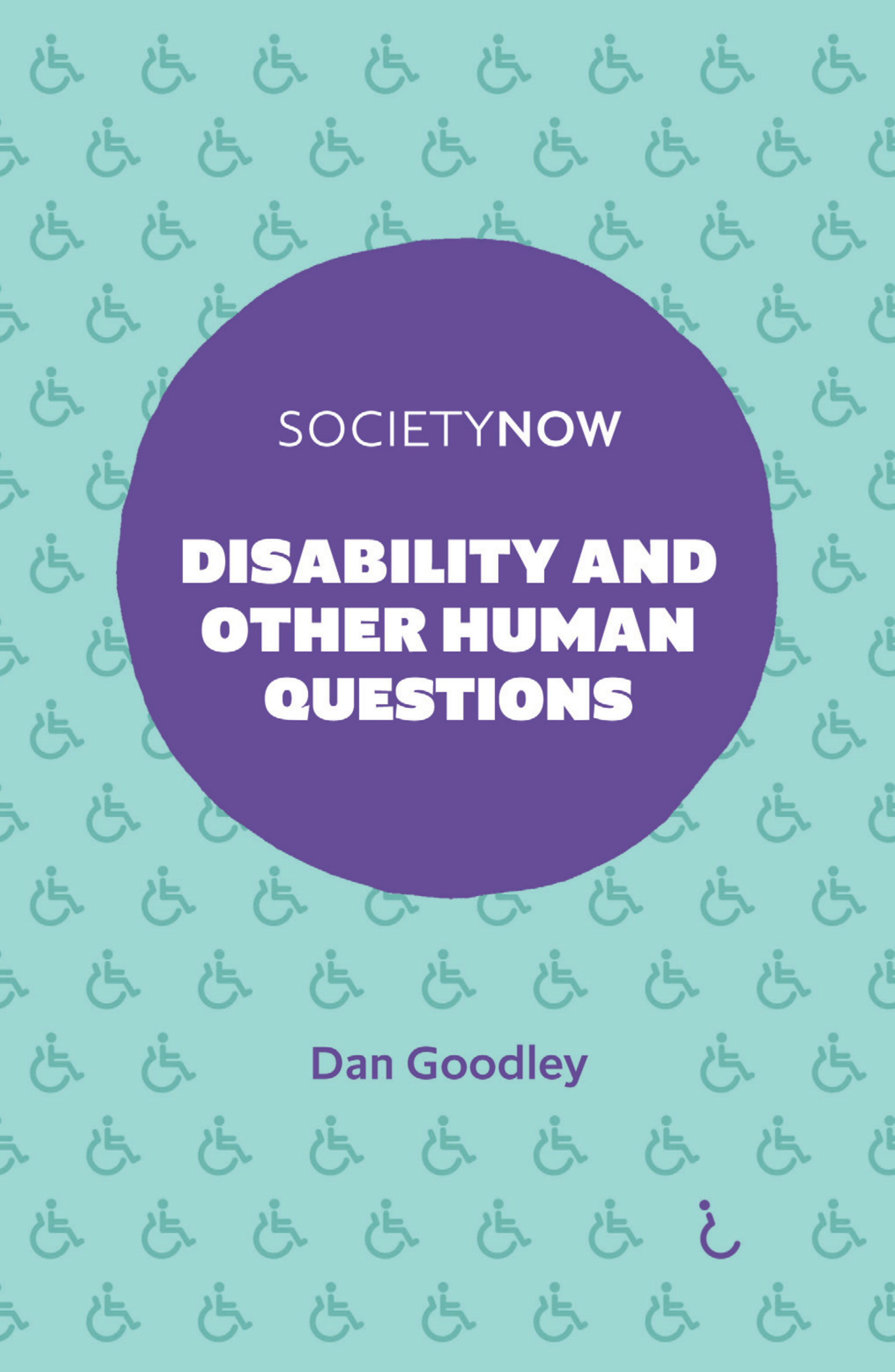

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DISABILITY AND OTHER HUMAN QUESTIONS

Dan Goodley

DISABILITY AND OTHER HUMAN QUESTIONS

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This social theory text is quite a page-turner. In a skillful balancing act, it combines academic scholarship with vivid accounts of lived experience. Insightful, but also provocative, compassionate and witty in equal measure, Goodley's narrative engages productively with multiple interdisciplinary fields of critical theory, making for compelling reading as it goes. It positions disability as a process-oriented indicator of shared concerns and emergent trends in contemporary discussions about being human and becoming posthuman. Most of all, it argues for a relational ethics towards humans, nonhumans, animals and machines – a passionate call for community in these turbulent times.

Rosi Braidotti, Distinguished University Professor, Utrecht University

Dan Goodley is one of the most original, opinionated, thoughtful writers in all of disability studies. I can't think of anyone better to introduce you to disability, and to explain why thinking about disability makes us better at thinking about humanity.

Tom Shakespeare, London School of Hygiene and Tropical Medicine

DISABILITY AND OTHER HUMAN QUESTIONS

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To the beautiful soul that is Jonah Senior.
May others wild and rewild in your inimitable style.

CONTENTS

About the Author *xi*
Preface *xiii*
Acknowledgements *xix*

1. What Brings Us to Disability and Other Human Questions? 1
2. Who's Allowed to Be Human? 21
3. What Is Human Desire? 41
4. Are Human Beings Dependent? 57
5. Are We Able to Be Human? 75
6. What Does It Mean to Be Human in a Digital Age? 91

Conclusion 111

References *129*
Index *143*

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Dan Goodley is Professor of Disability Studies in the School of Education and co-director of iHuman: the interdisciplinary research institute for the study of the human at the University of Sheffield. Dan has written numerous books on disability including *Dis/ability Studies* (2014: Routledge) and *Disability Studies* (2016, second edition: SAGE). He is a Nottingham Forest Football Club and Sleaford Mods fanatic.

PREFACE

This book draws on two decades of research and writing. I include personal stories, scholarly literature, social media and other cultural narratives. And I weave together these stories with concepts from the interdisciplinary field of disability studies. I pull in data from research studies, opinion pieces, official reports and ideas from psychology, sociology, education, psychoanalysis, philosophy and cultural studies. I assume that you, the reader, will have no prior engagement with disability studies nor any of these academic disciplines. I *do* presume that you will be interested in disability and other questions of the human. My thesis is simple: disability invites great insight into the wider project of understanding the human condition. I will make clear through my writing that you *should* engage with disability studies; not simply because the study of disability is of great importance in its own right (which it is) but because disability has much to offer us when we contemplate what it means to be human in the twenty-first century. Throughout the text I write into a number of themes that I consider to be timely. Six chapters address a singular human question:

(1) What Brings Us to Disability and Other Human Questions?
(2) Who's Allowed to Be Human?

(3) What Is Human Desire?
(4) Are Human Beings Dependent?
(5) Are We Able to Be Human?
(6) What Does It Mean to Be Human in a Digital Age?

I approached this book project with an overriding desire to write something readable. You might think that this is a rather trite statement of intent. After all, doesn't any would-be-writer seek to write something readable? The truth is that academics – a profession that I sometimes admit to being part of – are notoriously bad at putting the reader before the writer. By this I mean to say that academics tend to write for one another. And this circulatory practice means that academic writing is not really the kind of stuff one wants to be subjected to (unless one is engaging in the academic pursuit of theory and knowledge generation). Who would really want to be stuck in an elevator with an academic for an extended period of time? I am not suggesting that academia is a useless practice. Nor that academics are, by definition, prone to bore others to tears. That's for you to decide. The point is; there is nothing better, more liberating, insightful, therapeutic, generative and powerful than a good theory. Nevertheless, the academic production of theory has produced a community of writers and readers that are in danger of engaging only with one another. So, I have written this book with a different audience in mind; at least different from the usual academic audiences I envisage when I am usually tapping away on my computer writing the latest academic book or journal article. I have in mind someone who likes reading, is curious about the human condition and is sympathetic to a dull academic trying to do something a little different from what he normally does. If you are a reader and curious then that is enough for me. The sympathy vote would be a bonus. I have also written this book with a different kind of writer in mind: someone with something to write in a style that people might want to read.

It is important to acknowledge that this book was written at a particular moment in global and national politics. I am writing this after the landslide election of the British Conservative party. Now, regardless of your politics (or mine for that matter), I think it is fair to say that many of us are grappling with questions of community, inclusion and social justice. Add to this the global pandemic of Covid-19 and we are living in troubled times. This text is my attempt to engage with a number of big human questions and to centralise disability in these discussions. I want to ask questions of desire, autonomy, ability, dependence and technology as they impact upon what it means to be a human being. And I want to respond to the questions in a way that is generative; that gets us thinking about how we might productively engage with, listen to and understand one another. Community is exactly what we need in these turbulent times.

The first chapter asks what might bring us to disability and other human questions? If disability studies is a theoretical, activist and artistic community – as many within the field would describe this space – then what brings us to this space? This question provides as much as it asks. It says something about the history, foundations and aspirations of disability studies. This question is one commonly asked in feminist, queer, black, working class, trans and other kinds of radical scholarship that exist as a consequence of oppression and are developed as response to this discrimination. One comes to disability studies for numerous reasons. No one account is the same. And one person's entrance into disability studies will have a particular hook to it. So, in this chapter I introduce the field of disability studies through writing some of my own familial stories of disability.

In Chapter 2 I ask who's allowed to be human? I ponder the meaning of the human category and consider who is invited to have access to this category. I seek to explore the ways in which normal, everyday and typical understandings of the human being are, in reality, incredibly exclusionary: including some and omitting others. And this potential for the human category to divide and rule – to let in some and force out others – is a category that is currently, worryingly and deplorably being rewritten in popular discourse. The consequences are potentially wide-reaching and terrifying. And so our responses have to be immediate and inclusive.

Chapter 3 explores the phenomenon of human desire. The dominant story of desire in our late capitalist societies is one aligned to the desire of those things we lack; power, recognition, status, money, consumables, property, vacations, Twitter likes, Botox, Apple's latest, BMWs, lip fillers, perfect partners, Gifted and talented kids, smooth pathways through life and an orderly death. I ponder, is this really what we want? Might there be another way of doing desire? I explore how human nature might actually be better understood as the desire for connection with other humans and non-human animals. I suggest that it is possible to have more altruistic forms of desire that are not muddled up with the materialism of everyday life. And, again, the chapter addresses these questions through reference to narratives of disability. A case is made for a more productive and positive conception of human desire: one which is at the heart of disability studies.

Are human beings dependent? This is the question framing Chapter 4. I kick off with a discussion of addiction; specifically a reliance upon alcohol. My own reliance on the booze. A story is told to comprehend the negative associations that are, understandably, associated with this all too familiar story of dependency. In order to get to the meaning of dependency then we need to also grapple with the meaning of independence. Indeed, as the chapter explores, independence is en vogue in our contemporary times as we witness the claims for autonomy and self-sufficiency that have been propelled forward through the ideas associated with Brexit, Trump and Austerity. I reflect on stories of addiction, austerity and TrumpBrexit and separate these out from a more enlightening discussion of dependency. I write about the dangers of separation – giving up on a reliance upon others – and the problems of false attachments. I then explore how disability gets us to think differently about our dependencies. I consider how we might desire dependency. And I explore how we might organise ourselves around our shared precariousness and desire for interdependency.

In Chapter 5 I ask 'are we able to be human?' Studies of disability have, obviously, tended to emphasise disability. We live in a global world where disability is becoming more and more ubiquitous. Some disability labels have become increasingly widespread (e.g., autism) and we know from the World Report on Disability (written by the World Health Organisation and World Bank, 2011) that there are one billion disabled people (constituting the world's biggest minority group). But what do we know disability's antithesis: ability? This concept is what we might call the hidden referent of disability: the object that quietly and unassumingly exists in opposition to disability. But what is ability? What does it mean to be able? And what human abilities do we value? This chapter revisits the nebulous concept of ability – a phenomenon that we really subject to critical analysis – in order to consider the ways in which we all often uncritically deploy this term without realising its potentially negative impacts.

Chapter 6 contemplates the following; what does it mean to be human in the digital age? Three billion people are now connected to the internet. There are, undeniably, huge digital divides that still exist between rich and poor people. Having said that, digital participation has grown exponentially across the globe. And many of us hold a view that we already know the digital world. It envelops every aspect of our daily lives. We are rarely far away from the flickering demands of a screen or the beckoning notification of a smart device. The digital world divides us into different technological classes: those that are fully plugged in and those that are not. And yet we continue to tap away, download, upload, click, open, close and reopen. And like any dominant cultural practice – that we think we already know – it is incumbent upon us to revisit our assumptions with a critical perspective. In response, then, this chapter considers some of the historical, applicable and consequential aspects of digital technologies by addressing three subjects: 'digital subjects', 'digital activists' and 'digital victims'. Throughout I will return to my primary question: the question of disability.

The final chapter revisits some of the key themes of the book. I revisit these themes and do so with reference to a number of recent events, imaginations and reflections. My reflections move through Chapters 2–6 and consider the story of Bethany (Who's Allowed to Be Human?), the 'Living life to the fullest' research project (What Is Human Desire?), the Brexit debacle (Are Human Beings Dependent?), school (Are We Able to Be Human?) and Twitter in a time of Covid-19 (What Does It Mean to Be Human in a Digital Age?). Throughout, as usual, I will be foregrounding disability as the phenomenon through which to think about our shared humanity.

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I am truly grateful to my mother Debbie Goodley who took the time to comment on every chapter. Ma; your insights have been incredibly helpful and insightful and I can't thank you enough. You have offered some incredibly thought-provoking critical feedback. I can't thank you enough. Much love. A big hug to Rod Michalko for encouraging me to write a book in a style outside of my comfort zone. So, here it is Rod, I do hope you like it. To Dorothy Corbett, Mary Doddemeade, Dorothy Davies, Adam Wallace and Horace Goodley and their conduits – good socialists Al and Deb – who helped shape the telling of their stories that appear in this text. To Huddersfield People First members past and present. Cheers to Tanya Titchkosky, Katherine Runswick-Cole, Kirsty Liddiard and Paul Martin for counsel and feedback. To Sleaford Mods for agreeing, via Twitter, to the use of lyrics in Chapter 5. Cheers Jason and Andrew. To Ros and David and all the Senior family for reminding me of the expansive nature of our human relationships. And to Rosa Cariad and Ruby Haf Lawthom Goodley who – along with their mother Professor Rebecca Lawthom – continue to be my harshest critics and most precious things.

1

WHAT BRINGS US TO DISABILITY AND OTHER HUMAN QUESTIONS?

One *comes to* disability studies for numerous reasons. No one account is the same. And one person's narrative of engaging with disability studies can be told in many different ways; depending on whom one is trying to impress. Why should we contemplate disability and other human questions? If disability studies is a community of writers, political activists and artists, then what brings us here? This question gives away as much as it demands. This question says something about the intentions and aspirations of those that study disability. This question is one commonly asked in feminist, queer, black, working class, trans and other kinds of radical scholarship that exist as a consequence of oppression and are developed as responses.

Now, I write as an academic. This is a job title I have held for over 20 years. Academics are notoriously loose in their alliances and fleeting in their affiliations. Some move like butterflies from theory to theory. Others are like cuckoos, taking over another's home and making it their own. Others are stalwarts in their place of residence: stubbornly sticking to what they (think they) know. Some academics have passionate attachments to particular theories (or ways of thinking about the world). Others fall into methodolatry – a put-down term coined by the American sociologist C. Wright Mills (1959) – to describe those commonplace academics who uncritically worship and slavishly commit to their chosen methodological persuasion (whether it be the experiment or the confessional interview). Others come to disciplines, fields and communities of knowledge-making (sometimes called paradigms) because they are really pissed off; because they feel injustice and they want to do something about it. Others fall into things by chance. Some are reluctantly pulled into fields of enquiry. And many others find solace in communities simply because they share common values with one another. Looking back I realise that I was *ready* for disability studies. And this might be explained in terms of my biography, my training in psychology and my politics. But I also think my story captures a common narrative of why many might find themselves in the world of disability studies. So, I want to personalize a response to the question of being in disability studies mindful of the more collective engagement with this field of enquiry by many people over the last couple of decades.

FAMILY

Disability studies resonated with my experiences of disability and family. Let me give you a little from my own backstory.

HODGE

My grandfather experienced a stroke that had a huge impact on his speech. He was a central part of the first 13 years of my life. I only ever knew him with his distinctive style of talk. And his voice – and our relationship – was going to play a big part in how I came to engage with disability and society. I remember total strangers mocking his voice. A shopkeeper – in a newsagents in North Wales – shouting loudly into his face as he was sure my Grandad was deaf (ironically, though he wasn't, his wife, my Grandmother, was). I watched family members struggling to understand him. There was the time when we sat on a wall eating fish and chips by the harbour front in Whitby (on England's North West coast) and a nearby group of teenage boys mimicked his speech. To me he was speaking normally. I knew no different. He was always Grandad or 'Hodge' (short for Horace). Full name: Horace Eugene Goodley. And he had, as I came to learn later, a 'severe speech impediment'. Ah, the totalising language of medicine. Now, curiously, my comprehension of his chat was superior to that of many in our family. I recall a wet morning holed up in his caravan in Scarborough in British summer time. We were sharing a read of a tabloid newspaper's sports back pages. In the UK the back page is invariably centred around football. I noticed how my grandfather's eyes lingered over the image of Graham Souness: the self-pronounced hard man and midfield leader of the invincible Liverpool Football team (apart from between 1979 and 1980 when Nottingham Forest were the champions of Europe).

'Fucking bully bastard' my grandfather pronounced.
We laughed aloud.
'Fucking bullying bastard Souness' he repeated.
My dad, who was sitting across from us, asked my grandfather what he had just said.
'Nothing'. 'Nothing'.
I recall the twinkle in Hodge's eyes. His knowing wink. Our shared secret.

Of course there was more to him than his unusual speech. When camping on holidays he would take his daily morning wash in the campfield. Whatever the weather (and it was often cold and drizzly during a Northern English summer) he would strip off his shirt before neatly folding and draping it over the open passenger door of the family car. With his impressive torso on full show – lean, muscular, strong core – he would ladle out hot water with his huge hands from a plastic bowl borrowed from the caravan kitchenette and lather himself clean with a bar of soap. His hands were often commented upon. They were worker's hands. Perfectly shaped for – or perhaps misshaped by – his time working in the Nottinghamshire coal mines. A job that my own father followed him into.

People used to say Hodge had the look of the American actor Burt Lancaster. And for 17 years Hodge had been in the British Army – some of these during war time – experiences he never really liked to share with his family. He had told us about exotic locations such as Singapore, Australia, North America, Canada and India. And he had documented these travels with tattoos inked over his shoulders and arms. He was, to me, an exotic creature. But to strangers in the street he was an inarticulate old man. An object of confusion, ignorance or ridicule. These adverse responses to my Grandad killed me inside. My feelings of anger and upset are still there with me now, four decades later. The sense of injustice lingers. I can recall the patronising facial expressions of the shopkeeper. The black training shoes of one of the teenage boys (they were ADIDAS). And I can picture my Grandad's shame and humiliation: etched on his handsome features. I can also remember how great those fish and chips tasted on that day in Whitby. And this is but one family story of disability.

My sense is that many of us come to disability studies because we have experienced similar emotions and experiences to those I have described above. Disability appears in the world and makes a difference. This difference that disability makes – a phrase I have borrowed from the disability studies scholar Rod Michalko (2002) – is a difference often understood in terms of difficulty, stigma and social harm. Disability is oftentimes constituted in our social relationships as a problem of individual functioning and a disrupter of social conventions. Disability studies, then, exists as a field of ideas, concepts, theories and debates that sit with disability to try to make sense of our relationships with the phenomenon of disability. We might be brought to disability studies – or bring ourselves and our stories to disability studies – to make sense of how disability becomes constituted as a problem and, crucially, how we feel and contemplate disability. We might come to studies of disability because of feelings of anger, sadness or confusion. We might be searching for relief, clarity, hope or alliance. And, crucially, many disabled people come to disability studies because of their own everyday experiences of being cast as a problem by the societies and cultures that they inhabit. Significantly, disabled scholars, writers, theorists, researchers, practitioners and artists *came* to disability studies and, as a consequence, *made* disability studies through their actions. Some did not know they were *doing* disability studies. Others were more clear about their presence from the outset and were soon to name their location as one entitled as disability studies. There would, of course, be no disability studies without disabled people. And there could never be disability studies without disabled people.

The late Mike Oliver (1990), the first Professor of Disability Studies in Britain, adopted the terminology of another pioneering disabled activist – the Italian Marxist philosopher António Gramsci – to describe disabled activists as ‘organic intellectuals’. I still hold this view that disability studies are grounded in the accounts and aspirations of disabled people as they work through their disability stories. I find it impossible to conceive of disability studies without disabled organic intellectuals. Now, my stories of disability reflect my social position, my status and my biography. One might describe my stories as those of a white, middle aged, straight, British (therefore colonial) cis-male, working-class-born-now-middle-class breeder who has never received any disability diagnosis. Some might argue that my disability stories are second hand. And, to some extent, I would agree with this evaluation. You are reading *my* familial story. *My* recollections dominate the telling. And if stories of disability are dominated by people like me then I think we have a problem. It is precisely because of the ubiquitous nature of disability in our life stories that people already have much to story about disability. Sometimes when people announce that they have much to say about a phenomenon – the latest global news story, a Facebook status, an influencer's Instagram recent, a controversial Tweet – they/we risk confusing this with expertise: an authoritative view on the matters at hand. It is important to acknowledge my status and position. Some readers will describe me as occupying a position of white-able-bodied-and-minded privilege. And I would accept that I enjoy such a privileged position. Whenever I type my narrative I risk recreating what the Jamaican novelist and philosopher Sylvia Wynter (2003) defines as the white man's institutionalisation of himself in terms of himself as absolute being. And that is not a good look. Non-disabled people like me have much to do in order to think about their relationships to the phenomenon of disability and the lives and aspirations of disabled people. Too often, particular world views have been pushed by powerful non-disabled people that threaten to dominate the stories told of disability. I am thinking here of medics, politicians, priests, therapists, teachers, journalists, academics, screenwriters, song-writers, film-makers, curators and authors. Fresh stories of disability need to be recounted. And non-disabled people need to ponder the stories that they tell about disability as well – and more importantly – attending to disability stories recounted by disabled people. Finding oneself in disability studies can involve engaging anew with disability and the stories that we tell of disability. We all have our own accounts to tell of disability, but how often do we get these stories evaluated by others? An opportunity for critique is as good a reason as any to be in disability studies.

Hence, my stories should not be written off because they are only from one life and offered by one teller. Nor should they be dismissed because of my non-disabled status. My story of family and disability has much to say about participants of a given social and historical time and of the kinds of meaning making that were taking place around disability in those moments. While familial characters lurk around in the background of the narrative (like my Dad) and others take centre stage (as my Grandfather does), others populate what the French sociologist Daniel Bertaux (1981) describes as the wider socio-historical horizon of the narrative. The teenage boys and shopkeeper are living enactors of more nebulous cultural practices that we might define as ignorance, stigma and discrimination. Reducing my disability story to a descriptor that coins it to be just that of a white, cis-gendered male risks misrecognising the wider relational qualities of my story or indeed any story that is told of disability. Misdiagnosing my narrative as *just* a story of a non-disabled teller does a great disservice to the centrality of disability in my family. And it potential risks denigrating the powerful impact my Grandfather had on his own family's engagements with and understandings of disability. My point is that we *all* come to disability studies with innumerable stories of disability already lived, told and at times repressed as part of our personal biographies. Disability is, as David Mitchell and Sharon Synder (2000) remind us, ubiquitous. One reason for entering the fold of disability studies relates to subjecting this ubiquity to interrogation. Disability studies us to be inquisitive about our own disability stories.

While disabled people and their representative organizations have led the way in restorying of disability, we must not leave the non-disabled like me off the hook. It is entirely incumbent on all of us to subject our disability stories to analysis. And, I would assert, it is particularly the ontological duty (or personal, subjective and psychological priority) of non-disabled people to unpack their own understandings, conceptions, prejudices and troubles in relation to disability. Why? Because, quite simply, non-disabled people's disability stories have throughout history been powerfully influential and immeasurably problematic for disabled people. Some non-disabled people might presume that they are distanced from the lives of disabled people. Disability studies would firmly disagree with this viewpoint. Non-disabled people are, rightly or wrongly, central to the enveloping nature by which disability – and our understandings of disability – emerge in the world. The non-disabled amongst us have a moral obligation to countenance how they relate to the phenomenon of disability. And it is the telling of our stories that we will find our common humanity.

PSYCHOLOGY

I also came to disability studies as a recovering psychologist. I am only half joking. Thirty years ago I fell into an undergraduate psychology degree at Manchester Polytechnic as it was then known. Up until about two weeks before I moved to Manchester I had been all set to train as a dentist in Leeds. But my soon to be Arts School girlfriend at the time had turned my head. She had no doubt that the relationship between