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Dis(en)abled: the lived experiences of inclusion policies amongst disabled young people

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Abstract

This paper explores the tension 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 formed part of a small pilot study of young people defined as disabled and in receipt of a Statement of Special Educational Need, the paper utilises theoretical concepts around 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.

Focussing on the young men's experiences of further and higher education, the paper argues 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. It goes on to suggest that, in this way, inclusion comes to form part of the complex and multi-layered behaviours, structures and social practices that we refer to as exclusion.

. It concludes 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.

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. This paper presents 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 exclusive.

Inclusion in education has become big business internationally over the past two decades and is enshrined in law in many countries including those making up the United Kingdom. Curtin and Clarke (2005:196) argue that this movement originated in the 1989 United Nations Convention of the Rights of Children (United Nations, 1989) and the Salamanca Statement on Principles, Policy and Practice in Special Needs Education (United Nations Education Scientific and Cultural Organisation, 1994). They go on to suggest that both these statements were significant influences on the subsequent move towards inclusion and eventually contributed to a human rights ideology which suggests that segregated special schools are not only divisive, but contribute to ongoing inequalities in access to education. However, this ideology has been contested 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.

Despite concerns such as those raised by Shah, the 'SEN industry' is now an international activity underpinning mass education in both developed and developing countries (Tomlinson, 2012; 2013). Concomitant with this, much has been published on the desirability of inclusion in education, as a means of working towards (a largely undefined notion of) social justice, as well as on what may or may not be described as 'good practice' in terms of inclusion. This body of work encompasses all stages of education, and much of it is predicated on the assumption that inclusion, in terms of strategies such as addressing individual needs in the classroom, is a 'good thing'. This raises concerns about the uncritical use of inclusive policies and practices which have the potential for unintended and often un-noticed consequences for the young person being 'included'. 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 (2008:277) 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-granted assumptions about the Other as well as on a set of beliefs about the relative effectiveness of strategies for inclusion. Secure in the knowledge that we are 'doing' inclusion, as practitioners we often fail to question or even consider these critical issues. And yet, if as education practitioners our aim is to make social justice, then we have a *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 different forms of exclusion and marginalisation in the context of their positioning within a homogenised and deficit model of disability.

Methodology

This paper draws 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. 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. One of the young people profiled here later participated in a telephone interview. The narratives developed from the data, which was analysed using a thematic approach which explored responses related specifically to instances of inclusion and exclusion, 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 paper. Focussing on two narratives, this paper does not claim definitive or even relatable results. Rather, it draws on the stories told by these young men to critique current approaches to inclusion,

and to highlight the need for more extensive research exploring the educational lives of young people with disabilities.

Conceptual Framework

This paper utilises theoretical concepts around structure and agency, power and control as well as disability to inform its exploration of the ways in which inclusion can create subtle (and sometimes not so subtle) forms of exclusion. Bourdieu (2000:214/215) argued that ‘Those who talk of equality of opportunity forget that social games ... are not ‘fair games’’. In drawing attention to the inequalities and oppression impacting on the educational lives of disabled young people, the paper draws on Bourdieu’s theories on structure and agency, which relate to his primary concern of inequality within society, provide a useful framework for understanding the injustices imposed by social, educational and political structures on disabled students. They also provide the opportunity to develop an understanding which avoids ‘a polarised explanation focused either on social structures or individual free choice’ (Hodkinson, 1998:100). This understanding provides a basis from which to consider ways of challenging and addressing those inequities.

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. This paper utilises the term in the context of my own definition, which forms part of a more extended discussion elsewhere, and which argues that:

In the context of work and education, 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 their 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, 2009:45).

This paper also draws on literature exploring the normative, medicalised perceptions of disability (e.g Tomlinson, 2012; Graham and Slee, 2008; Shah 2007). The concepts explored in this literature inform much of the policy on inclusion: the paper draws on it to explore how it contributes to limiting the ability that agents (individuals) have to control their own actions or destiny within the normative and centrist structures which form the education system in England.

Tom and Ollie

The following stories are about Tom and Ollie. Both define themselves as physically disabled and, whilst 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 – dates back to their time at Athelstan School, which is a specialist residential school catering for young people with complex medical conditions. Both progressed to Wharram Percy Further Education College at aged 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. Ollie's narrative focusses on his college experience. Tom was still at university at the time I met him, and chose to focus on his HE experience.

Ollie

Ollie has a rare degenerative and life-limiting condition akin to muscular dystrophy and now uses a wheelchair fulltime. Hearing impairment, complex physical disability, significant medical problems and dyslexia meant that he had particular difficulties at his mainstream primary school, where one teacher told his mother that that he would never learn to read and write. His parents subsequently fought a successful legal battle for a Statement of Special Educational Needs which provided funding to enable him to be educated at a specialist residential school which had onsite medical as well as educational facilities. 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 secondary school, and retains many of the friendships he established there. He is a confident and gregarious young man who also has a wide circle of non-disabled friends. His responses focussed on the time he had spent in college. He acknowledged the efforts the college made in terms of inclusion, 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 to routinize 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 contexts of young people's lives.

Tom

Tom is 23. He has a severe form of cerebral palsy and uses an electric wheelchair. 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 degree 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 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'. Whilst the note-taker is clearly an essential support in terms of inclusion, 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 be both inclusive and exclusive. 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 (2007:425) argument it was apparent that these practices, designed by non-disabled adults, 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: further, such practices also fail to acknowledge young peoples positioning within a stratified education system constitutes layers of inclusion and not just a distinction between inclusion and exclusion (Bathmaker, 2005:83).

Social in/exclusion

These stories reflect tensions between the students and the commitment to inclusion and equality 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 is 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, 2009:140) social and leisure activity is a significant aspect of identity formation in these young people's lives as they move towards adulthood and is the aspect of their lives to which they attach the greatest importance. This social aspect of education is of considerable importance to young people both with and without disabilities, although it is often overlooked. 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 social exclusion for other young people in similar circumstances.

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. They have a professional role so are likely to inhibit relationships between the supported young person and their peers. And what is their role 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)? And 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 access to his chosen programme, and the way her presence created barriers to his personal interactions.

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 become normalised and legitimated within institutions – even those committed to inclusive practice and equality - 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 misrecognize the logic of the practices they engage with (Bourdieu, 1990:66). But such practices contribute to the marginalisation of certain groups of young people. Experiences such as Ollie's highlight the need for practitioners to constantly 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

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 (e.g. 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 people who are unable to conform to the requirements of secondary education are described as 'disaffected' and 'disruptive' or 'disengaged'. Similarly, we discuss *disability* as opposed to ability and describe some young people (often including the 'disaffected' or 'disengaged') as having *special* educational *needs*. The term *need* implies a want or deficit, as well as a form of dependency. There is also anecdotal evidence to suggest that some (non-disabled) young people use the word 'special' as a derogatory noun. The anecdotal evidence relates to an overheard discussion amongst a group of new undergraduate students about some of their peers at

University. 'Othering' these young people, and speaking of them in disparaging terms, they referred to them variously as being 'Widening Participation' (in which Widening Participation became a noun) and 'a bit Special' (from Special Educational Needs). Whilst these comments were made largely in relation to perceived social skills deficits they reflected the subtle and overt forms of exclusion that such language engenders towards marginalised groups, even amongst those who have been educated in the context of a long standing inclusion agenda in schools and universities and raises questions about the extent to which practices intended to address marginalisation and exclusion –such as the use of 'appropriate' language – are at all meaningful or effective. It is worth noting here that this anecdote reflects the power of particular policy discourses which homogenise and marginalise specific groups of young people. Such discourse inevitably finds its way into popular discourse and in doing so, reinforces normative and discriminatory attitudes amongst the wider population.

The use of such discourses of deficit amongst young people also raises the question whether their use of language is simply reflective of wider societal attitudes, or whether they have been influenced by a particular ethos or message they have met with in education. In the context of the inclusion agenda, and wider education, we tend to assume that all teachers are committed to the principles of equality and social justice in education. The assumption that all teachers are so committed is one of the taken-for-granted surrounding the discourse of inclusion, and yet, as research amongst trainee teachers demonstrates, they hear messages in schools that conflict with the pro-inclusion messages they hear in the university (Beacham and Rouse, 2012: 12). It seems that some teachers retain negative, normative societal attitudes and perceptions which influence the ways in which inclusive practice is implemented, and which communicate conflicting messages, perhaps not only to trainee teachers, but also to the young people they teach. This tends to support earlier work by Avramadis and Norwich (2002:142) which argues that teachers differentiate between those with mild disabilities and those with more complex needs and are more likely to hold negative attitudes towards the latter group.

That the conflict between negative, normative societal attitudes and those of the inclusion agenda continue to be played out in educational contexts is reflective of the failure of the educational system to effectively confront power by challenging marginalisation and exclusion and thus moving towards a more socially just and democratic system of education.

The marginalisation arising from the use and manipulation of terminology associated with special education, both in a policy context and amongst the wider population, merely reflects a single aspect of multi-faceted negative and exclusive societal attitudes which arise from centrist and normative perceptions of the 'other' where those at the centre have effective control over those at the margins. For example, in or out of mainstream, special education continues to be based on a model of disability and learning difficulty as individual pathology (Tomlinson, 2012:275 citing Barton, 2001; Allan, 2010 and Slee, 2011). Tomlinson's use of the word pathology is instructive: its association with disease process implies individual fault or disease, which if not attributing a degree of responsibility to the young person, certainly implies forms of deficit amongst individuals so described.

Such discourse homogenises all young people with disabilities, irrespective of their individual needs and abilities within a deficit model. A key aspect of this is the linguistic pluralism which conflates physical disability with intellectual impairment, something which is apparent in a number of policy documents. These include the Government response to Wolf (2011: 8), which, in two sentences, makes reference to disability and SEN in the context of developing new English and maths qualifications for lower attaining pupils. It is worth noting here that both young men whose stories are presented here are, according to the government's own benchmarks, high attainers, albeit with some support or adjustment from the 'SEN industry' (Tomlinson, 2012;2013). The fact that disability and low educational attainment or cognitive deficit are not necessarily mutually inclusive is a factor which tends to be absent from policy associated with SEN. The conflation of SEN with low educational attainment, such as that cited above, is not new. As Tomlinson (2012: 276) argues, the eugenics movement [and later] both public and expert views conflated low educational attainment with low social class and social vice. This argument goes some way to explaining contemporary negative social attitudes towards the disabled and those with special educational needs, reflected in discourses of deficit which place the individual squarely within a deficit model associated with what they cannot do, rather than what they can do. In this way, for some young people, disability can come to define the individual rather than being an aspect of what makes them unique as an individual (e.g. see Atkins, 2009: 117) and in doing so not only constrains their potential for agency but constrains all their opportunities for achieving their potential as they make the transition from school to adulthood.

In the context of 'inclusive' education the use of discourses of deficit are indicative of a tension, or *illusio*, between our normative assumptions, reflected in the discourses we use, and the generally held belief that we are successfully 'doing' inclusion. Moreover, certain professional discourse when used unthinkingly 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 light of their perceived characteristics which differ from the accepted norm. Characterising young people in this way has significant implications for their identity formation, something which is likely to have a major impact on their potential for agency and thus also on the relative success of their transition from school to adulthood.

Normative perceptions of in/exclusion

Tom and Ollie attended 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 centrist and 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' (2008:279) and also reflects 'inclusion's need to speak of and identify otherness' (Harwood and Rasmussen, 2002 cited Graham and Slee, Ibid).

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, it was achieved at the Olympic Park and Athletes Village. So why not 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 normative perceptions of the world which effectively exclude anyone perceived to be different. Thus, achieving change demands far more than thoughtful planning: it demands 'disrupt[ing] the construction of centre from which the exclusion derives' (Graham and Slee, *ibid*). 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 overwhelming societal attitudinal change it would require. At least in the short term, a realistic mover towards this might take the form of a more radical and critical approach to inclusion in education which listens to the voice of the 'included' and is focussed 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. This would indeed mean a radical re-consideration of the education system whose structure, it may be argued, merely legitimates exclusionary practices.

Lloyd (2008:227), citing earlier work by Benjamin (2002) argues that 'exclusionary practices are legitimized within a policy for inclusion preventing the dominant discourse and approaches from being challenged' (2008: 227). He suggests that this occurs because young people with SEN are 'included' in a target driven mainstream through the media of learning support and Individual Education Plans, and suggests that this places them in a deficit model in the context of real life opportunities. In real life, Lloyd argues, league tables, national school standards, and critical measures such as 16+ exams mean that these young people are, in the eyes of the world, doomed 'failures' and as such effectively socially excluded.

Lloyd's argument highlights the need for radical new forms of education which enable disabled young people to fulfil their potential. This has implications for all young people, and not just those currently at the receiving end of inclusion policies. Only a minority of young people are well served by the English education system. All those who are marginalised – low attainers in the context of government benchmarks, and those who exhibit exclusionary characteristics, such as gender, social class and ethnicity as well as disability – need a radically different system which will enable them to fulfil their potential and compete effectively in the labour market in a way which is more consistent with social justice.

Conclusions

This paper has drawn on a range of arguments which critique contemporary inclusion policy from a variety of perspectives. It is apparent from those arguments as well as from the limited empirical evidence presented in the paper, that the policies and practices associated with inclusion are, in many cases, resulting in, or colluding with, the effective social and educational exclusion of young people

with disabilities. The literature suggests that we 'include' young people in a target driven mainstream which effectively places them in a deficit model in the context of real life opportunities (Lloyd, 2008:227), that we position ourselves, as education professionals, within a 'barren and fictional' centre (Graham and Slee 2008:279) from which 'we speak of and identify otherness' (Harwood and Rasmussen, 2002 cited Graham and Slee, Ibid) as we, largely non-disabled people, design and implement systems and practices which disabled students may perceive as barriers to their full participation in mainstream education (Shah, 2007:425) .

The evidence from these narratives is largely consistent with these arguments. It is apparent from Tom and Ollie's stories that some inclusive practices have the potential for an exclusionary impact on young people that can go unnoticed – except by them - implying an uncritical implementation of inclusive practices on the part of education professionals and institutions who fail to acknowledge that their own centrist and normative positioning cannot comprehend the lived lives of disabled students. This must be addressed. Morally, practitioners have a responsibility to critically 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 and Clarke,2005:211). 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.

These stories also demonstrate that the forms of exclusion that most concerned Tom and Ollie were the aspects of social exclusion which prevent them establishing and maintaining peer relationships in the same way that less marginalised young people can. The importance of leisure and social networks amongst young people has been highlighted in earlier research (e.g. see Ball et al, 2000; Atkins, 2009). However, those studies focussed largely, though not exclusively, on young people in the 'mainstream'. Work by Curtin and Clarke (2005) and Shah (2007) amongst 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 this has for identity formation are significant, and this is clearly an area which demands further investigation.

In summary, the most important point is that the disabled students referred to in the literature and in policies and procedures in educational institutions are not actually a theoretical other. They are real people with real lives and, like Tom and Ollie their struggle to navigate difficult transitions from school to adulthood is made more challenging by the oppressive and discriminatory practices we legitimate throughout the education system in the name of inclusion.

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