

'They never pass me the ball': exposing ableism through the leisure experiences of disabled children, young people and their families.

HODGE, Nick <<http://orcid.org/0000-0001-5706-1865>> and RUNSWICK-COLE, Katherine

Available from Sheffield Hallam University Research Archive (SHURA) at:

<https://shura.shu.ac.uk/6137/>

This document is the Accepted Version [AM]

Citation:

HODGE, Nick and RUNSWICK-COLE, Katherine (2013). 'They never pass me the ball': exposing ableism through the leisure experiences of disabled children, young people and their families. *Children's Geographies*, 11 (3), 311-325. [Article]

Copyright and re-use policy

See <http://shura.shu.ac.uk/information.html>

'They never pass me the ball': exposing ableism through the leisure experiences of disabled children, young people and their families.

Dr. Nick Hodge, The Autism Centre, Department of Education, Childhood and Inclusion, Sheffield Hallam University.

Dr. Katherine Runswick-Cole, Research Institute for Health and Social Change, Manchester Metropolitan University.

Forthcoming in Children's Geographies (2013)

Address of corresponding author:

Dr. Nick Hodge

Principal Lecturer in Education Research Development
Sheffield Hallam University
Arundel Building
Room 10007
122 Charles Street
Sheffield
S1 2NE

T: +44 (0)114 2254554

E: n.s.hodge@shu.ac.uk

'They never pass me the ball': exposing ableism through the leisure experiences of disabled children, young people and their families.

Abstract

In this paper, we explore the participation of disabled children, young people and their families in leisure activities. Drawing on the accounts of disabled children, young people and their parents and carers, we reflect on the leisure spaces that they access and record some of their experiences within them. Using the concept of 'ableism' (Campbell 2009) we interrogate the data gathered as part a two-year project funded by the Economic and Social Research Council (RES – 062-23-1138)

(<http://www.rihsc.mmu.ac.uk/postblairproject/>): 'Does every child matter, Post-Blair: the interconnections of disabled childhoods'. By doing so we identify some of the inherent and embedded discriminations in favour of those children and young people who are perceived to be 'able' that simultaneously work to exclude the young 'kinds of people' (Hacking 2007), categorised as 'disabled', and their families from leisure facilities and opportunities . We suggest that currently, disabled families and children occupy a mix of 'mainstream', 'segregated' and 'separate' leisure spaces. We discuss the impact of occupying these spaces and ask:

1. What do the experiences of accessing leisure by disabled children, young people and their families reveal about the processes and practices of ableism?
2. To what extent are children and families required to 'pass' as 'normal enough' to gain access to leisure spaces?
3. To what extent are 'segregated' leisure opportunities regulated and produced by a kind of 'diagnostic apartheid' (Campbell 2008a: 155)?

4. What is the role and value of 'separate' leisure activities?

Introduction

Currently, there is a new international focus on the inclusion of disabled children in mainstream service provision, including leisure services (Evans and Plumridge 2007). 'Mainstream' is a term that is popular in usage in countries such as the United Kingdom, Australia and the United States of America to refer to services that are set up to provide for 'typically developing' children. By definition the term mainstream places some children as outside of these services with the presumption that their requirements can only be met within some minority, specialist provision. Therefore, 'mainstream' facilities might be more accurately termed 'normate' (Garland Thomson 1997) services, to reflect that they are constructed and constituted for those who 'can represent themselves as definitive human beings' (Garland Thomson 1997:8). In this paper we use the term mainstream albeit with some reluctance and concern that it continues to promote the ableist assumption that certain spaces will remain inaccessible to those disabled people who are positioned as not being able to be accommodated within the mainstream. We use the term 'mainstream' only because the term reflects the language used within the policy documents that are under discussion here.

In England, under the policy *Aiming High for Disabled Children: Better Support for Families* (HM Treasury and DfES 2007: 31), there has been a commitment to 'children with complex needs accessing mainstream education, inclusive play and leisure opportunities'. Similarly, *The Play Strategy* (DCSF 2008) makes a commitment to including all children, regardless of their circumstances and including 'children with disabilities', in the plan for improving play opportunities. However, McConachie et al. (2006) argue that although there may now be more participation in leisure by disabled children, 'more' may not be 'better' if the child does not have a say, does not enjoy the activity very much or is made to feel 'lesser' by the process of doing so.

This paper considers the nature of access to play and leisure opportunities for disabled children and young people and reflects on what these might reveal about the nature and practice of 'Ableism' (Campbell 2009). This focus on leisure forms part of a wider two-year project funded by the Economic and Social Research Council (RES – 062-23-1138)

(<http://www.rihsc.mmu.ac.uk/postblairproject/>): 'Does every child matter, Post-Blair: the interconnections of disabled childhoods'. This project explored what it means to be a disabled child/young person in England today, by drawing on the accounts of disabled children and young people, their parents/carers and allied professionals. For clarity, the phrase 'disabled children' is used in this paper to refer to disabled children and young people.

This paper uses the concept of 'Ableism' to interrogate these leisure experiences of disabled children and their families. Therefore, we will begin by presenting our understandings of 'the project of ableism' as it is formulated by Campbell (2008a; 2009).

The project of ableism

Campbell (2009) describes the project of ableism as, 'the compulsion to emulate ableist regulatory norms' (p.3) resulting in '(a) network of beliefs, processes and practices' (Campbell 2001 cited Campbell 2009: 5) that cast 'disability', 'as a diminished state of being human' (ibid). Inherent within ableism are, '*the notion of the normative (and normate individual)*' (Campbell 2009: 6) and 'the enforcement of a *constitutional divide* between perfected naturalised humanity and the aberrant, the unthinkable, quasi-human hybrid and therefore non-human' (ibid). Ableism, constructs bodies as 'impaired' and positions these as 'Other': different, lesser, undesirable, in need of repair or modification, and de-humanized. The project of ableism creates a different 'kind of people' (Hacking 2007), a sub-human species that is the 'Inferior Other'. Hacking proposes that the human sciences categorise people into 'kinds of people', groups that are alleged to share common characteristics and

ways of being that set them apart from others. Ableism creates and sustains the context in which this 'impaired kind of people' is then subject to disablism, 'the differential or unequal treatment of people because of actual or presumed disabilities' (Campbell 2008b: 2). Those who are placed outside of the ableist norm are then devalued, disenfranchised, disempowered and subject to social and material exclusion. In his definition of ableism, Hehir (2002) captures some of the regulatory norms that act as the markers of normate identity. For Hehir ableism is:

the devaluation of disability... [that] results in societal attitudes that uncritically assert that it is better for a child to walk than to roll, speak than sign, read print than Braille, spell independently than use a spell-check, and hang out with nondisabled kids as opposed to other disabled kids etc (p.3).

And yet, ableism is a nebulous concept that by its very nature evades identification and definition. Campbell (2008: 3) notes that within the literature it is, 'often referred to in a fleeting way with limited definitional or conceptual specificity'. It is something that is known, and adhered to and yet remains illusive. For us, the critical elements in ableism are the creation and control, through disablism, of the 'Inferior Other' while the beliefs, processes and practices that allow this to happen remain obscured. We will now attempt to explicate some of these by considering the ways in which disabled children's leisure is conceptualised within the current research literature.

Disabled children's leisure

The discussion of disabled children's leisure is inevitably complicated by the confusion that persists about how to define children's 'leisure activities'. Gilligan (2000) suggests that it may be helpful to think of leisure activities in terms of five areas: cultural pursuits; the care of animals; sport; helping and volunteering, and part-time work. Murray (2002), however, offers a wider definition that includes 'doing nothing'. Murray suggests that leisure is:

any chosen activity/pastime when not engaging with school,

college, or paid employment. Thus, leisure time is viewed as: time spent at home when not doing schoolwork; watching television; reading; talking on the phone; using the computer; time spent at an after- school or holiday club; time spent in the gym; the cinema; the countryside; the nightclub; the coffee bar; on holiday; and, finally, time spent having a break from all activities – time spent doing nothing at all (p.1).

Murray's inclusion of 'having a break from activities' or 'doing nothing at all' is useful as it promotes the value of space to 'be' and the right to step out of 'doing' for a while; leisure can be about being rather than becoming (Goodley and Runswick-Cole 2010). This is particularly important for disabled children as all too often their access to leisure opportunities is framed as opportunities for rehabilitation, helping disabled children to meet developmental milestones (Ibid). Too often leisure becomes rehabilitation 'work' for some disabled children.

Leisure and Child Development

Children's access to leisure is frequently conceptualized in terms of enabling child development regardless of the child's perceived ability. However, for disabled children, whose development is framed by 'the compulsion to emulate ableist regulatory norms' (Campbell 2008b:1), this expectation increases in intensity and urgency. Play and leisure become key sites for rehabilitation, development and cure (Goodley and Runswick-Cole 2010). Some even see the primary value of disabled children's participation in leisure activities as *the* opportunity for 'development', a chance to encourage the 'generalization of skills' and 'adaptive behaviours across a variety of settings' (Buttimer and Tierney 2005: 25).

So powerful is the acceptance of the ableist premise that normal is the best and only option, that the expectation that disabled children should spend all of their time 'chasing normal' (McLaughlin *et al.* 2008) is rarely challenged. However, in considering how we arrived at the notion of the statistical 'norm' Hacking points out that 'normal' is a value laden concept that represents

different meanings for people. Hacking illustrates this by contrasting two competing perspectives. First Hacking outlines a Durkheimian presentation of normal in which Durkheim frames 'normal' as the correct form, the right way of being and development that diverts from this is always an example of pathology. Hacking then contrasts this with a Galton understanding of the term. Galton viewed 'normal' as not necessarily being an ideal state: it could also be a mundane average point of existence that human beings should strive to surpass. Whilst there is some promotion of the Galton perspective in disability literature, often focused around a 'defence' of Asperger Syndrome as a valued way of being (see Baron-Cohen (2002) for example), where difference can give rise to exceptional ability and contribution, the literature relating to disabled children's access to leisure generally demonstrates a Durkheimian position in relation to achieving normal. One example of this is illustrated within McConachie *et al.* (2006: 1160) who promote, without question, the notion that leisure activities should be considered in relation to children's development in the hope of achieving, or at least approximating, 'normal':

There are at least three aspects of activity and participation which are essential for normal development. The first is social interaction which assists the child's development. The second is the opportunity for play and exploration; spontaneous exploration of the child's environment is highly desirable. The third is mobility...

A difficulty with prioritizing child development within these environments is that this promotes the idea that disabled children must 'emulate ableist regulatory norms' (Campbell 2009), even within play and leisure. Therefore, they need always to be working (or worked upon) to 'improve', and preferably 'cure' or 'repair' themselves. Moreover, there is an implicit assumption in the provision of play and leisure services for disabled children that only when a child progresses into the required band of normal can he/she be permitted time for leisure per se as opposed to leisure as a site for development. This sense of urgency for disabled children to work towards normal is reflected in the rarely challenged mantra of the criticality of 'early and intensive intervention' (Siegel 2003:34). This is a call to capitalise on the window of opportunity for 'catch up'

development before a child is, presumably, 'lost' forever to disability. As Hacking (2007) notes, '[in] many cases, we try to make the unfavourable deviants as close to normal as possible' (p. 311).

Leisure and the barriers without

Structural barriers, including physically inaccessible environments and lack of equipment, have often been identified as standing in the way of disabled children's access to leisure. Indeed, in England within the policy of *Aiming High for Disabled Children: Better Support for Families* (DfES 2007: 47), the English Government highlighted such barriers:

Equipment, from wheelchairs to communications aids, is essential to help disabled children and young people access school, leisure and other services, and to facilitate independent living.

Similar findings emerge from research with community recreation administrators in the United States and Canada. These identified limited financial resources and unqualified staff as the major reasons for the exclusion of disabled children from community facilities (Jones 2003/4). Such exclusions then limit the range and nature of available leisure activities for disabled children. In a later study by Jones (2003/4), this time with parents of disabled children instead of administrators, additional barriers emerged as significant. The majority of parents identified that their children had 'been excluded from participating in community recreation programs because of behavioural issues and social skills deficits' (p. 59). Ironically the ensuing social isolation and the denial of the opportunity to learn from peers tended to exacerbate the behaviours that had led to the exclusion. Another barrier that was reported by the parents was the focus, within children's leisure activities, on competitive sports. One mother illustrated how this type of barrier without can also become 'a barrier within' as her daughter takes the failure of the activity to be inclusive and internalises this as a personal failure: '...she gives it her all, but she doesn't have the ability to help her team out... For her that's

a failure, I think. And she gets really depressed and it bothers her, especially when other children leave her out ' (Jones 2003/4: 58).

It is perhaps not surprising, therefore, that Buttimer and Tierney (2005) found that disabled children most frequently reported leisure activities that were passive and solitary in nature, and included watching television, listening to music/radio, or leisure activities that were carried out with family members. Structural barriers will certainly be a reason why some disabled children find themselves excluded from peer-social leisure activities (Dunn *et al.* 2004; John and Wheyway 2004). Other examples of structural barriers to disabled children's participation in leisure reported in the literature include lack of affordable and accessible transport, particularly for those in rural areas, coupled with the limited financial resources of families of disabled children (McConchie *et al.* 2001). In England, the development of local, accessible and inclusive play spaces was a priority for the Labour government (1997-2010) (Dunn *et al.* 2004; John and Wheyway 2004) however, it is not yet clear what impact the current financial challenges will have on the continuance of this policy as a priority for the new Coalition government¹. Yet, despite the increase in the numbers of inclusive play spaces, and increased resources for equipment provided from Government funding through the policy of *Aiming High for Disabled Children: better support for families* (DfES 2007), barriers to participation persist. The tackling of physical barriers alone would not appear to be sufficient to ensure social inclusion. There are clearly other ableist practices that also maintain the exclusion agenda.

Leisure and the barriers within

Nabors *et al.* (2001) suggest that a focus on equipment and material resources does little to disrupt the attitudinal barriers to disabled children's participation in leisure activities. Buttimer and Tierney (2005) argue that not having a friend, not feeling welcome and not knowing how to join in a leisure activity were revealed in their research as being the biggest barriers to disabled children's participation. In addition, disabled children saw their

parents' over protective attitudes, as significant barriers to their participation (ibid.). Parents/carers' attitudes are the product of the wider societal attitudes and discourses which circulate about disabled children (Chivers and Mathieson 2000). For example, the fears of these parents/carers, for the well being of their disabled charges, might be seen to reflect the dominance of ableist notions of disabled children as dependent, vulnerable and in need of protection. Such discourses underpin what John and Wheyway (2004) describe as pervasive 'polite discrimination', often based on health and safety fears, which prevents disabled children from accessing leisure activities, as these are deemed too risky for such a 'delicate' group of children. These 'polite discriminations', the framing of 'othering' as an altruistic act for the benefit for the segregated group, often disguises quite different, less palatable and therefore largely unspoken reasons for exclusionary practices. Hacking (2007), gives an example of this when he suggests that, 'Autism is among other things a bureaucratic concept, used in the administration and management of awkward schoolchildren' (p.311). Rather than working to change environments and practices to accommodate those made awkward by unsatisfactory settings it seems easier to locate the problem in the 'oddness' of the child. Being conceived of in this way can inflict significant psycho-emotional damage on disabled children.

Writing from Britain, Thomas (1999, 2007) and Reeve (2002, 2008) address the issue of psycho-emotional trauma, drawing attention to the 'barriers in here' experienced by disabled people (Reeve 2008: 1) Frequent experiences, such as being stared at, ignored and made to feel an unwelcome inconvenience, or, as in the earlier example from Jones's study (2003/4) of letting the team down in competitive sports, can result in disabled people foregoing the challenges of being in the social world and limits what people feel they will be able to achieve: disability affects not only what people can do but also what people can be (Reeve 2004).

A focus on the 'inner worlds' of disabled people has been criticised by those who view these issues as 'private troubles' (Oliver 1996: 48), yet the 'barriers within' continue to be the focus of disability scholars. Hacking (2007) argues

that the private and the public are entwined, working together to create and maintain 'kinds of people' (p.293). These 'kinds of people' are then subject to study. In this process of investigation and explication the relationship between the studier and the studied changes the very nature of the phenomenon under scrutiny: the studied begin to take on and act out the very roles that are now being prescribed for them. Hacking refers to this as the 'looping effect' and suggests that it is part of the process of 'making up people' (p.293). Campbell (2008b) does not use the term, 'looping', but she does refer to the same effect when she describes how ableist 'orderings' are 'not just repressive but they are ultimately productive; they tell us stories, they contain narratives as to 'who' we are and how we 'should be' (p.7). Here we use the barriers 'in here' , not as private and personal issues but as reflections of public, ableist discourses and practices that are 'out there' and which are absorbed and then repeated within the process of making up disabled people. For disabled children, and their parents, access to leisure is significantly determined by their security and confidence in finding welcoming leisure activities. Certainly research shows that the negative experiences of leisure, limit what families can do, expect to do, can be and their imagined future selves (Ryan 2005; McLaughlin *et al.* 2008; Thompson and Mahmoud 2011).

For researchers to expose and challenge the nature and practices of ableism new ways of thinking and working are required. In the next section we consider some of the issues that researchers are required to address in order to capture what is known but what is never expressly articulated.

Researching Ableism

Davis (1995:23) calls upon researchers 'to focus not so much on the construction of disability as on the construction of normalcy ' as the problem is not the disabled person but the way that 'normalcy is constructed to create the "problem" of the disabled person' (Davis 1997: 3). Ableism is rooted in notions of normalcy and so Campbell (2009) also argues that researchers should therefore look not at disability but at 'the production, operation and

maintenance of ableism' (Campbell 2009: 4).

The problem then arises as to how to do this. It is not yet clear what this shift of focus means in terms of research practice and what changes might be required with how researchers engage with data. Campbell (2008a) suggests that the study of ableism rather than disablism 'may produce different research questions and sites of study' (p.153) but there are very few examples available to illustrate how researchers are doing this. Traditionally disability research has focused on the experiences of disabled people to demonstrate the impacts of disablism, rather than on the understandings, motivations and negotiations of normates as they create the Inferior Other. There have been good reasons for a focus on disablism; not least, the long standing exclusion of disabled people from the research process and the tendency by non-disabled researchers to do research 'on', rather than 'with' disabled people (Barnes and Mercer 1997). However a focus on disablism only works to include the 'Other': it does not disrupt the very concept itself (Campbell 2009)

To illustrate the potential impact of a shift in focus from disablism to ablism we will look again at the example given earlier from Buttimer and Tierney (2005). These researchers identified the leisure experiences of disabled children as being not having a friend, not feeling welcome and not knowing how to join in a leisure activity. Had they been working to expose the project of ableism then their findings might have taken a different emphasis. Their research would have revealed that some of the ableist concepts and practices that exclude disabled people from participation in leisure include: non-disabled people viewing disabled people as either not worthy of friendship or not worth the effort for non-disabled people to learn new methods of communication; regulatory ableist norms that position children with impairments as not belonging in leisure spaces and that it is only necessary to inform normates how to access these leisure opportunities.

Campbell (2008a) views such exposure of ableist practices as a political act, arguing that '[f]or scholars there is an ethical imperative to interrogate the

violence of ableism and speak of its injuries' (p. 159). In this sense research which seeks to expose ableism fits well into the paradigm of emancipatory research that positions researchers as part of the political struggle (Hodge 2008): rather than just recording the violence that happens to disabled people as random acts that create 'private troubles' (Oliver 1996: 48) a commitment to exposing the ableist project requires researchers to seek to expose the systemic, pervasive and public nature of ableism.

Reeve (2004) considers one of the most disabling of the 'in here' barriers as being 'internalised oppression', 'its unconscious and insidious effects on the psycho-emotional well being of disabled people...' (p.10online) Campbell (2009), too, has also turned her attention to the internalised oppression in the lives of disabled people. Following Rosenwasser, writing from the context of anti-Semitism, (2001 cited in Campbell 2009: 18) Campbell understands 'internalised oppression' as:

... An involuntary reaction to oppression which originates outside one's group and which results in group members loathing themselves, disliking others in their group, and blaming themselves for the oppression – rather than realizing that these beliefs are constructed in them by oppressive socio-economic political systems.

Internalised oppression can lead to acceptance, and even promotion of, segregated spaces by and for disabled people (Imrie, 1996). Such spaces are described by Campbell (2008a:115) as the product of a form of 'diagnostic apartheid' (2008a: 155) where people are sorted by 'type' and 'severity' of impairment into different categories and spaces. Crucially, however, Campbell distinguishes these from separate spaces, which, she argues, act as a sanctuary for healing internalized oppression (ibid.) and time away from the omnipresent ableist gaze. In valuing separate spaces, Campbell challenges the presumption that mainstream institutions and methods are always and naturally superior to separate settings (Imrie, 1996; O'Brien and Murray 1996 cited in Campbell 2009: 155).

Madriaga (2010) illustrates how a geographical analysis can be, 'significant in drawing attention to the taken-for-granted, axiomatic relationship between ableism and public space' (p.40). In the discussion below, we follow Campbell in our exploration of children's leisure activities by focusing on children's occupation of 'mainstream', 'segregated' and 'separate' leisure spaces to expose some of the ways in which ableism captures and maintains these environments. We ask:

1. What do the experiences of accessing leisure by disabled children, young people and their families reveal about the processes and practices of ableism?
2. To what extent are children and families required to 'pass' as 'normal enough' to gain access to leisure spaces?
3. To what extent are 'segregated' leisure opportunities regulated and produced by a kind of 'diagnostic apartheid' (Campbell 2008a: 155)?
4. What is the role and value of 'separate' leisure activities?

Methodology

The participants, in this study, include 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. In order to protect their anonymity, the names of all participants have been changed.

Their accounts have been collected as part of a two-year project funded by the Economic and Social Research Council (RES – 062-23-1138)

(<http://www.rihsc.mmu.ac.uk/postblairproject/>): 'Does every child matter,

Post-Blair: the interconnections of disabled childhoods'. The project set out to

understand what it means to be a disabled child growing up in England. The study was based in the north of England and ran from September 2008 – April 2011. The data for this paper was gathered from interviews with eleven disabled children and young people, twenty-three parents/carers of disabled children, three focus groups with professionals and ethnographic research on the community lives of disabled children. The interviews were open-ended and covered a range of issues including families' experiences of health, social care, education and, of course, leisure. The children who participated in the study had a range of impairment labels and the methods used varied in response to each child's communication style. The ethnographic phase of the research involved one of us (Katherine) attending children's birthday parties, bowling, shopping with families as well as impairment-specific leisure activities, including an autism specific social club and parent groups, to access views. The methodological approaches used with children and parents/carers are described in detail elsewhere (Runswick-Cole forthcoming a; Runswick-Cole forthcoming b). In the course of the analysis the research team visited and re-visited the data to search for themes (Snow *et al.* 2004) with two emphases in mind: (i) explore the 'project of ableism' in the lives of disabled children (ii) to seek rich data: that speaks of the leisure opportunities available to disabled children and their families.

Analysis

In the paper we explore three types of leisure which following Campbell (2008a) we call mainstream, segregated and separate leisure activities.

Able enough for the mainstream?

Campbell (2009) has drawn our attention to the 'ableist project' and the requirement to have an able, perfectable body, species-typical body in order to be deemed to be fully human. Despite the drive in Britain to ensure that there are no physical barriers to disabled children's access to leisure and the focus on providing equipment, from wheelchairs to communication aids to allow them to do so (DfES 2007¹), a focus on barriers and attitudes has not resulted in the shift of the gaze which Campbell (2009: 5) advocates for. The ableist project remains undisturbed. Indeed, stories from children, young people, parents/carers and professionals reveal much about the ableist assumptions which permit or deny young people's access to mainstream leisure.

The evidence from the project shows that disabled children continue to struggle to gain access to mainstream leisure activities. Sometimes, disabled children were permitted into mainstream activities, but only if a parent was prepared to stay with them. Sometimes, professionals assumed that the child was not 'able enough' to be left at a mainstream leisure activity without their parents to support them. At other times, parents assumed that adults supporting the leisure activity would not have enough 'knowledge' or 'skill' or even 'commitment' to support their disabled child. In all cases, the nature of the ableist mainstream leisure activity, how it was constituted and operated, was never the subject of debate. The problem was seen as being located within the child rather than the environment. The ableist norms and expectations which require parents to stay or to doubt the suitability of the disabled child for the leisure environment remained intact. The child stays with the carer or leaves but the exclusionary activity continues.

Parents and carers in this study offered other examples of exclusionary practice. Roberta, a mother, told us about catalogue of rejection of her

disabled daughter from mainstream spaces. Parents at her mainstream primary school (in Britain primary schooling is generally between the ages of 5-11 years) had organised a petition to get her daughter out of the school. Roberta also took her daughter, Cerys, to Girl Guidesⁱⁱ in an attempt to help her make friends in the local community, but when other mothers removed their children in protest at Cerys's behaviour at the group, Roberta was asked by the group leader to withdraw her daughter. Her daughter now accesses no mainstream leisure activities. Cerys and Roberta have been subjected to a sustained attack on their sense of selves, a volley of experiences that illustrate the devastating impact of psycho-emotional disablism on the lives of disabled children and their families and which resulted in their withdrawal from mainstream community life. Yet again, the ableist normativity in communities, which produce such exclusion, remains unchallenged. We can only guess that the parents who petitioned for the exclusion of nine year old Cerys felt justified and entitled to do so.

Mainstream schools might, perhaps, offer significant opportunities for mainstream leisure activities. Break times and lunch times offer opportunities for children to 'hang out' together or to play. However, Greg, a young person, told us that when he played football at school, they 'never pass me the ball'. He was unable to break into the game, to be seen as 'one of us', not 'one of them'. He simply withdrew from football and stayed on the lower playground; he added that he found this easier, in part, because of the difficulty he had in pushing the wheelchair up the steep ramp to the top playground. One of our concerns in the example of Greg's withdrawal from football is that this was not addressed by staff within the school. Either it went unnoticed or perhaps it was accepted as an inevitable outcome of being a wheelchair user. Schools, like Greg's, fail to reflect on the leisure opportunities provided to ensure that these offer 'co-operative activities in which people support each other's efforts instead of competing against each other' (Jones 2003/4: 64).

Reeve (2004) argues that disabled children are particularly vulnerable to internal oppression. People's lifeworlds are unique but they also share common characteristics (Hodge 2008). Lifeworlds contain experiences of hope, disappointment, pleasure, pain, belonging and rejection, ability and

challenge. One way of bridging the 'constitutional divide' (Campbell 2009) here might have been for school staff to look for ways to support Greg and the other pupils with recognising the shared aspects of their existence. Campbell (2008b: 2) argues that, '[ableist] normativity results in compulsive passing, wherein there is a failure to ask about difference, to imagine human beingness differently'. In doing so we deconstruct the concept of the Inferior Other to reveal the shared identity of being human: although we are different we are also the same. In describing what he terms the 'dismodernist' project, Davis (2002) claims that this recognition of the fragility and uncertainty of being, positions us all as a 'partial, incomplete subject whose realization is not autonomy and independence but dependency and interdependence' (p.30). This does not mean that all the pupils just have to learn about Greg and accommodating Greg's needs. Rather this requires that pupils are supported with the development of skills to reflect on what it means for us all to be human, to understand 'that we are all disabled by injustice and oppression of various kinds' (Davis, 2002:31-2) and that 'teamwork' is the best chance for survival and success. Currently there is very little attention paid to the development of the attributes of self reflection and empathy in the school curriculum and Baron-Cohen (2011) argues that this is leading to the production of adults who can often have little understanding of, or regard for, what it means to live a different life.

A volunteer worker gave us an illustration of how this lack of thinking about the shared meanings of being a child led to an inequity of behavioural expectations for disabled children. She reported how difficult it was for disabled children to access mainstream leisure activities. Indeed, she described how, rather than having to match up to ableist norms, disabled children were expected to exceed them in order to be accepted. She described how the young people she supported had to be 'better behaved' than other young people at the youth club in order to be able to continue to attend. This is yet another example of disabled people having to be 'more normal than normal people' in order to be granted access to leisure (Bogdan and Taylor 1994; Booth and Booth 1994; Hall, 2004): they not only required to emulate under articulated norms, they have to excel them. Again the

discourses and structures that enforce ableism remain unquestioned. The inevitable consequence is that disabled children have to fit existing structures, and meet ableist expectations, or face exclusion from the mainstream. There is, perhaps, an irony that compulsory ableism denies those characterized as most in need of leisure for their 'development', access to it.

Segregated provision

When I picked up Bill from the youth club for children with additional needs, for the first time, Sarah, the youth worker came out. She told me he's been wonderful, what a lovely son I have. I ask how the Club is funded and she tells me it is from the mainstream Youth Service. In fact, she said Bill, could go to any of the youth clubs locally, she said 'we can't refuse him' paused, then said 'we wouldn't want to, but we find it is better if they come here where there is more support and where they can be with the others.

Alex

Many of the children and young people in the study accessed what we are calling segregated leisure opportunities. We call these activities 'segregated' because access to the activities is dependent on having a diagnosis or label, normates do not attend them and there is an element of compulsory attendance through an absence of other options. Often, as in the story above, the 'diagnostic apartheid' was practised discretely – Alex was told her son could go to 'any youth club' but that he would be better in segregated provision. Imrie (1996b) argues that the practice of segregation is often made palatable by such a presentation: segregation is in the best interests of the disabled person. The extract above suggests that the youth worker had judged Bill to be unable to access the mainstream youth club; there was no questioning of the provision at the mainstream youth club, no discussion of

why this was or how it could be made inclusive. The strong message was that Bill did not match up, so he would be better off in segregated provision.

Separate, not segregated, leisure

Campbell (2008a) usefully reminds us that segregation should not be confused with separation. Campbell sees separate spaces as providing opportunities for sanctuary – a space away from ableist values and assumptions and a place to recover from internalised oppression. Certainly, parents and children in this study valued separate provision. Interestingly, separate provision was often provided for children with the label of ‘autism’. A brief survey of autism specific provision on the internet reveals a range of activities intended to support children ‘on the spectrum’, including trampolining, Tai Kwando and cinema showings (where the lights are on, the sound down and children are able to walk around). Sally told us how much she valued her membership of a club that supports families of children with autism. The club allowed her to overcome the financial barriers her family faced in accessing affordable leisure because activities were subsidised but it also offered protection from the psycho-emotional aspects of disablism. She said that if her child behaved differently or ‘had a bit of moment’, she would have the other parents/carers’ support. She said that she simply would not take her children bowling without the support of the club members – she simply could not face the ableist gaze on her own.

There is a danger in that separate leisure activity centred around impairment labels, can be seen to tap into the process of diagnostic apartheid as bodies are ranked in terms of type or severity of impairment. However, the value of such 'healing' spaces cannot be underestimated. The need to be separate, at least some of the time, was expressed by both parents and children. Shelley talked about the relief she felt going to a toddler group for children with additional needs, after facing what she saw as the 'pretentiousness' of the competitive mothers comparing their children's developmental milestones at the mainstream toddler group. Greg enjoyed his time at the Conductive Education centre, staying away from home with children his own age and with the same impairment label.

While being separate does little to turn the gaze or to expose the pathologies of ableism, it has value in allowing time for healing and recovery and an oasis of calm in an ableist world. It is also an act of resistance: the taking ownership of the exclusionary, segregated and enforced provision and reconstituting it as a separate and 'safe' (Hall, 2004) choice, a site of sanctuary, healing and support (Butler, 1997; Kitchin, 1998). '[A] geography of being 'out of place' ' (Hall, 2004: 301) is then reframed and reformed into a place of acceptance, belonging and control.

Conclusions

The findings of the 'Post-Blair' project, presented here, illustrate that 'Ableism' is a very real phenomenon through which different kinds of people are created, examined and managed. The practices of ableism are known,

negotiated and agreed without ever being overtly recognised and acknowledged. Ableism operates both 'out there' and 'in here' as its oppressive practices become internalised and reproduced by the 'Disabled Other'. Through the looping effect, expected ways of being are absorbed, reproduced and confirmed but sometimes resisted. Analysis of the findings of the part of the 'Post-Blair' project that focused on the leisure experiences of disabled children illustrates that it is possible to make explicit these spectral ableist practices, to give them form and thereby subject them to challenge. Private troubles reveal public violence. The sharing of stories between disabled and non-disabled people can help to bridge the constitutional divide between 'normate' and 'other' by deconstructing the ableist notion of the other. Ableism creates and maintains the exclusionary nature of mainstream leisure settings. The findings from this study suggest that in spite of government initiatives, in England, and the promotion of the inclusion agenda, disabled children can still only access most mainstream leisure settings if they can 'pass' as 'normal enough'. Those children who can not do this continue to be subject to a diagnostic apartheid, sorted into different kinds of people according to type and severity of impairment and then compelled to attend segregated provision. We have identified here some of ableism's exclusionary processes. These include the creation of different kinds of people that are presumed to be, and accepted as, 'inferior'. To gain access to mainstream activities these groups must 'chase normal', sacrificing leisure time to focus on developmental activity. The practices of ableism are pervasive and obscure and it will take time to expose their nature. In the meantime disabled people will continue to seek refuge in separate spaces that are both the result of, and

the escape from, ableism. Hehir (2002) argues that ' progress towards equity is dependent first and foremost on the acknowledgement that ableism exists...' and that 'the absence of discussion and dearth of scholarly inquiry within mainstream educational circles concerning the effects of ableism is stunning' (p.22). This study into leisure shows that this is not unique to education; the exclusion of disabled children from mainstream leisure spaces and activities is left largely unchallenged; the problem of exclusion continues to be located within the child and not the leisure environment or its practices. In the process of making up disabled kinds of people the essential characteristics of 'difference', 'specialness' and 'vulnerability' are assigned. These attributes are then given the status of fact through the acceptance and promotion of these by 'experts' in the professional field. The stories of disabled people can challenge the apocrypha of ableism, emphasising the shared experiences of being human. Not all stories can be told: some will need to be read through empathetic observation. For Greg, if his story had been witnessed by the school's staff then ways of developing shared understandings with his peers could have been negotiated. All might then have been enriched in their knowledge of what it means to be human; they would have understood the importance and value of passing the ball.

References

Barnes, C., and Mercer, G., 1997. Breaking the mould? An introduction to doing disability research. *In*: C. Barnes and G. Mercer, eds. *Doing disability research*. Leeds: The Disability Press, 1-14.

Baron-Cohen, S., 2002. Is Asperger's syndrome necessarily viewed as a

disability? *Focus on autism and other developmental disabilities*, 17(3), 186-191.

Baron-Cohen, S., 2011. *Zero degrees of empathy: a new theory of human cruelty*. London: Allen Lane

Bogdan, R., & Taylor, S., 1976. The Judged not the Judges: An Insider's View of Menal Retardation. *American Psychologist*, 31, 47-52.

Booth, T., & Booth, W., 1994. *Parenting under Pressure: Mothers and fathers with Learning Diffiulties*. Buckingham: Open University Press.

Butler, J., 1997. *Excitable Speech: a politics of the performative*. New York: Routledge.

Buttimer, J., and Tierney, E., 2005. Patterns of leisure participation among adolescents with a mild intellectual disability. *Journal of Intellectual Disabilities*, 9 (1), 25-42.

Campbell, F.K., 2001. Inciting legal fictions: disability's date with ontology and the ableist body of the law. *Griffith Law Review* 10, 42-62.

Campbell, F.K., 2008a. Exploring internalized ableism using critical race theory. *Disability & Society*, 23 (2), 151–162.

Campbell, F.K., 2008b. Refusing able(ness): a preliminary conversation about ableism. *M/C Journal*, 11 (3), 1-15.

Campbell, F.K., 2009. *Contours of ableism*. Basingstoke: Palgrave Macmillan.

Chivers, J., and Mathieson, S., 2000. Training in sexuality and relationships: an Australian model. *Sexuality and Disability*, 18 (1), 73-80.

Davis, L.J., 1995. *Enforcing normalcy*. London: Verso.

Davis, L.J., 1997. Constructing normalcy. The bell curve, the novel, and the invention of the disability body in the nineteenth century. *In*: L.J. Davis, ed. *The disability studies reader*. London: Routledge, 3-16.

Davis, L.J., 2002. *Bending over Backwards: disability, dismodernism & other difficult positions*. New York: New York University Press.

DCSF (Department for Children, Schools and Families), 2008. *The play strategy*. London: Department for Education.

Dunn, K., Moore, M., and Murray, P., 2004. Research on developing accessible play space: Final Report. Available on-line at: <http://www.communities.gov.uk/documents/communities/pdf/158484.pdf>.

Evans, R., and Plumridge, G., 2007. Inclusion, social networks and resilience:

strategies, practices and outcomes for disabled children and their families. *Social Policy and Society*, 6, 231-241.

Garland Thomson, R., 1997. *Extraordinary bodies: figuring disability in American culture and literature*. New York: Columbia Univ. Press.

Gilligan, R., 2000. Adversity, resilience and young people: the protective value of positive school and spare time experiences. *Children and Society* 14, 1, 37-47.

Goodley, D. and Runswick-Cole, K. 2010. Emancipating play: Dis/abled children, development and deconstruction. *Disability & Society*, 25, 4, 499 - 512.

HM (Her Majesty's) Treasury and DfES (Department for Education and Skills), 2007. *Aiming high for disabled children: better support for families*. London: HM Treasury.

Hacking, I., 1990. *The taming of chance*. Cambridge: Cambridge University

Hacking, I., 2007. Kinds of people: moving targets. *Proceedings of the British Academy*, 151, 285-318.

Hall, E., 2004. Social geographies of learning disability: narratives of exclusion and inclusion. *Area*, 36, 3, 298-306.

Hehir, T., 2002. Eliminating ableism in education. *Harvard Educational Review*, 72, 1, 1-32.

Hodge, N., 2008. Evaluating Lifeworld as an emancipatory methodology. *Disability & Society*, 23, 1, 29-41.

Imrie, R., 1996. Ableist geographies, disablist spaces: towards a reconstruction of Golledge's 'Geography and the Disabled'. *Transactions of the Institute of British Geographers*, New Series, 21, 2, 397-403.

Imrie, R., 1996b. *Disability and the City: international perspectives*. London: Paul Chapman.

John, A., and Wheway, R., 2004. *Can play, will play: disabled children and access to outdoor playgrounds*. London: National Playing Fields Association.

Jones, D., 2003/4. "Denied from a lot of places". Barriers to participation in community recreation programs encountered by children with disabilities in Maine: perspectives of parents. *Leisure/Loisir*, 28, 1-2, 49-69.

Kitchin, R., 1998. 'Out of place', 'Knowing one's place': space, power and the exclusion of disabled people. *Disability & Society*, 13, 3, 343-356.

- Madriaga, M., 2010. 'I avoid pubs and the student union like the plague': Students with Asperger Syndrome and their negotiation of university spaces. *Children's Geographies*, 8, 1, 39-50.
- McLaughlin, J., Goodley, D., Clavering, E. and Fisher, P., 2008. *Families Raising Disabled Children: Enabling Care and Social Justice*. London: Palgrave.
- McConachie, H., Colver, A. F., Forsyth, R. J., Jarvis, S. N., and Parkinson, K. N., 2006. Participation of disabled children: how should it be characterised and measured? *Disability & Rehabilitation*, 28, 18, 1157 — 1164.
- Murray, P., 2002. *Hello! Are you listening? Disabled teenagers' experience of access to inclusive leisure*. York: Joseph Rowntree Foundation.
- Nabors, L., Willoughby, J., Leff, S., and McMenamin, S., 2001. Promoting inclusion for young children with special needs on playgrounds. *Journal of Developmental and Physical Disabilities*, 13, 2, 170-191.
- Oliver, M., 1996. *Understanding disability from theory to practice*. Basingstoke: Macmillan.
- Reeve, D., 2002. Negotiating psycho-emotional dimensions of disability and their influence on identity constructions. *Disability & Society*, 17, 5, 493-508.
- Reeve, D., 2004. Psycho-emotional dimensions of disability and the social model. In: C. Barnes and G. Mercer, eds. *Implementing the social model of disability: theory and research*. Leeds: The Disability Press, 83-100.
- Reeve, D., 2008. *Negotiating disability in everyday life: The experience of psycho-emotional disablism*. Lancaster: Unpublished PhD thesis.
- Runswick-Cole, K., forthcoming. Interviews, in P. Bannister, ed. *Qualitative Methods in Psychology 3rd Edition*, Buckingham: Open University Press.
- Runswick-Cole, K., forthcoming. Ethnography, in P. Bannister, ed. *Qualitative Methods in Psychology 3rd Edition*, Buckingham: Open University Press.
- Ryan, S., 2005. "People don't do odd, do they?" Mothers making sense of the reactions of others towards their learning disabled children in public places. *Children's Geographies* 3, 3, 291-306.
- Siegel, B., 2003. *Helping children with autism learn*. Oxford: Oxford University Press.
- Snow, D.A., Morrill, C., and Anderson, L., 2004. Elaborating Analytic Ethnography: Linking Fieldwork and Theory, in *Ethnography* 4, 2, 153-5
- Thomas, C., 1999. *Female Forms: experiencing and understanding*. Buckingham: Open University Press.

Thomas, C., 2007. *Sociologies of disability and illness. Contested ideas in disability studies and medical sociology*. Basingstoke: Palgrave Macmillan.

Thompson, D., and Mahmoud, E., 2011. 'They say every child matters, but they don't': an investigation into parental and carer perceptions of access to leisure facilities and respite care for children and young people with autistic spectrum disorder (ASD) or attention deficit, hyperactivity disorder (ADHD). *Disability & Society* 26 (1), 65-78.

Acknowledgements

The authors wish to thank Professor Dan Goodley, Manchester Metropolitan University for his support and Professor John Coldron, Sheffield Hallam University for his constructive feedback on an earlier draft of this paper and to members of the Disability Research Forum at Sheffield Hallam for comments and suggestions on a presentation of this work.

ⁱ The Coalition Government in the UK is a coalition between the Conservative Party and the Liberal Democrat parties.

ⁱⁱ Girlguiding UK is the United Kingdom's largest voluntary organisation for girls and young women, with around half a million members including about 100,000 trained volunteer adult leaders and supporters (www.girlguiding.org.uk).