Disability studies and human encounters[1]

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ABSTRACT

What does it mean to be human in 2020? How might disability help us answer this question? What knowledge is already out there – from scholarly studies of disability and the global politics of the disabled people's movement – that we might draw upon to think again what it means to be human? And if one element of humanity is our desire to relate to and with one another, how might we extend our human relationships in these difficult geo-political times? Might we foreground disability as the driving subject in conceptualising and practicing our mutual engagements with one another during the current pandemic? These are just some of the questions we are trying to address in our interdisciplinary research centre dedicated to the study of the human at the University of Sheffield; iHuman. And these are questions that I will seek to tackle through this brief exposition of disability studies.

Introduction

What does it mean to be human in 2020? How might disability help us answer this question? What knowledge is already out there – from scholarly studies of disability and the global politics of the disabled people's movement – that we might draw upon to think again what it means to be human? And if one element of humanity is our desire to relate to and with one another, how might we extend our human relationships in these difficult geo-political times? Might we foreground disability as the driving subject in conceptualising and practicing our mutual engagements with one another during the current pandemic? These are just some of the questions we are trying to address in our interdisciplinary research centre dedicated to the study of the human at the University of Sheffield; iHuman.[2] And these are questions that I will seek to tackle through this brief exposition of disability studies.

But first a few background considerations to get out there. I write this at a time when Britain has left the European Union. I remain a committed 'remainer' and I acknowledge here the damage done by Brexit. This damage is not simply economic. It is worse than that. It is cultural and psychological. Brexit builds up barriers and walls between the UK and the rest of the world. The message it sends out to other countries and their citizens is xenophobic, isolationist, elitist and plain racist. Brexit has hit me and many of my friends and family hard. This pain is felt psychoemotionally and politically. *It just feels so inhuman.* And the impact will not just be felt by those in Europe looking onto the island

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[1] This paper is an unpublished, minimally updated version of the original, written for a prospective book titled *Disability Studies: A Reader*, edited by Anita Ghai, and, indeed, was cited in Whitburn and Goodley (2019) as such.

[2] http://ihuman.group.shef.ac.uk/

of Britain. We risk changing the perspectives of all people from all countries who, understandably, will view the UK as a segregationist island nation state literally and metaphorically cast off as distinct from others. 'No man is an island' wrote John Donne but Britain definitely feels like one. And let us acknowledge too that Brexit and Trump are not coincidental events. The latter fed off the former and worked on a cocktail of disconnection, unemployment, racism and a lack of trust in the political elite.

After stating all of the above, over the last couple of years in the UK we have witnessed a re-energisation of left politics; evidenced by affiliations with the Black Lives Matter movement. While it is a shame that we are still Brexiteers, there is definitely – and defiantly – an optimistic atmosphere in Britain that appeals to a collectivist politics. This is exactly the kind of activism associated with the disabled people's movement and social theories emerging from the scholarship of disability studies. In this paper I want to indirectly address the questions of disability and the human posed at the start of my chapter. By indirect I mean that the questions posed are hugely complex and difficult to answer in absolution. Instead I use the questions as provocative statements that will push me to consider how we might draw on disability theory to think more productively of how we live with one another as human beings in these politically turbulent times. While scarred by Brexit, Trump and the pandemic we might seek solace and inspiration in social theories of disability. While some of these theories are explicitly political in the sense of seeking to understand and eradicate the discrimination faced by disabled people, I also understand disability as a phenomenon from which to think about how we might live our lives together (Goodley, 2020). So, let us engage with a number of disability positions with the question of the human kept firmly in the foreground of our considerations.

Disability studies

Robert McRuer's 2018 book *Crip Times* documents the many ways across different nations in which disabled people have been at the vanguard of political responses to austerity, marginalisation and inequity. While disability is often ignored by radical politicised collectives, McRuer rightly makes the case, in my opinion, that disability is *the* source of radical manifestos and alternatives to global capitalism and neoliberalisation. But this argument is not new. As Mike Oliver (1990) argued in the *Politics of Disablement*; if one is thinking of addressing oppression then one would do well to start with disability politics. Just as working class, feminist and black politics have re-centred the marginalised other as the epicentre of community from which to rethink how we live our lives together, so the disabled people's movement provides another kinship network for growing positive alternatives. Oliver saw no distinction between his Marxist politics sharpened in his trade union work and his disability activism refined through his involvement with the disabled people's movement. This approach to disability studies – originating in Britain and incubated by a powerful disabled people's movement – politicises the lives of disabled people. It considers the dehumanising practices associated with contemporary modes of economic production, cultural practices and social norms that treat disability as a pathological object in need of cure and rehabilitation. Practices of medicalisation (where we narrowly conceptualise disability in terms of impaired senses, physiology or cognition as understood through limiting medical concepts) and psychologisation (where disability is reduced to nothing more than a problem of the mind and body) constitute disability as deficiency. Disabled people, unsurprisingly, often experience relational moments with other people (especially non-disabled people) as demanding and difficult. Why? Because disabled people are related to as a problem: a deficiency, a lack or a failing of the body or mind. The rules of the game are already set – disability is a problem that society seeks to solve (Michalko, 2002). Disability studies unpacks, understands and then refutes the foundations on which are built the social oppression of many disabled people.

Studies of disability seek to understand the conditions of disablism: the exclusion of people with impairments and the undermining of their sense of self and personhood (see Thomas, 2007). The three remaining perspectives that I outline below build on these social oppression theories to develop what we now understand as critical disability studies (Meekosha and Shuttleworth, 2009; Shildrick, 2012; Goodley, 2012, 2014, 2016). Critical disability studies is a sub-theme or emergent area of scholarship and activism that starts with disability but never ends with it. Critical disability studies came as a response to postmodernism (see Shildrick, 2012) and late capitalism (articulated by Meekosha and Shuttlework, 2009). In addition, I would posit, critical disability studies seek to establish the human at the centre of analysis. While social oppression theories have been fundamental to the theoretical landscape of disability studies – indeed, it would be fair to say that there would be no disability studies without their foundation – at times one wonders where the human is in these largely structuralist analyses of oppression and discrimination. Too often disability is worked on as an object and condition of capitalism; this risks dehumanizing the very subject of disability studies – disabled people. A critical disability studies response might, in part, be conceptualised as rehumanising the field. So, let us consider three critical disability studies sitpoints that permit us to merge the desire to understand disability and the human.

Crip studies

Crip perspectives articulate the possibilities of disability (McRuer, 2006, 2012, 2018; McRuer and Wilkerson, 2003). The word crip is pulled out of its pathological associations with the derogatory term 'cripple' and is reappropriated as a term of deference and disruption. Much has been made of crip theory's potential in terms of the arts and politics but one of the excited applications as far as I understand it is the celebration of disability to reenergise human relationships. To 'crip' relationships is to attend to the myriad ways in which disability might offer new ways of relating with one another. Through our relationships we might understand and approach the essence of one another in different ways to the ones we might have started with. One example I like to think of is the example of profound intellectual disabilities. Consider the anonymised case of John who has this label. John does not use words to speak but communicates through technology and via close friends, family members and supporters who are in tune with his style of communicating. He lives in his home situated some 100 metres down the road from his parents. 24/7 John has different personal assistants, supporters, carers, family members who come in to offer support. John keeps down a job delivering promotional materials around the neighbourhood. He goes to local music concerts and is often found in the local pub with family and friends especially on a Thursday night. Traditionally, and by that I mean from an individualising or medicalising stance, profound intellectual disabilities denotes lack, deficiency and incapacity. Such perspectives have little to say about the humanity of people so-labelled. A crip perspective reads profound intellectual disabilities in a different way: to consider what disability gives to the world and to other human beings. From a crip orientation John provides employment opportunities. He boasts an extended network of friends and supporters. He provides numerous prospects for other people to relate to him and one another. And John enjoys rich affiliations with his community. He also participates through his work and leisure. Crip studies short-circuit well-worn pathological tropes associated with disability. Crip studies encourage us to find the potential in our human relationships. Our human connections constitute complex assemblages. We become who we are through the material and immaterial interdependencies that hold us in place, tension and connection with other humans (and non-humans for that matter) (see Michael Feely, 2016). Such a viewpoint resonates with new materialist theories that attend to the relational networks that we are plugged into (see Susan Flynn, 2017 for a wonderfully written overview of these emergent ideas). Social oppression theories of disability risk conceptualising disability as a marker of exclusion. In contrast, a crip perspective encourages us think of disability as a marker of extended relationalities. Disability demands interconnection. Disability petitions for interdependency; cripping the commonsenseical notion that a life worth lived is a life lived independently. And it is these very taken-for-granted ideas associated with independence that critical disability studies must contest, as we shall consider in the next perspective.

Critical studies of ableism

Critical studies of ableism ask us to consider the kind of individual valued by contemporary society. Global austerity measures and neoliberalisation of our everyday life have led to a receding welfare state (in those countries that had one in the first place) and a retracting government (a move from left-leaning involvement in private matters of the home). Individual citizens (and those close to them like their families) are left to take control as self-sufficient autonomous agents who are responsible for their standards of living, well-being and work. Independence and individual sovereignty mark the preferred citizen of our times and encourage particular kinds of relationships with one another. We are encouraged to draw ever thicker lines of the boundaries between ourselves and others. In times of austerity it makes no sense to be contaminated by the neediness of others. In contrast, we must occupy the idealised consumer-labourer of late capitalism; the self-sufficient global citizen responsible for themselves (and their immediate family where relevant). Ableism is, according to Fiona Kumari Campbell (2009), the ideology of individualism that demands able-bodied and minded self-governance and autonomy. Ableism lurks behind every articulation of individual achievement. It shapes the social contours of everyday life to the extent that even those of a radical disposition embrace its logics. Critical pedagogues, Marxist revolutionaries and anarchistic activists are prone to ableist assumptions that state that given the right social and political conditions human beings are ready, willing and able to take on responsibility for their own emancipation. But these assume an able participant with the potential to take up the challenge. Rarely are society's activists disabled people. Critical studies of ableism seek to throw a proverbial spanner into the workings of contemporary political life.

Recently I have developed the concept of neoliberal-ableism to account for the elision of national economic independence with individual and cultural celebrations of autonomy (Goodley, 2014). This particular cultural economy ties individual and national progress to independence and, by virtue of this, associates happiness with self-sufficiency. The kinds of human valued by contemporary culture become ever more narrow and individualised as the ideology of ableism threatens to colonise our mindsets. To ask for help, assistance or support is a request at odds with a wider cultural politics that values self-sufficiency. Fortunately, critical disability studies has the potential to chip away at the façade of ableism: revealing its empty promises. In reality we all fail to match up to the ideals of neoliberal-ableism. Cast off as atomistic individuals responsible only for ourselves, we risk being reduced to an ontological loneliness.

Critical studies of ableism remind us that autonomy is a myth perpetuated by late capitalist reformations of the role of the State in the lifeworlds of individual citizens. Independence is an empty signifier that we would do well to resist. We do not have to simply accept the globalised discourse of self-governance; we can pursue a politics of 'For the many not the few'. Here we may learn much from our disability studies scholars writing in the Global South. The work, for example, of the Indian scholar and critical feminist psychologist Anita Ghai (2002, 2006, 2014) provides but one key resource for us to contest the individualisation of everyday life. Her work develops an interdependent analysis of psychology that owes as much to her Indian context as it does to her psychological training. Her work reminds us that the self can only ever develop in relation to the other and this intertwining of self/other is key to more collectivist notions of personhood found in countries outside of the confines of Western Europe and North America. Ableism is yet another imperialist project that requires resistance. In contrast, the ground-breaking work of Ghai and other Global South scholars repositions analyses of disability in the majority world. Contributors to the open access journal open up new ways of approaching disability.[3]

Dis/ability studies

My third theoretical approach considers the ways in which we encounter one another. Human beings have a desire to relate to and with one another. This is not the same as saying that all human beings enjoy relating to other human beings. Nor should we assume that there is some standardised acceptable way of relating with others. Whether one likes

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[3] *Disability and the Global South*, https://dgsjournal.org/.

another human being or not, human activity inevitably is and leads to the making of various relationships. And out of these relationships we come to know one another. Let me introduce something into this consideration of relationships. Let me bring in disability in the form of blindness: something I am learning about through a set of particular relationships. When I think back over my lifetime, I know that I have had some kind of relationship with blindness. I remember childhood books and TV shows where blindness was presented to me as a tragedy. I recall conversations between friends along the lines of 'what would you prefer, blindness or deafness' (a strange question when none of us had experienced either). I have in my memory TV news items and documentaries about medical treatments for blindness (perhaps claims for cure) and I also remember watching a show on guide dogs. I try to think harder here, to unblock any repressed memories, but I soon find myself moving into a period of my life that I will term 'From the social model onwards'. During my first degree in psychology I came across the social model of disability and, like many, found this utterly liberating (Goodley, 2020). This approached segued neatly with my Marxist student politics at the time. Its structural offerings complemented the economic explanation of Karl and Fred. The social model repositioned disability as a social rather than individual pathology. But where was blindness in this? How was blindness represented?

Blindness is known by the social model as a sensory impairment that fits badly with a society geared up for sight. Children with visual impairments have endured an historical legacy of segregation: separated from their sighted peers into specialist schools (captured in the emotive piece of Colin Barnes, 1996). I devoured texts that explained the pathologisation of impairment, the discrimination and oppression of disabled people by a wider society designed for able-bodied and minded people. I also learnt to hate special education as a dangerous specialised knowledge that constituted people with impairments as merely objects of expert knowledge from medicine and psychology. Yet, thinking back, I learnt nothing about blindness. I knew an activist with a visual impairment but when we spoke, we only spoke of disablism. I once tried to speak of impairment with a work colleague with a visual impairment who reminded me of the social model mantra developed by Mike Oliver (1996) that disability is a public concern but impairment is a private and personal matter. I shut up quickly. Fair enough.

And then I met Rod Michalko and his partner Tanya Titchkosky, both disability studies academics from the University of Toronto. We quickly bonded over a shared love of the Beatles and storytelling and then, in what seemed like a whirlwind, my partner Rebecca Lawthom and our two kids Ruby and Rosa were sharing holidays with Rod and Tanya. This is when I started to actually learn about blindness. And its hidden referent; sightedness. *Learning* is the key term here. I am not sure if I have *learnt* anything. I do know that with Rod, Tanya, Rebecca, Ruby and Rosa we are learning about blindness amongst other stuff. This other stuff includes the weather in Winnipeg, the Northern Quarter in Manchester, Nottingham Forest Football Club, American baseball, parenting young adults, being a young adult with parents who are learning to be parents of young adults, low salt recipes, pulling out crab meat, Canadian rock n roll, Welsh culture. And blindness. And sightedness. Let me say something about learning about blindness.

I suppose in one sense, before knowing Rod and Tanya, I had been formally (perhaps academically) learning about blindness through reading Rod's texts (e.g. Michalko, 1999, 2002) and Tanya's (Titchkosky, 2003, 2011) and their joint work (Titchkosky and Michalko, 2009). This is all very well and good but given a choice between a book or a beer and I would probably go for the latter (okay, definitely beer over books, if I am being truly honest). Rod and Tanya's books have been profoundly impactful because of the message they give about disability more generally and blindness more specifically: that we come to understand ourselves and complex phenomena such as disability, blindness, sightedness, humanity through our relationships with one another. As phenomenological sociologists Michalko and Titchkosky urge us to spend some time with the human condition; to figure out how we relate to ourselves and with one another. This is precisely the rehumanising that I alluded to earlier when introducing critical disability studies. While both Rod and Tanya are cognizant of social oppression theories – and draw analytical traces from these perspectives into their work – they are also interested in the human condition and the place, resonance and possibilities of disability to think again about what it means to be human. These theoretical assertions have taken on more life through my relationships with Rod, Tanya and those close to us, including Rebecca, Ruby and Rosa. Through our spending time together we continue to learn about one another and, I would assert, to learn about disability. And we do so, I think, through our relating with one another. And this connecting with one another – like any good relationship – is about anticipating one another's moves, of checking out with one another what we are doing now and what we might do next. And, most importantly of all, learning is at its most heady and exciting when we are just getting on with being with one another. The word 'just' in the last sentence should not be read as a denigration of the mundane. In contrast, the mundane is precisely where it is at and the level of the mundane is where we do most of our relating and also our learning (a central observation to be found in the work of Rod and Tanya).

So, what examples of learning can I give you? And, just as importantly, which precious stories of friendship with Rod, Tanya and our close others am I prepared to share? Let me try a couple of stories.

Driving blind

We are in a Chinese restaurant in a small town in Ontario, Canada (sadly not Winnipeg which we will holiday in one day). The meal has been a success. Ruby and Rosa have eaten their body weight in ice cream, I managed to find the salt n pepper squid, and Rod, Tanya and Rebecca have been enjoyed the Coors Lite © and red wine respectively. I am on the diet coke. It is lunchtime after all. Finished, we stand up as Rod produces his white stick. He quickly unfolds it from its three-section-snap-down-resting-position and releases it like a piece to tap the floor in style. Rod grabs Tanya's arm and they follow me as we leave towards the door. Impatient, as always, I take the lead. The hired car is just outside in the parking lot. Rebecca and the girls are close behind Rod and Tanya. Rod then has a lightbulb moment. Rod pulls to a stop. He happens to be by a busy table of a family of six. He asks, 'Dan, shall I drive?'. I reply. 'Sure, here are the keys'. I throw the keys. They beautifully land and nestle in Rod's right hand. His left hand clutches the white cane. The family of six onlookers nearly drop their chopsticks in shock.[4]

Welsh nights

It is a late Saturday evening. Rod, Tanya and I are with a group of friends in a big open plan kitchen. It is beautifully chaotic or so I believe. The Barbecue has been worked to perfection even in the rolling winds and rain that hit the patio of the farmhouse. We are staying in the hills of North Wales; a place on the planet where you can experience four seasons in one day. Food has been eaten and the drinks are still following. A guitar is pulled out. Someone is singing. Badly. Glasses are raised. Cheers are made. Pots clash in the sink as the washing up is done.

Rod and I sit together touching shoulders.

'What did you say?' Rod asks.

I lean further in and, slightly tipsy, mumble some story, no doubt dull, of office politics to Rod.

He offers nothing back.

'Did you get that Rod?', I ask.

'Sorry, no, what did you say?'

I reoffer the story.

'What!', Rod shouts.

'Rod, I'm leaving the room', shouts Tanya.

Someone plays a New Order song through the WiFi speaker.

These narratives can be interpreted in a number of ways (see for example Whitburn and Goodley, 2019). However, before reading these stories I want to consider an analytical approach that might help us frame the two stories and this is dis/ability studies (Goodley, 2014). This perspective encourages us to attend to the ways in which disability and ability are always reliant upon one another for their constitution. By this I suggest that whenever we think of encountering disability we will find ability close by. Indeed, in order for disability to reveal itself it has to do so, often, as in direct opposition to ability. And, crucially, ability needs disability as its referent. Dis/ability studies seek to explore the ways in which disability communities, imaginaries and politics are always enacted, shaped and constituted through disability's relationship with ability. In order to demonstrate this argument, let us read the two stories.

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[4] This story was cited in Whitburn and Goodley (2019).
and cited as Goodley, D. (Forthcoming a), in prospective book edited by edited by A. Ghai (see Note 1, for further details).

In many ways *Welsh nights* reads like a good night out. Indeed, it was a helluva party. But what other stories could we offer? The social model might read *Welsh nights* as the constitution of an inaccessible space by thoughtless sighted people. This is probably a fair analysis but it does not – and should not – stop there. Phenomenological studies of disability offer at their very outset the opportunity to consider how we become in the world through our bodies as our bodies touch other humans and non-humans. Dis/ability studies would attend to the ways in which blindness and sightedness imaginaries appear in the background of the narrative. A blind imaginary rears itself when Tanya excuses herself from the table and during the touch of shoulders. This is an imaginary that starts with blindness as the opening encounter. It is an imaginary that does not assume sight. A sighted imaginary is found in those moments when, too often, people in the room fail to communicate. This is clunky communication that fails at particular moments.

In *Driving Blind*, the reason that the joke works is because 'the blind guy' catches the keys on his way to drive the car. For one moment he is misrecognised as a blind man driving a car. Rod's seeming abilities (note the *see* in seeming) contrast markedly with the cultural imaginary we associate with blindness and driving (in short, blind people are not expected to drive cars). But blindness is not simply a signifier of lack or deficiency. Blindness in this story opens up some fascinating moments of human encounter. The white cane signifies the presence of blindness and permits the wonder of the gag to occur. Blindness is an important element of the encounter of those human beings caught up in that moment but it is not the only important element. Other elements relate to expectations around driving. Driving blind is also a story of performance; a moment where expectations of onlookers were disrupted. A time when individuals might not be clear on how to react. A public encounter that was wholly unexpected; one not foreseen. Dis/ability studies seek to consider the interplay of disability and ability, blindness and sightedness, abnormality and normality, the unanticipated and the already expected. And this interplay takes place at the level of human relationships.

Conclusions

In this paper I have tried to unpack a number of theoretical responses to disability. Each has particular merits and provide theoretical angles that sharpen our understandings of the relationship between disability and human relationships. The burgeoning field of critical disability studies has gifted us with a number of analytical tropes to make sense of the problem and promise of disability. By problem, I am referring here to the ways in which disabled people are cast off as unwanted elements of society. Disabled people risk being dehumanised as they are understood only as a conundrum in terms of the demands they make on normative society. The promise of disability lies in its potential to centre relationships in the foreground of our explorations of what it means to be human. And it is this potential that we need to realise especially in these unprecedented times (Goodley, 2020).

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