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Dis(en)abled: legitimating discriminatory practice in the name of inclusion?

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This article explores tensions between the policies and practice of inclusion and the lived experiences of disabled young people in education. Drawing on the narratives of two young men who participated in a small pilot study, it utilises theoretical concepts related to disability, structure and agency, and power and control, as it explores the ways in which inclusion can create subtle (and sometimes not so subtle) forms of exclusion. Focusing on the young men's experiences of further and higher education, it is argued that inclusive practices and policies, however well intentioned, can create new and subtle forms of marginalisation through the structures and discourse intended to address exclusion. I conclude by questioning whether, in a diverse and disparate society, in which all our lives are defined by the extent to which we are more or less equal than others, inclusion can ever be anything other than an illusory concept.

Key words: **disability, in/exclusion, marginalised, Bourdieu**

Introduction

It is well recognised that individuals who belong to non-dominant or marginalised groups, such as those with disabilities or those from minority ethnic groups, are subject to various forms of overt and covert discrimination in their daily lives and in their interactions with organisations, institutions and broader structures such as the education system. In this article I present the stories of two young men who formed part of a small pilot study exploring young people's experience of inclusion in the English education system. Both had

physical disability and complex medical needs: since both progressed to higher education, they were high academic achievers according to UK Government benchmarks. Their stories suggest that some of the strategies put in place to facilitate their inclusion in education actually resulted in experiences which they considered to be exclusionary.

The term inclusion is a somewhat slippery concept. It is generally held to be an opposition to concepts of exclusion associated with segregated special education and considered by many to relate to the education of young people with disabilities and special educational needs in mainstream settings and the discourses and practices surrounding that (Hodkinson, 2010). In addition, it is often expressed in aspirational terms (for example, see UNESCO, 2008), implying that, in common with the related concept of social justice, it is a journey rather than a destination.

Policy development and philosophical thought in relation to inclusion has been subject to significant development in England, and internationally, over the past two decades (Hodkinson, 2010) and is enshrined in law in many countries including those making up the UK. Curtin and Clarke (2005) argue that this movement originated in the 1989 United Nations Convention on the Rights of the Child (United Nations, 1989) and the Salamanca Statement on Principles, Policy and Practice in Special Needs Education (UNESCO, 1994). They go on to highlight some of the ongoing debates about inclusion and inclusive education in terms of the human rights ideology arising from these statements, which suggests that segregated special schools are not only divisive, but contribute to ongoing inequalities in access to education. The ideology that conflates inclusion with location in mainstream schools has been critiqued by some researchers. For example, Shah (2007) argues that mainstream schools can be discriminatory, often failing to facilitate full access to the curriculum, resources or, perhaps most importantly, friendship networks for disabled young people, while Hodkinson (2010) eloquently summarises arguments in favour of, and against, segregation, calling for mainstream inclusion to be a choice of children and their parents, and not a compulsion.

Despite concerns such as those raised by Shah, the 'SEN industry' (Tomlinson, 2012, 2013), of which policies and practices designed to promote inclusion form a part, is now an international activity underpinning mass education in both developed and developing countries. Concomitant with this, much has been published on inclusion in education, including a plethora of online and printed guides

on how to develop inclusive schools and classrooms (for example, see Teach-Hub.com, 2015) and, perhaps most influentially in England and Wales, Ofsted requirements (for example, see Ofsted, 2015) to promote equality of opportunity and respect diversity, which are consistent with the rhetoric of inclusion but in tension with the neo-liberal notions of performativity and accountability that underpin the inspection regime.

The notion that inclusion is something that can be reduced to a set of strategies or inspection criteria is concerning. It raises particular issues about the uncritical application of inclusive policies and practice which may, as Popkewitz and Lindblad (2000) argue, 'elide certain ... complexities'. A lack of awareness of the complexities of individual experience of disability among policy makers and practitioners can engender practices which, however well intentioned, have the potential for unintended and often un-noticed consequences for the young person being 'included', something that can have profound implications for individuals. Over time, education professionals have become so comfortable with the concept of inclusion (and, in some organisations, comfortable with the belief that inclusion is 'successful') that it has evolved into a notion that is now largely unquestioned, in terms of both the discourse and the practice surrounding it. Instead, as Graham and Slee (2008) have suggested, we are increasingly using inclusive education as a means for 'explaining and protecting the status quo' rather than as a means for developing more radical and democratic forms of education. In other words, inclusive education is predicated on taken-for-granteds and assumptions about the Other (Popkewitz & Lindblad, 2000) as well as on sets of beliefs about the relative effectiveness of often diverse strategies for inclusion (for example, see Ofsted, 2012; and EADSNE, 2003, for contrasting advice on good practice) Thus, secure in the knowledge that we are 'doing' inclusion, as practitioners we often fail to question or even consider these critical issues. Yet if, as education practitioners, our aim is to 'make' social justice, by which I mean to act in ways which contribute to the creation of a more equitable society, then we have a moral responsibility to explore and to problematise such issues. Only by doing this can we try to understand what is *really* happening in the educational lives of young people who experience exclusion and marginalisation as a consequence of disability. Such understandings are critical: they have the potential to encourage new debates and developments which are located in positive discourses of capability rather than polarised debates about the deficits of the individual and/or the deficits of the schooling systems in accommodating diversity (Hedge & Mackenzie, 2012; Terzi, 2005).

Methodology

In this article I have drawn on two personal narratives to illustrate the ways in which young people with different abilities can experience or perceive different degrees of exclusion in the context of the inclusive practices in educational institutions. The small-scale project in which these young people participated was developed as a pilot for a more extensive study exploring the school-to-work transition experiences of young people with disabilities. The proposal for this remains under development. It utilised a snowball sampling method, recruiting participants via a professional contact of the author with an interest in disability, and data were collected via online questionnaires which utilised a series of open questions. Some participants, including one of the young men profiled here, later participated in telephone interviews. The narratives developed from the data, which were analysed using a thematic approach which explored responses related specifically to instances of inclusion and exclusion, and were shared with, and validated by, the young people involved. All the young people who participated did so voluntarily after hearing about the study from a friend. Consistent with standard ethical practice, all participants and organisations have been anonymised in this article. Since the article focuses on two narratives, I do not claim definitive or even relatable results. Rather, I draw on the stories told by these young men to critique current approaches to inclusion in the UK, and to highlight the need for more extensive research exploring the educational lives of young people with disabilities.

Conceptual framework

In this article I utilise theoretical concepts related to structure and agency, power and control, as well as disability, to inform an exploration of the ways in which policies and practices intended to promote *in*clusion in education can, at an individual level, create subtle (and sometimes not so subtle) forms of exclusion. According to government rhetoric, inclusion offers a means of achieving equality of opportunity for young people with disabilities. Indeed, both the Disability Discrimination Act (1995) and the Special Educational Needs and Disability Act (2001) legislate for equality of opportunity between people with and without disabilities in terms of their access to, and participation in, education, employment and their community. However, as Bourdieu (2000) has argued, 'those who talk of equality of opportunity forget that social games . . . are not "fair games"'. In drawing attention to the inequalities impacting on the educational lives of disabled young people, I draw on Bourdieu's theories on structure and agency, which relate to his primary concern of inequality within society. These theories provide a useful framework for understanding the injustices imposed by social, educational and political structures on disabled students, in terms of, for example,

accessing the curriculum and establishing friendship networks within the context of entrenched (predominantly negative) societal views of disability. They also provide the opportunity to develop an understanding which avoids 'a polarised explanation focused either on social structures or individual free choice' (Hodkinson, 1998). This understanding provides a basis from which to consider ways of challenging and addressing those inequalities.

I also make reference to the notion of social justice: this is widely used though largely undefined in contemporary literature (despite being an ancient moral tradition) and tends to be somewhat over-used. I utilise the term in the context of my own definition, which draws on ancient and contemporary understandings, including, for example, work by Hume (1740/2000); MacIntyre (1981); Griffiths (2003) and Avis (2007). This definition forms part of a much extended discussion elsewhere, and concludes that in the context of more socially just education systems, all young people would be able to access a critical and democratic curriculum which prepared them for lives as active citizens, able to make critical contributions in the workplace, rather than being socialised into particular types of work within a highly stratified society. Such a position would necessarily be underpinned by an equal respect for each individual arising from his or her status as a person, which recognises and values fundamental differences in terms of interest, aptitude and ambition but which is not associated with any material, intellectual or other perceived benefits and advantages (Atkins, 2009).

In this discussion I also draw on literature critiquing normative, medicalised perceptions of disability (for example, Tomlinson, 2012; Graham & Slee, 2008; Shah, 2007). The concepts explored in this literature inform much of the policy on inclusion: I draw on it to explore how it contributes to limiting the ability that agents (individuals) have to control their own actions or destiny within the structures which form the 'divided and divisive' (Tomlinson, 1997) English education system.

Tom and Ollie

The following stories are about Tom and Ollie. Both define themselves as physically disabled and, while academically able, both have required some degree of learning support throughout their educational careers. Both have spent time in both the mainstream and the segregated educational systems. Their friendship with each other – and with other young people who participated in the pilot study – dates back to their time at Athelstan School, which is a specialist residential school catering for young people aged from three to 19 with complex medical conditions. Both had joined Athelstan School at the age of 11 after attending

mainstream primary schools, and both progressed to Wharram Percy Further Education College at the age of 16. This was co-located with their school, and catered for young people from both the mainstream and segregated systems. At different times, both then progressed to different higher education institutions. Thus, both had experienced mainstream, segregated and integrated education at different times. At interview, Ollie's narrative focused on his (integrated) college experience. Tom was still at university at the time I met him, and chose to focus on his (mainstream, with support) higher education experience; thus, it is inclusion in these contexts which is addressed, rather than the issues related to segregated special schools.

Ollie

Ollie has a rare degenerative and life-limiting condition akin to muscular dystrophy and now uses a wheelchair full time. Hearing impairment, complex physical disability, significant medical problems and dyslexia meant that he had particular difficulties at his mainstream primary school where, aged 11, his teacher told his mother that that he would never learn to read and write. His hearing impairment and some physical characteristics also created difficulties for him in establishing social networks. His parents subsequently fought a successful legal battle for a revised Statement of special educational needs (a legal document defining the support required in school). They sought funding to enable him to be educated at a specialist residential school which had onsite medical as well as educational facilities, which they believed would be most appropriate for his social and educational needs, as well as his medical needs. He progressed from here to Wharram Percy Further Education College, and after a break of several years due to health problems, he moved to Eastern University to do a combined honours degree. Unfortunately, again due to health problems, he withdrew during his second year. Ollie enjoyed his time at residential school, and retains many of the friendships he established there. He is a confident and gregarious young man who now also has a wide circle of non-disabled friends. His responses focused on the time he had spent at further education college rather than either his school or his university career. He acknowledged the efforts the college made in terms of inclusion – for example, in facilitating him to do a hospitality programme and providing access to an adapted kitchen – but asked 'why, *when everything was so inclusive in the classroom, did they make all the disabled kids sit together at lunchtime?! You couldn't move around and talk to your friends*'. In his responses Ollie initially appeared to have a primary concern with physical access: however, as discussion with him progressed it became apparent that, although physical access remains an issue of broader concern to him, he was more concerned with communicating his perception that issues of access were used uncritically to

routinise practices within the college which, in turn, mediated his social activities, as in the example given above. In raising this issue, Ollie highlights the fact that for inclusion to be truly effective, it has to involve philosophy and actions which do not begin and end in the classroom, and which acknowledge the wider social contexts of young people's lives and experiences (and see Kamenopolou, 2012).

Tom
Tom is 23. He has a severe form of cerebral palsy and uses an electric wheel-chair. He requires the support of a 24/7 carer and uses a motability vehicle. Tom is studying for an undergraduate degree at a UK university. The university, like the other educational institutions Tom attended, has made considerable efforts to enable him to access his learning programme.

Yet Tom feels socially excluded at university, and recounts stories of both subtle and unsubtle forms of exclusion. For example, he describes feeling excluded because, as a wheelchair user, *'you can't sit with mates in class because the lecture halls are like cinemas and stepped'*. Similarly, social interactions are hampered because *'between lectures I have to go the accessible way which isn't always the main route'*, thus separating him from his peers. The solution to these difficulties is obvious as far as he is concerned: *'[organisations should make] disability access the* main *focus rather than a spin off'*. In addition to these challenges, which exemplify ways in which he feels excluded, Tom describes facing subtle forms of exclusion. Tom's disabilities mean that he requires a note-taker; he explained that in terms of learning *'[I] need help note-taking and revising [and] struggle to write lots'*. While the note-taker is clearly an essential support in terms of *in*clusion, Tom noted that *'in group activities my note-taker can get in way of my own interactions'*, illustrating the way in which some interventions intended to support an individual can, albeit unintentionally, be both *in*clusive and *ex*clusive. His comments covered both formal and informal practices within the institution, all designed to include and support the disabled student. However, consistent with Shah's (2007) argument, it was apparent that these practices, intended to facilitate the inclusion of disabled students in mainstream education, were perceived by Tom, and possibly other disabled students, as barriers to their full participation in mainstream education.

Social in/exclusion
These stories reflect tensions between the students and the commitment to inclusion and equality that the institution makes explicit. Importantly, both Tom and Ollie give prominence to the role of social in/exclusion in their lives. In short spaces of time, such as that when Tom is using the 'accessible route' or sitting

apart during lectures, the thread of conversations can change or be lost and group dynamics can shift, however imperceptibly. These changes in a group dynamic effectively leave young people such as Tom, who is compelled to leave his friends at times, constantly on the margins of their friendship group. This is significant since, whatever the intended acts of inclusion and integration, what appeared to be most important to both young men was to be socially included in leisure activities such as simply chatting or having lunch together with a peer group which included both disabled and non-disabled peers.

This suggests that, consistent with earlier research (Atkins, 2009), social and leisure activity and social networks are a significant aspect of identity formation in these young people's lives as they move towards adulthood, and in many cases the one to which they attach the greatest importance. This social aspect of education is of considerable importance to young people both with and without disabilities. However, those with disabilities often experience more difficulty in forming and maintaining social networks because they, or their friends, may be educated in segregated provision rather than local schools, or because of difficulties associated with achieving full integration with non-disabled peers in mainstream schools (Curtin & Clarke, 2005; Shah, 2007). Despite the significance of leisure and social networks in the lives of young people, these are aspects of identity formation which are often overlooked by policy makers and practitioners. Importantly, however, the challenges for disabled young people of overcoming social exclusion imply that the social aspects of education may assume proportionately greater significance for them than for their non-disabled peers as they make their transition to adulthood. Failure to see beyond the classroom in terms of inclusion will result in exclusionary practices such as those described by Ollie and Tom, and have the potential to engender greater, rather than less, social exclusion for other young people with disabilities during their educational careers.

Within the classroom, failure to take account of changing group dynamics when a note-taker or other support worker is introduced also creates the potential for further exclusion. As Kamenopoulou (2012) has argued in the context of deaf-blind children, the support assistant's professional role is likely to inhibit relationships between the supported young person and their peers. This issue raises a number of questions in the context of support provided for young adults. What is the role of the support worker in a group activity? Is it to remain silent and scribe (which might create constraints in some group activities) or to participate (which could deny a voice to the young person)? If interaction between the young person and their support worker is necessary, how might that impact on the peer group dynamic in that moment? Irrespective of the approach taken, as Tom says, the

very presence of another person has implications for the relationships between the supported student and his peers. Thus, there was a tension between his need for a note-taker to facilitate *educational* access to his chosen programme, and the way her presence created barriers to the *personal* interactions which are part of the wider educational experience for all young people.

Wharram Percy College created another barrier by requiring their disabled students to sit in a designated area at lunchtime. Irrespective of the reasons for this, which may have had some validity in terms of, for example, health and safety in the event of evacuation, approaches such as this reflect the way in which certain discriminatory practices can become normalised and legitimated within institutions – even those committed to inclusive practice and equality – to the extent that professionals cease to question them. A failure to question is reflective of Bourdieu's notions of *illusio* and *doxa*. The professionals involved have a 'commitment to the presuppositions of the game' and as such misrecognise the logic of the practices they engage with (Bourdieu, 1990). But such practices contribute to the marginalisation of certain groups of young people. Experiences such as Ollie's highlight the need for practitioners constantly to problematise and question their own practice and that of the institution in order to ask: 'What are we doing and why are we doing it? What are the consequences of our actions and for whom?'

Discourses of in/exclusion: disability, power and control
Discourses and constructions of the individual within both educational and social contexts have implications for their positioning in terms of the relations of power within which they relate to others. I have argued before that the education system exerts particularly oppressive forms of power and control over certain groups of young people in the context of the discourse it uses to describe them (for example, see Atkins, 2009, 2010). It does this by homogenising young people into deficit models associated with specific characteristics the group is perceived to have, and the discourse used always has negative connotations. Thus young people who are unable to conform to the requirements of secondary education are described as 'disaffected' and 'disruptive' or 'disengaged'. Similarly, we discuss *dis*ability as opposed to ability and describe some young people (often including the 'disaffected' or 'disengaged') as having *special* educational *needs*. Those words beginning with the root 'dis' express negation or absence (*Oxford English Dictionary*). Similarly, the term *need* implies a want or deficit, as well as a form of dependency.

In the context of inclusive education, the use of discourses of deficit, in both policy and practice, can also be indicative of a tension, or *illusio*, between the unspoken assumptions upon which the discourses are predicated, and the philosophies and rhetoric of inclusion to which most professionals subscribe. Moreover, the use of discourse such as disabled, or disaffected, even when used in a professional context, can communicate negative messages to others. Terms associated with models of deficit, such as special educational needs, exert considerable power in terms of the way they define and Other specific groups in the light of perceived characteristics of difference. Hodkinson (2010) has argued eloquently that where young people are defined in deficit terms such as these, the impact is to 'shackle' individual needs to 'entrenched societal views of disability', a process which he considers 'inevitably leads one to a narrow and contrived view of inclusion', ultimately leading to toleration (and not inclusion) through a process of integration (rather than inclusion). Hodkinson's argument about 'narrow and contrived' views of inclusion resonates with Graham and Slee's (2008, p. 289, citing Deleuze, 1988) view that:

> 'institutional attempts to "include" through processes that identify the other result in an illusory interiority due to the adoption of discourses and practices that are both normative and confer exteriority'.

The discourses of deficit referred to above are reflective of 'entrenched societal views of disability' and, by definition, normative, since, as Popkewitz and Lindblad (2000) have argued, they highlight differences between the (normative) child whose unnamed dispositions and capabilities stand in direct opposition to those of the child characterised in terms of difference. They go on to argue that what is characterised as different (named), and what is not (unnamed) is an effect of power. This is a significant point and reflects not only the power of discourse, but also its contribution to the naturalisation of 'the structures of domination' (Wacquant, in Bourdieu & Wacquant, 1992).

Where young people are characterised within deficit models, and these are not questioned, it has the potential to disadvantage them in a number of ways. Firstly, where particular assumptions and characterisations implicit in the language used to characterise them are perceived to be normal and natural – and thus not questioned – this contributes to the maintenance of a status quo in terms of societal views of disability, and makes the journey towards full inclusion and social justice more difficult. Secondly, the implication that particular characteristics make an individual less able has the potential to form part of embodied structures which can determine and reproduce how people think and behave and are

'constitutive of, rather than defined by, social structures' (Reay, 1998). The impact of such embodied structures is to constrain aspirations and agency, as well as maintaining a societal status quo, and is thus contrary to social justice. Therefore, if we aspire to work towards a more socially just and inclusive society, we must be prepared to interrogate the discourses, perceptions and practices which might militate against the aim of full educational and, by extension, social inclusion. This might begin with a re-consideration of the language we use to characterise young people, and a debate about different and more positive ways of alluding to all young people.

A more critical and reflexive approach to inclusive practice, and a debate about the impact of discourses of deficit, has the potential to contribute to a more truly inclusive system in which disability, rather than having the potential to define a person, is merely an aspect of what makes them unique as an individual. A focus on capabilities such as that highlighted by Hedge and Mackenzie (2012) and by Terzi (2005) would enable, rather than constrain, young people's potential for agency as they make the transition from school to adulthood, something which would have significant implications in terms of their potential for social inclusion through work and leisure activities in later life.

Perceptions of in/exclusion
Tom and Ollie attended educational institutions with significant commitment to equality and diversity, yet they both perceived themselves as experiencing certain exclusionary practices. This highlights the importance of interrogating practice and exploring the issues surrounding and consequences of inclusive practice. But equally crucially, it raises questions about the normative perceptions of disability and inclusion held by policy makers and professionals at all levels and how such perceptions are communicated through professional discourse. These perceptions assume that we should be including the marginalised into a centre described by Graham and Slee as 'but a barren and fictional place' (2008) and also reflect 'inclusion's need to speak of and identify otherness' (Harwood & Rasmussen, 2002, cited in Graham & Slee, 2008; see also Popkewitz & Lindblad, 2000).

Normative perceptions obstruct possible solutions to problems of exclusion such as those experienced by Tom. His idea that *'[organisations should make] disability access the main focus rather than a spin off'* seems simple and instrumental; after all, if, as he argued, it was achieved at the London Olympic Park and Athletes Village, why could similar approaches not be used in educational institutions? Apart from the financial costs, prohibitive even in the time before global recession, the most significant barrier is that all aspects of education are

constructed around perceptions of the world in which disability is regarded as exceptional rather than ordinary. Thus, achieving change demands far more than thoughtful planning: it demands 'disrupt[ing] the construction of centre from which the exclusion derives' (Graham & Slee, 2008). Given that normative perceptions and power are co-located in this fictional centre, the implications arising from the disruption of the construction of centre are significant in terms not only of transferring power from the centre but in terms of the overwhelming societal attitudinal change it would require, and the implications for an educational system whose structures are complicit in the legitimation of exclusion. For example, the educational system into which young people with disabilities are currently included is concentrated around a target-driven mainstream, associated with league tables, national standards, and expected outcomes for examinations at particular stages. Thus, schools experience tensions between their accountability in terms of 'standards' and the requirement for inclusion, something which Hodkinson (2010) suggests may result in some being reluctant to accept children whose level of attainment may 'depress the SAT score'. Within this context of accountability, many young people are 'included' through the media of learning support and individual education plans, which effectively place them a deficit model in the context of real life opportunities and from which they are doomed to become 'failures' in terms of government benchmarks, and as such, socially excluded (Lloyd, 2008).

At least in the short term, a realistic move towards a more socially just system that addresses some of these issues might take the form of a more radical and critical approach to inclusion in education. Such an approach would require those in positions of power to listen to the voice of the 'included' and focus on maximising their potential for agency in the context of marginalising structures of society, the education system and the labour market they hope to enter. It would also imply a move towards discourses of capability and away from discourses of deficit among practitioners in education and wider society.

Conclusions

In this article I have drawn on a range of arguments which critique contemporary UK policy and practice on inclusion from a variety of perspectives. It is apparent from those arguments, as well as from the limited empirical evidence presented in the article, that the policies and practices associated with inclusion can result in, or collude with, the effective social and educational exclusion of young people with disabilities.

Tom and Ollie's stories demonstrate that the forms of exclusion that most concerned them were the aspects of social exclusion which prevented them from establishing and maintaining peer relationships in the same way that less marginalised young people can. The importance of leisure and social networks among young people has been highlighted in earlier research (for example, see Ball et al., 2000; Atkins, 2009). However, those studies focused largely, though not exclusively, on young people in the 'mainstream'. Work by Curtin and Clarke (2005) and Shah (2007), among others, indicates that disabled young people face particular difficulties in forming and maintaining social networks, in part due to the fact that they, or some of their friends, are often educated in segregated special schools some distance from home or because of issues associated with integrating fully with non-disabled peers in mainstream education. The implications of this for identity formation, and for young people's potential to make transitions to adult lives which are socially included in terms of both work and social networks, are significant, and this is an area that warrants further exploration.

The evidence from the narratives is largely consistent with the literature. It is apparent from Tom and Ollie's stories that some practices which are intended to be inclusive have the potential for an exclusionary impact on young people, and that this is something which can inhibit full participation in mainstream education (Shah, 2007). More importantly, this can go unnoticed – except by them. This implies an uncritical implementation of inclusive practices on the part of some education professionals and institutions who fail to acknowledge their own normative positioning and cannot comprehend the lived lives of disabled students. This must be addressed. Morally, practitioners have a responsibility critically to examine inclusive practices within the classroom and the institution to understand how they impact on the education and lives of young people, and to find ways in which 'each young person with a physical disability can be listened to, so that their individual needs may be identified and then accommodated' (Curtin & Clarke, 2005). Curtin and Clarke also suggest that such actions may be a means for 'realising the goal of inclusion'. Such an aim may be laudable, but it seems doubtful whether, in a diverse and disparate society, in which all our lives are defined by the extent to which we are more or less equal than others, and in which we all view the other from our own normative and often more powerful position, inclusion can ever be anything other than an illusory concept.

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