

Therapy for EVERY BODY

How can therapists help clients with disabilities live in a society crippled by prejudice? asks **John Barton**

Last year a friend messaged me to say she had a spare theatre ticket. We met for a meal and arrived in the upper stalls just before the curtain went up. But the only way to get to our seats was to walk up a steep aisle, then along the back, then down the steep aisle on the other side. The latter - a series of irregular, steep, narrow steps with no handrail - was my downfall.

I wobbled and stumbled. I felt under pressure; my performance was in front of an actual audience. I fell backwards and was suddenly sitting in a man's lap. He and an usher tried to lift me to my feet. A woman with a clipboard and a walkie-talkie appeared. I had created 'a situation'. When I finally got to my seat, rejoining my bemused friend, my overriding thought was, 'I don't belong here any more.'

These are the kind of microaggressions that many people with a disability - one in seven humans - face every day. Then there are all the macroaggressions. Since time immemorial, people who are 'different' have been excluded, shamed, pitied, patronised, punished, attacked and killed. In supposedly fair-minded and tolerant Britain, disabled people have been deliberately targeted in a decade of austerity that dismantled public services, decimated local council budgets and destroyed any meaningful sense of welfare. The basic provisions many needed to live were withdrawn while at the same time, disabled people have been scapegoated as benefit cheats and scroungers in media, government and cultural discourse. A 2017 United Nations report concluded that the UK Government has 'totally neglected' disabled people, precipitating a 'human catastrophe'.¹

In my doctoral research project on the experience of progressive disability - including my own - what emerged was an overriding

picture of isolation, secrecy and invisibility. A kind of grand dissociation. The physical losses and impairments relegate people to 'disabled world', while discrimination and the way identities are formed serve to keep them there. They are denied the opportunity to participate, to have their unique skills and knowledge used, appreciated and rewarded. Their opportunities for growth are now circumscribed.

Disability apartheid

Society thus operates largely under a system of disability apartheid. As Tom Shakespeare, author of the book *Disability: the basics*, says, 'Good societies enable people to cope ... by removing barriers, providing supports, and by treating disability as part of normal human variation, rather than an abnormality to be discarded.'²

Therapy is often part of the problem, rather than a part of the solution. Therapists are often quick to offer clients victim-blaming explanations for their ill health or unhelpful metaphors that all too often, as Susan Sontag points out in *Illness as Metaphor*, can be moralistic and punitive.³ 'Psychological theories of illness are a powerful means of placing the blame on the ill... Nothing is more punitive than to give a disease a meaning - that meaning invariably being a moralistic one.'

'Psychological theories of illness are a powerful means of placing the blame on the ill'

I was genuinely surprised and disappointed to discover both the paucity and prejudicial nature of psychological research into disability. Our profession is supposed to be enlightened, progressive and inclusive; our disciplines exist to serve the dispossessed, the alienated, the outsiders of this world. Yet people with disabilities, human beings often most in need of support, compassion and love, remain largely uncared for, untouched and untouchable. While the therapy profession is increasingly interested in working with difference and diversity in an enlightened way, especially in terms of contexts of race, sexual orientation, class, gender and age, this multicultural interest does not seem to extend very far towards disability.^{4,5}

The extensive reading lists provided for my counselling psychology programme included not a single reference on disability. The field of body psychotherapy, which could be enormously beneficial to those with impaired bodies, is almost entirely silent on the subject. Its totalitarian rejection of anything other than idealised, normative, healthy and pain-free bodies is oppressive.

Olkin and Pledger identify two broad kinds of disability research.^{6,7} What they call 'paradigm one research' tends to be static, pathology oriented, and to be about but not by people with disabilities. These studies reflect either the moral model or the medical model - research into what 'we' think about 'them': attitudes toward the disabled, the countertransference of therapists with disabled clients, or client transference towards a disabled therapist. A recent study⁸ found that therapists working with people with neurological conditions can be unsettled and worry about their own health; the clients are present only as mute vectors of therapist unease. 'Paradigm two research', by contrast, enquires about

health and resilience as opposed to deficit. It reflects the 'minority model' or 'social model' of disability; it highlights the agency, voice and lived experiences of disabled people and actively strives to improve their conditions, services and place in society. It is often conducted by disabled researchers.

There is precious little research on disability and the vast majority, argues Olkin, belongs squarely to paradigm one.⁶ Such work, she says, often not only fails to produce any positive changes but reinforces unhelpful stereotypes. Researchers form a negative hypothesis about a pathology that they don't have, and then construct research around verifying that hypothesis, which becomes a fait accompli. This kind of research assumes that a pathology causes suffering. 'Prejudices, stereotypes, and myths about disability are infused into every stage of the research process until the inevitable outcome is to verify these misconceptions.'

My research focused on the degenerative neurological condition Charcot-Marie-Tooth (CMT). It is an unfashionable disease with a peculiar name, bereft of celebrity spokespersons. It turns its chosen few into people who are ungainly, clumsy and slow. Few have heard of it, and it often comes with a lot of intrafamilial shame and blame. It isolates and excludes, and it only ever deteriorates. It affects every aspect of one's way of being in the world, and the only constant is change as the unstoppable condition unfurls.

I identified four fundamental pillars that create and shape the psychological experience of living with CMT (and by extension any disabling condition): loss, discrimination, identity, growth. The nature of the response to the first three dictates the extent to which the fourth can happen - it can inhibit growth or sometimes accelerate

'There is sometimes an almost wilful lack of empathy from some healthcare professionals that borders on cruelty'

it. People with progressive conditions need help: to mourn and accept the losses; to contend with the daily discriminations; to build an authentic, cohesive, integrated and unconflicted identity; to discover, believe in and nurture the potential for growth within. These processes require, or at least can benefit from, ongoing psychological support.

Dysfunctional machines

When you are diagnosed with CMT - typically via a nerve conduction test and/or a genetic test - the NHS website says: 'You may experience feelings of shock, denial, confusion or fear.' You might then be 'taken on' by a neurologist for periodic check-ups and outpatient care. You may undergo a series of tests of your functionality. You may be offered physiotherapy, occupational therapy, ankle-foot orthoses and other walking aids. Surgical options will probably be presented. A multidisciplinary team will be at your service. But it's most probable that at no stage will counselling, psychotherapy or any kind of emotional support be offered. The very last bullet-point item on the NHS CMT page (www.nhs.uk/conditions/charcot-marie-tooth-disease) is 'your emotional health', for which it provides a phone number and an email address to the charity CMT UK.

It is my view that the medical model of disability that treats people like dysfunctional machines inevitably stigmatises people with health conditions like CMT and exacerbates the psychological challenge of coping. Too often, healthcare systems in the West are literally soulless. Particularly around diagnosis, there is sometimes an almost wilful lack of empathy from some healthcare professionals that borders on cruelty - and which, anecdotally at least, can exacerbate symptoms.

At the same time, the system does not care to offer any professional psychological care. As Thomas and Siller write: 'The role of psychoanalysis in the treatment and rehabilitation of those with disabilities (physical or other) has withered in the face of the imperative of physical and functional improvement, the institutional context where care is often given, and the multifaceted nature of rehabilitation.'⁹

Below I offer 12 recommendations for practitioners, built around the four themes identified from my research participants' experiences, and from my own, too. They are

intended for any counselling psychologist, psychotherapist or counsellor working with a client who has CMT, but they might prove helpful for a broader group of service providers, including consultant neurologists, physiotherapists, GPs and researchers, and a broader group of service users, including anyone with a progressive health condition or disability.

Loss

1. Arm yourself with knowledge of disability culture, the medical and social models and the client's condition. Read Rhoda Olkin's *What Psychotherapists Should Know About Disability*.⁶ Find some disability-related CPD days. There's no excuse for ignorance, warns Olkin; it 'can be expected to have the predictable problems inherent in cross-cultural counseling, such as premature termination, insufficient rapport, or negative outcomes'.⁶

At the same time, don't make any assumptions about the client's relationship with their condition, illness or disability. One of the worst things is dealing with other people's reactions. The assumption that life must surely be hardly worth living is bad enough; the opposite - the demand to be relentlessly cheerful and upbeat - isn't much better. Two of the most common countertransference issues with clients with disability revolve around pity, leading to unhelpful expressions of sympathy, and curiosity, leading to an unwanted, insensitive interrogation. While there may be similarities in the problems they face in a disabling world, every client is (dis)abled in their own, unique way. Each therapeutic dyad is unique, dictating a bottom-up psychology that emerges from the relationship rather than a modernist, top-down imposition of theories, techniques and methods from expert clinician to grateful client.

2. Consider where you are coming from. How have you and people close to you been impacted by health issues, and how might that impact the work? What are your attitudes and assumptions? Notice and reflect on your transference reactions, but try to keep things real. Your job is to be a solid, steady secure base. From that place, you can offer emotional support and embark on a strong working alliance, a co-created venture, a joint exploration. The work may be all about the client's physical condition, or it may not be about that at all.

'Role models can help the client see what is possible; they in turn can become role models to others'

3. Invite the client to acknowledge what has been lost, to connect with all the emotion surrounding that; to mourn. There are no shortcuts. People with health conditions or disabilities are often regarded as objects of shame; inevitably shame can be internalised, where, by definition, it often remains hidden because it's so shameful. Be alert to clues to shame and endeavour to cultivate a relationship in which it is safe for shame to be explored.

Discrimination

4. Introduce the client to the idea of disability apartheid and explore their relationship to the 'abled' and 'disabled' world. What do they believe, say or do that sustains the two-world status quo, and what do they do to subvert the mainstream and promote 'one world'?

5. Take a systemic approach. Who is around - family, friends, colleagues, carers, service providers? Explore with the client what support they have in their life, and what they need. Respect boundaries; be on the side of client agency and autonomy. Are they good at asking for help? A life audit can be helpful - who are the people (and what are the activities, places and things) that are life affirming? And what brings them down? Who or what is discriminatory? And what can be changed? What promotes resilience?

6. Join the client in solidarity in understanding and empathising with the daily insult of hassles, discriminations and challenges they may face as a disabled person. Utsey, Bolden and Brown¹⁰ suggest that counsellors should become activists, seeking to deconstruct the oppressive social order in their own worlds. Both the therapist and client thus strive for emancipation. As Olkin says, 'There is no such thing as an unpolitical therapy.'⁶

Identity

7. On an ongoing basis, but especially around diagnosis, explore with the client their relationship with their physical self. How do they see their identity as a diseased or disabled person, and where do those ideas come from? What is introjected? What is projected? What would their body say if it could speak? Take a 'community of selves' approach - how do they conceptualise all their other identities and how do they all integrate and work together? The victim, the angry self, the withdrawn self, the rapturous, the suicidal, all are welcome in the consulting room.

8. Invite the client to tell their whole story.¹¹ How does being ill or disabled fit in their life story and their sense of self? What sense or meaning is to be made? What is their narrative identity? The therapist does not have to collude in the client's self-blaming or self-critical moralistic interpretations.

9. Introduce Judith Butler's idea^{12,13} of 'queering' - rejecting the bleak identity assigned to you by the medical establishment, friends and family and instead wearing your cloak of disease and disability in your own, unique way. Role models can help the client see what is possible; they in turn can become role models to others.

Growth

10. As the therapeutic relationship develops, you might like to invite the client to explore whether any good things have come from their condition or disability. What are they grateful for? Where is the growth - what are their progressive abilities? Where is the love? Introduce the concepts of hormesis,¹⁴ advantageous disadvantage¹⁵ and post-traumatic growth.¹⁶

11. Health conditions can be an opportunity to care for yourself, after perhaps years of neglect. And I believe caring for yourself can slow the progression of symptoms. It can be useful to be reminded about the importance of the basics: healthy eating, drinking, sleeping, exercising. In a direct, CBT way, the therapist may take on the role of a coach (or parent).

12. In searching for meaning in disease and disability, a way to live, a purpose, *ikigai*, the client may be supported in accessing and developing greater meditative, spiritual, numinous, religious or transcendent aspects of themselves and life. For all the pain and suffering, sometimes disease can be healing. ■

REFERENCES

1. www.disabilityrightsuk.org/news/2017/august/human-catastrophe-%E2%80%93new-un-condemnation-uk-human-rights-record
2. Shakespeare T. *Disability: the basics*. Abingdon: Routledge; 2018.
3. Sontag S. *Illness as metaphor*. Harmondsworth: Penguin; 1978.
4. Goodley D, Lawthorn R. *Disability and psychology: critical introductions and reflections 2005*; London: Palgrave Macmillan.
5. Siebers T. *Disability theory (corporealities: discourses of disability)*. Ann Arbor: University of Michigan Press; 2008.
6. Olkin R. *What psychotherapists should know about disability*. New York: The Guilford Press; 1999.
7. Olkin R, Pledger C. Can disability studies and psychology join hands? *American Psychologist Special Issue: Fundamental challenges in disability and rehabilitation* 2003; 58(4): 296-304.
8. Ashworth J. Implications of providing psychotherapy to people with neurological conditions. *Counselling Psychology Review* 2017; 32(4): 70-77.
9. Thomas KR, Siller J. Object loss, mourning, and adjustment to disability. *Psychoanalytic Psychology* 1999; 16: 179-197.
10. Utsey SO, Bolden MA, Brown AL. Visions of revolution from the spirit of Frantz Fanon: a psychology of liberation for counseling African Americans confronting societal racism and oppression. In: Ponterotto JG et al (eds). *Handbook of multicultural counseling*. Washington: Sage Publishing Inc; 2001.
11. Frank A. *The wounded storyteller*. Chicago: Chicago University Press; 1995.
12. Butler J. *Gender trouble*. London: Routledge; 1990.
13. Butler J. *Bodies that matter: On the discursive limits of 'sex'*. London: Routledge; 1993.
14. Mattson M P. Hormesis defined. *Ageing research reviews* 2007; 7(1): 1-7.
15. Bjork RA. Memory and metamemory considerations in the training of human beings. In: Metcalfe, J, Shimamura JP (eds). *Metacognition: knowing about knowing*. Boston: MIT Press; 1994.
16. Tedeschi RG, Calhoun LG. Posttraumatic growth: conceptual foundations and empirical evidence. *Psychological Inquiry* 2004; 15(1): 1-18.



About the author

Dr John Barton is a counselling psychologist and integrative psychotherapist in private practice in London. He is a former writer and editor for Condé Nast USA and has written for *The New York Times*, *Golf Digest*, *Psychologies*, and *The Society of Existential Analysis Journal*.