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## **Together, we are all kinds of minds**

*A group of neurodiverse occupational therapists talk to OTnews about how they experience the world around them*

As a group of seven people, we embody a wide range of diversity (both neuro and otherwise). Each of us has a unique profile of skills, interests, abilities, disabilities, difficulties, strengths, challenges, and lived experience of occupation.

We all identify as neurodivergent; as people with diverse ways of thinking and perceiving, due to our different wiring, and we all have a broad and inclusive approach to neurodiversity. It is estimated that approximately one in seven people are neurodivergent, meaning that their brains function, learn, and process information in different ways to their neurotypical counterparts (ACAS 2019).

Neurodivergence can either be genetic and innate (such as autism and dyslexia), occur as a result of a brain-altering experience (such as trauma), or be a combination of the two (Walker 2014). It includes cognitive and behavioural divergences, whereby a person's neurocognitive functioning diverges from dominant societal standards of normal.

These differences and divergences include relatively well known diagnostic labels such as autism, attention deficit disorders, dyscalculia, dyslexia, dyspraxia, epilepsy, and Tourette syndrome. It also includes other neurological differences resulting from affected brain development.

However the concept of neurodiversity is not without controversy, particularly in regards to its defining features. The term has increasingly come to be associated most strongly with autism spectrum disorders, and some commentators suggest that medical conditions (such as epilepsy) should be excluded.

### **Our experiences**

Neurodiversity challenges the idea that there is one normal or healthy neurotype. With its origins in the Autistic Rights Movement, the Neurodiversity Movement recognises that neurological differences need to be recognised, accepted and respected like all other human variations, and not be pathologised.

As a group, our neurodiversity means that, while we share some similarities, we also have unique subjective experiences of occupation, and of life. Common amongst us is the shared experience of environments, including work, in which acknowledgement or support of our neurodiversity has been limited or, at times, non-existent.

Rebecca Twinley, senior lecturer in occupational therapy at the University of Brighton received the official diagnosis that she is autistic on 29 October 2019. Rebecca took to Twitter and shared about receiving her diagnosis and was immediately met with support and comments that offered her further insight and revelations.

As a late diagnosed person, Rebecca says she shares some experiences of other late-diagnosed autistic women, such as the costs of masking (which involves camouflaging or compensating for difficulties), difficulty maintaining relationships, being misunderstood in the working environment, and being sexually victimised (Bargiela, Steward and Mandy 2016).

‘Feeling somewhat liberated from this mask, I was keen to share my experience and to involve others in this venture.’

Collaborating with six others to share their individual narratives, Rebecca says that ‘at its heart is the understanding that neurodivergent people are everywhere’.

She says: ‘These narratives of our daily lives are intended to describe the lived experiences of neurodiverse occupational therapists, as insiders in the worlds of both occupational therapy and disability’.

‘Our narratives are informed by both our lived experience (as them) and our professional training and socialisation (as us). The extent to which we, as a group of individuals, feel we fit in, belong, are accepted, understood, or even are open about our neurodivergency differs. Indeed, many of us have learnt to blend in or to mask and some of us have been misunderstood or misperceived’.

‘We have chosen to state our neurotypes for the purpose of navigating the reader to our individual forms of wiring, while being aware this may be perceived as undermining the neurodiverse principle of being more than our disability’.

Rebecca’s neurotype is autistic and post-traumatic stress disorder (PTSD). She has insomnia, often waking in the early hours and never getting back to sleep - a result of sleeping to an imposed pattern.

‘I tend to go over any conversations from the day; like a check to make sure I didn’t say the wrong thing,’ she says. ‘Often I lay in a high state of anxiety – worrying about everything possible.’

Rebecca has auditory sensitivities to certain frequencies, loud noises, and combined sounds; she masks the car heater sound by turning the music volume up ‘It doesn’t cause pain, but it feels like an intrusion in my ears,’ she says. ‘My hearing is definitely a sense that is turned up too high.’

When it comes to work, Rebecca is in the office by 8am, 'then I can be confident my usual parking space will be free, and there aren't many people about'. She adds: 'In my previous job, I kept getting thrown because the usual car park was closed for repairs, so my space was less predictable, which caused a palpable sense of anxiety.'

As the first person in, this means Rebecca can set the lighting - 'so I am not directly under the invasive fluorescent LED ceiling lights' and she aims for 'as dark as possible' by switching desk lamps on.

'My colleagues seem to not mind,' she says. 'A previous colleague used to come in, switching all the lights on. Each time I was momentarily debilitated, and then it completely distracted me. It can feel like wanting to press a refresh button and hope the over-stimulating light disappears...'

'My office flooring is the worst type of carpet for me. It is a Nylon or Polypropylene and it can make me feel very itchy. When I am very sensitive – usually when extremely tired – I can hear it. If people walk on it or, worse, roll their office chair across it, I can hear an electric crackling sound.'

'My GP asked how I "coped" with working as an occupational therapist or, now, as a lecturer. I tried to explain these roles are well defined, have pre-set rules, boundaries, and expectations. The challenging part is when the floor opens for discussion. Conferences are particularly overwhelming and exhausting, with the sounds, lights, and audience questions. Even when talking about a topic I know well, I fear these unstructured moments.'

'This is compounded by my awareness that I have unreliable auditory processing. When noticed, people (including those close to me) have thought I was ignoring them or was not interested in what they were saying... I have learnt to try to listen for the important points while a person talks to me, but I'm often reminded of the content I lose when another person was listening to the same conversation and we discuss it together afterwards.'

Danielle Hitch, senior lecturer in occupational therapy, Deakin University in Australia, has attention deficit disorder and epilepsy. While the early moments of a day are 'peaceful and calm', she explains that 'after about 20 seconds my brain roars into life'.

'My thoughts quickly accelerate, multiply, tumble over each other - they say having ADHD is like being driven by an engine; sometimes I am in the driving seat, but sometimes my brain drives me.' She says of a typical day: 'I need at least an hour to have a shower, get dressed, and eat breakfast - about 25 per cent of that time I'm doing those things and the rest of the time I'm wandering aimlessly, twisting my already curly hair, getting lost on the internet, or looking for the many things I lose every day.'

'My drive to work is filled with music, played at high volume and frequently shuffled partway through the song. I work in a small office with four other people, and it's an extremely challenging environment for a brain like mine.'

'My current colleagues know I have ADHD and are supportive, but in the past, I've had colleagues try to have me removed from my job, because they thought my epilepsy (well controlled) was a risk.'

'They even said: 'It's such a shame because you are actually quite a good occupational therapist''. Does being anything other than neurotypical mean you can't also be a good occupational therapist? So I don't tell everyone about my different wiring.'

For Danielle, email is both her nemesis ('the notification that an email is waiting is too tempting to ignore') and her best friend ('severe auditory processing issues make phone conversations really difficult to participate in').

'Being a researcher has many advantages, as you are largely mistress of your own time,' she reflects. 'I never write lists unless I'm feeling very overwhelmed (even though everyone treating people with ADHD suggests this).

'People assume that medication for ADHD solves everything, but I am still left with significant hyperactivity (which I actually love), variable self-regulation (which can be exhausting) and absolutely no internal sense of time (which screws up any attempt at time management).

'I know I get much less done in the afternoons - the medication is starting to wash out of my system, and I can't sustain paying attention and sitting still for a whole day. However, this is the time of the day when I feel most like me and I get my best ideas.

'So I use this time for creativity. At home time I do my little ritual of tidying my desk to help me transition from work to home. But it's just a change of location - work is in the whirlwind of my thoughts all the time, emerging from the background of family, friends and life ideas at all hours of the day. And that's OK - occupation is everywhere.'

Bill Wong's neurotype is Autism Spectrum Disorder (Asperger's Syndrome). He reflects that 'unless he needs to do something important', he doesn't have an alarm in the mornings, and wakes anywhere between 6.30am to 8am.

'Having this flexible schedule helps me, because I do not have to be worried about being on time to work,' he says. 'There are days where I don't have a sense of time and knowing that I can come as late as noon for an eight hour day reduces the panic I have if I feel I have a slow morning.

'At work, I might have been told something the evening before. However, things can change by the morning - like co-workers calling in sick, or patients getting discharged or admitted overnight. So, I can't really plan for my next day.'

Music on the drive to work helps Bill with marking the transition time to and from work, he says.

'But mostly because working in a nursing home setting can be depressing - knowing that some

patients will never return to their homes, seeing some decline with my very eyes over time, and frustration about lack of progress sometimes made.'

At work, Bill has to deal with intensive sensory input in the setting sometimes. 'It can be the smell of faeces, hands with skin integrity issues, diapers – all of which usually make me want to leave the room so as to avoid the sensory disturbances,' he explains.

'It can also be unexpected fire alarms. It can be fluorescent lighting. It can be smoke when going through smoking areas. These experiences made me think - do I think autistic individuals want to live in this setting when they grow older?'

For Michelle Perryman-Fox, an occupational therapist and PhD candidate at the University of Cumbria living with attention deficit disorder and dyspraxia, medication has a huge impact on her day in terms of regulation.

'Today I am on the other side of a hyper-focus,' she says. 'I took my meds wrong yesterday; I took my morning meds in the afternoon and my afternoon meds in the morning. The life of living with ADHD and dyspraxia. Lost in time, place, and space.'

She adds: 'The impact this has on my following day really depends on how I can hide my symptoms. If I am around people I am close to, they ask me what's wrong, but if I am not, I fall into a shell of trying my best to make it through without offending anyone with my nonchalant exhausted way.'

'My main challenge of making it through is that I do not share my condition, unless it's for a teaching moment with my students. I find people define me through it, over the confident sociable and outgoing person that I am.'

'I never blame it, because it's me, but I am aware of it, oh so aware, and I reflect, learn, and take responsibility for how it impacts my daily function.'

Michelle uses coping strategies to avoid the overstimulation. 'I don't drink coffee, I maintain regular exercise and I make sure that I have my safe zone to enter when I'm feeling exhausted. My safe zone could be a person (and it is typically) who I feel I can be myself with, and who is accepting of my ways, or it is simply, Netflix, which provides distraction and a continued structure to see my world.'

Despite the impact on her daily function, Michelle's condition enables her to be creative. 'I become frustrated at the unwanted inattention to my tasks. Yet, that inattention enables me to think outside of the box, make wider connections and see the world very differently.'

'At times, this is a blessing, especially with my research, and if I am in a hyper-focus it is so effective, but also scary, because I do become lost in time, and at the other end, I really don't know what happened in that time zone or space when concentrating on something that is fascinating and challenging.'

Diana Sheridan, a dementia specialist occupational therapist, was diagnosed as dyspraxic three years ago. Having also had a bilateral hearing impairment since age four, she experiences debilitating episodes of anxiety & depression which impact on attention & concentration.

A recent audiology appointment illustrates this perfectly. 'Anxiety makes me doubt all the preparation I've done the night before,' she says. 'I have the nagging doubt that I am not actually appropriately prepared.'

'Yet again I go through everything I prepared the night before and anxiety makes me repeat the checklist: bag, purse, glass/hearing aid cases, door and car keys, mobile phone.'



'Despite giving myself plenty of time (which seems to slow down and speed up with confusing irregularity), parking is an issue, making me late for my appointment.

'I get through the appointment with a new audiologist, whose manner makes it difficult for me to judge if he is a jokey sort or otherwise. Anxiety makes me doubt my judgement about others and I don't trust my ability to read non-verbal body language.

'I'm told I need two hearing aids, not just the one that I have spent most of my 50 years of life adjusting to wearing. I feel deflated, shocked, fearful of the ageing process, and I'm already anticipating more difficulty communicating at even a basic level.'

She adds: 'I want to retreat to the safety of home, but try to re-focus on practical things; tea and biscuits to collect and calm my thoughts.'

Diana's manager supported her in getting a dyspraxia diagnosis three years ago, however she admits that she has been in denial since that initial diagnosis.

'Living with several conditions has impacted significantly on my mental health; accepting, later in life, that I have a disability and justifying the need for help has resulted in feelings of isolation and imposter syndrome.

'Practically, it has necessitated significant time off due to depressive episodes, and menopause has exacerbated the impact. I wonder if I will ever get back to feeling me again and not expending so much energy just to focus and get through each day, which sometimes feels like trying to see a beacon through fog, whilst wading through treacle.'

Sarah Selvaggi Hernandez, autistic advocate and an occupational therapist in the US, is autistic and says that she is 'finally learning to navigate the diverse landscape of my neurology'.

Reflecting on a recent experience, she says: 'We are a therapeutic foster home that specifically supports neurodiverse children. A few days ago, two young, non-speaking autistic sisters came to stay with us for as long as they and their family needs.'

'I have never washed, conditioned, and combed through a little Black girl's curly hair. I have watched YouTube videos, talked to my Black friends, reached out to my community, and spent the last few days touching their hair gently to acclimatise my new little friends to my touch.'

'Their hair needs significant attention and I am committed to doing so in the most compassionate way possible. With soft words and warm water, we are successful and we get them dressed for a visit that, during bath time, had been cancelled.'

'Mindfulness pairs well with my sensory practices; I mentally scan my body to give gentleness awareness to the signs of my stressed neurology... to some, it seems as though I am staring into nothing when I am internally channelling chants of healing pressure with every deep and steady breath.'

Sarah is in the third month of recovery after 'a massive shutdown', where she could barely find the executive function to shower, but acts of self care ('a lunch date with my son, prescription refills, a movie date with my daughter, delicious meals, and snuggles with my foster children') are all important.

'My heart tells me that my soul is emerging once again from its protective cocoon and I am grateful not only for the existential awakening, but the knowledge that the withdrawal was equally therapeutic and necessary.'

Clare Keogh, an occupational therapist in Melbourne, Australia says her neurotype is Dandy-Walker Syndrome, Agenesis of the Corpus Callosum, and autism. She explains that, on a day-to-day basis, she is constantly classifying her days in her head: is today usual or different?

'Social media is one of the ways I chill out when my brain needs a break, or to wake up slowly, so checking it in bed has become a routine for the start of most non-workdays... I'm a planner; it's a coping mechanism. I'm learning to plan for two scenarios if I know there's potential for stuff to go wrong or change. I don't like it when I can't follow my own plan or when someone or something changes it without warning.

'I'm reliant on public transport and walking, as I'm working towards my license, using specialised driver training lessons. I hate being late, but I frequently am. I story-tell as I walk along, muttering under my breath as I create fanfic. I've done this since I was a little kid; it's very soothing and particularly useful if my anxiety-brain is trying to ruminate on something.'

Clare wears her sunglasses outside, due to the intense sunlight, and her noise-cancelling headphones inside and out to dampen the sounds and filter others' conversations, so that she can focus on one conversation at a time.

For Clare, being a part of her local community is very important to her. Participation in her work and local church and choir give her meaningful opportunities to contribute, often in ways that make her feel seen and loved. Especially when it comes to one of her passions, music. 'Music – performing and listening to it – is a big, big, big, big occupation of mine. It's part of who I am and something that gives me a lot of pleasure.'

Music gives Clare 'that happy stimmy feeling of where the emotion feels too big to be contained by feeling/ acknowledging it in my body. I have to express it somehow. Frequently this is through bouncing, shaking, flapping, jumping, pacing, facial expression and vocalisations.'

### **Our shared experiences**

These narratives tell of the similarities and the differences in our subjective experiences, and how contexts influence these. The insights into our respective lives show how what we - the person -

bring to the context and our subjective experience of occupations does alter, depending on such an array of factors.

That is, features such as our skills, knowledge, experience, self-concept, backgrounds, personality, physical status, cognition, health, and sensory processing status are certainly dependent and affected by our occupations and the environment.

### **The role of necessary distractions and occupations**

As a group, we value our occupations for the multitude of benefits they can afford, ranging from the implicit (such as providing a sense of respite, reflection, and spirituality) to the explicit (such as economic gain, productivity, and upholding our human rights).

For many of us, occupations that mitigate the impact of other occupations are necessary. Rebecca and Bill mention their use of music and Michelle her use of Netflix for the intended purpose of providing a necessary distraction.

Other occupations are necessary for reasons such as self-regulation (Sarah uses mindfulness, Michelle regularly exercises, and Diana's consumption of tea and biscuits), self-soothing (Clare's story-telling, Danielle twirls her hair), self-care and restoration (ranging from Sarah's lunch with her son and movie with her daughter to getting her prescription), relaxation (Clare's engagement with social media), self-expression (Clare's expression of her faith and performing music), and routine.

### **Medication**

In Danielle, Michelle's, and Sarah's stories, the role medication plays is prominent and demonstrates its impact (its control and its regulation) upon their subjective experiences.

While medication can help with control and regulation, it can also mean neurodiverse people need to make a trade off with some of the more valuable aspects of their being, such as their creativity and nonconformity.

### **Sleep**

For Rebecca, Michelle, and Sarah, the influence of a lack of, or disrupted sleep is key to their feelings of competence, confidence, enjoyment, and their ability to regulate themselves or to manage their symptoms.

Little is known about the impact of ongoing sleep disruption upon people and their subjective experience of occupations. Unlike the necessary flexibility that Bill's workplace affords him, not all workplaces are designed with neurodiversity in mind and therefore may not be doing their best to retain staff, to foster creativity and innovation (ACAS 2019), to facilitate accessibility, or to respect (neuro)diversity.

Now, in the midst of the COVID-19 pandemic, we wonder what the impact of different work patterns and arrangements will be.

## **Belonging**

It is also clear from our accounts that if the ability to control our interactional selves is compromised, so then is our ability to actively seek to belong - which is necessary for being a part of our respective communities.

However achieved, a sense of belonging is important to our wellbeing, as is the acceptance of our neurodiversity and related needs.

## **Performance of self**

Though not without challenges, we have all been fortunate to exercise our rights to education and to work. A common experience has been the need to consciously alter our performance of self.

Thus, at work some of us have daily challenges and expend many efforts that go unseen or, when observable, are commonly misinterpreted or misunderstood.

For example, hypersensitivities can make workplaces uncomfortable, stressful, chaotic, and tiring environments. Feeling overwhelmed can lead to periods of shutdown or overload lasting anything from several seconds to several months.

Auditory or language processing issues, different (negative) body language, or a lack of eye contact can lead to us being misperceived and labelled by our colleagues as rude, uncooperative, or disinterested. On the flip side, being perceived as too 'high functioning' can mean colleagues doubt we struggle at all.

Our narratives - which were either shared in the context of a workday, or involved being at work, or being elsewhere, outside the home - demonstrate the differences in performance of self between home (private) and elsewhere (public). Clare demonstrates how being involved with her community is important to her, but also how such a day can then compromise her energy levels the next day. Diana demonstrates the impact of a morning appointment and the desire - need, even - to return 'to the safety of home'.

### **We are all kinds of minds**

Written in November, 2019, prior to the COVID-19 pandemic, our narratives shared in this feature were intended to provide insight into how - as neurodiverse people - we experience the world (as it was, then) around us, embedded within a context (employment as an occupational therapist) familiar to all members of the profession. Daily life has of course since changed, including how we all access and undertake our occupations. Everyone's narrative would certainly now have a different plot, and we are all contending with new challenges.

While each of us are living relatively independently (to varying degrees), we acknowledge that in Western societies like ours, there are many neurodivergent people who struggle to meet the pace that is set, due to the prioritisation of productivity, and are consequently marginalised and isolated. We hope our occupational therapy colleagues may address these insights into our worlds as useful in understanding that neurodiversity is not something to be fixed and, in fact, we advise the need to look at these different ways of thinking, being, and even doing as part of the person and their engagement in their world; a celebration of the fact that, together, we are all kinds of minds.

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