Transcript of Voices of the Market call with Gillian Burgis-Smith 11-Dec-23

### Tell us about your job – what do you do?

It doesn't feel like a job – it's more like a journey with a mission and commitment to making experiences and environments more inclusive, diverse, equitable and accessible. It was pointed out to me recently that companies often refer to DEI policies and miss accessibility. It starts with education and awareness.

I'm very conscious that all the time of being an Architect, designer, strategist and change consultant (30+ years) I had designed for people with visible disabilities and not always fully considered non-visible disabilities (including neurodiversity, visual and hearing impairments).

In some cases I had tried to design for wheelchair accessibility but been told we don't have anyone in a wheelchair, we will just provide an access statement. But disability doesn't not have to be permanent it can be temporary and/or situational.

For instance, you could be born with one arm, you could be paralysed in one arm or you could be carrying a child in one arm. Someone recently shared with me that when they were pregnant, they felt disabled moving around buildings and then even after the birth, they continued to have access issues. Therefore, an automated door (that warns you which way it's opening!) would benefit all above.

Over the last three years I have specialised as an inclusive design consultant working with organisations, teams and individuals to co-design buildings, spaces, products, and experiences that welcome everyone.

Earlier this year a chance encounter led me to becoming part of an organisation called 'Citizens with Experience' and within the organisation I have had the pleasure to mentor an early career Indian architect and learn from their thesis on biophilia and ADHD. Another level of diversity, inclusion, and protected characteristics.

### Within the organisations I consult with:

- we carry out audits that help identify potential barriers to create design solutions that are accessible diverse equitable and inclusive.
- our audits go beyond access audits to become inclusion audits looking at physical, physiological (sensory-how the body reacts to an emotion) and psychological (cognitive-how we interpret emotions and think about situations) based on lived experience of individuals and community outreach – across 7 key areas).
- We provide bespoke consultancy, including WELL Equity (I'm not a WELL AP, I would find it hard to study being ND but the ratings are accessible and manageable)
- we provide learning, training, and awareness.
- as part of user-experience cohorts, we ensure that the design has appropriate representation of people with a range of lived experiences.
- we help clients, architects, and other built environment professionals to set out inclusive design strategies and facilitate effective implementation.
- our focus is on assisting clients adopt strategies to include neurodiversity and creating psychological safety within their own business to training guiding and strategies, supporting the wider conversation within their own product marketing and product development.

### How did you end up doing it?

In 2019 I had two strokes one of which was whilst I was in the office, and I was diagnosed with rare, incurable brain tumour. It wasn't long before I was having a different experience in the built environment, living with a neurodegenerative condition. This coincided with a 5-year battle for my father with MND – we cared for him at home until he passed away in 2021 and my

mother who has been bed bound since his funeral and is in the last stages of vascular dementia.

This experience of having to adapt a house for disabled living such as where to put handrails, fixings for hoists, furniture positioning for two elderly people trying to communicate and both have hearing loss shifted my perspective and I my passion increased for inclusive design.

I began to understand that inclusive design is also around safety, independence, and dignity. It is not just about getting into a space (and exiting safely) it's also about being able to function and save energy. Personal physical energy. Your physical, psychological, and physiological health is crucial.

I also have chronic pain and suffer from osteo spondylitis — the degenerative nerve damage has left me paralysed from my neck to elbow left side. I think more everyday around conserving my energy. I think of this when I'm travelling as I'm going up to the platform I need to hold onto a handrail with my right arm — as I have limited movement in the left — and often wide stairs don't have central handrails, so I find myself struggling against people coming down the stairs on the left. It takes energy and I've nearly fallen several times. I struggle with proprioception, vestibular sense and being postmenopausal thermoception. I also have a caring role, and this affects my mental health and wellbeing, interoception.

One of the earlier experiences that made me realise I wasn't an inclusive designer was around wayfinding.

### Toilet example

Signposts are one of the most important elements of any experience. Spaces where there are an infinite number of paths leading in all directions, inclusive and accessible design should keep people aware of where they are within the overall 'experience' and where than can go (and can't go), at all times in a consistent and clear way. This includes websites. I often pre-plan now.

Thinking back to my Dad it's not just about turning circles on a drawing but thinking about the 'journey'. Early on my Dad wanted maintain his dignity and sleep upstairs. However, there wasn't enough room at the top of the stairs to transfer back onto a wheelchair so my husband literally had to lift him off the

stairlift and onto a chair. From Day 1 of using a wheelchair he couldn't get into the kitchen because of the door widths. Plug heights were impossible for him to reach.

We are all neurodiverse, and disability is not always something you are born with and is not always temporary. Age is also a key factor and particularly with the pressure on the NHS we need to remember ageing in place.

For this reason, if we design for people with different abilities, 'the outliers' we are creating more inclusive designs and environments for everyone.

What has been really humbling over the last 3 years is the people that have told me their stories, experiences, and feelings.

To put it in context approximately 1/5 of the human population are neurodiverse one in five people cannot be seen as errors of genetics we have to acknowledge there is diversity of human neuro cognitive capacity and we're all richer for it."

When we talk about disability, we think firstly about physical disability, but 70-80% of disabilities are non-visible.

5% of the population have ADHD.

1-2% of the population is autistic.

10% of the population are dyslexic.

5% of the population are dyspraxic.

1-2% of the population have Tourette Syndrome

7 % of the population have mental health needs.

5% of the population have an acquired brain injury.

Only 70% of the population have 20:20 vision and that is with the aid of glasses and contact lenses.

1: 12 men are colour blind and 1:200 women

### Tell us about you work journey over the years

I actually left school at 16 and followed my Dad into what was considered a stable and secure job. A junior clerical trainee for local government, moving

between departments. After Housing, Finance and Trading Standards I was moved to the Architects Department. I saw architectural trainees on drawing boards and new that's where I wanted to stay.

I approached the Chief Architect, but his response was 'you can't do that you're a woman'. So, I enrolled in an evening class for an ONC in Building Studies. This was enough for them to make me an Architectural Technician-but to get into university to do a degree I was advised to do a Foundation course into Women & Building at PNL. I completed this one-year course and was admitted for a 4 year part-time BA (Hons) Greenwich University. For my Part 2 was 3 years part-time, by this time I had.

Greenwich was great there was only a small group of day release students (6) that went straight through from beginning to end together and we formed a strong bond. I recently found the ceremony book at there were only 3% of women in the year.

In 1998 I was given the opportunity to go and work in Toronto, Canada. Eighteen months later I was transferred to Vancouver to work as part of a joint venture on Vancouver Convention Centre, but the project was put on hold and I was transferred to Florida. Florida didn't suit me and I moved back to the UK joining Jack Pringle, Chris Brandon and Melvin Starling at Pringle Brandon (since acquired by Perkins and Will).

I loved Pringle Brandon and was offered a partnership but in 2006 the project for the Vancouver Convention Centre resurrected for the 2010 Winter Olympics and Architecture firms got busy.

HOK decided to open an office there and I'd been recommended through peers in London.

Sadly, by 2010 my parents' health was declining and we made the decision to came home.

A position opened in DEGW because of maternity leave. Then NBBJ London was starting a Corporate Division in London. However, the practice was still predominantly Architecture and I left to continue in Interior Architecture at IA in 2013.

### What has had the biggest impact on your design thinking?

Lived experience. Outlier design being a fundamentally important part of Inclusive Design

### What type of impact do you hope to make?

Creating a design-thinking that is truly inclusive by a focus on Outlier Design within Inclusive Design that is based on Life-Centre Design so that the outliers of People, Place, and Panet have equity and then equality. (Equality means each individual or group of people is given the same resources or opportunities. Equity recognizes that each person has different circumstances and allocates the exact resources and opportunities needed to reach an equal outcome)

Enabling as many people as possible to experience products, environments, and experiences safely, independently whilst preserving their dignity.

# What new challenges and opportunities has the pandemic created for you and your organisation?

I think it's both a challenge and an opportunity but it's to create more inclusive environments for individuals with non-visible disabilities.

Any form of isolation of people resonates with those with non-visible disabilities so the pandemic and its lockdowns were not dissimilar to their experiences. This initially levelled the thinking and design for all but with easing this lessened.

I'm going to talk about the opportunities first:

At the beginning of the pandemic, we wanted to understand more about creating neuro-inclusive environments where everyone can reach their full potential.

Especially given some of the changes I was experiencing I became interested in Neurodiversity.

I'm not a professional assessor but to give you a broad understanding.

When professionals are assessing and looking for Neurodiversity, they are looking for statistical differences between four main cognitive skills.

Firstly, verbal comprehension. That's how we make sense of the world using language.

Secondly our reasoning skills this is our ability to problem solve and make sense of visual and abstract information.

These two skills are very much like an engine what we do with information once we've learnt it.

Thirdly our working memory which is often thought about as a one-stop shop for new information it's also linked to our attention and our short-term memory stores.

Finally, are processing speed this is how quickly we can move between tasks.

Human beings have this wonderful idea that we can multitask but it's a fallacy the human brain cannot multitask!

What we can do is to move between task very quickly which helps us to believe we are multitasking. Also, once we have learned at skill it so it stays somewhere on a very low conscious level.

So, if we think about Neurotypical brain typical, we think about these four elements:

Verbal, visual, working memory and processing speed.

And these four elements are working at about the same speed and efficiency.

What happens from when you are neurodiverse, or brain different is that across these four pillars there are significant differences.

Between neuro typical and neuro diverse thinkers there are millions of different possibilities. Our brains are as unique as our fingerprints and our brains change over time.

In short neuro diverse is having significant differences typically because their working memory or processing speed isn't keeping up with their main engine.

This mean that for them to reach their full potential and have a level playing field adjustments should be made and recognised.

Some professional assessors like to use the analogy of speed (although not exact) to help people consider these 4 parts of their brain travelling. Two sometimes three are steaming ahead and one is overwhelmed/distracted etc. Once your cognitive resource is used for the day it has a significant impact on emotional regulation too.

Since 2019, my whole perspective shifted, and I wanted to change the way architects and designers design for people with disabilities (visible and non-visible) - before it had mostly been a tick box exercise.

That's when I started the research in form of one-to-one interviews with individuals that are diagnosed and/or identified as neurodivergent or neurodegenerative and creativity is part of the role of function.

The context for the research was:

- 1) To listen to people on teams and understand how they have adapted their creative work processes during the pandemic and as we move forward.
- 2) To create a framework for continued creative effectiveness across remote and in person work environments

One of the main takeaways is that whilst every one of us has a unique set of different connections with our billions of nerve cells and the way that we interact with our environment varies from person to person there are some similar patterns that emerge.

Our connection with the environment is intrinsically linked to sensory perception, sensory reactivity, and sensory processing.

Sensory reactivity and processing differences are a common theme across neuro divergent and neurogenerative groups.

This can include hypersensitive, over, above normal, or high - people who are hypersensitive experience sensory overload. This can be characterised by those who become uncomfortable when experiencing minor encounters with environmental stimuli.

Or- hypo (meaning under), - people who are hyposensitivity may not feel things from one or more sense and seek them out. Such as an individual who can't sit still and is constantly seeking stimuli.

I remember walking around open plan offices with the project team and the team showing concern that some people were sitting there with headphones on (when they wanted them to learn by listening to others). However, through my research I've learnt that some people need to listen to all kinds of music, including rock music, to be able to be creative – those that are hypo sensitive or those with noise cancelling headsets that are hypersensitive.

Individuals can experience both hypersensitivity, over responsiveness and hypo sensitivity, under responsiveness, to a range of stimuli. Most people have a combination of both.

When I'm discussing sensory processing differences, I'm talking about 9 senses:

vision, proprioception (body awareness), hearing

smell, interoception (internal sense – such as your heart beating faster), touch, taste, vestibular (movement or balance), temperature

There are more – including our sense of agency.

As inclusive consultants we consider physical, sensory, and cognitive differences.

Similarly, CWE (Citizens with Experience) has not returned to pre-pandemic design solutions but incorporated those, and the Outlier Design, solutions into Inclusive Design, this includes neurodiversity and health and wellbeing.

Then some of the challenges of the pandemic.

Individuals with Long Covid (c 2 million in UK) have been documented as having neurocognitive physical changes and reduced neurocognitive capacity, as well as increased sensory sensitivity to light and sound.

I've spoken to individuals that suffered not just to light and sound but also smell. In a talk recently an individual shared they have endured years of both anosmia and then parosmia following an early Covid exposure which has completely changed their perception of the world around them with smells and tastes becoming daily challenges, both from a disgust/enjoyment perspective through to a severe safety perspective (not being able to smell gas at home), meaning they've had to implement safety measures to protect themselves and their family at home.

With more awareness, advocacy and 'lived experience.' I also feel that individuals masked, and a lot came out of my research from working better being closer to a toilet, to the etiquette and touch example – this was also the spoken about with people wanting stim, move around, avoid strong perfumes – and being diagnosed say with ADHD or Dyslexia during covid.

## How do you work with others in the industry?

Collaboratively rather than in competition so that inclusive diversity is enabled. When I was within Architectural organisations there was always competition. I now lead co-chair co-ability groups where everyone is open book, it's about life-centred design and best practices.

Moving at the speed of trust so that everyone has a psychologically safe space. We have had a lot of outreach from students and young architects, including the Indian Architect I mentioned so this is of critical importance.

Understanding the needs and wants of others whilst being open and honest of my needs and wants.

Tension based innovation where the differences and diversity illuminate issues and allows open innovation without harm to anyone.

Not chasing perfection, nor the minimum viable product, but looking the minimum valuable product where the optimal result for all is enabled.

Not Win-Win but Win-Win-Mitigate where mitigation is the key and Degrees of Wrongness lessened for all rather than perfection for one is the focus. We

heard from a client who shared that they had automated all journeys in the building, tested braille on surfaces we touch – with positive and negative responses- we learn from each other and test and learn and continually user feedback is key.

## Where do you think your profession is headed... how will roles like yours change over time?

I hope that the profession is leading to be more inclusive with a participatory approach to design, continually learning and adapting 'designing with not for' "Nothing about us without us."

It's not so much about roles changing as to mindsets, designers and architects becoming more aware of their own cones of bias and experience. It aligns with MillerKnoll's Design with Impact.

The profession must move away from the medical model of disability to the social model of disability. We should design inclusively that means considering a range of intersecting factors such as physical capabilities, cognitive capabilities, neurodiversity, gender, sexual orientation, age, education, culture, ethnicity and more. We should be thinking about the systemic structural and economic barriers that many people we should be considering these things can be long term, temporary or situational.

Thinking about a door, I can't open my front door with thumb turns, not because I'm disabled but because there is a mismatch between my environment and my ability. Similarly, someone who is in a wheelchair would not be able to reach the thumb turn.

The role of Outlier and Inclusive Designer will transfer incrementally from the first adopters to teaching the principles, thinking and methods.

Design for the Outliers will be seen as relevant to all.

All designed things will be remeasured on the Outlier Design basis so that a truly inclusive design can be created.

New designs will incorporate Outlier Design thinking.

# Tell us a little bit about your product and place assessment processes related to inclusivity

We recognise that to benefit from inclusive design we must work and learn from people with a diverse range of perspectives. This includes be co-design sessions, user research and incorporating people with different perspectives and/or disabilities into the design and project team.

Recently we have been appointed by designers and companies to look at product and space audits and validations. Reviewing products and carry out user testing. A development from this has been the creation of icons that show how the product and places we are testing rate against certain criteria. We have been able to advise on quick wins, medium- and long-term solutions.

## What are good examples of things an employer and co-workers can do to assist their employees?

Create a culture of psychological safety.

Open cultures, safe space, inclusive and proactive practices, and processes are key to creating environments where all individuals feel comfortable and reach their full potential.

The industry needs to continue to lift the barriers to entry, disclosure, recognition, and promotion. (ADHD Engineer story)

Giving individuals a platform to excel through listening to different perspectives, ideas, communication and raising awareness (for everyone).

Research commissioned by Neurodiversity in Business in October 2022–conducted by Birkbeck, University of London's Centre for Neurodiversity Research at Work revealed that neurodivergent employees feared discrimination from more than half (55 per cent) of colleagues.

The research team surveyed 127 employers and 990 neurodivergent employees and found two fifths (40 per cent) felt there were not enough knowledgeable staff at work to support neurodivergent workers.

A range of "barriers" have been discovered to disclosing neurodivergence at work, as two thirds (65 per cent) of neurodivergent employees fear discrimination from management, research has found.

Employers also said there were barriers to helping employees, as three fifths (65 per cent) of managers said they did not have enough knowledge to support workers, and a third (30 per cent) of employers admitted they had "little faith" in workplace adjustments.

My recommendation would be to create open and psychologically safe spaces, where employees will feel able and willing to speak up about their experiences, without fear of repercussions.

ERG's or Forums can be excellent resources and sources of insight around all the protected characteristics including disability (visible and non-visible).

Employers can ask for feedback and suggestions for improvements, and then, most importantly, listen to the answer," and act on it.

Test and learn. User testing with outliers.

What would be your advice to generating more awareness and an inclusive community within an environment or with an individual that is not as open minded or willing to have difficult conversations regarding hidden disabilities?

Take away the onus from the individual.

Training and awareness. We provide training and CPD's. I'm humbled by the feedback, both from individuals who share their stories after and others that say, 'once you've learnt something you can't unlearn it.'

- a) Test and learn. Be flexible and adaptable.
- b) Promote inclusion, diversity, equity, and accessibility to gain greater data, experience, and solutions. Look at schemes like the WELL Equity scheme, Nov 2022 (an actionable framework to promote health and wellbeing that celebrates diversity).
- c) Promote an open, inclusive, sharing and no-blame culture. Include inclusion in the culture, wider people management practices and policies. Support particular groups (affinity groups/ERG's), organisations

- and individuals. Ensure the policies are easy to understand, implement and accessible to all. Hold events like this!
- d) Generate buy-in. This is key to ensuring the policies are supported and implemented by managers, teams, and individuals. Examples include listening circles, shadow boards, open seat at the board, etc.

## Can you any share refreshing experiences that people on the call might be able to adopt that has made you feel your disability was better understood?

I went to one event recently where they had 3 lanyards, red was not open to connect, orange was open to connect but might need help starting a conversation and blue was happy to connect and start conversations.

Similarly, The hidden disabilities sunflower lanyard. The Scheme draws attention to the fact that that not every disability is visible. The Scheme is a way of letting others know that a person has a hidden disability and may need a little support. Living with any disability (visible or non-visible) can make daily life more demanding. I bought a sunflower lanyard back 2 years ago having spent the last couple of months really suffering with frequent balance attacks and dizziness. Going out for even a simple short walk became difficult because I felt dizzy, bright lights were disorientating, and with my balance out of kilter I struggled to walk in a straight line, I felt so unsteady on my feet and I'm not drunk!! It does get me seats on the train and strangers whether on the street, in a shop, office etc. offer assistance.

What I find interesting is organisations often ask about dietary requirements but not physical or sensory. The University of Cambridge created an empathy design tool called the Inclusive Diverse Equitable and Accessible (IDEA) Design Canvas. It's open source and we can share a link after. The toolkit looks at physical, sensory, and cognitive design. It enables me to think about my cognitive and sensory overload as well as physical energy to be more aware of my own needs and requirements.