



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

Nick Hodge & Katherine Runswick-Cole

To cite this article: Nick Hodge & Katherine Runswick-Cole (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, DOI: [10.1080/14733285.2013.812275](https://doi.org/10.1080/14733285.2013.812275)

To link to this article: <https://doi.org/10.1080/14733285.2013.812275>



Published online: 04 Jul 2013.



Submit your article to this journal [↗](#)



Article views: 1405



Citing articles: 19 View citing articles [↗](#)

## **‘They never pass me the ball’: exposing ableism through the leisure experiences of disabled children, young people and their families**

Nick Hodge<sup>a\*</sup> and Katherine Runswick-Cole<sup>b</sup>

*<sup>a</sup>Reader in Education, Childhood and Inclusion at Sheffield Hallam University, City Campus, Howard Street, Sheffield S1 1WB, UK; <sup>b</sup>Research Fellow at the Research Institute for Health and Social Change, Manchester Metropolitan University, All Saints Building, All Saints, Manchester M15 6BH, UK*

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 careers, we reflect on the leisure spaces that they access and record some of their experiences within them. Using the concept of ‘ableism’ [Campbell, F. K. 2009. *Contours of Ableism*. Basingstoke: Palgrave Macmillan] we interrogate the data gathered as part of a two-year project funded by the Economic and Social Research Council Does Every Child Matter, post-Blair? The interconnections of disabled childhoods’ (RES-062-23-1138). 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, I. 2007. “Kinds of People: Moving Targets.” *Proceedings of the British Academy* 151: 285–318] 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 what the experiences of accessing leisure by disabled children, young people and their families reveal about the processes and practices of ableism.

**Keywords:** ableism; disability; leisure; childhood; inclusion; children

### **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 Anglophone countries to refer to services that are set up to provide for ‘typically developing’ children. By definition the term mainstream places some children outside 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); those who walk rather than roll, speak rather than sign, read print rather than use Braille and who are interested in people rather than objects (Hehir 2002). In this paper we do 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 this reflects the language used within the policy documents that are under discussion here.

---

\*Corresponding author. Email: [n.s.hodge@shu.ac.uk](mailto:n.s.hodge@shu.ac.uk)

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 *Does Every Child Matter, post-Blair? The interconnections of disabled childhoods* (RES-062-23-1138). 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/careers 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' (3) resulting in '(a) network of beliefs, processes and practices' (Campbell 2001 cited in Campbell 2009, 5) that cast 'disability', 'as a diminished state of being human' (Campbell 2001 cited in Campbell 2009, 5). 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' (Campbell 2009, 6). Ableism constructs bodies as 'impaired' and positions these as 'Other': different, lesser, undesirable, in need of repair or modification and de-humanised. 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 spite of its dramatic effects Ableism is a nebulous concept that by its very nature evades identification and definition. Campbell (2008a, 2008b, 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 practised 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 'time spent doing nothing at all (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 (Goodley and Runswick-Cole 2010). Too often leisure becomes rehabilitation 'work' for some disabled children.

### Leisure and child development

Children's access to leisure is frequently conceptualised 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 'generalisation 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, for example, Baron-Cohen 2002) 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. McConachie et al. (2006), for example, 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'.

A difficulty with prioritising 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 for its own sake 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’ (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* (HM Treasury and 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 USA 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 programmes because of behavioural issues and social skills deficits’ (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, Moore, and Murray 2004; John and Wheway 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 (McConachie et al. 2006). In England, the development of local, accessible and inclusive play spaces was a priority for the Labour government (1997–2010) (Dunn, Moore, and Murray 2004; John and Wheway 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 government.<sup>1</sup> 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* (HM Treasury and 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 (Buttimer and Tierney 2005). Parents/careers' 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/careers 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 (Holt 2007). Such discourses underpin what John and Wheway (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 (Holt 2007). These 'polite discriminations', the framing of 'othering' as an altruistic act for the benefit for the segregated group, often disguise 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' (311). Holt (2007) offers a further insight into why children are expected to change rather than systems and environments. Holt argues that adults often blame disabled children for their social isolation seeing this as the inevitable result of their impairment and failing to recognise the disabling effects of the world around the child. Rather than working to change environments and practices to accommodate those made awkward by unsatisfactory settings the problem becomes located in the 'oddness' of the child.

Writing from Britain, Thomas (1999, 2007) and Reeve (2002, 2008) address the issue of psycho-emotional trauma and draw 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' (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. This can be an unconscious or conscious process. Holt (2007), for example, reports that sometimes children accept their "'disabled'" positioning' (798) in order to be included in social activity. Hacking refers to this phenomenon of expected role absorption as the 'looping effect' and suggests that it is part of the process of 'making up people' (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' (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 practised 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' (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 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' (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' and 'its unconscious and insidious effects on the psycho-emotional well being of disabled people...' (10 online). 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 1996a). 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 internalised oppression (Campbell 2008a, 115) 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 1996a; 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' (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/careers 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 Does Every Child Matter, post-Blair? The interconnections of disabled childhoods' (RES-062-23-1138). 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 to April 2011. The data for this paper were gathered from interviews with eleven disabled children and young people, 23 parents/careers of disabled children, three focus groups with professionals and ethnographic research on the community lives of disabled children. Participants included children and young people with a range of impairment labels including cerebral palsy, learning difficulties, autism and global developmental delay. Families were recruited through a range of voluntary organisations that support families of disabled children and there was an element of snowball sampling. The parents were interviewed without their children being present and children/young people chose whether to have their parents or another familiar adult with them or whether they preferred to be interviewed on



their own. The interviews were open-ended and covered a range of issues including families' experiences of health, social care, education and, of course, leisure. As the children who participated in the study had a range of communication styles the methods used varied in response to each child's requirements. 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/careers are described in more detail elsewhere (Runswick-Cole 2011a, 2011b). In summary, the researchers attempted to respond to the children's individual communication styles using a variety of methods including interviews, photography, mapping and artwork to listen to the children. Interviews were transcribed and copies of photographs and artwork were given to the children to keep. The team tried to be flexible in their approach so, for instance, one young person chose not to meet a member of the research team and made a series of short films about his life and another young person enjoyed chatting whilst doing something else including eating a meal or playing on the computer.

Ethical issues were of paramount importance in the study. The primary concern was to enable the participants to have a voice while at the same time avoiding harm. All participants were afforded anonymity and confidentiality in the study. However, they were also made aware of the research team's duty to pass information on should they discover information that might lead them to believe that the participant was at risk of harm. A variety of information and consent sheets were used in order to meet individual participants' communication styles and the study was reviewed by the ethics committee at Manchester Metropolitan University and the project funder. In the course of the analysis the research team visited and re-visited the data to search for themes (Snow, Morrill, and Anderson 2004). Two of the key areas of emphasis that emerged from the data are focused on here: (i) the impact of the 'project of ableism' on the lives of disabled children and their families and (ii) the concerns of participants about the lack of opportunity to access mainstream leisure opportunities.

'[P]lace and space matter in shaping opportunities, behaviours and realities' (Matthews 2003, 34, cited in Holt 2004, 220). In this paper we explore three types of leisure experiences to explicate how ableism shapes the recreational experiences of disabled children. Following Campbell (2008a) we call these 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, 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 (HM Treasury and DfES 2007<sup>1</sup>) a focus on barriers and attitudes has not resulted in the shift of the gaze which Campbell (2009, 5) advocates for. The evidence from this study with disabled children and their families suggests that the ableist project remains undisturbed. Indeed, stories from children, young people, parents/careers 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. A worker from a voluntary organisation told us:

I mean, we've had cases where we've had, we had a young woman who was very articulate, she had a physical disability, she was a wheelchair user, she had moving and handling needs to assist to go to the toilet, and she very much wanted to go to her local youth club and went and staff said, 'Oh, well when you need the loo your mum'll have to come down and take you to the loo if you're in the club' and she said to me, 'Well nobody else's mum has to come down and' you know, and it's issues like that that I think really do need to be addressed.

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. As Isobel, a mother, told us:

You have to take your time, you have to talk slowly ... I'm worried they [youth club workers] won't do that and then they'll blame him [disabled child] for kicking off!

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 teacher and a mother of two daughters Cerys and Fiona with learning difficulties aged 11 and 14, told us about a 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 and 11 years) had organised a petition to get her daughter out of the school. Roberta told us:

there was a group of parents who said, 'Oh we've got a trouble-maker child [Cerys] coming into this school,' and that has kind of lived on to haunt us really, that this group of parents were not happy that Cerys had suddenly joined her class. And that's kind of escalated, you know, they seemed to have identified Cerys with any trouble in the class and also alerted their children to the fact that Cerys [i]s trouble and so that any problems in the class Cerys is blamed for it. And it may be she contributes to quite a lot of the trouble in the class, but not all of it. To the point that just before Christmas a parent came up to my husband before school to say that a group of them are trying to get Cerys out of the school that they don't think she should be there.

While this may seem to be a very extreme example of disablism during the course of the project we came across another young person who was similarly the target of a campaign to get him out of his local primary school. Sadly for Roberta and Cerys, they also had a similar experience at Girl Guides.<sup>2</sup> Other mothers removed their children in protest at Cerys's behaviour in the group and then Roberta was asked by the group leader to withdraw her daughter. As a result Cerys no longer accesses any mainstream leisure activities.

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 aged 11 with a physical impairment, told us:

Like in football at school today I did get about three touches but not much. They just didn't pass me it. So it's kind of annoying because you're like 'Come on, I'm in!' and they just like pass it to someone else.

He was unable to break into the game, to be seen as 'one of us', not 'one of them'. There appeared to be no support given by the school's staff to Greg's peers to make the activity

accessible. Therefore, Greg 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. Greg said:

the ramps are kind of annoying because you're like almost there and then you just bounce back down.

Greg told us that what people failed to understand was that he is 'just a kid, like other kids' and yet he was not seen that way by his peers or adults around him. Holt (2007) claims that this exclusion from football is a common experience for disabled boys and that such disabling practices cannot be overcome simply by the sharing of spaces. Holt (2004) argues that it is necessary to actively 'confront, contest and transform' how identities are produced and reproduced within these settings (233). Left unchallenged, so prevalent and persistent are ableist discourses of disability that these become internalised and accepted as natural fact even by disabled people themselves (Kitchin 1998, cited in Holt 2004). 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'. Through the exploration of difference we can also 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' (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, 31–32) 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.

Sarah, director of a voluntary organisation that provides short break provision for disabled children, 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 1976; Booth and Booth 1994; Hall, 2004): they are 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 characterised 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, a mother of a fifteen-year-old son with learning difficulties)

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 (Garland Thomson 1997; Hehir 2002) 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 there to be more 'suitable' provision, outside of the mainstream facilities, for people like Bill; 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.

### 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. Sally, a mother of a five-year-old son with autism and learning difficulties, told us how much she appreciated her membership of a club that supports families of children with autism:

I arrived at the bowling alley and a few minutes later Sally arrived with her son Mark and daughter Mary. Gradually, other members of the autism support group arrived with their children. ... Over lunch Sally told me how important the support group was for her. The fact that they were able to get some money to subsidise events really helped but it was also the fact that she felt that if Mark 'had a bit of a moment' she could rely on the other parents' support. She said she wouldn't take the children bowling on her own – she'd only ever go with the support group. (Researcher's ethnographic notes)

There is a danger in that separate leisure activity centred on 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. Such spaces can also become an embodied habitus of segregation as disabled children internalise their sense of place as separate and apart (Holt 2004). 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, a social work student and a mother of a daughter with learning difficulties, 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.

Holt (2007) emphasises the complexity of spaces being constituted as both segregate and separate. 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. And in so doing separate spaces can, through the facilitation of 'bonding ties', sometimes then empower members to work, individually or collectively, to challenge and disrupt the practices of ableism by forming 'bridging ties' with mainstream leisure organisations (Holt 2010).

## Conclusions

The findings of the Does Every Child Matter, post-Blair? The interconnections of disabled childhoods' (RES-062-23-1138) project, presented here, illustrate that for these participants 'ableism' is a very real phenomenon through which different kinds of people are created, examined and managed. The practices of ableism are 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 Does Every Child Matter, post-Blair? The interconnections of disabled childhoods' (RES-062-23-1138) 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. The sharing of stories between disabled and non-disabled people can help to form bridging ties across 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 cannot 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 that disabled the young people and their families who participated in this study. 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 were compelled to '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' (22). This study into leisure shows that this is not unique to education; the exclusion of these disabled children from mainstream leisure spaces and activities was 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 the [disabled] kind of people' (Hacking 2007) 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 by emphasising the shared experiences of being human. Disabled children will not always be able to articulate their experience of ableism. They may assume that the fault lies in them because of their impairment rather than in disabling environments. For Greg, if the nature of his exclusion had been recognised by the school's staff

then ways of developing shared understandings, and more inclusive activities, 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.

### Acknowledgements

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

### Notes

1. The Coalition Government in the UK is a coalition between the Conservative Party and the Liberal Democrat parties.
2. 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](http://www.girlguiding.org.uk)).

### References

- Barnes, C., and G. Mercer. 1997. "Breaking the Mould? An Introduction to Doing Disability Research." In *Doing Disability Research*, edited by C. Barnes and G. Mercer, 1–14. Leeds: The Disability Press.
- 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., and S. Taylor. 1976. "The Judged not the Judges: An Insider's View of Mental Retardation." *American Psychologist* 31 (1): 47–52.
- Booth, T., and W. Booth. 1994. *Parenting Under Pressure: Mothers and Fathers with Learning Difficulties*. Buckingham: Open University Press.
- Butler, J. 1997. *Excitable Speech: A Politics of the Performative*. New York: Routledge.
- Buttimer, J., and E. Tierney. 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 (1): 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 S. Mathieson. 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 *The Disability Studies Reader*, edited by L. J. Davis, 3–16. London: Routledge.
- Davis, L. J. 2002. *Bending Over Backwards: Disability, Dismodernism & Other Difficult Positions*. New York: New York University Press.
- Department for Children, Schools and Families (DCSF). 2008. *The Play Strategy*. London: Department for Education.
- Dunn, K., M. Moore, and P. Murray. 2004. *Research on Developing Accessible Play Space: Final Report*. <http://www.communities.gov.uk/documents/communities/pdf/158484.pdf>
- Evans, R., and G. Plumridge. 2007. "Inclusion, Social Networks and Resilience: Strategies, Practices and Outcomes for Disabled Children and Their Families." *Social Policy and Society* 6 (2): 231–241.



- Garland Thomson, R. 1997. *Extraordinary Bodies: figuring Disability in American Culture and Literature*. New York: Columbia University 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 K. Runswick-Cole. 2010. "Emancipating Play: Dis/abled Children, Development and Deconstruction." *Disability & Society* 25 (4): 499–512.
- 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.
- 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.
- Hodge, N. 2008. "Evaluating Lifeworld as an Emancipatory Methodology." *Disability & Society* 23 (1): 29–41.
- Holt, L. 2004. "Children with Mind-body Differences: Performing Disability in Primary School Classrooms." *Children's Geographies* 2 (2): 219–236.
- Holt, L. 2007. "Children's Sociospatial (re)production of Disability within Primary School Playgrounds." *Environment and Planning D: Society and Space* 25 (5): 783–802.
- Holt, L. 2010. "Young People's Embodied Social Capital and Performing Disability." *Children's Geographies* 8 (1): 25–37.
- Imrie, R. 1996a. "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 R. Wheway. 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.
- Madiaga, 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.
- McConachie, H., A. F. Colver, R. J. Forsyth, S. N. Jarvis, and K. N. Parkinson. 2006. "Participation of Disabled Children: How should it be Characterised and Measured?" *Disability & Rehabilitation* 28 (18): 1157–1164.
- McLaughlin, J., D. Goodley, E. Clavering, and P. Fisher. 2008. *Families Raising Disabled Children: Enabling Care and Social Justice*. London: Palgrave.
- Murray, P. 2002. *Hello! Are you Listening? Disabled Teenagers' Experience of Access to Inclusive Leisure*. York: Joseph Rowntree Foundation.
- Nabors, L., J. Willoughby, S. Leff, and S. McMenamin. 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 *Implementing the Social Model of Disability: Theory and Research*, edited by C. Barnes and G. Mercer, 83–100. Leeds: The Disability Press.
- Reeve, D. 2008. "Negotiating Disability in Everyday Life: The Experience of Psycho-emotional Disablism." Unpublished PhD thesis, University of Lancaster.
- Runswick-Cole, K. 2011a. "Interviews." In *Qualitative Methods in Psychology*. 3rd ed., edited by P. Bannister, 75–87. Buckingham: Open University Press.
- Runswick-Cole, K. 2011b. "Ethnography." In *Qualitative Methods in Psychology*. 3rd ed., edited by P. Bannister, 63–74. 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., C. Morrill, and L. Anderson. 2004. "Elaborating Analytic Ethnography: Linking Fieldwork and Theory." *Ethnography* 4 (2): 153–155.
- 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 E. Mahmoud. 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.