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**Reference:** Twinley, R., Hitch, D., Wong, B., Perryman-Fox, M., Sheridan, D., Selvaggi Hernandez, S., & Keogh, C.A. (2022). Feature: Neurodiversity: Together, we remain all kinds of minds. *OTnews*, (3), pp. 17-21.

## Feature/Neurodiversity

### Neurodiversity: together, we remain all kinds of minds

**A group of neurodivergent occupational therapists reflect on how they have continued to experience the world around them, since first sharing their stories about their lives in a pre-pandemic world two years ago**

In 2019, we came together as a group of seven people who each identify as neurodivergent: people whose brains process, learn and can function differently from what is considered 'typical'.

The purpose was to join Rebecca Twinley in their aim to collectively share our individual, subjective and unique experiences of occupations, and of (pre-pandemic) life (Twinley et al 2020).

Neurodiversity is the belief that everyone (whether neurodivergent or not) has a unique brain and therefore different skills, capacities and needs. Neurodivergence can be formally diagnosed or self-identified; the group see the latter as valid and important, especially given the privilege involved in being formally diagnosed.

Here we reflect on our continued lived experiences, further highlighting how neurological differences should be recognised, accepted and respected, like all other human variations. This is written with the key underlying recognition that diverse factors have intersected in different ways to shape our individual experiences of the COVID-19 pandemic.

### Our experiences

Returning to our original article, we further share our experiences through narrative for the same stated reasons:

'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 neurodivergence differs. Indeed, many of us have learnt to blend in or to mask and some of us have been misunderstood or misperceived' (Twinley et al 2020).

'We have chosen to state our neurotypes (see box out) 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' (Twinley et al 2020).

## Our neurotypes

Rebecca Twinley, senior lecturer in occupational therapy at the University of Brighton, is Autistic (formally late diagnosed in 2019) and has post-traumatic stress disorder.

Danielle Hitch, senior lecturer in occupational therapy, Deakin University in Australia, has attention deficit disorder and epilepsy.

Bill Wong is an occupational therapist in the US and Adjunct Faculty at Stanbridge University, California. Bill is an Autistic individual.

Michelle Perryman-Fox is a lecturer in occupational therapy at Queen Margaret University and is living with attention deficit disorder and dyspraxia.

Diana Sheridan, a dementia specialist practitioner/occupational therapist at Ashford and St Peter's Hospitals NHS Foundation Trust, is living with hearing impairment (since childhood) and dyspraxia (late diagnosis as an adult).

Sarah Selvaggi Hernandez, an advocate and an occupational therapist in the US, is Autistic and Deaf.

Clare Keogh, occupational therapist and sole trader of a paediatric occupational therapy business in Melbourne, Australia, has Dandy-Walker Syndrome, Agenesis of the Corpus Callosum and is Autistic.

## The 'great lockdown'

In the beginning of March 2020, 'the great lockdown' steadily extended across the world and now, two years later, the impact of COVID-19 extends far beyond those who have been infected.

Governments around the world enforced differing advice and measures that have changed people's occupational experiences. Here, the group look at the impact it has had on themselves as they also consider its impact upon other people and the world around them.

Rebecca had not long started in a new position with the University of Brighton when everyone left the campus to begin working from home: 'Environmentally, my home was not at all set up for working there, but I did at least, and unlike many, have a safe home environment from which I could work.'

Rebecca recalls: 'I was immediately more comfortable: to have choice over lighting, temperature, noise, even clothing I wore (or didn't wear, such as socks), and having no impromptu distractions or visitors to my new office space'.

Daily experiences became easier: 'Having a phone in my office on campus stirs feelings of anxiety. The unpredictability of receiving an unexpected call is stressful because, if I do take the call, the attention is all on what is being said.'

'Sensory wise, sometimes it can hurt to have a phone next to my ear, with the noise all channelled directly into it. Having unreliable auditory processing also means I have no visual cues to help process the auditory input.'

Danielle Hitch says of her experience in Australia: 'My hometown of Melbourne experienced the most lockdowns of anywhere in the world - 260 days across six separate lockdowns. My experience was very different to most, as I was redeployed to clinical COVID response duties, working at a hospital every day.'

'As the epicentre of local outbreaks, the hospital felt chaotic and frenetic, and I worked more hours than I ever have under extreme pressure. Ironically, I experienced this positively as a person with attention deficit disorder (ADHD) as I consistently got the dopamine I needed to function optimally.'

'Between home schooling three children and long work hours, my hyperactivity became an asset rather than an impairment'.

The difference between work and elsewhere was profound for Danielle: 'My community was empty and the city was silent at night due to enforced curfews. While not condoning their actions, I could understand the Melbournians who railed against lockdown in the second year of this lesser life – riots are the voice of the unheard. The emotional sensitivity of ADHD made all of me red raw and ultimately exhausting'.

Bill Wong says: 'In the US, in the middle of March 2020, I was in fear of being among the first individuals to catch COVID-19. I was scrambling to find new ways to maintain my wellbeing, while achieving a good work-life balance'.

In his work roles, Bill experienced many changes: 'I often found myself in a confused state. For my clinical job, COVID unit protocols seemed to change every two to three weeks. Moreover, COVID unit protocols could be different from one nursing home to the next. I had to ask for updates if I had not been to any nursing home I worked at for at least two weeks.'

'For my academic job, I had to be vigilant about the ever-changing university policies, which is extra difficult because I am currently an adjunct faculty.'

Michelle Perryman-Fox questions if we can call it 'great', remembering: 'At the time I was working, writing up my PhD, pregnant and living in the US. At first it was a sense of grief knowing I wouldn't get to see my family and colleagues. Also, I missed my free car time: the time that regulates me and gets me in the zone for some serious straight up focus.'

'Over time, I found myself shifting into a routine of exercising daily, focusing on writing and taking needed afternoon naps (pregnancy).'

The change became harder for Michelle: 'I was becoming frustrated at the lack of stimulation, the lack of important conversations that trigger my creativity, it felt as if my support had closed and I was needing to vent me and my creativity...

'So, I began to paint. But I got bored of that (ADHD trait), so instead channelled my skills into additional arts and writing; things to find the level of stimulation I needed to maintain my active and purposeful engagement.'

Diana Sheridan had mixed feelings: 'I feared for the health of friends and family, particularly for my clinically vulnerable mother and my daughter living in a hugely mobile student community.'

'As a hard of hearing/deaf person, the anxiety for myself was due to anticipating mask wearing, which would make communication very challenging in the workplace, as well as being frontline in a highly risky environment. There were continual demands on mental energy required to be highly adaptive at fast pace.'

Sarah Selvaggi Hernandez felt the lockdown changed her life in unexpected ways: 'I have transitioned to at-home entrepreneurial opportunities for work, and reinvented the ways I connect to family, colleagues, and friends.'

'I also had to increase my sensory strategies at home, because I was no longer getting necessary, positive stimuli from community interactions and mobility.'

Clare Keogh says: 'While I know of many neurodivergent people who enjoyed the shift to working from home, more opportunities for downtime and the necessity of smaller, more intentional social contacts reducing overwhelm, for me it was almost the opposite.'

'I think of myself as an extraverted Autistic person and I worked in an environment that had a set structure, I went to the gym for heavy work regulation, and I had my social bucket filled by weekly choir and church gatherings in person.'

'The pandemic shifted that totally. I was glad to go into lockdown after the weeks of scary headlines at home and dread from overseas. But my life changed overnight, and it took some weeks or even months to recover.'

## Easing and lifting of restrictions

There have been conflicting and differing feelings about the easing and lifting of restrictions. Some have and are yearning for the return to 'normality', others are completely and utterly terrified (Colombo 2021).

Rebecca perceives there to be ableist norms inherent in phrases like 'return to normality', saying: 'A return to "normal" isn't ideal for everyone; for many, "normality" was difficult. It meant discrimination, inaccessibility, disability bias, and failure to accommodate – returning to this is a return to systemic injustice, including systemic ableism, and we are leaving people behind.'

'The treatment of "the most vulnerable" in our society has exposed ableism and has hurt our communities.'

Danielle reflects: 'I feel deep ambivalence about restrictions easing. On one hand, lockdowns have caused immense and deep-rooted damage to my community, entrenching the pain of this pandemic across the whole population.'

'On the other, I cannot and will not forget the thousands of Australians who are dying or have died, or the ongoing trauma of people living with Long Covid'.

Bill reflects: 'When the first phase of restrictions lifted, I was looking forward to things being relatively normal relatively soon. I wasn't prepared for not having the ability to travel as freely as I did before COVID-19, for almost two years.'

'I used to space out my vacation time so that I would not get burned out from my clinical job as easily. While my week-to-week pre-COVID-19 life is back, I currently do not have true opportunities to refresh my mind yet'.

Michelle wonders if she feels different to others: 'I was nervous about the over stimulation of returning to heightened social interaction, sensory fatigue, tiredness, and not knowing how to communicate so effectively.'

'Although, I was able to grade it to slowly increase my interactions, it still isn't at 100% capacity at my workplace, but I have noticed I remain to thrive with the in-person interaction so I can read peoples body language.'

Diana experienced the lockdown and easing as both freeing and frightening: 'I was living life at a slower pace with a simplified daily routine, within the cocoon of local community, although I was not able to visit and support my parents, as I was both a risk and a resource to them (working on C19 wards)'.

Sarah feels uncomfortable with the easing of restrictions: 'We are still in the middle of an active pandemic. It has made me feel "othered" by society because I, an immunocompromised and disabled individual, have not been able to participate in communal social events.'

Clare's household has been keeping things low-key: 'There were some good things, like finding new ways of connecting with others online. I spoke at a virtual conference for Corpus Callosum Disabilities, which led to further opportunities.'

## Exposing ableism and disablism

COVID-19 has exposed new and pre-existing inequalities, not least those experienced due to the oppressive systems of ableism and disablism: 'Health systems around the world have prioritised the young and the "healthy" and disabled bodies have been de-prioritised as hospitals become overloaded (Ryan 2020)' (Thorneycroft and Asquith 2021).

Rebecca has reflected on her role as a lecturer and upon neurodivergent students' needs. Rebecca says: 'I had assumed employers and education providers would have learnt about the differential impacts of learning and studying through a pandemic for neurodivergent people.'

'Even being able to stim whilst using online/remote learning has been helpful for me. But any learning requires an intersectional analysis to understand the interaction of people's different social locations and within the context of the oppressive systems and the structures of power in which they live. The need to rethink inclusion in education has never been greater.'

Danielle considers the lives of disabled people and those with 'pre-existing conditions', saying: 'I will always rage against the ableist nonsense of caveats on the COVID-19 death toll - the death of a person with pre-existing conditions is no less a tragic loss for our community.'

'I'm craving the return of my busy, buzzing community, so I can socialise and get the sensory input I desperately need. But the potential cost of getting back to normal is profound.'

Bill feels strongly about the exposure of ableism through COVID-19, saying: 'Over time, I learned that some people felt more comfortable in video chat meetings if turning on the camera is optional instead of mandatory.'

'So, if someone requests everyone to turn on their cameras, that is actually ableism in the COVID era. It has impacted my instructional style for my academic job. For each class, on day one I told students that turning on their cameras would be optional'.

Michelle also thinks it has exposed ableism and disablism experiences: 'I need that social interaction, that engagement and ongoing stimulated buzz. The online world, to me, has opened many doors and I think it has been beneficial to so many.'

‘So, I do not advocate for a full change, but, for example, for me, attending a conference has such a bigger impact when I am in person’.

Diana has experienced mixed responses to her needs: ‘Hearing impairment is a tangible disability recognised by most people, yet there hasn't really been any change in lack of empathy with regards to dyspraxia.

‘Attempts to get clear window masks into usage in my workplace have failed and there is no awareness training given in truly recognising the needs of those with communication difficulties’.

For Sarah, ableism has always been present in community responses to crisis, but she has been disappointed at the supports, accommodations and modifications denied to disabled individuals to receive services:

‘Towns all over the US have begun releasing free testing kits they are receiving from the government. However, they are “first come, first serve” and are only accessible to those with reliable transportation, the physical and mental ability to go to a mass distribution event and the available time to attend and recover from such events. Disability access is not a priority and I am hoping that changes’.

Clare says: ‘There is still a lot of fear and anxiety about what “living with COVID” really means, as well as sheer frustration that it’s come to this point. It’s not over yet, not by a long shot’.

## An opportunity for change

Through the deadly, exceptional, scary, uncertain, restricted, instable, stigmatising and discriminatory times of the pandemic, there is some sense of optimism that the group hope is realised and enacted.

COVID-19 has created a space for critical disability studies (to include, for instance, Black disability studies, post-colonial disability studies, crip theory, disability justice movement, feminist disability studies, mad studies and neurodiversity studies) to support people’s survival, growth, relationships, opportunities and occupational experiences - and all with ableist notions and ideals rightly abandoned.

Rebecca is concerned the opportunities revealed are already diminishing, saying: ‘Inequality has the power to divide us from the solidarity that can keep us well. The exposure of inequalities and inequity that existed long before COVID-19 should have become a time to learn; to better understand new and existing realities and to improve the lives of, for instance, people living in poverty, of indigenous, racialised, and marginalised groups.

‘This therefore concerns persons with disabilities, including those who are neurodivergent. I feel like any exposed opportunities are quickly disappearing and my strategies of masking, blending in, coping, to live and work in an ableist world still remain.’

Likewise, Danielle says: ‘I’m also wary of walking back the opportunities for people with disability that were one of the positives of the pandemic. After years of having to fight to work from home as a disability

management strategy, the world quickly accepted that you can be productive away from the office when everyone had to do it.

‘I could finally attend courses and conferences previously inaccessible and could better manage the impact of scattered attention, as I used movement breaks to put washing on or get dinner started.

‘But the old ways are creeping back. Demands are growing to return to the office and more meetings are being held in person only. There’s no reason not to continue online access unless the pushing of people with disability back into the shadows is perceived as just part of going back to normal.

‘I choose to be hopeful, but I also know that old, ableist habits die hard’.

Bill adds: ‘Since the pandemic, I realised occupational therapy should adapt to how we advocate as quickly as we adapted to telehealth. Just before the pandemic, I made up my mind to not organise any more TEDx events.

‘When TEDx events went virtual at the beginning of the COVID pandemic, I was cautiously optimistic but, over six months I began to realise organising them virtually was more feasible. I have since created a structure for organising TEDx events, inviting my own speakers with ease.’

Michelle feels it is with no doubt that actions should have been taken before the pandemic for all of the exposed inequalities and inequity for communities: ‘I think the essential conversations are being exposed by strong, powerful people.

‘I want to acknowledge this is tiring for them and that they are more than likely exhausted beyond any privileged comprehension that I have. And I want to thank them, to allow us to join the continued discussions and support the activism of change.

‘For me, the opportunity has been to be able to stop, listen, to be able to reflect and be reflexive in my daily “doing”. It has provided a wider understanding of the experiences of others I have advocated for throughout my career on a much deeper level.

‘And to even unearth my understanding of how I contribute to the marginalisation of others and how I am marginalised within my own neurodivergent condition.’

For Diana, positives include embracing some technology, such as Zoom and MS Teams for online social interactions, with the options for using headphones and live subtitles:

‘This has been a huge advantage for me’, she says, ‘as well as simplifying my time management with a click of a button to attend a meeting, in addition to the acceptance of being able to work from home.’



Diana thinks so much more could have been embraced, including: 'Text-to-speech apps for deaf people, or consideration for clear window masks that would help those who rely on facial expression in social interactions. However, like others in our group feel, there are real concerns that any progress made will be swept aside in the rush to get back to "normal".'

Sarah echoes Diana: 'For many of us, opportunities were broadened by society's newfound acceptance of the virtual context. My social media advocacy work has grown and I have had the opportunity to give workshops and consultations worldwide.

'I am able to regulate myself before and after events in the comfort of my own home and am less taxed by the expectations of a neuronormative society. I am reclaiming my vocational footing as an occupational therapist on my Autistic terms.'

Clare values the opportunities on a personal level: 'These days, I have a schedule of yoga and gym activities I do from home, tapping into my passions to keep me motivated. Dog walks are regular part of my routine.

'Also, I now work for myself and my business incorporates my lived experience of disability with my professional occupational therapy knowledge to assist children and families. It's a big change from 2019, that's for sure.'

## We remain all kinds of minds

Written at the start of 2022, our narratives shared in this feature were intended to provide some further insight into how, as neurodivergent people and as occupational therapists, we continue to experience the world around us through experiencing the world and life-changing global phenomenon of the COVID-19 pandemic.

We uphold our assertion that being neurodivergent should no longer be considered an inherent limitation, but purely a difference (one of many) in how we process, experience and understand the world around us.

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