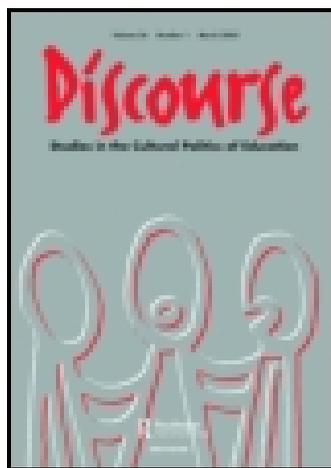


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## Becoming dishuman: thinking about the human through dis/ability

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In this paper, we seek to develop an understanding of the human driven by a commitment to the politics of disability, especially those of people with intellectual disabilities. Our position as family members and allies to people associated with this phenomenon of intellectual disability influences our philosophical conceptions and political responses. This has led us recently to develop a theory of *dis/human studies* which, we contend, simultaneously acknowledges the possibilities offered by disability to trouble, reshape and re-fashion the human (crip ambitions) while at the same time asserting disabled people's humanity (normative desires). We sketch out four dis/human considerations: (1) dis/autonomy, voice and evacuating the human individual; (2) dis/independence, assemblage and collective humanness; (3) dis/ability politics, self-advocacy and repositioning the human; and (4) dis/family: desiring the normal, embracing the non-normative. We argue that this feeds into the wider project of dis/ability studies, and we conclude that we desire a time when we view life through the prism of the *dishuman* (note, without the slash).

**Keywords:** disability; humanism; human; civil society; dishuman; inclusive education

### 1. Introducing dis/ability studies

Our personal and professional associations with the politics of people with the label of intellectual disabilities<sup>1</sup> have driven the writing of this paper. Our aim is not simply to write a theoretical paper for theory's sake (a naval gazing indulgence according to some disability studies scholars, such as Barnes, 2012 and Shakespeare, 2013). However, we do seek to find new vocabularies in order to honour the humanness inherent in dis/ability alongside its disruptive potential. Hence, we find that, at times, there *is* nothing better than doing theory for theory's sake because dis/ability's disruptive potential urges us to engage in such doings. This contrary relationship with theory captures a more generalised ambivalence. We seek to develop an understanding of the human being that is driven by a commitment to the politics of disabled people associated with the label of intellectual disabilities. Let us be honest here – we hate having to use these labels at all, and worry that they violently mark our children, peers, friends and allies. Our position as family members and friends to people associated with this thing called 'intellectual disabilities' directly influences our 'philosophical conceptions of cognitive disability' by virtue of our personal experiences that create an 'inextricable relationship between the personal, the value of the political, and the philosophical' (Kittay, 2009, p. 606). We do, though, note the ways in which the offerings and takings of labels function in disabled people's lives to include or exclude. Moreover, we recognise a tradition in which the presence of disability,

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no matter how we define it, does some profound things to our thinking about the human (Kittay & Carlson, 2010). Intellectual disability is always profound because it enlarges, disrupts, pauses, questions and clarifies what it means to be human. Intellectual disability ‘disses’ (or disrespects) the human but it also desires the human. People with intellectual disabilities seek to be recognised as human: ontologically, materially and politically. In our personal and professional entanglements with people who are associated with the label of intellectual disabilities we have discovered some bound and freed moments as disability and humanity come together. Disability has the radical potential to trouble the normative, rational, independent, autonomous subject that is so often imagined when the human is evoked, social policies are made, social and human sciences are developed and forms of activism are enacted. This is the *dis* of our dis/human approach.

Indeed, people with labels of profound intellectual disabilities offer us exciting new ways of thinking about our humanness in relation to interdependence, mutuality and interconnection (Goodley, 2014). They extend and expand what it means to be human beyond the narrow, normative and rigid view of the neoliberal capitalist self (Kittay, 2002). Simultaneously, many of these same individuals, their families and allies crave recognition from the human register. It feels like they occupy this strange and precarious no-man’s land in-between disability and humanity. One only has to recall recent media stories of abuse of disabled people with intellectual disabilities in the British care system to see evidence of this precarity.<sup>2</sup> On closer inspection, however, we are relieved to find, that intellectual disabilities is a phenomenon that illuminates humanness *and* disability. We describe this reality as a dis/human one which, we contend, simultaneously acknowledges the possibilities offered by disability to trouble, reshape and re-fashion traditional conceptions of the human (to ‘dis’ typical understandings of personhood) while simultaneously asserting disabled people’s humanity (to assert normative, often traditional, understandings of personhood).

Our dis/human approach builds upon our recent theoretical writing (e.g. Goodley & Runswick-Cole, 2012; Goodley, Lawthorn & Runswick-Cole, *in press*; Runswick-Cole & Goodley, 2011) and our commitment to both critical disability studies (CDS; Goodley, 2011) and the fledgling *dis/ability studies* (Goodley, 2014). These interdisciplinary approaches to the study of disability and its antitheses (ability) have emerged in what has been termed second-wave disability studies writing. If the first wave of disability studies was about securing a political and sociological handle on the workings of disability in capitalist society, second-wave analyses were connected with other transformative politicised agendas including feminism, queer and post-colonial politics. Second-wave writers drew across the disciplines of the human and social sciences to develop what we consider to be CDS. Proponents of CDS emphasise the complex social, cultural, material and economic conditions that undergird the exclusion of disabled people – a term Thomas (2007) refers to as *disablism*.

As one of us has argued, CDS hold up the disability identity as a moment of reflection that Davis (2002) coins as *dismodernism*, and impairment and disability are interrogated as phenomena enacted at the levels of the psyche, culture and society (Goodley, 2011, 2012). While CDS might start with disability, they never end with it: remaining ever vigilant of political, ontological and theoretical complexities. And in order to analyse *disablism* we need to be mindful of the complementary hegemony of *ableism*. CDS contest both *disablism* and *ableism*. One key theoretical development of CDS relates to the disruptive, desirable and resistant or *crip* qualities of disability. *Crip* theory is one of the strongest growing insights in contemporary CDS. The work of Robert McRuer (2006)

has catalysed relations between disabled and queer activists. For Sykes (2009), disability studies have:

interrogated what gets counted as a 'normal' body, challenging taken-for-granted ideas about mobility, productivity, and even that anybody is able across different circumstances and times of life. (p. 248)

She continues:

focusing critical analysis and politics on the construction of normative bodies, in this case 'able' bodies, has obvious similarities with queer theory and has recently developed into crip theory, which seeks to analyze, and challenge, connections between the social construction of heteronormativity and able-bodiedness. (Sykes, 2009, pp. 247–248)

Queer and disability studies have the potential to unsettle one another and find shared vocabularies embodied in McRuer's term of crip theory (Goodley, 2014). Recently, this has led us to an emerging analytical approach of CDS which one of us (Goodley, 2014) refers to as *dis/ability studies*.

Dis/ability studies acknowledge the theoretical, practical and political work that takes place either side of the binary, a binary denoted by the presence of '/' (the slash). Dis/ability studies ask us to consider how we value the human and what kinds of society are worth fighting for. One might suggest that many disabled people have been denied the opportunity to occupy the position of the modernist humanistic subject: bounded, rational, capable, responsible and competent. Being recognised as having these ideals is understandably a big deal (it is a mark of being considered human after all) and emphasises one side of the *dis/ability* binary in order to make a case about a valued human. Consider, for example, any Paralympic athlete whose work, preparation and conditioning were recognised in terms of sporting athleticism rather than achievements in spite of his/her disabling impairments; consider parents with intellectual disabilities who have been judged fit enough to keep their children. Each athlete and parent has proven their individualistic worth in their respective fields of sport and parenting. They have shown they are (uber) *able*. We know, too, that this modernist ideal of the human subject that undergirds and feeds our philosophical, sporting, educational and legal frameworks – if left to be the only way to live life as a human subject – would displace large sections of the population who will, perhaps, fail to match the ideal. Disability has the potential to emphasise the other side of the *dis/ability* binary; disability asks of ability: 'Is that all you've got: ability?' 'Are you really that superficial in what you consider to be worthy of merit?' and 'Is individual achievement all you desire and live for?' Dis/ability studies allow both poles of the binary to be held in tension precisely because this is what happens everyday in the mundane and ordinary lives of those who find themselves working with the *dis/ability* complex. Dis/ability, we suggest (and the ensuing analyses provided through *dis/ability* studies), has the potential to fundamentally destabilise things that we have taken for granted. Moreover, *dis/ability* studies permit a moment of critical reflection or reflexivity: to revisit ideas that we might have taken for granted.

In this paper, we argue that a *dis/ability* studies approach allows us to recognise the ambivalent relationships that disabled people with intellectual disabilities have towards traditional notions of the human. A *dis/human* analysis allows us to claim (normative) citizenship (associated with choice, a sense of autonomy, being part of a loving family, the chance to labour, love and consume) while simultaneously drawing on disability to trouble, reshape and re-fashion liberal citizenship and, thereby, to invoke what we call

dis/citizenship (to rethink how we choose, act, love, work and shop). This perspective draws on the lessons from *crip theory* (which we have discussed above) to celebrate the disruptive qualities of disability, whilst acknowledging the complex associations of *disablism* with other forms of oppression including hetero/sexism and racism, and sets out an analytical agenda of contemplating how the *dis* and the *able* are always working in tandem as simultaneous processes that are, at times, in contradiction and, at other times, in line with one another (Goodley, 2014). *Ableism* is, following Fiona Kumari Campbell (2009), a world view, a preferred ontology and methodology for the making of humankind that will eventually, if left unchallenged, bulldoze the disparate variegated nature of humanity. *Ableism* is an entity around which many ethical political souls can organise against. When we start to interrogate *ableism* and *ability*, then *disability* emerges not just as the Other side of the oppressive coin but also as a resistant alternative. *Dis/ability studies* draw attention to the work that takes place either side of the binary. As researchers and activists who associate our work with CDS, we also seek to address criticisms identified by Vehmas and Watson (2013). In their paper, they suggest that CDS writers are in danger of committing ‘normative disorientation’, specifically around the difficulties such writers have with *ableism*. They suggest that in viewing *ableism* as always oppressive, CDS writers such as ourselves are in danger of ignoring normative desires of society for well-being, health and a good life:

Is the promotion of the use of folic acid before and during pregnancy based on an anti-disablist or perhaps ableist viewpoint; and if so, should CDS be campaigning against those who seek to promote these views? (Vehmas & Watson, 2013, p. 3)

We acknowledge that, at times, equating all things *able* to all things *oppressive* is problematic. Moreover, we have found in our work with the politics of people and with the label of intellectual disabilities, an appeal to normative idea(l)s including a right to work, education, a healthy love life, heteronormative desires for family, marriage and parenting. A CDS approach need not inevitably lead us down a path where we ignore the importance of normative, perhaps even, *ableist* ideals, but, and this is the crucial point here, the presence of *disability* always disrupts, shakes up and interrogates the normative position. We may desire normative but what we might define as a *dis/normative* desire demands us to think again about the values and consequences of what we desire. *Disability* inevitably disorients *normativity*. Take, for example, these tricky questions (taken from Goodley, 2014, p. 155):

- When you celebrate one of your children excelling and getting A grades in their end of year exams, are you being ableist?
- If my football team beats your football team and I punch the air with glee, am I embracing ableist normativity?
- By treating his depression with antidepressants, has Brian bought into ableism?
- Does the treatment of Dan’s short-sightedness with eye laser treatment denounce the ontologies of blind people?
- When activists with the label of intellectual disabilities use the term *People First* to describe their politics are they distancing themselves – in a normative fashion – from other disabled people?

The answer to each question, and to the question posed by Watson and Vehmas above is ‘no – as long as the debates, questions and conversations about the *dis/ability* complex

continue' (Goodley, 2014, p. 155). We all feel a fundamental problem of the seductive nature of (hyper)ability in terms of its individualistic tendencies. It:

yearns to internalize: to find a home in each and every one of us; to reside in our interiorities; to fuel our desires; to narrow our ambitions; to shape our worlds; a periscope concern for only *our* child and *our* team, distinct from an Other's. (Goodley, 2014, p. 155)

We argue in this paper that a critical dis/ability studies perspective politicises the experience of living with (or without) an impairment in contemporary society. Critical dis/ability studies then keep in mind the pressure of both disablism and ableism and contemplate how we circumnavigate these often-contrary and conflicting positions.

## 2. Dis/human: a post-human condition

There are times when it is essential to embrace the able or the normal. After all, like them or loathe them, these phenomena undergird the language of citizenship, law and humanity. We also recognise an imperative to 'dis' ability. To 'dis' is a slang term from African-American culture: to put down, fail to show respect, abuse and disparage. At times, we will 'dis' the normal (necessarily refusing to show the normal the respect it expects), while, at times, respecting the normal (when one thinks, for example, about normative notions of human rights, morality and universal notions of basic respect of the human). The prefix *dis* indicates negation, lack or deprivation: to deprive something of its power. We feel this when we disagree. To negate is to nullify, invalidate, render null and void, make invalid, neutralise, cancel out, undo, reverse, revoke, rescind, abrogate, overrule, over turn, avoid and retract. To *dis* is to trouble. There is no doubt, whether or not we like it, that the dis/ability complex does some troubling work to the register of the normal and the condition of the human. This is hardly surprising when, paraphrasing Tanya Titchkosky (2012), making lives on the edges of humanity takes some guile and creativity. A dis/human position means that we recognise the norm, the pragmatic and political value of claiming the norm, but we always seek to trouble the norm. Becoming dis/human does not offer a prescriptive opposite to the conception of the norm, rather it works away at a norm that is always, and only can be, in flux. Disabled and human are, we suggest, too often set up as opposites, as the antithesis of one another. However, following Puar (2012, p. 50), we argue that they need not be oppositional but, rather, viewed as frictional: rubbing up against one another in interesting, dare we say, desirable ways.

In thinking about our recent work with disabled people, their families and their allies, we have come to think of dis/ability studies as having a number of bifurcated complexes (Table 1).

Our thinking is still in the early stages of germination in relation to this list of dis/human concepts. This paper allows us to start pulling apart, interrogating and testing out the conceptual clarity and utility of these ideas. We want to ask what disability does to typical, common-sense normative human categories of adult, youth and family. How might disability affirm some of the ways in which these categories are lived out whilst, simultaneously, demanding new ways of living (dis/life)? When we think of the goals of capitalism, science, medicine and citizenship, what assumptions are these huge societal practices based upon, and in what ways does disability disrupt these assumptions (dis/capitalism, dis/science, dis/medicine and dis/citizenship)? Similarly, were we to accept that disability has the potential to rethink how we might approach labour or independent

Table 1. Dis/ability studies: becoming dis/human and other possibilities.

Dis/ability studies
Dis/human
Dis/life
Dis/citizenship
Dis/autonomy
Dis/neoliberal
Dis/normative
Dis/normal
Dis/choice
Dis/development
Dis/ablement
Dis/labour
Dis/advocate
Dis/qualify
Dis/science
Dis/youth
Dis/family
Dis/medicine
Dis/populate
Dis/recognise
Dis/reason
Dis/adult
Dis/capitalism

living, what would this look like in reality (dis/work and dis/independence)? What do disabled children do to the widely held phenomenon of the ‘normally developing child’ that is at the epicentre of many national educational systems (dis/development)? Equally, though, what normative aspects of the child do we (should we) hold on to (dis/child)? Dis/ability usefully disarms, disrupts and disturbs normative, taken-for-granted, deeply societally ingrained assumptions about what it means to be human and what it means to be able (*dis/human*). At the same time, however, we are mindful of keeping hold of the human: not wanting to abandon it (*dis/human*). Who would want to give up the human? When so much political work has been done around the human and his/her rights, it would seem unthinkable to dismiss the human. But, we also worry about what the human is (or what it has become) and the foundations on which this human is based. We are, of course, not alone in having these anxieties. In the arena of dis/ability studies, Titchkosky (2011, 2012, 2014) in particular has explicitly raised questions about the human as it relates to disability. She observes:

Critical projects such as feminist research, gender and queer theory, and cultural and critical race studies share an interest in questioning how certain people are regarded as on the edge of all that counts as human. Disability studies shares this interest as well; it explores how disabled people figure on the edge of the ordinary orders of daily life, including education, work, leisure, and love, and it studies how such exclusion is normalized. (2012, p. 82)

She is especially concerned about the rigidity of what we often pass off as human. It remains the case today, she argues, that despite the universal human condition of

embodiment, and even with efforts to establish a universal and transcendent sense of human, not all bodies are granted the status of persons (let alone of human). In this sense, she concludes, 'segregated from life, disability appears as though it is detached from the wider question of what it means to be human' (2012, p. 82). Titchkosky's work parallels the post-colonial studies of Sylvia Wynter (2003) who describes her analytical-political project as: Human Struggle vs. Ethnaclass Man (the capitals are in the original paper). Her project circles around two questions: who is excluded from ethnaclass man and, in contrast, who is engaged in human struggle? Those categorised as outside, excluded and often invisible are that:

category defined at the global level by refugee/economic migrants stranded outside the gates of the rich countries ... with this category in the United States coming to comprise the criminalized majority Black and dark-skinned Latino inner-city males now made to man the rapidly expanding prison-industrial complex, together with their female peers – the kicked-about Welfare Moms – with both being part of the ever-expanding global, transracial category of the homeless/the jobless, the semi-jobless, the criminalized drug-offending prison population. (Wynter, 2003, p. 260)

To this list of outsiders we can add, we would argue, those people caught up in the dis/ability complex. For citizens to claim a 'normal' North American identity entails putting up of a 'visible distance between themselves and the Black population group' (Wynter, 2003, p. 260), and then over-presenting their normative selves as the only way to live. Hence, the struggle of our times, 'one that has hitherto had no name, is the struggle against this over-representation' (p. 262). She notes:

The central over-representation enables the interests, reality, and well-being of *the empirical human world* to continue to be imperatively subordinated to those of the now globally hegemonic ethnaclass world of 'Man'. (p. 262; italics added)

Our dis/human studies remain, therefore, ambivalent about the human because too often they represent only a minority and bypass the empirical human world (to use Wynter's vocabulary). Ambivalence is the state of having mixed feelings or contradictory feelings about something or someone. Becoming dis/human is our response to the ambivalent state we find ourselves in relation to the human. We are interested in the experience of having simultaneously conflicting feelings towards this concept of the human. In trying to understand dis/ability, we find ourselves necessarily ambivalent. Ambivalence – we are told by the Oxford English Dictionary – relates to equivocation, doubt, uncertainty, irresolution, vacillation, tentativeness, shilly-shallying, haziness and equivocacy. This latter term also resonates with our feelings about the human. Our intimate experiences of dis/ability have meant that we have found our interpretations lacking and are therefore forced to commit the fallacy of equivocation. The fallacy of equivocation occurs when a key term or phrase in an argument is used in an ambiguous way, with one meaning in one portion of the argument and then another meaning in another portion of the argument.<sup>3</sup> Our equivocacy around the human – and the ambivalence intrinsic to the equivocal phenomenon of dis/ability – has been further illuminated through our work with people with the label of intellectual disability and their allies and alliances. As we shall develop in detail below, they have drawn our attention to the complex work they are involved in around dis/human moments. Like Eva Feder Kittay, our lives with the phenomenon of intellectual disability, both personally and professionally, have demanded us to rethink our philosophical positions on the meaning and nature of what it means to be (dis)human:

When we try to look at the world in the sunlight, we continue to see the very real shape of many things too easily missed by others in the exposure of too much light. Even if philosophy whitewashes disability and therefore passes over children such as ours, with their impairments, with the special care they require, their lives direct us to the point and purpose of philosophy – the pursuit of wisdom. Their lives help us in our quest to discern what the meaning of life is; what makes life worth living or what makes a life a good life; what makes relationships ethical; what personhood is; how to understand beauty, anomaly, function, capacity, joy; what justice and equality are. (Kittay, 2002, p. 239)

Such philosophical work comes from rejecting the fiction that ‘philosophy is news from nowhere’ and, instead acknowledging, ‘we’ve spoken from a position’ (Kittay, 2002, p. 240). One position that we have spoken from before – and one from which our interests in the dis/human originates – is that of post-human theory (see for example Goodley & Runswick-Cole, 2012). Now is not the time or space to capture this complex area of theory and analysis. Suffice to say, though, that those of a post-human persuasion are sceptical about the centrality of the individual in our everyday thinking. The fully functioning person as an entity psychologised, internalised, rational, autonomous and individualised self – distinct, bounded and separated from others – is a classic humanist trope. Appropriating Rosi Braidotti (2003, 2006), this categorisation of the same individual human as distinct from many monstrous Others has a number of origins, one of which is the enlightenment in which rational man emerged as victorious over irrational nature. Following Goodley (2014, p. 63) are not only valued forms of humanness found to have deep historical roots in the rise of science, rationality and capitalism, but they also have been moulded further into preferential categories (reified types of humanity) and their opposite (disposable forms of humanity). Erevelles (1996) carefully guides us through this changing relationship with humanness:

[W]hen even those who espouse radical discourses seem unable to reconceptualise an alternative world without being locked into the political constructions of what constitutes appropriate humanness, then it becomes apparent that the disability movement has a task that goes above and beyond merely extending the boundaries of the discourses that celebrate humanism and instead needs to focus its energy on re-theorising itself. (p. 522)

Post-human advocates are primed ready to debate humanness and the taken-for-granted assumptions that underpin such a ubiquitous though nebulous term (see Goodley et al., [in press](#)). What it means to feel human is also a matter of how one is meant to feel as a human in contemporary society. We suggest that, like post-human interventions, becoming dis/human allows us to interrogate the kinds of human currently valued by society: humankinds that are contested and directly contravened by the presence of disability. At the same time, desiring the dis/human allows us pragmatically and politically to claim the human in the lives of disabled people with intellectual disabilities. This, for us, is key to our project because of the ways in which the status of human has been and continues to be denied in the lived experiences of disabled people with intellectual disabilities.

### 3. Our research study and some emerging dis/human considerations

This paper emerges from the beginnings of a research project *Big Society? Disabled people with intellectual disabilities and Civil Society*.<sup>4</sup> The project runs from June 2013 to June 2015 and is a partnership between four universities (Manchester Metropolitan University, the University of Sheffield, the University of Bristol and Northumbria

University) working with three partner organisations (Speak Up for Action, the Foundation for People with Learning Disabilities and independent living consultants) in the UK. The overall research question is: *How are disabled people with intellectual disabilities faring in Civil Society and Big Society?* Big Society is a contemporary policy narrative associated with devolving state power to communities and creating a small state. Big Society is premised on the assumption that free and equal citizens will participate in their communities and this preoccupation with independent and rational citizen engagement has positioned disabled people with intellectual disabilities in an ambiguous position in relation to Big Society (Runswick-Cole & Goodley, 2011). The research will be carried out through seven overlapping and interconnected phases as follows:

Phase 1: *Key stakeholder interviews*: interviews with disabled people with intellectual disabilities, members of the third sector, policy-makers and lawyers.

Phase 2: *Longitudinal documentary analysis*: an extended analysis of academic and policy literature relating to Big Society.

Phase 3: *Ethnographic case studies with co-researchers*: an extended period of ethnographic work with the three partner organisations.

Phase 4: *Analysis*: a period of analysis following the data collection in phases 1, 2 and 3.

Phase 5: *Impact workshops*: a series of impact workshops to share our findings and develop analysis and impact.

Phase 6: *Researcher in residence*: a researcher from the project will work with partner organisations to promote knowledge exchange.

Phase 7: *Public Engagement Events*: a series of events to share research findings and increase the impact of the project.

[More details available at: <http://bigsocietydis.wordpress.com/>]

Ethical clearance has been gained and we are in the early stages of the overlapping phases 1, 2 and 3. This initial empirical work and meetings with research partners and the impact research management group have pushed us to think, together, critically and theoretically about the lives, ambitions and civil society of disabled people with intellectual disabilities. Our partners' practices, along with our own research experiences, led us to the ideas of dis/human and a number of emerging considerations which we will now expand on. Our analyses are necessarily tentative but do suggest some potency to our new analytical approach.

### **3.1. Dis/autonomy, voice and evacuating the human individual**

Once upon a time in Yorkshire: Rachel arrives at the meeting by minibus from the local Autistic Community. She does not speak often. She spends her time quietly and apparently contentedly smelling her fingers and looking around the room. She doesn't appear to interact with any of her friends. At break-time Bill asked her if she would like a cup of coffee or tea. Erica, who lives with Rachel, replied, 'She likes coffee, don't you Rachel?' Bill looked at Rachel, 'Coffee then?' (Goodley, 2000, p. 193)

At the beginnings of our research, we were reminded of this story. Now some 14 years old, the story relates to an event in a self-advocacy group, somewhere in Yorkshire, witnessed by Dan during his Ph.D. research. Our new project will involve us revisiting self-advocacy, post-Blair, the White Paper on Learning Disability, during a time of Big

Society. It seems apt to revisit this story now as we begin our work with self-advocacy groups. Dis/autonomy is made visible when self-advocacy group members participate as citizens through their collective actions and, thereby, contest ‘the meaning and extent of their citizenship’ (Armstrong, 2002, p. 342). Dis/autonomy recognises the relational, rather than the individual, nature of autonomy in the lives of disabled and non-disabled people. Dis/autonomy allows us to disrupt narrow notions of neoliberal citizenship while acknowledging the pragmatic and political imperative to engage in and to claim such discourse in neoliberal times. Interestingly, we as disability researchers have often encountered colleagues who ask of the self-advocates that we quote or whose opinions we cite: ‘Are they *really* learning disabled? Are they *really* representative of other people with learning disabilities? What about the ones that *cannot* speak? Is it ok for others to do the speaking for *them*?’ Such questions (admittedly with our italicised emphases) implicitly evoke an idealist vision of the individual human being (speaking clearly and rationally for themselves) and his opposite (mute and incapable of representation). In contrast, the story of Bill, Rachel and Erica deconstructs such normative assumptions. The answer to Bill’s query does not come from the individual it was aimed at; instead, we are treated with an answer from a distributed voice. The three work for one another in order to proffer an analysis. This notion of distributed competence is a crucial element of self-advocacy (Booth & Booth, 1994). At the same time, while the trope of voice as an individual’s asset is troubled by this encounter, the three members collectively claim their individual normative human worth in a self-advocacy group. We are people, individuals in our own right, with preferences not just for tea or coffee but also for other elements of our lives such as where we live, what we do in the daytime and who we would like to share our lives with. This claim for autonomy – a human quality historically denied to people with the label of intellectual disabilities – is often associated with the familiar discourse of giving one’s voice: ‘speaking up’, ‘telling others how you feel’ are the hallmarks of self-advocacy. ‘Being normal’, ‘being just like ...’, ‘having the same rights as ...’, ‘having a home, a job, a family just like everybody else’; just like other human beings, having a voice and others recognising this. Hence, again, we see disabled people with intellectual disabilities flipping from one side of the dis/human binary to the other in order to encapsulate their deeply complex political work. A dis/autonomous analysis of the ambitions of self-advocacy groups recognises why members would desire the quality of autonomy; precisely because this is a phenomenon often associated with an able individual human being – a category that many members have been excluded from (dis/autonomy). In contrast, but equally, Bill, Rachel and Erica’s interactional encounter displays the playing out of autonomy in a distributed, relational and extended manner: a form of distributed competence made so by the presence of disability (dis/autonomy).

### 3.2. *Dis/independence, assemblage and collective humanness*

An account from our Inclusive Living colleagues, Pete and Wendy Crane, along with colleagues including person-centred planning coordinator Max Neil, have developed the Circles of Support approach to community living. This involves individuals such as Matt (a pseudonym) using their disability benefits to recruit a network of advocates and support staff to support him 24/7 in his own home which is located a couple of streets down from his parents. (Goodley, 2014, p. 168)

Pete, Wendy, Max and others desire a normal life for Matt. Yet, when we interrogate the ‘normal life’ enjoyed by Matt we find it to be extraordinary (or dis/ordinary) in the ways

in which it draws upon myriad forms of community support. Like any good collective, Matt gets lost in the multitude of helping hands and collective gestures. Matt becomes enveloped within the community assemblage. The concept of the assemblage is developed by Deleuze and Guattari (1987) in an attempt to reappraise subjectivity by visualising self-and-others as types of machine and assemblages that are ‘composed of multiple and variously embodied parts that interchange and create new relationships, alliances, and communities’ (Ramlow, 2006, p. 181). Just as Deleuze and Guattari contest the centrality of the individually bounded self (distinct from others, solitary, alone and sovereign in his actions), Matt equally contests what it means to be an independent member of a community (*dis/independence*). But, simultaneously, he also necessarily claims his independence: Matt is a homeowner, he has a job and he has his ‘own life’ (*dis/independence*). Matt’s *dis/human* politics does what the disability theorist Nirmala Erevelles (2002a) seeks to do: radically disrupt humanist notions of autonomy and subjectivity (p. 29). Matt’s relationships with others also evoke the image of the assemblage: ‘a term that means design, layout, organisation, arrangement, and relations – the focus being not on content but on relations, relations of patterns’ (Puar, 2012, p. 55) which ‘de-privileges the human body as a discrete organic thing’ (p. 57) and proffers a ‘posthumanist framing that questions the boundaries between human and non-human, matter and discourse, and interrogates the practices through which these boundaries are constituted, stabilized, and destabilized’ (p. 58). Following Goodley (2014, p. 166), *dis/independence* is played with (or assembled) in some interesting ways here – shifting the perspective from individual with profound communication difficulties in to a distributed entity at the heart of a profoundly complex relationship between the human and their world. Following Puar (2012, p. 57), categories including race, gender and sexuality – to which we can add *dis/ability* – are considered as events, actions and encounters between bodies, rather than simply entities and attributes of subjects. This sounds very much like the *dis/human* project that we have in mind. Matt is both a person and an assemblage: *dis* and indeed *human*.

### 3.3. *Dis/ability politics, self-advocacy and repositioning the human*

A view from the grassroots: argues that people with learning difficulties face discrimination in the disability movement. People without learning difficulties use the medical model when dealing with us. We are always asked to talk about advocacy and our impairments as though our barriers aren’t disabling in the same way as disabled people without learning difficulties.

We want concentration on our access needs in the mainstream disability movement. (Simone Aspis, cited in Campbell & Oliver, 1996, p. 97)

Aspis displays a desire for her politics to be recognised and respected in similar ways to the politics of her physically and sensorily impaired brothers and sisters. Activists with intellectual disabilities are just as capable, she states, as their physically impaired comrades (*dis/ability*). That said, the politics of self-advocacy invites a deep engagement with the meaning of the human: captured perfectly by the choice of moniker for many groups across the globe (People First). As Gillman, Swain, and Heyman (1997) observed, the fight for many activists with intellectual disabilities has differed from the activism of their physically and sensorily impaired brothers and sisters, precisely because People First seeks recognition of personhood that exists in spite of or behind the often deficit-making label of intellectual disabilities. As Erevelles (2002b, p. 6) puts it in her analyses of cognitive impairment and education:

Death-invoking discourses constitute disability as marking the outermost limits of human existence, and therefore, never engage the everyday reality of what it means to be a citizen with cognitive/severe disability. (Erevelles, 2002b, p. 6)

*Dis/ability politics captures activists to claim their humanity (we are *People First*) whilst also modelling new forms of interdependent politics and advocacy (we are *Assemblage First*).*

### 3.4. *Dis/family: desiring the normal, embracing the non-normative*

At the end of the [self-advocacy] meeting, Annie tapped me on the shoulder to show me the photographs on her iPad. Annie, who is in her fifties, told me she used to live with her mum but that her mum had died in June last year. At that point, Annie met Angela and Caron, social workers from the Shared Lives Scheme<sup>5</sup> in the local area. Angela and Caron helped Annie to find a new family. Now Annie lives with Jean and Keith, their teenage daughter and their three dogs. Annie showed me some photos with three lovely dogs and her new family. (ethnographic field notes from Katherine)

We must not lose sight of the very normal desires disabled people with intellectual disabilities have in relation to a sense of belonging, home and support (*dis/family*). Living in a family is a quintessential normative desire too often denied to people with intellectual disabilities confined to institutionalised care. The Shared Lives scheme is an example of what we might call the *dis/family*. Annie's family is a non-normative family in the sense that it is not constituted as a result of biological relationships or traditional parent/child roles; Annie is about the same age as Angela. The relationships described are between 'service user' and paid 'carer' – this emboldens the *dis* element of the *dis/family*. However, the *dis/family* is also responding to Annie's desire to live in a normal family and perhaps to recreate the closeness of the relationship she lost when her mother died. The *dis/family* is simultaneously normative and non-normative; it appeals to the notions of traditional family and yet it troubles traditional biological kinship and parent/child relationships that underpin the 'normal' family. Normal family life is a powerful contemporary public discourse that permeates policy and popular culture, an example of which we stumbled upon in a recent television programme. The programme is a part of a series in the UK in which each week a team of builders, plumbers, electricians and so on with a group of local volunteers, improve the home of 'deserving recipient'. In this episode, the recipient was a disabled child and his family, which led the presenter to reflect:

Michael [a carpenter on the programme] said an interesting thing to me this week: 'We undervalue normal'. Normal is doing the same thing sitting in front of the telly saying, 'We always do this. Why can't we do something else?' Normality is the kids fighting and running round the house causing problems. Normality is something that a family does together all the time. It's something that this family couldn't do because Josh was excluded from so much of the house. And the way these people have worked on the house has meant they've given him that back. They've given him a little bit of normality. It's really important when you think about it. Maybe you know someone who needs your help'. (Nick Knowles, TV presenter, *DIY SOS*, 2013)

## 4. Conclusions

Any theoretical account, especially in the social sciences, will be subjected to a number of questions about utility. The first usually goes along the lines of how relevant is this analysis to the lives of disabled people? The second relates to social policy; how can this

analysis be used to inform policies around disability. The third is a query about activism: does this have any connection with the politics of disability? We respond to each of these questions in turn.

First, how relevant is this analysis to the lives of disabled people? We would argue that our project of claiming the human while simultaneously seeking to trouble, to reshape and revise the human emerges from our enmeshment with the day-to-day lives of disabled people with intellectual disabilities. We have shown how the advocacy work by and for disabled people with intellectual difficulties necessarily demands a recognition of sameness (I have the same rights to a job, a home and a family because I am the same as you) but, at the same time, seeks to disrupt normative notions of work, home and family (in order to work and live might require more creative ways of being supported and enhanced). Being in a position where one is forced to equivocate not only disrupts the concept of the human but also disrupts the lives of disabled people with intellectual disabilities and their allies who are left holding the fallacy of equivocation on a day-to-day basis. A failure to recognise or, indeed, honour the work that disabled people with intellectual disabilities are doing to maintain a *dis/human equivocation* is a failure to recognise their experience (and reworking) of humanity. Through their lives ‘we learn that humanity is not discovered, but achieved through the taken-for-granted grounds of its assumed presence or absence’ (Titchkosky, 2012, p. 92).

Second, how might becoming dis/human inform social policy? Public policy discourse is always on the side of the *human*, conceptualised as a bounded, rational, independent, individual self. So the current personalisation agenda, enshrined within Valuing People (Department of Health [DoH], 2001) and the raft of policy documents that it gave birth to, focuses on individualised plans to enable individual disabled people with intellectual disabilities to become active and contributing members of their community. And yet, despite the policy rhetoric, the practice we have witnessed emboldens the other side of our dis/human binary (*dis/human*) so that employment is enacted as supported employment facilitated through an assemblage of the disabled person with intellectual disabilities, their family members, their colleagues and the job coach; independent living is achieved through circles of support or the Shared Lives Scheme in which assemblages or networks create what we see as dis/independence. A public policy informed by the dis/human would recognise, honour and promote these networks.

Third, how does becoming dis/human connect to a politics of disability? In the UK, disability politics has been built upon a conception of the human that asserts disabled people’s normative human identity. Identity politics emboldens the human to advocate for equality. However, disability politics and disability studies have been troubled by the dis. First-wave feminists in disability studies sought to emphasise the dis of *dis/ability* by bringing personal experience into the fray, rejecting the hard materialist analysis of first-wave social modelists (e.g. Morris, 1991; Wendell, 1996). Academics who locate their work in second-wave CDS have sought to embolden the dis by troubling normalcy (Davis, 1995), naming ‘compulsory able-bodied-ness’ (McRuer, 2006) and exposing the ableist practices that haunt disabled people’s lives (Campbell, 2009). We desire a time when dis/human becomes *dishuman*: when any thought about the human has in mind what disability does to it (see also Goodley et al., *in press*). It is not simply the case that we want to jettison the ‘/’ because we find it ungainly, we want to move to a time when thinking about the human will *always* involve thinking about disability.

## Notes

1. We use the term intellectual disabilities to recognise that this is a common term applied across the globe. Other labels would include learning disabilities and developmental disability. This term is often used in psychological and medical contexts to refer to someone with cognitive impairments. Traditionally, horrendous nomenclature has included mental handicap, mental retardation and educational subnormality. We acknowledge, of course, that many people so-labelled prefer no labels whatsoever.
2. For details see: Department of Health (2013), *Transforming care: A national response to Winterbourne View hospital*. Available at: <https://www.gov.uk/government/publications/winterbourne-view-hospital-department-of-health-review-and-response>
3. See this site for a really helpful overview of this philosophical position: <http://www.txstate.edu/philosophy/resources/fallacy-definitions/Equivocation.html>
4. Economic and Social Research Council (ES/K004883/1).
5. Shared Lives is a little-known alternative to home care and care homes for disabled adults and older people. It is used by around 15,000 people in the UK and is available in nearly every area. A Shared Lives carer and someone who needs support get to know each other and if they both feel that they will be able to form a long-term bond, they share family and community life. See more at: <http://www.sharedlivesplus.org.uk/what-is-shared-lives/shared-lives#sthash.PiGQBD2Q.dpuf>

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