Transcript - Practising what we preach: Disability and Inclusion.

I am going to explore occupational therapy, disability and inclusion, in theory and practice. I’ve made my own illustrations for the slides and will describe each one to you. The illustration on this slide is of two figures shaking hands over a barrier like a fence. One is speaking and the other is thinking.

To co-produce this talk, I’ve had a series of discussions with members of #AbleOT. Our experience suggests that being in a team which includes disabled colleagues makes us reconsider our work settings and routine practices: aspects like working hours and standard procedures can be ableist. To be ableist is to value people “based on their bodies and minds and what society deems to be ‘normal’”. This quote is from Samantha Renke, a disabled woman speaking in 2020. When people are devalued for an apparent lack of ability such as following a procedure or routine in the same way as everyone else, they can be disabled. Often in ways that others cannot see, especially those who work there. We can explore our values, practices and settings from fresh perspectives when working with disabled colleagues. Following my talk, there will be time for reflection and discussion with a panel of #AbleOT members.

You may or may not know that I’m a retired, disabled occupational therapist. I had to retire early because of my health, not my disability, and I’m going to come back to that later. I’ve had a hearing impairment all my life and didn’t see it as a disability until I was 30 and I realised that some adjustments could be made so I didn’t miss out, especially at work. The grinding pain of osteoarthritis began to restrict me from my mid-30s, but it took ANCA vasculitis, an autoimmune disease, to stop me working altogether in my mid fifties. My Casson lecture in 2016 turned out to be my last conference as a speaker. The last five years have involved several medical specialities, especially outpatient clinics for my vasculitis, eyes and lungs. I have regular contact with my GP. And fortunately not so regular contact with the Dept of Work and Pensions for my PIP benefit. Retired life has given me the time for all this, along with an honorary professor role at the University of Essex, editing the 6th edition of Creek’s Occupational Therapy and Mental Health, and exploring how to keep doing when the need to rest is fuelled by fatigue and pain. What I know is that there is always more to know.

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Here’s an overview of this talk. The illustration here is of a map, with roads, buildings, trees and solar panels. Yes that’s what they’re supposed to be.

I’m planning to take you through some ways of thinking about disability, inclusion and occupational therapy. Disabled occupational therapists can occupy an awkward space in the profession, challenging assumptions about identity, role and capacity.

Essential and desirable characteristics on job descriptions are interpreted in different ways in different places, suggesting there are many professional identities and roles, often underpinned by unspoken assumptions. It is important not to assume we are all-knowing experts because of our professional knowledge, as being disabled involves such a wide range of experiences. But we can use our professional expertise to engage with, identify and challenge ableism in partnership with the disabled people we work with.

So here is a chance to explore our assumptions and refresh our shared professional identity. I am going to share some critical thinking about how we engage with disabled people. There are five perspectives I am going to take, listed here on the slide.

> Disability and inclusion revisited. I'm going to briefly review terminology and definitions
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> A respected profession: I will consider how being a health or social care professional is powerful identity
>
> Fixing people and their lives: I'll explore the social model of disability in relation to occupational therapy values
>
> Form, function and meaning: there are many occupational theories so I've chosen one. I want to think not so much about what occupational therapists do, but on the components that change when we act.
>
> Reflection: if we reflect as much as we act, then we are open to the different implications the change might have.

Each of these perspectives could be an hour's talk in themselves, so what follows is a taster. If any of these ideas are very new to you, then I've created a list of further resources to share. I suspect that some ideas will stick with you while others pass you by. That's fine. It is an ongoing project for all of us, to make sense of the experiences of being disabled.

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Disability and Inclusion revisited.

The illustration here is of a head with a speech bubble with a question mark in it.

I am going to assume that you are all familiar with disability in theory and practice, and therefore some terms, even if you haven't thought about them for a while. I'm also going to assume that you understand there are different definitions of disability that reflect how society views it: sometimes a person's impairments are emphasised, sometimes the physical environment, while other definitions take a broader view. In this slide I've taken common question words (who, what, where etc), suggested questions (there are many possibilities here) and linked the questions to key words that are often used in disability studies. I'm going to share some of my experiences: they may be different to yours and that's ok. In a way this is a reflection. As we look carefully, we notice more and more.

Who am I?

Identifying as a disabled person is complicated. As I walk away from my car, I wonder if, in other people's eyes, my identity as a disabled person melts away the further I am from the blue badge. Then I sit on a bench to rest. That's ok. I stop in the middle of a crowded place to gather my breath and collect my thoughts. That's not ok. Behaving differently makes me seem different, or Other, with a capital O. It emphasises the distance between you and me, a space where discrimination flourishes and I get stared at and buffeted in the crowds. To be honest, I've avoided crowded places since well before the pandemic. So I'm not included in the rush. That's ok: it takes more time to make sure I'm doing things when it's quiet. But it isn't always possible and then I fear the reaction of others when I appear too different or Other. I fear their prejudice, their discrimination.

What identifies me as a disabled person?

My blue badge, grab rails, bath board, slowness and hearing aids signify my disability to some. I don't always use sticks because of the pain in my wrist joints, so I can appear not to be disabled. So much is assumed by what we see. I'd like to argue that most impairments are invisible. One of our strengths as occupational therapists is knowing that it's necessary to do everyday things together to start to appreciate what those invisible impairments are.

Why are we disabled?

My visible and invisible impairments are part of the experience of being disabled, but if I don't use my hearing aids or take a breather, it doesn't mean I'm not disabled anymore. The social model of disability focuses on how the external world creates barriers which prevent participation, disabling people. Overcoming disability is about changing attitudes and buildings so they are accessible and inclusive. Because if there's a barrier between you and me, first we need to get rid of the barrier (for access) and then we need to welcome you to the space where I am (inclusion). Independent living therefore is not about people doing everything for themselves in isolation, but about being supported to do and be included in the things that matter. Independent living has social and occupational dimensions. Without the supports I have, this talk would not happen because I would spending all my time and energy doing things that I used to do without thinking. But it has also happened because the Able OT group and the Royal College of Occupational Therapists wanted to include me and co-produce it with me, for support.

How is disability experienced?
These questions remind me of filling out the PIP benefit form, which is one of the most miserable experiences a disabled person can have. Deciding who is eligible for state support is a political decision, especially when resources are thought to be in short supply. I say "thought to be" because it's a political choice and we live in a wealthy country. In an earlier version of this talk I go on to make some comments about current political priorities. But I can do that on Twitter. The point here is that when we work with disabled colleagues, interesting thoughts about eligibility and barriers start to arise. I'll say more about those in a bit.

Where are the places associated with disability?
The important words here are segregation and integration as there are different views about how helpful it is to have segregated or special spaces for disabled people. The problem with those spaces is they create distance. After I'd been trying to work with my vasculitis for a year, I was moved to a different office as a safer working environment. Previously I was right by the stairs and the student working space, frequently encountering lots of people. I moved down the end of a corridor in the basement. This did reduce my risk of catching infections (although I still did) and reduce interruptions, but I was more isolated. So there's advantages and disadvantages to segregation and integration.

When does a difficulty become a disability?
It depends on how long it's a difficulty. Periods of ill health might give healthy people insights into restrictions on life, but I'm not so sure they get the full experience of disability. They seem to get awfully disappointed if the problems don't go after a week or two. They need a holiday. Sorry if I sound bitter, but I've not experienced a holiday in recent years where I didn't feel disabled at some point. It's not something you can take a break from. However, I also want to make the point that the reason I had to retire from work was because of my illness, not my disability. Many adjustments were made to enable me to carry on working, but the vasculitis treatment was and is all consuming. If my illness had been easier to control and more predictable, those adjustments would have made all the difference. Many people work with vasculitis. And of course, I've found another way of working, that fits and flows around the endless attention from health professionals. Aren't I lucky?

So finally, Who?

I want to make one final comment on this slide, about intersectionality. Multiple barriers to inclusion are revealed when we consider other forms of discriminatiion as well as ableism. These forms intersect with each other. For me, there have been some benefits to becoming an invisible older woman but it doesn't fully protect me from aggression from other people, if I'm a bit slow or hesitant when I'm fatigued or in a lot of pain.

A respected profession.

I'm going to take you round the elements of this figure, centred on the question of how we can use our power as a respected profession to reduce ableism. Each element has a lightning symbol next to it.

We are powerful:

Power can be understood in three ways. First as a source of energy, without power we have no heat, lights etc. Second, as capacity: powerful muscles give more physical strength, a powerful imagination might fuel more creativity. Third, as authority over others: people who have a powerful status have more control over what happens than those who do not. As occupational therapists we have this third sense of power to challenge ableism and other forms of discrimination.

We are respected

Being a registered occupational therapist gives us more scope to earn respect from the people we work with. In the vasculitis community and on Twitter, I hear and read how occupational therapists are respected by people whose lives have been changed for the better. It might be a constant challenge to advocate for the profession in relation to the media, policy and local health and care service politics. But I would argue this is not often about being disrespected. If you've ever shared your story, you'll know you have to simplify it to get attention. That's how mainstream and social media works. If you're deciding how to change direction in your life, again there could be a tendency to oversimplify things to get moving. That's what often happens in politics. This simplification excludes different abilities. We can use our power and our respected position to challenge the tendency to ableism.

Occupation-centred

It gets annoying when a panacea is proposed: that is, a cure-all, often involving crafts, plants, animals, travel to special places or food. These panaceas extend to vitamins, turmeric, breathing, and all sorts of other miraculous things given half a chance. Yes, they've been suggested to me. Being occupation-centred gives us deep understanding of the complexities of occupation. In the public sphere, we take care not to let important ideas like occupational balance get hijacked by superficial remedies of scented candles, glasses of wine and time off work. Those superficial understandings can be very ableist.

Professional

Think carefully about those inspiring people who are disabled: what is it about them? If it's about how amazing it is that they can work and be disabled, think again. What does that say about our ableism? Our power is in our professionalism, not our capacity to be inspired by ableist stereotypes. Being a professional is more than following a code of conduct, it's about thinking carefully about how to apply that code to specific contexts. Like a lawyer, sifting through possibilities. It is a powerful thing, to be a professional: we can focus on some aspects like efficient service delivery and marginalise others like the working environment, which may generate respect from colleagues, or may not. This is our privilege.

Privileged

Being privileged is to be more powerful that others, having access to more resources to keep us in that privileged position. Whether we are disabled or not, we have responsibilities about how we use our privileges and the impact our choices have on others, marginalising them. Disabled occupational therapists sometimes feel they are marginalised in events which are organised to bring the profession together. Who decides how these events are organised? Those with power to decide, of course. Being marginalised is therefore to be separated or excluded from decisions, limiting power. To gain power requires people to draw attention to themselves. The government, being full of the power to direct attention, can do this easily. Marginalised groups have to be creative and loud to get attention. This dynamic is repeated in working teams everywhere. If disabled colleagues are marginalised, what is keeping them that way? To challenge and change situations, people on the margins seek power: not necessarily to take over but to be heard and be part of the dynamic focus which marginalises and centralises issues.

How can we use our power?

So far I’ve traced how our power as occupational therapists comes from the respect we have earned, our focus on occupation, our professionalism and our privilege. How can we use our power to work with our disabled colleagues so we are mutually respectful and make the most of our individual capacities? How can we practice what we preach? What prevents us?

In the next part of this talk, I’m going to think about the particular tension of being a therapist and being a colleague to disabled occupational therapists.

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Fixing people and their lives

The illustration here shows a person holding up their hands to ward off a giant spanner.

I’ve deliberately chosen the word “fixing” because as a disabled person that’s often how it feels on the receiving end. People want to fix me and my life. Sometimes they can address issues really helpfully. In a large busy office, my team leader relocated me from the middle to a desk on the side by a wall, so my hearing aids could work more effectively. She did discuss the idea with me and the others involved first. It was agreed together in a partnership.

I want to think about what supports and undermines that partnership from three angles, starting with two body practice.

Two body practice

Cheryl Mattingly is an anthropologist who studied occupational therapists, considering how they think while they're doing their job. One aspect she identified was two body practice. She observed that occupational therapists switch rapidly between two ways of thinking about a person: as a living body and body as machine. The living body changes in unpredictable ways, acting and reacting to situations. The body as a machine follows general rules that can be applied to others. When we work in partnership with a disabled person, we consider the situation as we are experiencing or living it, and apply general rules to fix problems. Sometimes fixing is a process of trial and error, as we apply a principle to see how it will work in this particular situation.

So in our joint work, our disabled colleague might try assistive technology or different working hours. We all might shift where we usually work, to make space, like we did in that office. We might discuss when to use a general rule, for example it is not acceptable to come to work if you are not fit to work. Many years ago in the 1980s, I worked with a mental health team leader who introduced to the idea of mental health days. It was ok for all of us to ring up and say that we needed a mental health day. For most of us, that was fine. Other colleagues needed more than a day, from time to time. That was ok, too, mostly, but not always. Sometimes work was too much for a while.

Two body practice is an ongoing process. Thinking about the living body is a bit like sifting through a place where handy things are kept but rarely sorted, exploring all the different possibilities to scope out the issue. If the balance is tipped towards body-as-a-machine thinking, then there's a tendency to look for very particular aspects and ignore the others. If the balance is tipped the other way, then we will be more aware of other aspects, but there's also the possibility that we might go off on a tangent. To me, understanding this dynamic process of being open but also focused, together, is probably more helpful than thinking about person-centred practice in relation to our colleagues. We can all use our therapist brains together, because we work together. We are not focusing on our disabled colleague, we are looking at our shared work setting and practices.

Sounds good? Sounds ideal. But working together in this way requires careful thought and discussion, especially about questions like these:

How and when can we use our professional knowledge, skills and approaches to change our shared work setting and practices?

When is it appropriate for people to fix things for themselves?

How much can we focus on changing the way we work, when our service is under huge pressure to deliver occupational therapy to those who need it?

These are the kind of tensions that we all might feel and are potentially ableist, so let’s have another think about ableism and occupational therapy.

A better life

Our professional origins in social reform and rehabilitation are rooted in the idea that people and their lives could be better. This is a good value, so long as we are aware of what we think and feel a better life is. It’s important to be aware when we are being ableist, imposing our own interpretations on the lives of others. What we want for a better lives for ourselves might be quite different to our colleagues.

It’s interesting to consider what a better life means in terms of work. I’ve always been fascinated by utopias, where people can do satisfying work they enjoy in supportive contexts or in the case of utopias, ideal worlds. It’s not all about income.

My reasons have varied through my life. As a disabled person doing unpaid work through choice (because I’m all done with the pressure of a formal contract and I have my pension), my reasons are different to when I was a mother of young children (work was a welcome respite), when I led a team (work was all absorbing) to when I worked in my first job (work was all absorbing for different reasons). Exploring our common and diverse ideas of a better life helps us find ways of working together.

Yet as a group of disabled occupational therapists preparing this workshop, we all had experiences of occupational therapists (and many others) not working with us, but trying to fix us. Jumping to solutions without listening, not being able to see us as colleagues who share the working space. Jumping to solutions is poor practice regardless of who is involved. I freeze when someone says to me “have you tried…?” oh no, not more suggestions, please, no.

Which brings me back to the Social model of disability

I’m coming back to this model, because there’s something important I want to say about it. Often the social model of disability is contrasted with the medical model. To me this is service driven, contrasting health and social care and taking the focus away from disability. Originally, in 1983, Mike Oliver proposed that the opposite of the social model is the individual model, not the medical model. He contrasted disability with impairment. To address disability, fix society, not the person. (By all means address impairments too, it helps many of us stay alive). But when we are talking about disability, it is a social issue. It demands social solutions. If our disabled colleagues are struggling to work with us, maybe we need to stop suggesting solutions to them as individuals and start exploring how we might be part of the problem.

We had a rule at my last job that all student work would be submitted online. Ah, the wonders of technology. It might have saved paper and complicated hand in procedures, but I'm not so sure it was better. Marking meant spending hours reading from a screen. When I first got ill, my visual problems made this painful and difficult. I had admin support to print out all the student work so I could continue marking. Another disabled colleague had admin support to manage other tasks. Another disabled colleague in another job in a community team had a designated parking space. See what I did here? I jumped to the individual solutions for the story. Can you imagine the ongoing conversations that took place to make sure these arrangements were initiated and sustained? Because these solutions came about through changing work practices, not changing the individuals.

I now want to think about what we might change.

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The illustration here shows four figures connected to circles in different ways. One figure is sitting down, another seems to be balancing, another is squashed. There's one which might have fallen off the circle. There's another circle not attached to anyone and another one with a big face looking out.

My theory of choice today for thinking about change describes the relationships between form, function and meaning. I find it helpful for two main reasons:

- It pinpoints what can be changed with intention
- I have found it interesting and helpful to explore the links between occupational forms and alienation.

I'm going to resist going there but I'll share the reference for my Casson lecture where you can find the details.

So, if we can distinguish between the forms, functions and meanings of occupations, we can focus where we make changes. What's the difference between occupational form, function and meaning? I'm going to start with function as that's most straightforward.

Function does have two meanings. If we have function, we can do something. But in this theory, function is what we want to achieve, or purpose. It's important that everyone in the team knows the function, which might require communicating in different ways for different people. In co-producing this session, we identified that we wanted to have a balance between the talk and panel discussion, in order to include different voices. This session is one of a series hosted by the Royal College of Occupational Therapists, and the function of the series is to raise awareness of diversity and inclusion in the profession.

Meanings explain why in another sense: why it is important, the significance. We can spend a lot of time discussing meanings. Everybody has their own sense of the meaning or meaninglessness of an experience, but we might not feel empowered to share our individual meanings. For the past few years, occupational therapy has been preoccupied with meaningful occupation, as part of occupational science and changes in how we provide our therapy. But we rarely stop to fully question what meaningful occupation is. Whose meaning is the occupation full of? How do we know what meaning it is full of? How can we aim for meaningful occupation, when meaning is so subjective, elusive and something we understand in retrospect? I cannot know, now, as I write this, what meaning you will get from my words. Even with the co-production process, we can only hope for certain meanings, we can’t be sure.

Forms are the way we do something. The particular features that distinguish one occupation from other things we do: where, when, who, what happens in what order, what we use to do it. This session takes forms unimaginable even just two years ago. It echoes well established, ancient forms of speeches and dialogue, but uses new tools like zoom, chat boxes, screen sharing. These things we can take control of. Learn about, obtain, plan, adapt. Making this session together took different social forms, as we moved through the different stages of sharing ideas, refining them and discussing practical details. Different people came and went. These features of the occupation were forms we could change.

I want to suggest that too often we get diverted by discussing functions and meanings, overlooking our collective responsibility for very practical discussions about forms. Yet as occupational therapists we specialise in designing and adapting occupational forms that are inclusive and accessible. This is where we can really use our professional knowledge and skills in a helpful way, in partnership: exploring and revisiting possibilities for access and inclusion. We know working in this way is worth it because of its meaning: life is enriched when we made more effort to engage with the wider social and occupational world. We also know that in order to fulfil the function of broadening the horizons of our profession, we must sustain and develop our awareness of how to address ableism. Attending to the forms our work takes will make us aware of what is ableist and how to address those forms. This attention is not easy, because our work is so familiar to us: fresh eyes are often helpful here.

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At the beginning of this talk, I suggested that if we reflect as much as we act, then we are open to the different implications the change might have. The illustration is of distant trees or maybe a crowd of people reflected in dark water.

So I want to finish by briefly reflecting. *I’ve included several perspectives in this talk:*

There are different terms used in relation to disability and experiences of being disabled vary hugely, but the social model of disability is generally accepted. This model suggests it is not the individual who needs to be fixed, but external factors such as the built environment and attitudes. As respected professionals, we have the power to address these factors, but also to be part of them with ableist attitudes and practices. We switch between engaging with people as living bodies and thinking about general rules that apply to everyone, as if people were machines. This is particularly true when it comes to our work settings and practices. Familiarity can limit our capacity to see how our occupational forms could be different. Engaging in dialogue and reflection with our disabled colleagues could bring fresh eyes to the situation.

This will not be a perfect process and takes effort: it is challenging to know what to do and how to do, and who is going to do it. Addressing ableism and other forms of discrimination is not a separate part of our working life. Any of us can become disabled at any time but none of us can fully know how it feels or what it means for others. We might think we can protect ourselves but thinking it won't happen to me prevents us from engaging with many aspects of disability. I'm not suggesting it's time to engage in speculation about what might happen in the future. I'm asking us to look at our working life, see what's happening and see the challenges for living with disability, and consider how we can situate ourselves in relation to those challenges. This isn't a case of us and them: as a disabled person, I can oppress and create challenges for other people just as much as you can.

So my question for you and the panel is:

How can we work together to practice what we preach?

Thank you.