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# Reflections and intersections: disability, 'ableism' and metamodern leadership

Chloe Orkin  <sup>1,2</sup>

<sup>1</sup>Blizard Institute, Faculty of Medicine and Dentistry, Queen Mary University of London, London, UK  
<sup>2</sup>Barts Health NHS Trust, London, UK

## Correspondence to

Professor Chloe Orkin, Blizard Institute, Faculty of Medicine and Dentistry, Queen Mary University of London, London, UK; c.m.orkin@qmul.ac.uk

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## ABSTRACT

In this article the author, the eightieth President of the Medical Women's Federation and a clinical academic, reflects on disability, gender, and leadership. She draws on lessons from her sixteen-year NHS career in HIV Medicine in East London, UK. She explores her experiences and challenges as a Consultant Physician who became invisibly disabled and reflects on how her chosen leadership style has evolved in parallel. Readers are encouraged to reflect on invisible disability, 'ableism' and how to navigate conversations with colleagues.

One in five people in the UK report a disability.<sup>1</sup> In contrast, within the NHS, only 2.9% of the clinical workforce and 3.6% of the non-clinical workforce report a disability to their employer.<sup>2</sup> In academia, 4.5% of academics in Science Technology Engineering and Mathematics report disability and the percentage is lower (3.1%) in those working at the most prestigious universities.<sup>3</sup> Why do so few employees choose to report their disability to their employers?

Cue the term 'ableism' which is defined as 'discrimination against people who are not able-bodied, or an assumption that it is necessary to cater only for able-bodied people'.<sup>4</sup> Like racism and sexism, ableism is a form of structural barrier that disempowers disabled people.

As someone who lives with invisible disability, I know the trepidation of completing the disability section in a job application. I know the discomfort of completing the health section in my annual appraisal that informs my revalidation. This is because the declarations on health and probity (honesty/integrity) are presented together. As someone who takes my duty of care extremely seriously, seeing this coupling of the two declarations creates a sense of deficit around ill health of doctors. It implies that being disabled or having long-term health problems goes hand-in-hand with a need for heightened probity, until proven otherwise. To me this feels unfounded and punitive. As President of the Medical Women's Federation, I am part of the equality diversity and inclusion advisory forum for the UK's medical regulator, the General Medical Council (GMC). Within this forum, I have heard others raise similar concerns about the coupling of probity and health declarations. The 'Your Health Matters' guidance piece from the GMC seeks to provide reassurance. It advises that action will not be taken against disabled and unwell doctors provided they are managing their condition and engaging with occupational health/medical advice.

Perhaps unsurprisingly, disabled medical role models are in short supply. Hearing and learning from the experiences of disabled colleagues is a vital step in breaking down the stigma around being a sick doctor. As a medical woman I know the importance of visible role-models. I am willing to be seen and heard as a medical woman and profiled as an LGBTQ+ doctor. Yet until now I have remained resolutely silent about my disability, which has been both visible and invisible at different points in my journey. Shame and fear of being disbelieved or disempowered has underpinned my reticence. I think this piece will come as a surprise to many who know me professionally. I have done my best to conceal my physical difficulties from all but my closest colleagues.

I was not disabled when I took up my consultant post as an HIV Physician at St Bartholomew's hospital in 2003. In fact, I was raring to go. It was my dream job. In-patient work and a remit to establish clinical trials to develop life-saving novel HIV therapeutics. On the wards, I had a few quirky habits like sitting on the wide skirting boards or squatting at beside level to talk with patients if no chair was available. I did not want to be a looming figure towering over sick people lying in hospital beds. My juniors interpreted my actions as kindness and sometimes commented that it was unusual to see such a concerted effort to be at eye-level with patients. This interpretation was a partial truth. The other truth was that I found it very difficult to stand for the lengthy and complex conversations needed to take care of very sick people.

Growing up I always knew I was a bit of a contortionist and was certainly no stranger to orthopaedic issues. I had experienced more subluxations, sprains, strains and dislocations than anyone I knew. More insight came during my orthopaedics block as a medical student in Johannesburg. I vividly remember a rambunctious clinical session where students were asked to pair up and explore the range of movement of each other's joints. My colleagues quickly cottoned on to the difference between my range of movement and theirs. My clinical tutor overheard the squeamish giggles emanating from the little crowd of students gathered around me. He took the opportunity to demonstrate hypermobility to the group on the beaming model that I was. I felt like I had just discovered a superpower. A few years later while studying for my specialist exams, I saw photos of the fish-eye scars, stretch marks and stretchy skin that resembled my own. 'Ehlers-Danlos syndrome' was written in the caption below the photographs. I shoved this dawning realisation to the back of my mind.



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I spent the first 7 years of my consultant post, working with colleagues to establish the clinical trials unit that has become my life's work. Successful HIV therapy is one of the triumphs of modern medicine and we now have few ward patients and many outpatients—a sign of better times. Meanwhile my own health was deteriorating incrementally. I tried to ignore it but by the time I was willing to face it, I was struggling with multisystem problems and had come to look gaunt and skeletal myself. I saw my general practitioner and shared my suspicions of a unifying diagnosis to explain much of that I was experiencing. I asked for a referral. My suspicions were confirmed at an appointment in which I had my wing-span measured with my arms splayed against the wall, was examined from head-to-toe, and filled in pages of questionnaires. A somewhat mediaeval instrument, a scolimeter, was used to evaluate my spine curvature. I came away with a diagnosis of Ehlers-Danlos syndrome, Marfanoid features and sporting three eponymous signs I had never heard of.

During the space of 6 months, I was referred to a gastroenterologist, an autonomic neurologist, an orthopod, a cardiologist, a gynaecologist, an oral medicine physician, a dermatologist, a colorectal surgeon, a dentist, a podiatrist and a physiotherapist. Collagen, it seemed, was ubiquitous. Each doctor ordered further investigations and invasive tests, and doled out various medications and prostheses.

My line manager referred me to the occupational health physician who asked me how my condition was affecting my work. She asked me to describe my workday starting with my journey to the clinic. I told her how I squatted on the train because I couldn't stand for the length of the journey, getting off to vomit into a sick bag and then getting back into squatting position to continue the journey. On the wards, I was no longer able to stand around talking with the team. Cranio-cervical instability meant I found it increasingly difficult to support my neck while seated and had severe pain and neurological symptoms when carrying even a very light bag.<sup>5</sup> I was frequently nauseous and had started fainting. I had little effort tolerance.

The occupational health doctor said the word 'disability', describing it as a protected characteristic which carried with it a duty around reasonable adjustment and referred me for an occupational assessment.<sup>6</sup> The occupational therapist assessed me and provided a thirteen page report, recommending a suite of 'reasonable adjustments'. The most major of which was an electronic reclining chair that would allow me to work recumbent with full neck support. She directed me to an equipment shop for people with disabilities. The electronic chairs were not what I was expecting. They resembled chairs I had seen in care homes and rehabilitation facilities. I hesitated to bring one to my workplace, but I knew that I had no choice if I wanted to keep working.

The 'special chair' (as we all called it) was delivered to my shared office by a kind man who demonstrated its features, including incontinence-proof lining. The sight of this chair in my workplace challenged my pretence at being able-bodied in a profound way. My computer was placed above me on a tray-table like those used on the wards to feed patients. My colleagues understood that I was too ashamed to meet new people while recumbent in the chair. I used an additional upright chair with neck support in the office for meetings and in my clinic room. The receptionists knew not to bring anyone external in while I was recumbent in the chair and to give me time to move to the upright chair. The occupational health report had suggested a solo office for 'dignity' but there was no space for this and I was very grateful to stay in the shared office with my colleagues. It

felt normal. We spent a lot of time discussing ways I could keep going on the wards. We concluded that I would stop ward work and do clinics and lead the clinical trials. I will always be incredibly thankful for their sensitivity and support when I was at my most unwell.

Using the recumbent chair reduced my neck pain considerably. With the help of the gastroenterologist, my most unpleasant problem started to improve. Within a year, the sick bag was no longer needed during motion. I put on weight, started looking better and people stopped asking me what was wrong with me. I started Pilates and morning walks to build up stamina and effort tolerance. Standing without leaning and sitting without neck support remain problematic. However, while walking and sitting in my upright chair, I looked 'normal' again.

And just like that, my disability shifted from visible to invisible. And that is when things got tricky. It was much harder to explain my difficulties in doing seemingly simple things. Things like carrying a heavy set of notes or a laptop, sitting for many hours in a meeting without neck support, sitting in an upright position on a long flight, standing around at conferences, or eating certain foods. I met with scepticism. People who had not witnessed the worst of my problems first-hand seemed to think that my weird constellation of invisible problems must be exaggerated, psychological or both.

Then COVID-19 hit. As an HIV Physician, I should have been among the first to be redeployed to the wards. My clinical director knew that I could neither stand for long periods nor tolerate an FFP3 mask on my fragile skin. I was assigned to do virtual HIV clinics and manage my clinical trial patients from home. I experienced a tsunami of moral distress at not going to the COVID-19 wards until I was asked to co-ordinate clinical aspects of research delivery across the Barts Health hospitals—something I could do from home. Eventually this involved establishing systems to deliver a vaccine trial in a community library—a mammoth logistical task. It was a privilege and joy to work with talented, committed colleagues across the Trust, most of whom I had never met and may never otherwise have encountered. After five intense months of hard work, we finally opened the doors to the vaccine trial centre. I turned up in person on the first day and quickly understood that I could not work from the library. I was confronted by the reality of how much the reasonable adjustments help me and how impossible it felt without them. I did not know where to start in explaining this.

Some of my new colleagues were vaguely aware that unspecified health problems had stopped me being redeployed to the wards. In all the months of working with these new colleagues on Microsoft Teams, I had never elaborated on what these problems were. Amid the urgency of the pandemic, it had seemed irrelevant and gratuitous to mention it to people who were not my managers and did not need to know. However, when these people saw me walking about at the vaccine trial centre, I looked 'normal'. The early days onsite were exceptionally challenging and fraught. When I did not base myself at the vaccine centre, some relationships started to fray and comments were made about my 'choice' to work from home. Although the negative sentiments were not held by all, I felt powerless, guilty, ashamed and as though I had failed the team. Over time, I also began to feel like something very unjust had happened.

It took a year for me to understand that what I had experienced was structural ableism and exemplifies how invisible disability can lead to disempowerment. People are sceptical of what they cannot see. I was too ashamed to push past the scepticism and be explicit about why I could not work from the vaccine trial centre. I was cowed by how exposing and borderline inappropriate it

had felt to talk about my reasonable adjustments in my usual workplace. It forced me to ask myself as a team leader, how and when I could have better facilitated these discussions to foster greater understanding within the team.

It made me reflect on my own leadership style. Although I have been elected to lead two national organisations, I have had no formal leadership training. Having read about leadership theories, I realise that my leadership style has morphed over the years. In my early consultant years, my natural leadership style was collaborative, and this really worked for me. During the pandemic, at a time of crisis, my leadership style changed to most closely approximate the servant leadership style.<sup>7</sup> In this style, people are driven to ‘serve first, lead second’—to prioritise and serve the organisation’s highest purposes first and foremost. Servant leadership can facilitate meaningful stability in a team during times of rapid change.<sup>7</sup> On reflection, I concluded that adopting the servant leadership style had effectively effaced who I was and hidden an unwanted but important part of my identity. This may have been a key driver of my experience of ableism.

My disability is neither wanted nor convenient. The ableism I experienced was both internalised and all around me. My story is about more than disability and ableism. It is about my experiences as a disabled woman. Through the lens of health feminism, I understand that the shame and fear I felt around being disbelieved originates from how unwell women are (and have always been) perceived in society.<sup>8,9</sup> Women’s bodies have been seen as mysterious and women’s illnesses have been ascribed to mental weakness, instability, and anxiety.<sup>9</sup> The psychiatric label ‘hysteria’ was exclusively used to describe women with undiagnosed medical problems, many of whom turned out to have autoimmune diseases which affect women disproportionately.<sup>9</sup> These implicit biases about women’s reliability as narrators of their own stories still lead to epistemic injustices and women like me being considered to be unreliable historians.<sup>10</sup> Disabled men may experience different pressures related to traditional constructs of masculinity which we know affects how men express symptoms and access healthcare.<sup>11</sup>

As a female LGBTQ+ leader who is living with disability, I am ostensibly different from the majority male, straight, able-bodied leaders around me. What I have taken from this experience is that I would like to lead in a more authentic way, a metamodern way that incorporates role-modelling into my leadership style.<sup>12</sup> As President of the Women’s Federation, this activism seems prosaic in comparison with the activism of the early medical women who were suffragettes fighting for equality as voters, for the right to drive a car, to own a property and to be on the medical register.<sup>13</sup> Nonetheless, making the choice not to disown this unwanted aspect of my identity is not easy. However, I hope and believe that owning my full identity as a leader will show others that there is a place for people like me and like them in the medical workforce and in leadership. I hope too that readers will take away that talking about health problems that cannot be seen is complex and can feel shameful. The conversations touch on physical vulnerability and are unlikely to feel comfortable to either the speaker or the listener. However, they are essential to enable disabled people to access what they need in order to do their jobs. Ableism is a far less well-known, less commonly used word than racism or sexism. Like racism and sexism, open

conversations and honest reflection are needed to drive change. If you have never heard the word ableism before, then please give it a name when you next notice it in yourself or in others. The words we choose shape our actions and our world.

**Twitter** Chloe Orkin @profchloeorkin

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**ORCID iD**

Chloe Orkin <http://orcid.org/0000-0001-6168-6745>

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