

## **Slide 1: Education is not a chocolate biscuit: needs, rights and humanity in education**

*A bit of housekeeping from me. I will say all the words on the slide. I will audio describe any of the images that are needed for meaning. The session is being live streamed, the camera is on me! But if you ask a question at the end, I hope you will, then you may be heard on the live stream.*

When the title of this lecture was announced I was asked two questions: 1) will there be chocolate biscuits? 2) will it be the same lecture as your first inaugural lecture?

You'll be relieved to hear that the answer to the first question is an unequivocal 'yes'! And the answer to the second question is a more nuanced no.... and if you were here at the last lecture, and thank you very much for coming again!

As many of you will know an inaugural lecture is (according to that reliable source: Google) "an ideal opportunity for new professors to introduce themselves and to present an overview of their own contribution to their field to academic peers, students and research collaborators". So, given that this is my second chance to give an overview, you might say that I will be repeating myself!

But as there really is no such thing as 'my contribution'. All the work I've been involved with has been a collaboration with colleagues, many of whom are in this room, and with the support of my lovely family. You could say that we will be *repeating ourselves* - see what I did there!!

## **Slide 2: The projects**

So today, I'm going to draw on discussions of these ideas generated from several research projects to think about needs, rights, disability and the human and think about change for children. I'll be drawing on a number of research projects completed since I began my PhD here at The School of Education back in 2003.

*READ slide*

*Explain soap box*

### **Slide 3: The publications**

It's also based on publications with a host of lovely colleagues and friends ...

Wordle slide

### **Slide 4: Critical Disability Studies**

For those of you who don't know, my disciplinary home is critical disability studies. As many of you will know, British disability studies has its roots in Marxist materialist models of understanding disability as the social oppression of disabled people, Mike Oliver's much debated social model of disability (Oliver, 1990). As I was writing this lecture, Oliver's death was announced, it would be impossible for me to over emphasise his contribution to disability activism and to disability studies, and I would like to pay tribute to him today. But over time the disciplinary space has grown. Disabled feminists have intervened to remind us of the personal-as-political aspects of disability activism and academia (Crow, 1992; Morris, 1996; Garland-Thomson, 2005). People with learning disabilities continue to fight their way into the discipline in a context that has traditionally been dominated by white, physically

impaired men (Crow 1992). Mad activists and scholars have also demanded that their experience is part of the wider disability studies community (Russo and Beresford, 2016; Boxall, and Beresford 2015; Veronka, forthcoming; LeFrancois et al. 2013). Ideas from gender and queer studies have also been pulled into debates (McRuer, 2006). A critical realist turn (Shakespeare, 2006; Vehmas and Watson, 2013) has encouraged an exploration of new materialisms within disability studies (Feely, 2016; Mitchell and Snyder, 2016) while post-structuralist accounts persist (Shildrick, 1992). Despite the continued whiteness of disability studies (Bell, 2010), postcolonial theorists and voices from the global South have begun to puncture the disability studies culture and consciousness (Meekosha and Soldatic, 2011; McKenzie and Chataika 2017; Grech 2011). Critical disability studies have become, above all, an intersectional inquiry that are prepared to plunder shamelessly from a variety of theoretical resources that illuminate, challenge and seek to change the lived experiences of people who have been pushed to the margins [Goodley, 2013].

### **Slide 5 - Rights, needs and humanity**

So , now I've given you a bit of context, I'm going to focus on rights, needs and humanity in education before I get to the discussion of chocolate biscuits promised in the title, I am arguing that:

**In global North contexts, rights have been imagined in ways that have excluded disabled children (and others) from their protections and entitlements, with often devastating consequences.**

I am not claiming that disabled children are the only children who've been excluded; I recognize that dis/ability intersects with other forms of marginalization including: racism, (hetero)sexism, poverty and imperialism. And yet, despite a growing number of international and domestic human rights conventions and charters, progress in securing inclusion and full citizenship for disabled people has been limited (Bach, 2017).

In the *Origins of Totalitarianism*, Arendt (1951) argued that once whole groups are excluded from or consigned to the margins of social and political membership, they are at a greater risk of having their right to life threatened. Arendt set out a three-stage process: moving from rightlessness, to not belonging, and then to the right to life itself being threatened (Bach, 2017). Bach (2017) suggests that this trajectory is one that we should keep in mind in thinking about the lives of disabled people.

A host of statistics remind us that of the marginalisation of disabled children in education and beyond. Children with SEND are 7 times more likely to be excluded from school than non-disabled children; they are more likely to spend time in isolation; they experience unnecessary restraint and medication; they are incarcerated in institutions away from home. We see almost daily new stories that reveal disabled children's rightlessness, their exclusion from communities and we know, following the Learning From Deaths Mortality Review, that children with learning disabilities' life expectancy is 20-30 years less than their non-disabled peers.

So, as well as trying to unpack the processes that have led to this, I also want to conclude by thinking about what we can do to change this.

## **Slide 6 The shape of the talk**

So, the shape of this talk will be ...

- ∅ **A clarification of terms: disablism and ableism**
- ∅ **The social construction of learning disability**
- ∅ **The social construction of childhood**
- ∅ **The problem of rights and dis/abled children**
- ∅ **Some possible opportunities to think and to act differently**

## **Slide 7 Disablism and ableism**

A key contribution from critical disability studies has been to encourage us to think about the processes of disablism and ableism in the lives of disabled people.

Disablism has been defined as:

‘a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well being’. Thomas (2007: 73)

Ableism has been defined as:

“a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human.

Disability is then cast as a diminished state of being human” (Campbell, 2009:5)

To liken this distinction to an area you may be familiar with in feminist theory, *disablism* is similar to sexism, while *ableism* is similar to the idea of patriarchy. Ableism is concerned with the structures, practices and processes that assume, and work in favour of, those whom it deems ‘able’ and, in doing so, seeks to ‘erase’ disability (Mallett and Runswick-Cole, 2014).

As we will see, the workings of ableism and disablism are present when disabled children are excluded.

### **Slide 8 ‘Learning disability’ – a sticky label**

But for a moment, I want to focus on children with learning disabilities as they have been persistently constructed as a problem for and within education.

‘Learning disability’ is only one of a cluster of labels that has been used to refer to ‘lack of intelligence’. Across the globe, the terms ‘mental handicap’, ‘retardation’, ‘intellectual disability’, ‘cognitive impairment’ and ‘developmental delay’ are in widespread use (Goodley and Runswick-Cole, 2014a). These terms are all premised on individualistic and medicalised understandings of ‘disability’ that locate the ‘problem’ within a person ‘with a learning disability’ with the firm belief that the cause of any difficulty is to be found in the realm of bio-medicine (Oliver, 1990).

“Learning disability” is a sticky label; in other words, once you have attracted that label it is impossible to shake off, or even to set it down, just for a

moment. We academics, from the latter part of the twentieth century onwards, have played a significant part in both producing and sustaining the category 'learning disability'. The production of the category 'learning disability' continues to legitimize exclusion, marginalisation and worse.

Back in 1982, Bogdan and Taylor mounted a blistering attack on bio-medical and psychological understandings of learning disability:

Mental retardation (sic) is, in fact, a socio-political not a psychological construction. The myth, perpetuated by a society which refuses to recognise the true nature of its needed social reforms, has successfully camouflaged the politics of diagnosis and incarceration (Bogdan & Taylor, 1982, p. 15.)

In education, despite this and other concerted attempts to shift understandings and to explore the discursive and socially constructed nature of the concept of 'learning disability' (Chappell, 1998; Goodley, 2001; Rapley, 2004), policy documents still draw on individual and medicalised approaches. For example, despite the recent so-called SEND reforms, education and health policy re-iterates the understanding of 'special educational needs' as a within-child deficit:

A child of compulsory school age or a young person has a learning difficulty or disability if he or she:

- has a significantly greater difficulty in learning than the majority of others of the same age, or
- has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions (DfE & DoH, 2014: 15-16).

Children labelled with learning disabilities are marked as different from, and implicitly lesser than other children (Goodley and Runswick-Cole, 2014a). If we

are serious about protecting the rights of disabled children, we need to find ways to interrupt, trouble and resist labels of difference and disorder that position the 'problem' within the child.

### **Slide 9 - Labels are useful, aren't they?**

No doubt, for some, these claims for a social constructionist account of the category of 'learning disability' will simply seem like an argument against common sense. Labels are useful, aren't they? And learning disabilities are simply a reality for some children? (Goodley and Runswick-cole, 2015). It's true that learning disability is still widely understood as a 'naturalised impairment' (Goodley, 2001) beyond the realm or reach of the social. Contemporary discourses of neuroscience tantalisingly promise, but have so far failed to deliver, a 'real' account of the causes and aetiology of learning disability and yet this is a promise, to which, we, in contemporary global North cultures, remain optimistically attached (Berlant, 2011). Learning disability is a homogenising label which can threaten the rights and participation of those it is attached to. And yet, not all seemingly 'natural' categories have been so resistant to a social constructionist critique; and one such example of a natural category that has been shaped by social constructionism is the category 'child'.

### **Slide 10 Children & Childhood**

Indeed, over time understandings of the concepts of children and childhood as socially constructed have become broadly accepted within the academy in the global North. For example, James and Prout (2001) argue that 'childhood' is a social construction that can never be separated from other variables such as class, gender or ethnicity. In 1962, Ariès (1962) published a hugely influential text, *Centuries of Childhood*, in which he argued that, although 'childhood' is

often presented as a natural phenomenon, 'childhood' simply did not exist in the Medieval era as infancy and adulthood were distinguished without an intervening period of childhood being acknowledged. The shifting focus to see children as 'active social agents' within childhood studies represents a further change in how 'child' is seen. This change in understanding of the category of child has been crucial in rights-based advocacy for children and is reflected in both UK national and international law (HMSO, 1989, UNCRC, 1989). The Convention is underpinned by the view that children are subjects in their own right; they are to be seen neither as the property of their parents, nor simply the objects of charity.

If we accept that the deconstruction of the category of naturalized child has been crucial in rights-based advocacy for children then deconstructing the category of the 'normal' child must be a priority in claiming the rights of disabled children. And yet, while norms associated with class, gender and ethnicity are frequently troubled within childhood studies, a continued attachment to notions of 'normal' child development means that 'children with learning disabilities' remains firmly within the realm of the 'natural' (Mallett and Runswick-Cole, 2014).

### **Slide 11 – Relationships status 'it's complicated': disability and childhood**

As many of you know, the UN Convention on the Rights of the Child reflects shifts in the 'new' sociology of childhood in the 1990s. This shift has certainly contributed to children's voices being heard and their rights upheld inter/nationally. This is a humanist perspective, premised on an understanding

of the individual as “a pre-constituted, rational individual entering autonomously into power relations”. (McKenzie & MacCloud, 2012: 17).

The problem is that disability disrupts this seemingly progressive narrative. You see, childhood and disability have a complicated relationship. In her recent book, Karen Wells points out that there are only 71 mentions of disability since 1993 in the leading journal *Childhood*. Wells suggests the reason for this is that the presence of disabled children within childhood studies troubles some of the foundational principles of the new sociology of childhood (James, Jenks, and Prout, 1998). Children with learning disabilities disrupt the image of child as active social agent interacting with and shaping the world around them. In childhood studies, children’s agency is constructed as bounded within the individual child, that is, as free, independent, rational and, well, *able*. So those children who cannot conform to this account of agency become a ‘problem’ for childhood studies, a problem which, all too often, is simply erased by excluding disabled children and young people from research (Wells, forthcoming).

In contemporary socio-cultural contexts disability and childhood are bound up with one another. On the one hand, they are constructed as being in direct opposition to one another: childhood disability is unwelcome, unwanted and unmentionable. At the same time, disability is often described as something that is constituted in childhood - the consequence of experiencing childhood neglect, or poor attachment in the early years. And, of course, disability and childhood are conflated by the continued infantilization of disabled people as innocent, asexual, passive, but also leaky, unruly and, at times, as monstrous.

Discussion of the monstrous is inevitably bound up with discussion the human. Monsters provoke fear, but also fascination, as their ghostly presence, same but not quite, threatens to re-position or even to dissolve the boundaries of 'normality' (Shildrick, 1996). Shildrick (1996) describes monsters as 'out of control, uncontained, unpredictable, leaky': in other words, they are women (Shildrick, 1996: 2), children and disabled people (Goodley, Runswick-Cole and Liddiard, 2015).

Not surprisingly, given the conflation of disability and monstrosity, disability is often invoked in discussions of the human (Kittay and Carlson, 2010). The words 'person' and 'human' are used interchangeably but being born human is not enough for an individual to achieve the status of person (Taylor, 2013). And being seen as 'human but not quite', means that the associated human entitlements to and protections from rights-based discourses and legislation may also be denied (Taylor, 2013). Eva Feder Kittay (2011) describes the ways in which those with 'severe cognitive impairments' have often been consigned to the category of 'human non-persons' excluded from discussions about social justice because they are deemed to lack (narrowly defined conceptions of) 'capacity' and 'autonomy'.

If children labelled with learning disabilities fail to match up to the idealized image of the rational, autonomous child (re)produced in inter/national legislation, it is then, perhaps, not surprising that they are denied access to human rights (McKenzie and MacCloud, 2012).

**Slide 12: What's sayable?**

At this point, you may want to disagree with me. You may agree that children with learning disabilities experience disadvantage but that *no one would say* that they do not have rights. And this takes us into the realm of what Tanya Titchkosky has written about as the 'sayable' (Titchkosky, 2008), and what is sayable in public policy documents and international conventions is different from what is enacted in disabled children's everyday worlds.

Back in 2008, when Dan and I were beginning the Post Blair project, there was a government initiative to improve the lives of disabled children: *Aiming High for Disabled Children* (Reference). This was part of Ed Balls and Gordon Brown's attempt to reduce child poverty and they recognized that to do this, they must tackle the inequalities in the lives of disabled children. At the same time, the big disabled children's charities formed a consortium, Every Disabled Child Matters, which campaigned for the rights of disabled children. Its most notable success was some ring-fenced funding for disabled children to access short breaks so that they could exercise their rights to participate in their communities.

In 2010, the Coalition government decided that it would no longer ring fence those funds and they would be absorbed into a general early intervention grant. Since then short breaks for disabled children, which were widely agreed to have improved children and families' lives, have been cut year on year by local authorities. While it may still not be possible to *say* that the social exclusion of disabled children is acceptable, it is possible to act in ways that make this inevitable. Disabled children's rights to community life are being flagrantly violated.

And the response from the big charities? Well, they have formed another consortium, the Disabled Children's Partnership, to try to win back the gains made by the 'Every Disabled Child Matters' campaign – their chances of short term success seem slim, long term they seem impossible. Why? Because it doesn't seem possible for them to *say* that disablism and ableism are at work here: disabled children simply don't have the same rights as other children.

If we accept that disabled children occupy a precarious position in relation to the entitlements and protections afforded by a rights based approach, how, then, can we challenge this inequality?

### **Slide 13 - The biscuit argument**

Well, the first response we might give is simply to re-assert and re-claim rights in the lives of children with learning disabilities. We can remain optimistically attached to the promises of a human rights framework (Berlant, 2011). We can simply re-state our attachment to the human species 'as if it were a matter of fact, a given' (Braidotti, 2013:1). We can argue that disabled children should have the same entitlements and protections as other children because they are humans *too*. in other words, we can give the biscuit argument:

"If I tell you that I *need* a chocolate biscuit, you can tell me I don't have a *right* to it and you can choose whether or not you give me the biscuit. Similarly if we describe some children as having special educational *needs*, not *rights*, then there is also a sense that meeting that need is optional. If we agree that non-disabled children have a right to their education then so should disabled children, regardless of whether or not some, or all, of that education is labeled

as ‘special’. Education is a right for all. Education is not a chocolate biscuit.”  
(Runswick-Cole, 2018:13).

As you can see, I remain optimistically attached to the biscuit argument, but the problem is that we have been making the biscuit argument for a while now with little success. This may be because by demanding a recognition that disabled children are *human too* we are falling into the trap of implicitly accepting that their humanity could even be in question. It almost feels that more we chase ‘the human’ in the lives of disabled children the further away the human becomes.

#### **Slide 14 Abandon human rights?**

So if disabled children have been excluded from the protections of entitlements of human rights then a further response might be to suggest that we give up on the biscuit argument!

Post-colonial thinkers have criticized the UN Convention on the Rights of Persons with Disabilities for imposing an individualised global North model on a more collectivist global South. Grech (2010:91 argues that “the notion of individual rights is a global North idea or construct founded on Western values” and the discourse of individual rights sits uncomfortably within cultures where individual rights are subsumed by obligation to the community (Grech, 2010). There is an argument for a different approach that avoids universalism.

Whyte and Ingstad say:

“the basic approach is to start where people live, with their concerns and resources and the particular political ecology in which they are interacting. What is disabling for them there?” (Whyte and Ingstad, 2007:3)

Or we can turn to posthumanism. Braidotti (2013) is critical of traditional liberal models of rights which she argues are informed by an understanding of social relations that valorizes male power and capitalism. Braidotti challenges this model of rights and argues for a *relational notion of rights* which takes into account our relationships with other citizens, and, indeed, animals. Braidotti (2013) has become disillusioned with narrow versions of the 'human norm that stands for normality, normalcy and normativity' (p. 26). This leads her to describe herself as an 'anti-humanist' (p. 16).

### **Slide 15 - Advocacy**

However, in the political context of the global North where human rights-based discourse is often invoked to assert disabled people's entitlements and protections (eg: HMSO, 2010; United Nations, 2007) can we really give up rights? In the work we've done with disabled children, young people, adults and their families, we have found that they are strongly attached to their rights. They use this language in their everyday lives. Activists used the UN Convention to challenge the cumulative impact of austerity in disabled people's lives. In 2015, The Mathieson family used the Human Rights Act to challenge the rule which suspends payment of disability benefits to sick disabled children once they have been in hospital for 84 days. The ruling affects hundreds of families every year. Mark Neary used the Human Right Act to bring his son Steven home from being locked up in and Assessment and Treatment Unit. Eventually, Southern Health Trust admitted that the preventable death of Connor Sparrowhawk, who died in their care in an assessment and treatment unit, was a violation of his right to life.

Many self-advocacy organisations here and globally choose the title People First to emphasise their humanity. They are not ready to give up on the human, rather they desire the human, and are attached to a humanist politics.

As neither simply reclaiming or rejecting rights in the lives of disabled children seems a satisfactory strategy to address the injustices in their lives, perhaps, we need another approach. Perhaps it is possible to remain *critical of* the individualizing tendencies of human rights, at the same time as we *claim* human rights in the lives of disabled children. Perhaps disability has the radical potential to ‘trouble the normative, rational, independent, autonomous, subject that is so often imagined when the human is evoked’ (Goodley and Runswick-Cole, 2014: 3). Can we simultaneously contest and claim the (normative) human at the same time as we celebrate the diversity, difference and potentiality of disability (Goodley and Runswick-Cole, 2014)? We find ourselves disavowing the human (we desire it but also resist its narrow confines) whilst re-centering disability as the space through which to rethink what it means to be human (acknowledge disability as the frame through which to think again).

This leads me to the developing theory of DisHuman studies.

### **Slide 16 A Dishuman Manifesto**

Disability has always contravened the traditional classical humanist conception of what it means to be human. Working together with Dan Goodley, Rebecca Lawthom and Kirsty Liddiard, our response has been to start to develop a theory of DisHuman Studies (see Goodley et al. 2014; Goodley, Runswick-Cole and Liddiard, 2016) which, we contend, simultaneously acknowledges the

possibilities offered by disability to trouble, reshape and re-fashion the human while at the same time asserting disabled people's humanity.

We propose a DisHuman manifesto that:

- Unpacks and troubles dominant notions of what it means to be human;
- Celebrates the disruptive potential of disability to trouble these dominant notions;
- Acknowledges that being recognised as a regular normal human being is desirable, especially for those people who been denied access to the category of the human;
- Recognises disability's intersectional relationship with other identities that have been considered less than human (associated with class, gender, sexuality, ethnicity, age);
- Aims to develop theory, research, art and activism that push at the boundaries of what it means to be human and disabled;
- Keeps in mind the pernicious and stifling impacts of ableism, which we define as a discriminatory processes that idealize a narrow version of humanness and reject more diverse forms of humanity;
- Seeks to promote transdisciplinary forms of empirical and theoretical enquiry that breaks disciplinary orthodoxies, dominances and boundaries;
- Foregrounds dis/ability as the complex for interrogating oppression and furthering a politics of affirmation. (Online at [dishuman.com](http://dishuman.com))

### **Slide 17 A way forward? Having your (chocolate) cake and eating it too**

A DisHuman manifesto asks us to develop theory that pushes at the boundaries of what it means to be human. It demands us to expose and challenge the ableism that renders disabled people rightless, excluded and threatens the right to life. It demands that we try to find ways of challenging notions of the 'autonomous self' as *the* precondition of access to rights. Instead, we need to accept disability as the defining feature of humanity.

If we accept disability as the defining feature of humanity, we can remain *critical of* the individualizing tendencies of human rights and *at the same time as we make a claim to them for all.*

### **Slide 18 - The soap box**

And that takes me back to where I started, and the soap box ... University's have a different word for this kind of activity now, it is called ...

### **Slide 19 - Impact**

Three impact projects ...

Thank you for listening.

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