're a broken horse and it isn't until you find another zebra that you realize actually you're a zebra not a broken horse". As Jenny had listened to Emma talking about her fidget toy, it resonated with her as she was desperately trying keep her top half still in the Fireside Chat as her legs were jiggling around because she had forgotten her fidget spinner. "Finding other zebras and being honest about your zebra stripes is amazing".

#### **Spoon Theory**

Jenny gave a wonderful example of better understanding the transport system and its use through an appreciation of 'Spoon Theory'. In essence (thanks <u>Wikipedia</u>) **Spoon Theory is the idea of visually representing (with spoons) units of physical and mental energy we start with at the beginning of a day or week**. Each activity or task we undertake (physically or mentally) requires some number of spoons, which can only be replaced when we recharge through rest. **If you run out of spoons you have no choice but to rest and restore**. But that may not be easy. And energy demands can be much higher for neurodivergent people.

Jenny explained as follows. "When you're looking at me getting up in the morning and getting dressed and having to think how do I dress today to make sure I'm fitting this whatever I need to fit, and I need to have my breakfast but I've forgotten to buy the milk, and all of these things mean another spoon gone, right. And then I have to interact with the transport system in order to get me to work. Now that's the difference between losing one spoon before I get to work or 10 spoons depending on how that transport system is designed. And that can be a massive barrier to how you live your day, how you how you do at school". She goes on to underline that the transport system: "is one of the biggest barriers to people even being able to work which is why so many people prefer working from home to being in the office". She also points out something raised by Michael Whittaker, namely that neurodivergent people can act as the canaries in the coal mine, exposed to and affected by problems that offer an early warning system for wider society (see Further resource section too).

#### Understanding the building blocks and seeing the bigger picture

Jenny has proved to be a real asset in looking at the de-icing process at Heathrow which is critical to avoiding operational bottlenecks in winter. Her strength in bringing about changes at the airport with this has been **being able to see the big picture (by making sense of all the component parts in the system) while also understanding the building blocks, and then providing accessible narrative about this to help others come on board with addressing the de-icing challenge. She was able to empathise with and understand the ground handlers for example, could understand operational nuances, and could consider how different** 

stakeholders would be affected by changes alongside the importance of making sure they were all heard. "That's what I think those who think differently and experience the world differently have to be able to bring to the party". Such skills will be needed in future as society needs to innovate and evolve in the face of the challenges and opportunities it faces.

As I listened to the richness of insights from our Panel, I wondered whether our audience included (or might in future include, in terms of those watching the recording or reading this article) people who were themselves team leaders and recruiters. We need them to be able to effectively address neurodiversity in the workplace. Michael Whittaker in our audience had asked "if you got stuck in a lift with a bunch of HR directors in transport, what would you say to them?". While it wasn't discussed in the Fireside Chat, Emma Langman-Maher (who in 2024 was recognised by HR Magazine as one of the UK's Top HR Thinkers, related to her work on transforming work spaces for neurodiverse people) responded in our panel chat bar as follows. "I would ask that when people disclose a disability (which, for me, this is) that the conversation about adjustments starts straight away!"

#### **Sensory torture**

As Google about neurodivergence and sensory stimulation and the AI Overview reads as follows:

Neurodivergent people often have heightened or reduced responses to sensory stimuli, such as light, noise, touch, or smell. This can lead to sensory overload, which can cause: feeling extremely emotional, stressed, overwhelmed, or exhausted; and difficulty talking or interacting with others.

Emma Langman-Maher provided some of her own commentary on this. "I'm glad that things like my great big headphones are now considered pretty much socially normal ... I wear those all the time if I'm travelling in public transport pretty much". She described the sensory nightmare of a company event, and the maddening smells on the London Underground along with the sounds of her coat sleeves running against her coat. Emma explained that the biggest issue for her on public transport was misophonia. **Oxford Health Foundation Trust** explains this as follows: "**Misophonia is an extreme emotional reaction to certain everyday sounds that most people would find relatively easy to ignore**. The three main types of sounds that disturb people with misophonia are eating, nose and throat sounds, and repetitive environmental sounds like keyboard tapping and rustling paper".

Emma recounted her recent torture of two days prior to the Fireside Chat. "A lady got on the train opposite me and sat there with a big shopping bag with a packet of crisps inside the shopping bag so not only could I hear the crisps coming out the packet but the packet rustling inside the bag and they were smelly, they were probably like beef flavoured ones and she was crunching them...it just made me so cross and I'd wanted to get some work done and I just couldn't get the work done **because it was taking everything that I had to not just say** 'why are you such an unreasonable human being?' and yet obviously I recognise that eating a packet of crisps on a train probably isn't considered a crime against humanity". Emma concluded: "let's just say I can understand why throughout my life people have described me as controlling because it's better than hurting people".

#### **Event organisers pay attention**

Craig and I a little while ago had been in conversation with <u>Tom van Vuren</u>, <u>Stephen Cragg</u> and <u>Robin Cambery</u>. We found ourselves discussing transport conferences and whether they catered for neurodivergent people. Craig referred to one of his favourite conferences – the European Transport Conference – which is a three-day event. **"Even for neurotypical people**  by the end they've had enough; and for that event I was suggesting maybe you have a quiet Carriage a quiet room". Craig feels this is especially important to cater for some of the really clever people in the world of transport modelling "most of my kind of analytically astute colleagues who I'd really want to go to these kind of events kind of go 'oh no, I'm not going, that overload is just beyond real".

Let's hope some of the conference organisers out there are taking note.

#### Little coping strategies

Building upon reference to fidget toys by Emma Woods and Jennifer, Craig highlighted the importance of finding coping strategies. He gave the example of the challenge of being on the train with all his pockets and bag compartments and not being able to find his train ticket for the inspector. Would they start to conclude he was a fare-dodger? Craig's solution – to **carry a hidden disabilities** 



sunflower lanyard with you as a signpost to others (for more information visit <u>https://hdsunflower.com/</u>) and also keep his train ticket in a leather display wallet.

### Getting a diagnosis for neurodivergence and 'coming out'

Emma Woods offered some insights into whether and how to get a formal diagnosis for neurodivergence, faced also with the experience of 'coming out'. She began by referring to the sense of 'spikiness' where you might get a sense of possibly being neurodivergent, getting comfortable with the idea, and then something happening that pokes a bit too hard. Indeed Jenny indicated that the internal stigma can be the first barrier. Emma doesn't consider the process of self-discovery and (formal) diagnosis is linear. "I don't think there's this point where you suddenly go 'yeah I'm going to go to the doctors and they're going to give me this diagnosis', because the other challenge is the waiting lists and you don't know what reception you might get from your GP". Emma also warned of the prospect of long waiting lists and pointed people to Psychiatry UK and the 'right to choose' – details can be found <u>here</u>. She reflected on the added challenges to the process to go through because she had the benefit of having someone guide her as well as Emma being a 'form lover'. She still had a 12-18 month wait. Then there can be waiting lists for medication.

Her suggestion was to consider alternative (prior) routes such as **finding a community group to talk informally with**. "That is one step towards getting into the community, feeling a bit more you're in a bit of a safer space, you're able to share these things, it's all the people that kind of get it. So reach out to them, hear their experiences and just see if you're ready".

Emma Langman-Maher added the caution that undiagnosed neurodivergence can sometimes lead to being wrongly put on medication based on assumptions that other mental health issues are the cause.

#### Finding your tribe

An audience member asked if there were any networks for neurodivergent people in the transport sector. There is a <u>network</u> focused on neurodiversity in planning. The Panel did not identify a sector-wide network for transport but pointed, for example, to there being a neurodiversity in rail group, and more generally to there being Facebook groups. What Emma Woods did note in our Panel chat bar however, echoed by other Panel members, was that **"finding your "tribe" can be really powerful and supportive, I've definitely found that**".

Jenny had previously explained to me that **neurodivergent people tend to be magnets for other neurodivergent people**. So perhaps tribes to some extent naturally form. I'm wondering again about heavy metal! Jenny built upon this in the Fireside Chat. As Emma Langman-Maher had alluded to, "it takes less energy when you're talking to somebody who can mirror your brain activity, your way of processing, your communication style; and so you probably do know those people that you will gravitate towards or come away feeling energised after speaking to them".

Craig added to this explaining how he tends to put people into three camps. "There are those people who I just talk to and they understand what I mean and they're brilliant. Slightly better than that for me is **the people who not only do I talk to they understand it straight away, but they can then put the thing into words so I can then tell a neurotypical person the thing. They are my absolute go-to heroes and I love them**. And then there's the neurotypical ones where I have to go uhh, okay, I'm going to start by I need to explain that this is always linked with this I don't care if it's written down anywhere but it just is."

## **Closing remarks**

Our Panel members each gave some parting thoughts.

Emma Langman-Maher drew attention to the reciprocation of challenge between neurodivergent and neurotypical people. "A huge thanks to people who for whom this doesn't resonate for having sat through what to you must seem completely wild and weird and unstructured and difficult. And **please understand that that experience that you have is what we have most of the rest of the time, so if you're feeling a little bit tired you can understand why we do**". Emma also highlighted the importance of hearts and minds – support for neurodivergent people to understand how their minds work, and care and love for neurodivergent people and wanting the very best for them.

Craig was pleased to be having the conversation and raising awareness. And also wanted to highlighted the suggestion that '**evolution needs us**'.

Emma Woods is **keen to better understand neurotypical brains**. "I can't kind of get my head around what a neurotypical brain would look like, so if there is anybody watching this that thinks 'no I'm definitely in that neurotypical camp' you know I'd really like to talk to you and understand what the differences are." She also built upon Craig's point above on evolution and reflected on something she had recently seen on LinkedIn. "In some indigenous cultures there is no word for disability, there is no kind of understanding of this neurodiversity, there's just an understanding that you think differently and whatever you offer the tribe is a beautiful kind of gift, and that was quite profound for me". She wanted to leave the audience with the question of what is normal and who gets to decide what normal is?

Jenny wanted to go down the pub immediately to continue the conversation. I could relate to that strong sense of there being more to discuss. Her reflection was that "we all experience process, think, move, act differently. And then we all have a responsibility to anticipate that". This is important to help take away the stigma of difference.

For myself, I found in my head what for me was an awful Fox News clip I had watched on social media that involved the author of a book called 'Go Woke, Go Broke', reflective of the backlash against equality, diversity and inclusion in parts of corporate America. Our Fireside Chat had been stark reminder of a need for the opposite. Firstly because this matters - we're all humans and different, with a need for open minds, some humility and empathy. Secondly, because **it feels like evolution needs neurodivergence like never before**.

## **Further resources**

Our Panel members have also been a wonderful source of suggestions for where to look for further insight and support. Here are some further resources.

**Books** (try finding them on World of Books, Abebooks or Hive as an environmentally friendly alternative to Amazon):

- The Canary Code: A Guide to Neurodiversity, Dignity, and Intersectional Belonging at Work by Ludmila Praslova (listen to a podcast with the author <u>here</u>; read her <u>LinkedIn</u> <u>article</u>)
- The Neurodiversity Edge: The Essential Guide to Embracing Autism, ADHD, Dyslexia, and Other Neurological Differences for Any Organization by Maureen Dunne (watch a reel concerning the author here)
- Living Sensationally: Understanding your senses by Winnie Dunn
- Rebel Ideas: The power of diverse thinking by Matthew Syed
- Neurodiversity at Work: Drive Innovation, Performance and Productivity with a Neurodiverse Workforce by Amanda Kirby and Theo Smith
- ADHD an A-Z: Figuring it out step by step by Leanne Meskell
- ADHD Works at Work by Leanne Meskell (see Craig's LinkedIn article about the book)
- ADHD 2.0: New Science and Essential Strategies for Thriving with Distraction--from Childhood Through Adulthood by Edward M. Hallowell
- Understanding ADHD in Girls and Women by Joanne Steer
- Untypical: How the world isn't built for autistic people and what we should all do about it by Pete Wharmby
- This is Dyslexia: The Definitive Guide to the Untapped Power of Dyslexic Thinking and Its Vital Role in Our Future by Kate Griggs
- Empire of Normality: Neurodiversity and Capitalism by Robert Chapman

#### Videos / podcasts:

- How conversation can help change the world (featuring Helen Needham "Embracing Neurodiversity today, can help companies succeed in the new world tomorrow")
- Failing at Normal: An ADHD Success Story (featuring Jessica McCabe)
- Engineering Council <u>Guidance note on supporting neurodivergent applicants</u> (featuring <u>Professor Amanda Kirby</u>)
- <u>The ADHD Adults Podcast</u> covers ADHD in adults, sharing evidence-based information and personal experiences

#### **Research and reports**

 Design for the Mind. Neurodiversity & the Built Environment - PAS 6463 – "provides guidance on the design of the built environment for a neurodiverse society, to make places more inclusive for everyone"

- <u>Neurodivergent Tests | Neurodivergent Screening | Do-IT Profiler</u> this tool can be helpful, if you want to understand what your spiky profile is, and where you strengths and challengers are, for a starter for ten
- Adult ADHD Self-Report Scale (ASRS-v1.1) Symptom Checklist
- <u>ADHD Foundation The Neurodiversity Charity</u> services for adults (resources and support)
- Paradoxical career strengths and successes of ADHD adults: an evolving narrative lay summary, on LinkedIn
- <u>Streets for Diversity Exploring how neurodivergent people experience streets</u> a report from the Royal College of Art
- <u>The Value of Dyslexia Dyslexic capability and organisations of the future</u> report by Made by Dyslexia and EY
- <u>https://staringbackatme.org.uk/</u> women with ADHD campaign
- British Dyslexia Association downloadable resources