# **16. THINKING ABOUT SCHOOLING THROUGH DIS/ABILITY**

# A DisHuman Approach

#### INTRODUCTION

In this chapter, we develop and draw on an emerging approach – which we entitle the DisHuman – to explore how disabled children's lives are enabled and limited by their construction as simultaneously both 'different from' and 'the same as' other children. One institutional setting in which the child becomes known in their relationship with the dis/ability complex is the school. We write this chapter in the light of our wider thinking about 'sameness' and 'difference' in the lives of disabled people. This is an approach that we have characterised as DisHuman Studies (Goodley & Runswick-Cole, 2014; Goodley et al., under review). We explore how the presence of dis/ability has the potential 'trouble, re-shape and re-fashion' the conventions of schooling (Goodley & Runswick-Cole, 2014: 1). We remain hopeful that all members of school communities (children, parents, teachers, local authorities, wider community members) will continue to take the opportunity to disrupt the status quo and to become open to the possibilities unlocked by an awareness and acceptance of the DisHuman reality that plays out in schools.

In English schools, the category of "child with special educational needs and disabilities" is used to label children whose learning profile is considered to be atypical when compared with children without these labels. Membership of the category of "child with special educational needs and disabilities" (SEND) is determined by an assessment process, involving the child or young person, parents, or those with loco parentis, and practitioners. Inclusion into the category is determined by the extent to which children:

- have a significantly greater difficulty in learning than the majority of children of their age:
- have a disability which either prevents or hinders them from making use of the educational facilities of a kind generally provided for pupils of the same age in schools within the area of the local authority (DfE & DoH, 2014: 15–16).

Despite the rapidly changing policy context for disabled children in England over the last thirty years (Goodley & Runswick-Cole, 2011a), this definition of SEND has not changed significantly since the publication of the 1996 Education Act (HMSO,

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1996). Indeed the definition has recently been reiterated in the Children & Families Act (HMSO, 2014) that sets out a series of legislative changes described by the Coalition government as heralding the biggest reforms to special education since the Warnock Report (DES, 1978). Despite calls from inside the inclusive education movement, and from critical disability studies, to move away from within-child models of special educational needs (Skrtic, 1991; Barton, 1997; Runswick-Cole & Hodge, 2009; Goodley, 2014) the focus remains on the difficulties the child 'has' and what they 'cannot do'. The categorisation of a child "with special educational needs and disabilities" (note the child first language and the label appended afterwards) can only be made in reference to the norm. For example, a child has a 'SEND' if the child "has a disability which prevents or hinders him or her from making use of educational facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions" (DfE & DoH, 2014: 274). This suggests that although children with SEND are considered to be children, perhaps even children *first*, they are, at the same time different from other children and are identified as needing different "educational facilities" through a recognition of the coexistence of impairment which is deemed to be attached to their personhood. Implicit within the category of child with SEND is a claim to both sameness (in the use of children first language - they are children too) and difference (in the making of the category as a departure from and in reference to the "general"). Hence, any conception of the disabled child refers to those young people who are living at the intersections of childhood and dis/ability. The term dis/ability is chosen because, as we know, whilst some children are given labels denoting lack (disability) there are others that occupy the category of gifted and talented (ability or in some cases hyper-ability).

As we have noted elsewhere (Curran & Runswick-Cole, 2014; Goodley & Runswick-Cole, 2012), stories about disabled children's lives have often been told in ways that cast children in an unfavourable light in comparison to norms of childhood. Children whose lives are perceived to deviate from these norms, for a myriad of reasons (dis/ability, sexuality, race, class, gender), have historically been pathologised and seen as 'the problem' within education settings (Slee, 2001). However, while we acknowledge the ways in which the hegemony of the norm casts a shadow over the lives of disabled children, here we extend our analysis to consider how disabled children's lives are both enabled and limited by their construction as simultaneously both 'different from' and 'the same as' other children. Those living at the intersections of dis/ability and childhood are often viewed as being like any other child (they are children first) whilst also inhabiting spaces of difference: where their diverse educational needs, as expressed through categorisations associated with disability and impairment, are also illuminated.

One institutional setting in which the child becomes known in their relationship with the dis/ability complex is the school. The focus of this chapter is schooling, we use the term 'school' rather than education because we see schools to be communities in which a host of activities take place including: teaching, learning, friendshipmaking and relationship building. Schools are sites where being constructed as both

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simultaneously 'different from' (dis/abled) and 'same as' (child) other children plays out in the lived experience of disabled children. And we also recognise that each category of child and dis/abled brings with it social, political and cultural histories that are drawn upon in ways that make each category known and reacted to. We write this chapter in the light of our wider thinking about 'sameness' and 'difference' in the lives of disabled people. This is an approach that we have characterised as DisHuman Studies (Goodley & Runswick-Cole, 2014; Goodley et al., under review). We set out our thinking in relation to the DisHuman in more detail below.

#### DISHUMANISM

DisHuman studies is a response to what we 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 & Runswick-Cole, 2014: 1)

Like the feminist philosopher Rosi Braidotti's (2013), we have become disillusioned with these narrow versions of the 'human norm that stands for normality, normalcy and normativity' (p. 26). And yet, we do not wish to abandon the category of the human in the lives of dis/abled children, young people and adults. We suggest that it is possible to remain *critical* of the category of the human, while, at the same time, making a *claim* for the human in the lives of disabled children.

In our thinking about the DisHuman, we have suggested a number of bifurcated concepts that illustrate the pervasive reach of the DisHuman condition: DisHumanism.

To this list, we would add the DisChild (Goodley et al., under review). Our conception of the DisHuman seeks to recognise the practical and often political ways in which it is necessary, indeed desirable, to emphasise the ability side of the dis/ability binary whilst also wanting to attend to the disruptive work done by the presence of *disability*. In ways that are in tune with the deconstructionist tendencies of poststructuralist writers such as Michel Foucault and Jacques Derrida - and in response to the recent postconventionalist interventions of writers such as Rosi Braidotti, Gilles Deleuze, and Felix Guatarri - our engagement with the DisHuman condition seeks to recognise the work done with, for and against the disruptive qualities of disability and ability, difference and normality, the deviant and the human. For instance, we might want to emphasise the child side of the binary when we think about the DisChild in education and schooling (Goodley, Runswick-Cole, & Liddiard, under review). Here, it seems important to be able to claim that disabled children are *children* too, that they have a right to education because of their status as children under, for example, the United Nations Convention on the Rights of the Child (UNICEF, 1989). However, disabled children have not always been included within the category of children who should be educated in schools;

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DisAbility studies		
DisHuman	DisChoice	DisYouth
DisLife	DisDevelopment	DisFamily
DisCitizenship	DisAblement	DisMedicine
DisAutonomy	DisLabour	DisPopulate
DisNeoliberal	DisAdvocate	DisRecognize
DisNormative	DisQualify	Dis/Reason
DisNormal	DisScience	DisAdult
		DisCapitalism

Table 1. DisAbility studies: Becoming DisHuman and other possibilities

(Adapted and developed from Goodley & Runswick-Cole, 2014: 6)

until relatively recently, responsibility for 'handicapped children' in England was with health rather than education services. This situation only changed as a result of the 1974 Education Act. The 1981 Education Act, following the influential Warnock Report (DfE, 1978), was the beginning of a move towards the integration of disabled children to be educated in their local schools alongside non-disabled peers. However, it was not until the 1990s that the idea that disabled children should be 'normally' educated in the communities in which they live became more widely accepted in England and part of inter/national law (UNESCO, 1994).

While it is clearly important to continue to assert that dis/abled children are children too, it is also necessary to recognise, to claim and to celebrate the *dis* side of the DisChild binary: '[a DisH]uman 'position means that we recognize the norm, the pragmatic and political value of claiming the norm, but we always seek to trouble the 'norm" (Goodley & Runswick-Cole, 2014: 5). Emphasising the dis allows us to call into question normative categories of child, youth, adult and family and to celebrate difference and diversity. The presence of the phenomenon of disability disses (or disrespects) the normative tendencies inherent in traditional and hegemonic conceptions of childhood. We would argue that the inclusive education movement (Barton, 1996; Ainscow et al., 2006; Allan, 2006; Baker, 2002; Barton, 1997) has advocated for accommodations and practices that are inclusive of disabled children's perceived differences while claiming their status as children like any other, who have the right to be educated in their local communities. While a DisHuman approach recognizes that disability and humanity are always in friction, we have argued that they often rub against each other in ways that are productive and revealing of dis/abled children's potential (Goodley & Runswick-Cole, 2014). This frictional potential of the DisHuman condition is something that we think permits us to think again how we understanding notions of the human, dis/abled, child, learner and educational institution.

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Our commitment to exploring the possibilities of DisHuman studies in schools is driven by our professional and personal engagements with the lives of dis/abled children and young people. Over the past ten years, we have worked alongside dis/ abled children and their families and allies in research. We describe the research projects in more detail below. Our understanding of disability is guided by Carol Thomas (2007: 73) who defines disablism 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'. We argue that dis/ability studies allows us to 'acknowledge the theoretical, practical and political work that takes place either side of the binary, a binary denoted by the presence of '/' (the slash)' (Goodley & Runswick-Cole, 2014: 3). We remain painfully aware that "many disabled people have been denied the opportunity to occupy the position of the modernist humanistic subject: bounded, rational, capable, responsible and competent" (Goodley & Runswick-Cole, 2014: 3). In dropping the slash of dis/ ability and dis/human and replacing them with the elided concepts of DisAbility and DisHuman we seek to further recognise the dynamic ways in which the Dis and the Ability or Human rub up against each ways in potentially productive ways that might be of use to those interested in furtherering inclusive education. Moreover, by fusing Dis to these concepts, we seek to foreground the importance of those working the dis/ability context (or DisAbility) whilst recognising that one often has to appeal for recognition in a space rife with Ability. Ableism refers to those social, political and cultural practices that uphold a narrow conception of the citizen tied to idealized notions of independence, autonomy, rationality and cognitive progression. Capitalist and neoliberal societies are increasingly ableist places: where the role of welfare and government are rolled back and in their place emerge self-sufficient individuals who are capable of looking after themselves as part of the meritocratic architecture of our contemporary ideological times (Goodley, 2014). One place in which ableism is rife is the school.

We have written elsewhere (Goodley & Runswick-Cole, 2011b; Runswick-Cole et al., under review) about the ways in which disabled children and young people are routinely subjected to de-humanising practices. In our research with disabled children and young people, we have repeatedly found examples where disabled children have not been offered the opportunities and aspirations afforded to so-called 'typically developing children' in play, education, and in leisure activities (Goodley & Runswick-Cole, 2010; Runswick-Cole, 2011; Hodge & Runswick-Cole, 2013). Historically, disabled children have been characterized as monstrous (Runswick-Cole et al., under review) and in education, in particular, their leaky, uncontained, uncontrollable and unpredictable bodies are troubling for schools under pressure to conform to the demands of marketisation, inspection regimes and the requirement to move disabled children as close as possible to a mythical ableist norm (Runswick-Cole, 2011; Goodley, 2014). One way in which we might think of disabled children's impact on educational contexts is in terms of their disruptive potential. Disabled

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children often demand places such as schools to rethink their priorities, their usual modes of operation and their cultural foundations.

In this chapter we ask how does status of a 'child with special needs and disabilities', and their categorisation as both 'same as' and 'different from' their 'non-disabled peers' play out in the schools? What impact does this have on children and families and their experiences of schools? And how might these experiences inform wider understandings of schooling? We are especially interested to ask – when is ok to follow the normative workings of schools and in what ways do children and families 'dis' schooling?

# THE RESEARCH PROJECTS

Our engagement with the DisHuman child is informed by the three recent research projects described below. More information about each of the projects can be found by visiting the links to the projects.

1. Economic and Social Research Council (Grant No. RES-062-23-1138). Does every child matter, post Blair? The interconnections of disabled childhoods. 2008–2011 (http://www.rihsc.mmu.ac.uk/postblairproject/) (summary taken from Goodley, 2014: xx).

This project was based at Manchester Metropolitan University, Manchester, UK in collaboration with the University of Newcastle-Upon-Tyne, UK. The aim of the project was to understand what it meant to be a disabled child growing up in England during a time of policy change. The study was based in the north of England and ran from September 2008 - April 2011. The participants included disabled children aged 4-16, their parents/carers and professionals who work with disabled children, including teachers, third sector workers, health workers and social workers. Data collection included interviews using multi-media methods. The interviews were open-ended and covered a range of issues including children and young people's experiences of health, social care, education and leisure. A period of ethnography involved attending children's birthday parties, bowling, shopping with families as well as attending impairment-specific leisure activities, including an autism specific social club, parent groups, and user consultation meetings set up by local authorities, services and professionals to access the views of families. Finally, the research also included focus group interviews with professionals ranging from teachers, social workers, speech pathologists, advocates, and leisure providers (https://doeseverychildmatterpostblair.wordpress.com).

# 2. Resilience in the lives of disabled children across the life course (Scope) 2012–13

The aim of this project was to ask what resilience means in the lives of disabled people across the life course. As part of the project we worked with ten disabled children and young people using a life story approach. As might be expected,

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their experiences of school were a key part of their life story narratives. For more information about the project visit: http://disability-resilience.wordpress.com

3. Economic and Social Research (Grant No. ES/K004883/1); Big Society? Disabled People with Learning Disabilities and Civil Society, Economic and Social Research Council 2013–2015 (Summary taken from Goodley, 2014: xx).

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 organizations (Speak Up for Action; the Foundation for People with Learning Disabilities and independent living consultants) in the UK. The overall research question asks: how are disabled people with learning disabilities faring in Big Society? The research is being carried out through seven overlapping and interconnected phases including interviews and ethnographic encounters. [More details available at: http://bigsocietydis.wordpress.com/]. As part of the project we worked with young people in England who were in a transitional period as they moved from child to adult services in education, health and social care.

### THE ANALYSIS

In our analysis for this chapter, we revisited the narrative of children, young people and parents and family carers from Study 1 and 2, and Katherine's ethnographic notes from studies 1 and 3. In re-reading the data, we adopted a DisHuman lens, looking for moments where each side of the binary was emboldened or diminished and paying particular attention to the ways in which both sides of the binary are held in tension and rub up with one another. In re-visiting the narratives and ethnographic accounts, our aim was not to force the data to fit with our DisHuman approach, but rather to see what a DisHuman reading of the stories might add to our understanding of the lives of disabled children, family-carers and allies.

# THE DISHUMAN SCHOOL

Disabled children and young people demand us to think in ways that affirm the inherent humanness in their lives (and their alliances with other children) but also allow us to consider their disruptive potential (as an antitidote to some of: the typical and normative ways in which schools do their work). We suggest that the DisHuman child demands a DisHuman school. We draw on our research projects to explore a number of moments in which our *Dis*Human and Dis*Human* schools become visible. First, we explore moments where the *Dis*School emerges and disability provokes productive responses in schools. Next we consider when the Dis*School* appears in moments where the requirements of ableism expose, marginalize and exclude children. We conclude by thinking about the implications of our findings for children, families, schools and wider communities.

## The DisSchool

Now he's just started GCSEs<sup>1</sup> because [David] had not option but to do GCSEs but what he does now, we select the subjects so he's doing science subjects, drama and geography then on top of that he'll do PE and PSHE, so that works out at part time and we've done that all through secondary which means he hasn't done Maths for years because we weren't getting anywhere with Maths so ... Claire (mother, Participant 1, Study 1)

Claire describes the *DisSchool*. While there may be no other option for her son "but to do GCSEs" (Dis*School*) through a mixture of part-time schooling and home education David is doing the subjects he enjoys, and he's given up Maths because he 'wasn't getting anywhere'. In this brief vignette, the significant level of work done by Claire, David's mother, to push for the *DisSchool* to be appear is hidden but, nonetheless, Claire and David, and the presence of *DisAbility*, have disrupted the conventions of schooling, which require students in England to study Maths until sixteen and to study in school full-time. Claire's DisHuman approach is further evidence by her admission that:

as a parent I aspired for my child to be independent and have a job and relationships, and I didn't aspire for him to have GCSEs. Claire (mother, Participant 1, Study 1)

While Claire's aspirations for David to be independent, to have a job and to be in a relationship reveal very *human* desires for David, *Dis*Ability disrupts her aspirations – she no longer has any desire for him to achieve GCSEs.

Parents are often key players in setting up the *Dis*School. When, thirty years ago, William and Penny's son Neil was refused a place at their local village pre-school, they set up their own:

we opened our own playschool, so I could take Neil and Samantha [his sister] and they would both be part of the community. William and Penny (father and mother, Participants 6, Study 2)

Imogen described how she campaigned for post-16 provision for her son in their local area:

As soon as Jonathan started at secondary school, I knew that we'd have a problem post-sixteen. There was nothing in our area of children with complex needs who had been through mainstream school. My vision was a post-sixteen where young people could follow their interests ... fortunately someone in the local authority<sup>2</sup> agreed with me. Imogen, mother, Study 2, Participant 8

Kirsty also worked with her local authority to push for a DisSchool to emerge:

The mainstream secondary school was unsure about accepting my daughter. The head said: "she doesn't write she doesn't read or speak", and we've had people who don't do one of those things, but we've never had anyone who doesn't do all three. But the local authority was really supportive and the special school head teacher was too, and in the end, the school didn't have a choice. Kirsty (mother, Participant 5, Study 2)

While parents' contribution to the creation and maintenance the *Dis*School was often crucial, the presence of disabled children in schools was sometime enough for the *Dis*School to emerge. William and Penny explained that in Neil's primary school:

I mean it reached a point where the school teachers had to have a rota set up because some of the kids had starting to get into fights over who was going to support Neil each day. William and Penny (father and mother, Participants 6, Study 2)

As Imogen's story reveals, sometimes parents and practitioners worked together to create the *dis*/school. Certainly, teachers play a key role in the production of the *Dis*School as this vignette demonstrates:

The science teacher was constructing a display that would use lighting to move from day to night and different creatures would emerge throughout the day. This was alongside his construction of the solar system which glows under UV lights. He uses projectors to display moving pictures of animals and UV paint to bring to life a huge spider. He explained how he had used a projector to take the children to Mars and that they had asked 'where are we?' then speculated on the fact that they couldn't live there because there was no water. He said that there was no way his pupils could have learnt this looking at books. The science teachers from the mainstream school had said 'why can't we teach science like this?' (Katherine's ethnographic notes, Study 1)

As we have argued, the *Dis*School emerges when the presence of dis/ability disrupts normative practices in schools. In Claire and David's example, the *dis* disrupts normative notions of the curriculum content and curriculum choices and even where and when education might take place. While we do not wish to condone the exclusion that provoked Penny and William to set up their own pre-school for Neil, we suggest that the disruption caused by the presence of the *dis* was productive in setting up an inclusive pre-school for the whole community. Here is disability and humanity rubbing up against each other in sometimes difficult but also productive ways. The role of parents and practitioners is clearly important in creating *dis* schools, but children and young people are not passive in this process as the story of Neil and his friends illustrates above. For us, *Dis*Schools are places full of potential both disrupted by and enhanced by the presence of DisAbility.

# The DisSchool

We saw above that as a small child Neil was excluded from pre-school. We know little detail from William and Penny's narrative about the pre-school, only that it wouldn't accept Neil, so they set up one that did. We can imagine, however, that this pre-school was a dis/*school*: one in which to be accepted, even at the age of three, it was necessary for a child to match up to some hazily articulated image of the 'human norm that stands for normality, normalcy and normativity' (Braidotti, 2013: 26). Sadly, children and young people and their family-carers frequently encountered the Dis*School* in each of our research projects.

Gail explained her first meeting with her child's new class teacher in primary school:

"I [the teacher] was terrified of having him, absolutely terrified, but he's ever so good you know he just sits in the corner quietly," and I [the mother] thought, "Well that says everything." Gail (mother, Participant 2, Study1)

The teacher's terror harks back to the image of the monstrous disabled child we alluded to above. For the teacher, difference is a threat to the requirements of an ordered classroom, to the progress of the 'other' children and to her own well-being. The *Dis*human child has to be managed, by sitting quietly in the corner, while the 'real' work of educating the 'normal' children goes on around him. Imogen describes a similar story of exclusion:

I asked the [primary school] teacher why she never read with Jonathan. She said he had a teaching assistant to work with him and she had twenty-nine other children to think about ... I wrote a letter of complaint to the head teacher.

Jonathan's failure to be included in the category of the twenty-nine 'other children' reveals the persistent re-articulation of 'the human norm' in schools. To be included, you have to match up to standards of achievement and behaviour expected of the "majority". In the Dis*School*, children who fail to do so are relegated to the margins – to being quiet in the corner or to work apart from the other children with a teaching assistant. Often, in the Dis*School* there is what parents described as a 'lack of will' to include DisAbled children:

[Mainstream primary school] had to be able to fit Larry in with their timetable, you know it had to be something that you know Larry could participate in, you know sand play or water play, so both timetables had to fit in... there was really just a lack of will [to include him]. (Susan, mother, Participant 4 Study 1)

Patsy described the lack of flexibility that meant that even in the hospital school was emerged as a Dis*School* – lacking in flexibility or support for disabled children:

When I'm in hospital, the teacher comes round. They teach everyone whatever their intelligence, level, age or whatever – the same thing. The brought me a

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copy of the *Rainbow Fish* [a picture book]. The hospital teachers got in touch with my school then and school wanted the hospital teacher to help me write this Greek myth but I hadn't done any of the work and so I couldn't do that either because it was too hard. (Patsy, aged 13, Participant 2, Study 2)

For Patsy, the Dis*School* was also in evidence in her regular mainstream school, and she explains how ableist assumptions underpin not only approaches to teaching and learning but also to friendships and relationships:

I have the same amount of friends as everyone else, people assume I need help to make friends, like I need friendship groups and things, but I don't, not really. At break time, I have to sit in a room with all the disabled children. I don't really know why because, well, I used to have to go to the toilet at break, but I don't now. It seems like they're trying to club all the disabled children together, we're not *ordinary* friends, if I made an enemy of one of the people in there or something, if I had an argument with one of them, I'd still have to sit in there with them. (Patsy, aged 13, Participant 2, Study 2)

Sadly, the preoccupations with conformity and normality of the Dis*School* are evident beyond the classroom door seeping into the playground and contaminating relationships between parents and children in the school community, as Maria's story demonstrates below:

And nearly every day [my son] comes out of school and says: "Can so and so come round for tea?" and I can see their mother looking at me going: "Please no! Please no!" so I have to make up a hundred and one excuses all the time about why they can't come. (Maria, mother Participant 7 Study 2)

The Dis*School* is a difficult place for disabled children. Their status as same, but not quite (Shildrik, 1996) renders them vulnerable within the Dis*School* as their unruly bodies and minds unsettle the veneer of ableist normativity.

### CONCLUSION

What does our DisHuman analysis bring to the table in discussions about the inclusion of disabled children in schools that has not been said already? The systemic, material, relational, attitudinal barriers to the inclusion of disabled children have long been the focus of research and publications (Ainscow et al., 2006; Allan, 2006; Baker, 2002; Barton, 1997). We already know a lot about the discrimination that disabled children face in schools. Academics have spent a lot of time looking at the lives of disabled children, but a DisHuman approach has allowed us to see something different. We have been able to reveal both the tensions and potentials that emerge when a child is seen as same but different. Being 'same, but different' offers up a challenge to school communities to respond. As we have seen, school communities react differently, some exclude in order to maintain the sense of order that the Dis*School* requires

in order to manage its anxieties about league tables, inspections and performance. On the other hand, the *Dis*School's response is productive, and orientated toward change rather than maintenance of the status quo.

We remain hopeful that all members of school communities (children, parents, teachers, local authorities, wider community members) will continue to take the opportunity to disrupt the status quo and to become open to the possibilities opened up by an awareness and acceptance of the DisHuman reality that plays out in schools.

#### NOTES

- <sup>1</sup> General Certificates of Secondary Education (GCSEs) are standardized tests taken by most sixteenyear-olds in England.
- <sup>2</sup> The 'Local Authority' refers to the responsibility that local councils have for delivering education services to all children in England.

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