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Inviting disability

Disabled children and studies of childhood

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This chapter is an invitation to think with and through disability in order to consider what it is that we value, and what we disregard, in studies of childhood. We begin by introducing two interconnected fields of inquiry: critical disability studies and disabled children's childhood studies. We describe their emergence from their Marxist-materialist origins to their entanglements with poststructuralist, queer theory and new-materialist thinking, as we re-cast disability as an opportunity to disrupt taken-for-granted assumptions about *all* children's lives. We employ these disciplinary approaches to reflect on the story of Matthew, a disabled child, who we came to know as part of a wider research project *Living Life to the Fullest: life, death, disability and the human* which took place in England from 2017 to 2020 (ES/P001041/1). The research sought to forge new understandings of the lives, hopes, desires and contributions of disabled children and young people with life-limiting and life-threatening impairments (LL/LTIs). We reflect on Matthew's story keeping in mind key concepts that are often reproduced (and recuperated) within studies of children's lives: 'agency', 'voice' and 'development'. As we critically reflect on these phenomenon, we describe our growing disenchantment with the narrow versions of 'the human' that they recreate; a version of humanity which 'stands for normality, normalcy and normativity' (Braidotti 2013: 26) and which pushed us to sit (rather than stand) with posthuman approaches. And yet, as we read Matthew's story, we found ourselves unable to hold onto a flattened ontology which maintains that 'all entities are on equal ontological footing' (Bryant 2011: 2). We admit that our attention was captured by the human actors in Matthew's story (Brinkman 2019). This leads us to a position that we have described as a DisHuman reality in which disability demands that we trouble narrow and normative conceptions of the human while at the same time claiming disabled people's humanity (Goodley and Runswick-Cole 2016). We conclude by considering what this approach might have to offer to the study of *all* children's lives.

Introducing critical disability studies

We begin by locating our approach in the field of critical disability studies (Meekosha and Shuttleworth 2009; Shildrick 2012; Goodley 2013). For the greater part of the twentieth century, the academic study of disability was located in medicine and psychology and disability was medicalized and psychologized as a problem of unfortunate individuals (Oliver 1990). Disability was, and often still is, understood as ‘a thing’ that a person has because there is something ‘wrong’ with them. This ‘deficit approach’ underpins the view that disabled children, young people and adults are somehow ‘less than’ their non-disabled peers and that the focus on research should be on rehabilitation and cure, rather than social justice, in the lives of disabled people (Oliver 1990).

However, more than thirty years ago, disabled activists and academics began to challenge the idea that disability was a ‘problem’ for individual bodies and minds as they drew on sociological, rather than medicalized and psychologized perspectives, in conceptualizing disability (Oliver 1990). Across the Global North, disability studies emerged as a discipline united by a commitment to the rejection of any model of disability that locates (the problem of) disability within the person. In Britain, academics and activists working in disability studies made a key conceptual contribution to the discipline through the development of what is known as the social model of disability (Oliver 1981). The social model proposed an alternative understanding of disability, which rejected the idea of disability as a personal tragedy for unfortunate individuals, and argued instead that disability is the product of social oppression (Oliver 1990). To support their argument, social model theorists make a crucial distinction between impairment and disability. They argued that ‘impairment’ should be understood as ‘the functional limitation within the individual caused by physical, mental or sensory impairment’ (Disabled People International 1982 cited in Goodley 2011: 6). In contrast, ‘disability’ was understood as ‘the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers’ (Disabled People International 1982 cited in Goodley 2011: 6). This Marxist-materialist conceptual shift enabled academics and activists to argue that people were not disabled by their impairments but by barriers to their participation. The social model of disability is known as British disability studies’ ‘big idea’ (Hasler 1993), and it has had a tremendously positive impact on the lived experiences of disabled children across the globe, not least because of the role it has played in developing the project of inclusive education (Mallett and Runswick-Cole 2014).

In 2007, Thomas suggested that British disability studies had moved from the first wave of disability theory into a second wave of thinking, influenced by feminist and poststructuralist ideas. Disabled feminists had started to question social model analyses that were devoid of any discussion of disabled people’s subjective experience, including how they experienced their bodies (Morris 2001). A social theory of impairment had already begun to emerge which demanded that disability and impairment should be considered together, not separately (Hughes and Paterson 1997). Thomas (2007: 135) began to talk of impaired bodies as being *biosocial*, that is, simultaneously ‘biological, material and social’. And subjective experiences were theorized, as Thomas proposed, through the idea of psycho-emotional disablism. She persuasively argued that: ‘social barriers “out there” certainly place limits on what disabled people *can do*, but psycho-emotional disablism places limits on who they *can be*’ (Thomas 2007: 72, emphasis in the original). Psycho-emotional disablism is closely associated with the concept of internalized oppression which has often been discussed in relation to race (Crenshaw 1995) and to sexuality (Corbett 1994). In disability studies, Campbell (2009) has also described a culture in which

disability is cast as a diminished state of being human in comparison to the able-bodied ideal type and that, almost inevitably, results in internalized oppression.

Discussions in disability studies were increasingly influenced by poststructuralist theories. Such thinking challenged a social model that held onto an idea that impairment is 'real' (Feely 2016); albeit a real impairment that led to social oppression. Heavily influenced by the work of Michel Foucault, poststructuralist disability studies scholars argued that impairment and disability should *both* be seen as a social construction (Shildrick 2012). The division of human beings into 'normal' and 'devalued' subjects and the emergence of these categories as 'natural' and 'inevitable' was also contested (Feely 2016). At the same time, disability studies was influenced by queer theorists, who challenged 'impaired'/'non-impaired' binaries, offering more uncertain and expansive frameworks for understanding human diversity (McRuer 2006).

The impact of queer and poststructuralist ideas was not without its critics within disability studies. First wave Neo-Marxist disability studies academics were quick to criticize an approach which they characterized as downplaying the material realities of disabled people's lives and of diverting attention away from the forces which produce disablism (Barnes and Mercer 2010). The poststructural turn was, inevitably perhaps, also met with a critical realist backlash (Shakespeare 2006; Watson 2012), which resulted in calls for 'non-reductionist, multifactorial accounts that consider disability on a multiplicity of levels (the biological, the socio-economic, the cultural, etc.)' (Feely 2016: 868). The recent emergence of new-materialist ontologies and methodologies has also begun to shape disability studies and have been proposed as a middle ground between Marxist-materialist and poststructuralist approaches and as a way of bringing materiality back into disability studies without having to rely on essentialism (Feely 2016).

The application of these critical theories to the study of disability has become known as critical disability studies (Goodley 2013). Critical disability studies embraces an expansive approach to thinking about disability and disablement by paying attention to the intersections of race, class, gender, nation and sexual identity and by drawing on a range of resources, from feminist, postcolonial and queer thinkers, among others (Mallett and Runswick-Cole 2014). As Goodley (2013: 632) tells us:

Critical disability studies start with disability but never end with it: disability is *the* space from which to think through a host of political, theoretical and practical issues that are relevant to all.

Despite the significant role that the social model has played in the push for removing the barriers to disabled children's participation in mainstream education, there has been a sense of frustration from within disability studies about the application of social model theorizing in studies of children's lives. In 2007, Connors and Stalker (2007: 19) wrote:

The social model of disability has paid little attention to disabled children, with few attempts to explore how far it provides an adequate explanatory framework for their experiences.

British disability studies is still a predominantly an adult-centric discipline and the lives of disabled children remain under-theorized (Curran and Runswick-Cole 2014).

Disabled children's childhood studies

Entangled with and inseparable from the history of critical disability studies, disabled children's childhood studies emerged, in part, as a response to the adult-centric tendencies of first- and second-

wave disability studies. Curran and Runswick-Cole (2014) explicitly follow Goodley (2013) by agreeing that disabled children's childhood studies may start with disability, but does not end there. There has been a high level of personal engagement with disabled children's childhood studies by disabled children, disabled young people, parents/carers, allies, activists and academics (Curran and Runswick-Cole 2013, 2014; Runswick-Cole, Curran and Liddiard 2017). This has led to the passionate criticism of studies of childhood that exclude disabled children by implicitly or explicitly assuming that all children are non-disabled, by presenting disabled children in problematic terms or by exploiting disabled children as sources of 'data' for the 'greater good' (Naseem 2017).

A desire for disability is written through critical disability studies and disabled children's childhood studies. As Goodley explains (Goodley 2014a: 165):

Desiring disability invites us to study society and the individual in ways that are often at odds with generally taken-for-granted practices and activities associated with human emancipation including money, work, education, sex, material desire, independence, autonomy.

Making sense of these relationships, resources and connections has led us to an exploration of 'more-than-human' perspectives in our explorations of disability and childhood (Monforte, Smith and Pérez-Samaniego 2019). A posthuman world view is one which is critical of the European renaissance philosophy of humanism which is built upon the fundamental desirability of the bounded, rational, autonomous and sovereign human subject (Goodley, Lawthom and Runswick-Cole 2014). Our disenchantment with narrow versions of 'the human' which 'stands for normality, normalcy and normativity' (Braidotti 2013: 26) has led us to posthuman theory. We desire disability precisely because it threatens to unsettle the boundaries of 'normality' (Shildrick 2009). We understand emerging posthuman disability studies as a space to think about the ways in which disability and childhood can disrupt humanistic values of independence and autonomy (Goodley, Lawthom and Runswick-Cole 2014). Posthuman disability studies offer an opportunity to focus on *challenges* but, also, to engage with the *possibilities* of disabled bodyminds as leaky, unruly, irrational assemblages that demand connections with human and non-human actors (Goodley, Lawthom and Runswick-Cole 2014). A posthuman orientation removes 'the obstacle of self-centred individualism to embrace an *ethics of becoming*' (Braidotti 2013: 49). Furthermore, like Feely (2016), we are drawn to posthuman ideas because they appear to provide a map for navigating the often troublesome theoretical landscape marked by debates between Neo-Marxist social modelists and critical realists described earlier. We suggest thinking with and through disability in the lives of children has the potential to disrupt the individualizing and pathologizing tendencies of the humanist tradition revealing disability as: 'the quintessential posthuman condition' (Goodley 2014b: 846). It is not simply the case that posthuman theory is responsive to disabled children's lives; disabled children might be understood as enacting posthuman lives.

Matthew's story

Our interest in posthuman disability studies has been heightened through our work on the research project, *Life, Death, Disability and the Human: Living Life to the Fullest*. The study took place in England and was carried out alongside disabled young co-researchers via a co-researcher collective of young people who identified as living with 'life-limiting' and 'life-threatening impairments' (LL/LTIs). Through a commitment to participatory approaches and

experimentation with arts based and narrative methods, *Living Life to the Fullest* set out to forge new understandings of the lives, hopes, desires and contributions of children and young people with LL/LTIs. We recognize the tension, within our research, in reproducing individualized and medicalized labels such as ‘life-limiting and life-threatening impairments’ which reflect the prognoses and futures imagined by adults, not children and young people (Liddiard et al. 2019). The use of this term is certainly at odds with what we understand as the transformative potential of posthuman disability studies. And yet, we know too well that children and young people’s identities have been, in part, crafted through such discourse (Liddiard et al. 2019). And so, rather than feeling blocked by such tensions, we seek to recognize ‘the intersections between mobility, multiple identities, and ethical belonging and accountability’ (Braidotti and Regan 2017: 212) in the stories of disabled children and young people, like Matthew, who we introduce next.

When Matthew came home from hospital as a baby, he arrived with a twenty-four hour oxygen supply, a feeding tube in his tummy, a blood pressure monitor and a monitor to measure the oxygen in his blood and lots of medication. Ruby, his mother, said that she gave up everything and put everything into Matthew. As Matthew grew older it became clear that he loved speed. And so Matthew’s arms were gaffer taped onto a pod on skis to protect them so he could experience the speed of flying down the slopes. Matthew loved water so, at school, Matthew’s support staff would cover his arm in cling film, wrap it up in a plastic bag, and sit him in a paddling pool next to the swimming pool, where all his friends were swimming, so he was experiencing something similar to them.

On the night Matthew died, aged sixteen, he was disentangled from the machines that had, only a few moments ago, been keeping him alive. The medical staff turned all the monitors off, they took out all the tubes going into his body, they washed him, and put his pyjamas on. They moved him over a little on the bed so that Ruby could get into bed next to him. That night, Matthew was being looked after by a nurse he had known since he was six months old. Ruby said that when Matthew was taken to the morgue, the nurse waited with him until the last possible moment and as she left him, she brushed his hair to the side of his face and gave him a little kiss.

Ruby has struggled since Matthew died. She said that she was so ‘tangled in Matthew’ that she had lost a sense of herself, she couldn’t think about her favourite food or favourite colour without thinking of Matthew.

Matthew’s story asks us to think again about what we value in life, in terms of what it means to be human and the kinds of desires and aspirations we have. And Matthew urges us to engage in an ethical encounter with the theories, concepts and tropes that are used to understand children and childhood. Our discussion focuses on ‘agency’, ‘voice’ and ‘development’ in Matthew’s story.

Agency and voice

Matthew is a potentially troublesome child for studies of childhood. Many studies are attached to the image of the child as an ‘active social agent’ (James and Prout 1997: xiv). The agential child is characterized as ‘having a voice’ (Qvortrup 1997). Qvortrup (1997: 87) describes children as ‘the invisible group par excellence in our society’ and that ‘giving children a voice as a collectivity amounts to representing them on equal terms with other groups in society’ and argues that children already have the capacity to have ‘a voice’ if only adults will listen. This taken-for-granted assumption

that ‘voice’ is a ‘natural’ property of a child assumes individual agency and autonomy; a child has something to say if only adults would pay attention. And yet, Matthew relied on technological and human support to live his short life and to express his feelings and to make choices.

Matthew requires us to pay careful attention to precisely what we value and what we disregard when we think about ‘agency’ and ‘voice’ (Lesnik-Oberstein 2011). Too often, questions of when, why and how a child is considered to be ‘*speaking in their own voice*’ remain unanswered (Lesnik-Oberstein 2011: 7, emphasis in the original). Reading Matthew’s story, we agree with Lesnik-Oberstein (2011: 6) that we need to question the assumption that ‘agency’ and ‘voice’ are enacted by the ‘ideal or stereotypical child’ so often imagined in studies of childhood. The image of the ‘ideal’ child, which is so often conflated with the ‘able’ child, is implicitly, a rational, species-typical exemplar of childhood (human) normativity (Goodley et al. 2015).

Matthew’s story has the potential to disrupt taken-for-granted assumptions of ‘voice-as-standard-speech’ and ‘agency’ as the property of individuals. We follow a history of disability scholarship that has sought to trouble ‘agency and voice’ as the property of a rational, bounded individual. In her work with disabled children, Morris (2001) details the ways in which it is possible to listen to disabled children who communicate in a multiplicity of ways, not all of which are speech or text based or enacted by the child alone. Wickenden (2011) explores the complexities of ‘voice’ in her work with young people who use communication aids, and how ‘individual voices’ emerge in relational ways. And in their work with parents with learning disabilities, Booth and Booth (1998) posit the idea of distributed competence, where parents’ agency is contextualized as occurring within a network of support rather than within individual minds and bodies.

Writing from childhood studies, Murris (2016: 29), too, has troubled the idea of ‘agency and voice’ being attached to a single individual drawing on posthuman theorizing. She recognizes the fear of losing the idea of ‘the child as autonomous agent (child as I)’ that has only recently come to the fore in international theory, policy and practice. However, she cautions that the illusion of the individual, self-governing child cannot do justice to the complexity of causal factors and chains of events that make up the reality of all children’s lives. Concerned with social justice, Murris is convinced that transformation is only possible through a philosophical approach which sees human beings as multiple, rather than individual, and as assemblages that are always being (re)produced in relation to ‘material discursive human and nonhuman others’ (Murris 2016: 29). By conceptualizing human beings in this way, it is impossible to locate agency, voice and intentionality with Matthew. This fits well with Murris’s ambition is to unpack the very notion of ‘non-individualised’ agency (Murris 2016: 29). We welcome this approach which demands us to value, rather than disregard, kinship, relationality and interdependence (Goodley 2014).

We see the potential of Murris’s theorizations for understanding Matthew’s life. After all, the normative, singular ‘I’ which enacts ‘agency’ and ‘voice’ is missing from Matthew’s story. Matthew, his mother and his nurse can all be seen as bodyminds intra-acting with a host of material-semiotic forces: gaffer tape, cling film, nurses, tubes, speed, water, colour, food. Matthew and Ruby are entangled with one another and we, and we hope you, have become entangled with their story too.

The developing child

Applied child and developmental psychologies have relentlessly targeted children who sit outside the bell curve of ‘normative development’. One could argue that disabled objects have

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occupied a central and essential focus of psychologists; precisely because their non-normativity permits psychology to create notions of normality and abnormality especially in relation to theories of child development. We are struck by the ways in which ‘development’ emerges as an absent presence in stories of disabled children which are so often told under the shadow of the mythical norms of child development (Curran and Runswick-Cole 2013). Those children who fall foul of the ‘statistical average’ can easily fall foul of the category of the normal able child, often experiencing exclusion and disadvantage (disablism) as a result (Curran and Runswick-Cole 2013). As Davis (1995: 71–2) argues: ‘[a]n able body is the body of a citizen. Deformed, deafened, amputated, obese, female, perverse, crippled, maimed and blinded bodies do not make up the body politic’. Through developmental discourse, Matthew’s non-normative ‘development’ devalues him and opens up the possibility to disregard Matthew’s relationship to the category of child.

The discourses of developmental psychology cannot be disentangled from an increasing focus on the role of parents, more specifically, mothers. As Burman (2008: 3) says, women are made responsible ‘not only for care for their children, but also for their current and future development’. Mothers are responsible for raising ‘good citizens’ – those who pass through staged norms of child development to enter the body politic as able-bodied-minded citizens. In other words, those *who are seen to have* ‘agency and voice’. Burman (2008: 176) is clear that this ‘abstraction of “the child” and “the family” as the units of analysis from their socio-cultural context’ reflects a failure, within developmental psychology, to theorize within the social context. The process of abstraction makes it possible to hold mothers, like Ruby, responsible for the achievements or failings of their disabled children. We can trace a history of disability and mothering in which mothers are blamed for their child’s atypical development, either because of their faulty genetic inheritance and/or their lack of nurturing capabilities, while at the same time, they must lead the charge to remediate their child’s difficulties and move them closer to the ever elusive ‘norms’ of child development (Runswick-Cole and Goodley 2017).

A posthuman orientation offers a different perspective on studies of ‘child development’. In her book, *The Posthuman Child*, Murris (2016: 1) begins with the story of Laika, a ‘slow thinker’. Murris pulls on ideas of ‘slowness’, intrinsically linked as they are to the phenomenon of disability, as she defends Laika from the individualizing tendencies of the teachers around her who comment on the speed of her learning. Murris (2017) challenges the foundational tenets of Western developmental psychology in which adults distance themselves from the children around them as well as from their childhood selves (Murris 2017). The adult researcher is positioned as a fully formed ‘I’ and while the child is regarded as ‘a self-contained, bounded, object of study – but ‘not as fully human’ (Murris 2017: 187). The child is constructed as an ‘ind-i-vidual’, the child as ‘i’ is ‘passive – a person acted upon by others, rather than a subject acting on the world’ (Murris 2017: 187). The child as ‘ii’ represents social constructionist approaches to childhood in which children and adults are constructed as ‘being and becoming’ (Murris 2017: 189). The posthuman child – child as ‘iii’ – is discursive *and* material. The child as ‘iii’ is *part* of the world, not ‘in’ it as an object ‘in’ space and time’ (Murris 2016: 91). Individuals and meaning come into being through relationships. And so Laika’s ‘slowness’ is not ‘within her’; slowness emerges in intra-action with other bodyminds and material-discursive environments (bid). Murris explains the term ‘intra-action’ rather than ‘interaction’, drawing on Barad (2014), to explain that “‘nature” and “culture” are never pure, never unaffected by one another, but always in relation’

(Murriss 2016: 12). Disability then appears as a relationally constituted thing; a moulding of mind, body, family, culture and society.

We welcome Murriss's (2016) criticism of notions of 'the normal child' and 'normal development' and her rejection of the seemingly endless creep of psychologization into education so that both diagnosis and remediation, instruction designed to remedy the effects of the diagnosis, have begun to influence teaching. Again, we see the transformative potential of 'child as "iii"' for all children, and for Matthew, released from the burdens imposed on him through the psychologized 'I' of child development. And yet, we are wary when Murriss's 'child as "iii"' reappears in the text as the 'rich, resilient and resourceful child' (Murriss 2016: 119). Following Lesnik-Oberstein (2011), and with a sensitivity to disability, we ask: what counts as richness, resilience and resourcefulness and when is a child *seen to be* rich, resilient and resourceful? We desire disability as something to be valued, rather than disregarded, in Murriss's conception of a rich, resilient, resourceful 'child as "iii"'.

The DisHuman child

Despite our interest in material-semiotic forces and the human and non-human actors in Matthew's story, reading the story, again and again, we found ourselves unable to hold onto a flattened ontology, which argues 'all entities are on equal ontological footing and that no entity, whether artificial or natural, symbolic or physical, possesses greater ontological dignity than other objects' (Bryant 2011: 2).

Our attention was captured by the human actors (Brinkman 2019).

Matthew's support staff wrap his arm in cling film.

Ruby gets into bed with Matthew.

The nurse brushes Matthew's hair away from his face.

We recognize the risks of being drawn to the 'I', so often associated with the able, humanist human that underpins the representations of 'agency' and 'voice' that we are so troubled by. And yet the story challenges us '[t]o stay human without being anthropocentric' and to hold on to the idea that 'human being is not an ahistorical, disembodied and universal intellect, but rather a historical, embodied, affective creature that lives in a sociomaterial world of flux and uncertainty' (Brinkman 2019: 136–7). Humans are stubbornly relational in their making.

This is a struggle we have experienced before and have tried to make sense of by describing what we have come to see as a DisHuman reality:

one which, we contend, simultaneously acknowledges the possibilities offered by disability to trouble, re-shape 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). (Goodley and Runswick-Cole 2016: 6)

Writing from the context of the Global North, where human rights-based discourses are often invoked to assert disabled people's entitlements and protections (e.g. HMSO 2010), we find ourselves affectively and politically attached to the category of the humanist human. While at the same time, we remain resolutely critical of the category of the human which has consigned

disabled children, young people and adults to the category of ‘human nonpersons’ who, because they are considered to lack ‘agency’ and ‘voice’, are routinely excluded from debates about social justice (Kittay 2011).

And our attachment to the humanist human is also driven by our disability politics. Perhaps we are marked by the social model of disability and its humanist rearticulation of people with impairments being blocked by a disabling world. At the same time, as we began to be drawn into posthuman theorizing, we were working alongside adults with the label of intellectual disability who were repeatedly telling us that they wanted: ‘to be heard’, ‘to have a job, a family’, ‘to be normal’, ‘to be just like everyone else’; in their words, to be human (Goodley and Runswick-Cole 2016: 10). And so we found ourselves desiring disability as the space through which to think in more expansive and more inclusive ways about what it means to be human. For us, Matthew’s story reveals the radical potential of disability to ‘trouble the normative, rational, independent, autonomous, subject that is so often imagined when the human is evoked’ (Goodley and Runswick-Cole 2016: 3). By engaging with a DisHuman reality, we can begin to interrogate the kinds of human beings, children, young people and adults, who are currently valued, or disregarded, by society and what that may mean for all children who find themselves pushed to the edges of the category of human.

Conclusion

We began inviting people to think with and through disability to consider what it is that we value, and what we disregard, in studies of childhood. Disability invites us to think again about children, ourselves, our relations and our politics (Goodley, Lawthom and Runswick-Cole 2014). In studies of childhood, we sense that disabled children will continue to struggle to be recognized as children in the register of humanism. Despite this, we remain optimistic that children and young people, like Matthew, are already enacting forms of relationality, and, therefore, activism that will continue to demand us all to think critically and creatively about all children’s childhoods.

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