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The Challenge and Challenging of Childhood Studies? Learning from disability studies and research with disabled children

Abstract

Childhood Studies has argued for the social construction of childhood, respecting children and childhood in the present, and recognising children's agency and rights. Such perspectives have parallels to, and challenges for, disability studies. This article considers such parallels and challenges, leading into a (re)consideration of research claims to represent children's 'voices' and the current promotion of children's participation as researchers. It concludes how research with disabled children encourages due account of multiple communication methods to access, analyse and present research, and being more reflexive about assumptions of competency, expertise and agency in the roles of researcher and research participant.

Key words: Disabled children; childhood; research; participation; peer research

Introduction

Two decades ago, the 'new' sociology of childhood emerged out of a strong critique of the dominant child development and family studies paradigms.

Leading theorists and researchers took insights particularly from sociology and social anthropology to argue for the social construction of childhood rather than normalised development, a respect for children and childhood in the present rather than a focus on adults and adulthood as the 'gold standard', and recognition of children's agency and rights rather than perceiving them as passive and dependent in the private family. At least partially because of its focus on children as social actors and rights holders, children's own participation in childhood research has been of particular interest and discussion (see next section, Davis, 2009, Kellett and others, 2004, O'Kane, 2000).

The 'new' sociology of childhood is no longer so new. As will be discussed in the next section, leading academics expressed the counter-paradigm in the 1980s and 1990s and led to an explosion of childhood research and growing interest in social science disciplines. Indeed, as sub-disciplines within development studies, human geography, social anthropology and law gained interest in these ideas, 'childhood studies' became a term that could capture this diversity. Twenty years later, it is timely to re-consider the core theorisations and ensuing research practices of childhood studies, in light of the challenges recognised in both theory and practice.

Looking to disability studies can assist in such re-consideration (see also Connors and Stalker, 2007; Davis and others, 2003; Tisdall, 2001). Just as childhood studies has sought to re-conceptualise children and childhood, disability studies a decade earlier sought to re-conceptualise disabled people and disability. Such re-conceptualisations were not only theoretical, but closely aligned with the disability rights movement – just as childhood studies, and particularly its focus on children as active agents and social actors, links with those promoting children’s rights in policy and practice.

This paper reviews the core ideas of childhood studies and discusses how these could articulate with leading ideas within disability studies. Using resources from both childhood and disability studies, it (re)considers two aspects of children’s participation in research: the claim to represent children’s voices in research, and the current promotion of young researchers.

A note about terms used in this paper: The term ‘children’ broadly refers to the age group under the age of 18, as defined by the UN Convention on the Rights of the Child (UNCRC). ‘Disabled people’ or ‘disabled children’ is used in preference to ‘people with disabilities’ or ‘children with disabilities’, as the former is preferred by the UK Disabled People’s movement. The phrase ‘Minority World’ is used, contrasting with the ‘Majority World’. This acknowledges that the ‘majority’ of population, poverty, land mass and lifestyles lie in the Majority World and thus the phrase seeks to shift the balance of world views that

frequently privilege 'western' and 'northern' populations and issues (Punch, 2003).

Childhood Studies

In the 1980s and 1990s, a critique of theorisation and research on children was articulated. Older theories, such as Parson's socialisation theory and Piagetian child development, were criticised as presenting adults as mature, rational and competent whereas children were viewed as "less than fully human, unfinished or incomplete" (Jenks, 1996: 10). Childhood, the sociologists of childhood argued, had been wrongly seen as natural, "an enduring, historically consistent and universal" construct (Goldson, 1997: 19), which had been defined as the *absence* of adulthood. The social construct of childhood, therefore, was dependent on the construct of adulthood. While a child's biological immaturity was not necessarily denied, "how this immaturity is understood and how it is made meaningful is a cultural one" (Prout and James, 1990: 7).

Qvortrup (1994) made the explicit connection between the social construct of childhood as 'human becomings', rather than 'human beings', and the ensuing exclusion of children:

... the maybe unintended message, which seems to indicate that children are not members or at least not integrated members of society. This attitude, while perceiving childhood as a moratorium and a preparatory phase, thus confirms postulates about children as "naturally" incompetent and incapable. (2)

From such constructions came arguments that children were not citizens and, further, they did not even have rights because they lacked rationality, they lacked competence, they needed protection not autonomy, and they must be socialised into 'good citizens' (e.g. see Phillips, 1997; Purdy, 1992). Such ideas are related to, if not lead to, certain policy and individual ramifications:

- children are marginalised, both in terms of place and nature
- marginalisation is often coupled with children's need for protection
- while marginalisation may be protective it can also, or alternatively, be paternalistic
- children are the quintessential minority group, which is defined by its subordinate relationship to a dominant group (adults)
- children are in practice being individualised and institutionalised while ideologically they remain within the family (familialisation)
- while hidden from the public gaze by familialisation, children are actors and are an integrated structural form of society
- childhood is a permanent category in society, although for individuals it may be a transient phase. (Qvortrup, 1994)

Such defining features of (Minority World) childhood bear a noticeable similarity to certain policy patterns for disabled people. Disabled people have (at least in the past) been marginalised, and physical and social/ public space continues to

be inaccessible to many. Disabled children have been institutionalised and individualised within the educational system, protectively or paternalistically placed in segregated or 'integrated' schools. Yet disabled people have always been an integral structural form of society, as actors and contributors (Stone, 1985). In practice, then, the marginalisation, institutionalisation and familialisation of children, of disabled people have had certain historical and current similarities.

Like children versus adults, disabled people have been positioned theoretically as being non-able bodied, with the comparison continuously against a mythical gold standard of 'normal' – failing to recognise, for example, that most people have impairments at some point in their lives and capacities vary widely. People with learning difficulties have experienced exclusion, as have children, because they are deemed insufficiently competent and rational to take up their roles as citizens and contributors. Yet practice has shown that both disabled people's and children's capacities have been significantly under-recognised in the past; with particular approaches and information, they have frequently shown themselves well able to participate in decision-making. Children and disabled people have been treated as 'lesser' because they are positioned as dependent on adults or carers/ able-bodied people respectively. This ignores the realities of people's interdependencies and the different types of 'work' done (whether paid or unpaid) (Lewis, 2003). It ignores contributions made, by children and disabled people in their personal and more public lives. This was brought to the fore by debates on 'young carers' – children of disabled parents -- which finally

led to productive discussions about valuing dependency and interdependency, family 'work' and care, and where the state should support parents and carers in such roles (see Olsen, 2000). Writers from Oliver (1990) to Watson and colleagues (2004), within disability studies, have argued for some time for the recognition of people's mutual interdependence; similarly, in seeking to promote children's rights, Arneil (2002) seeks to privilege interdependency through developing an 'ethic of care' theoretical framework. Thus, both childhood and disability studies suggest theoretical and practical reconsiderations of 'normality', competency, independence and dependency.

As did disability studies with its social model (see Watson, 2007 for overview) childhood studies offered alternative conceptualisations. These were neatly encapsulated by the ideas put forward by Prout and James (1990):

- Childhood is understood as a social construction
- Childhood is a variable of social analysis
- Children's social relationships and cultures are worthy of study in their own right
- Children are and must be seen as active in the construction and determination of their own social lives, the lives of those around them, and of the societies in which they live
- Ethnography is a particularly useful methodology for the study of childhood

- Proclaiming a new paradigm of childhood is also part of reconstructing childhood in society.

Thus childhood studies has promoted a rethinking of children's status and childhood. Children are to be seen as agents and not passive objects of concern nor empty vessels to be filled with adult wisdom. There is a close affinity with children's rights and the UN Convention on the Rights of the Child (UNCRC), as a policy and practice agenda. If children were agents and worthy of respect, than their human rights – and particularly their civil and political rights – gain a foothold. The UNCRC incorporates the traditional protection of children as well as introducing new rights of participation (but notably not self-determination nor hard core political rights like voting).

Again, there are similarities with the history of disability studies. Leading founders of disability studies argued for the social construction of disability, albeit with a more Marxist or functionalist flavour in the UK (Abberley, 1987; Oliver, 1990). The capabilities of disabled people were emphasised and increased attention was given to disabled people's own agendas. The theoretical developments were deliberately harnessed to a political agenda of civil rights, articulated at national and UN levels (the most recent being the UN Convention on the Rights of Persons with Disabilities).

Inevitably, there are differences between childhood and disability studies, not fully developed here. For example, Connors and Stalker (2007) point out that

relying on personal experiences has been hotly contested in disability studies but widely accepted in childhood studies. While structuralist arguments at least originally defined disability studies, on-going debates in childhood studies pit micro- and macro-research agendas against each other (see Wyness, 2006). The former coalesced around the social model of disability, which drove forward anti-discrimination legislation. The latter led to an emphasis on diversity of children and childhoods (e.g. James and others, 1998) and more recent concerns about privileging Minority World and ignoring Majority World childhoods (e.g. Punch, 2003; Tisdall and Punch, 2011; Wells, 2009). But perhaps as a result, theorisation within childhood studies has not led to the sharp conceptual or policy focus on age discrimination, at either British or European levels, as has the social model of disability on disability discrimination (see Tisdall, 2009 for further legal discussion).

Childhood and disability studies both positioned themselves as counter-paradigms, as severely critical of what had gone on before. Both children and disabled people, and indeed disabled children, have been subject to considerable research inquiry and the professional 'gaze'. Childhood and disability studies argued for sharply different approaches. They perhaps needed to set themselves up oppositionally, to argue their cases vehemently, to stand firm in their tenets. But as they gained ground, both risked stagnating, with insiders fearing censure if they went against what had become established. For disability studies, for example, it was controversial to acknowledge the role of individualised pain and impairments in understanding disability (Thomas, 1999).

Childhood studies is just reaching this stage of 'maturity' (or is it adolescence?), with its ideas well-enough established that questions are emerging. For example, there are recent calls to rehabilitate the notion of children as 'becoming' beings. Though denigrated for its normalising use within traditional developmental psychology (Burman, 1994; see Hogan, 2005, for review), 'becoming', emergence and immaturity can be seen as valuable attributes of human existence (Prout, 2005; Gallacher and Gallagher, 2008; Uprichard, 2010). Thinking of both children and adults as 'becoming-beings' also raises questions about the focus on children's rights, since rights have historically been associated with a conception of the individual as a rational, stable, self-controlling being (Lee, 2001). The rights discourse remains powerful in Minority World political and practice agendas (Hill and Tisdall, 1997) but one can question whether the model of children as independent, competent, individual agents is inherently liberating (Rose, 1999; Gallagher, 2006). It can be a form of governance, creating the 'self-regulating' child and in fact inhibiting struggle and resistance (Moss et al., 2005; Prout, 2002). A focus on children's agency can ignore the negative, challenging and limiting contexts where such agency is circumscribed or not possible (White and Choudhury, 2010). Such questions resonate with the sections below.

Children's voices

It has become commonplace within childhood studies for researchers to promote children's 'voices'. Often this is done through presenting direct quotations from children, gathered in fieldwork and reported in written findings.

But does this necessarily put forward children's voices? Most obviously, the selection of quotes, their framing and analysis are generally carried out by (adult) researchers (see also James, 2007). Researchers are then determining what counts as a 'voice', often representing that 'voice' textually, and interpreting what that 'voice' might be saying.

Furthermore, post-structural understandings of identity and subjectivity as socially constructed, through relations of power and knowledge (Foucault, 1977; Deleuze, 1994), raise questions about the role of research in reproducing these relations. The metaphor of 'voice' may reproduce the very understandings that marginalise children: the voice as the property of a rational, articulate, knowledgeable individual, capable of speaking for herself (see Tisdall and others, 2009). Focusing on voice privileges comprehensible verbal utterances over other forms of communication, which risks excluding children and young people who communicate little or not at all through speech (Komulainen, 2007) or who remain silent or laugh in response to a researcher's questions (for example, Nairn and others, 2005; Lewis, 2010). It excludes other forms of communication from drawing to role play to observation, which are popular methods to engage with a diversity of children, but tend to be translated into text for analysis and presentation. This privileges text over other forms of communication.

The promotion of children's voices is not just an academic question. It has become a policy principle, fed into various parts of domestic law and practice

requirements. A recent review of family law in Scotland (Tisdall and Morrison, 2012) shows the positive progress made – and the potential limitations. Thanks to the principle's incorporation into the Children (Scotland) Act 1995 (s.11(7)), pivotal court decisions have established it is not *whether* but *how* a child's views should be accessed, when a court considers parental rights and responsibilities (*Shields v Shields* 2002 SC 246). Courts have become comfortable in paying attention to younger and younger children – age 3 currently seems to be a boundary. Appeals have been won solely on the basis of a child's right to participation being breached. Thus, Scottish courts – or at least judges in reported cases – can be seen to accept a childhood studies paradigm: children as citizens, social actors and active agents (Hunter, 2007).

However, more negative trends can be found in reported case law (see Tisdall and Morrison, 2012). When children's views are described as consistent, clear and definite, the court weighs them more heavily in its decisions; if views were described as ambivalent or anxious, the views have substantially less weight. Stated views are attributed to children's right to participate while nonverbal expressions are considered behavioural and solely factored into identifying children's best interests. Disabled children's views may be undermined by questions about their ability to have clear views. In such cases, case law shows that it would be wise to have a health professional's expert opinion that a child's views should be considered (Barnes, 2008). For all children, expert reports are the dominant mode for 'hearing' children's voices in courts; the reported case law itself at times reports verbatim the quotations of children's views that are

contained in such reports. Thus a double layer of selection and interpretation is made of children's 'voices'. Taken together, these trends show both the advantages and disadvantages of accepting the rationalist, individualist model of children's agency and its implications for children's 'voice'; it has dramatically raised the profile of children's views but risks excluding the emotional and the contextual and, particularly problematic for some disabled children, risks excluding nonverbal communication modes from key decisions about their lives.

The critique of childhood studies, and its promotion of agency, does not negate the valuable role that research or consultative activities, facilitated by adults, can play in raising children's issues and views to a broad audience. 'Children's voices' has been closely linked with the children's rights agenda, with both its flaws and benefits: certainly, it has been powerful politically to gain attention to children's issues. But this critique supports the growing use of communication forms beyond the written and verbal, such as visual arts, sound, video and multimedia. It recommends serious consideration of how these forms can meet robust research standards, harnessing the insights of visual anthropology and sociology, not only as a fieldwork method but for data analysis (e.g. Bolton and others, 2001; Thomson, 2008). And it leads to considering the role of children themselves in research construction, production and dissemination, addressed below.

Children's participation in research

The enthusiasm for children's participation generally as a rights argument has led to a considerable enthusiasm for children to be the researchers – and even for this to be seen as the ideal research mode, where the research is *by* children and not solely *on* children (e.g. Young People's Research Network <http://blogs.nya.org.uk/yrn/>; see James, 2007). Research by children has been promoted by non-governmental organisations on a more regularised basis – albeit with notable challenges (see Sinclair, 2004) – as innovation, and as part of a school educational programme (e.g. see Children's Research Centre at the Open University). But problems have arisen both practically and conceptually.

Very practically, any young person in the UK, under the age of 14, has difficulty being paid directly for work as a researcher, due to European regulations and subsequent UK legislation. (Exceptions are made in law for child actors/actresses but not for child researchers.) Young people may still face problems of limited pay for research work, combined with reduced social security benefits (if they were claiming), as adult disabled researchers have also found. Some funders have been willing to fund continuously research by 'service users', particularly in the non-governmental or charity sectors, but anecdotal evidence suggests more problems within traditional academic and government research funders in seeking to meet the 'rigour' of research tasks (Brownlie and others, 2006). The Centre for Children and Young People, at Southern Cross University in Australia, ran into difficulties with health and safety

regulations, when seeking to involve young people in advising their centre (Graham and others, 2006).

More conceptually, assumptions can be unexamined about why children as researchers is a 'good thing'. The phrase is often used in childhood studies, that children are 'expert in their own lives', but this does not necessarily translate into expertise in other children's lives. There is a risk that children are treated as a homogenous group, with a too-simplified dichotomy of childhood versus adulthood. Further, children can be 'ghettoised' into only researching a limited range of supposedly childhood issues, and disabled children have articulated this in particular.

Tough questions lie in what skills are required to undertake 'good' research, and whether children should go through substantial training in research skills or have less research-rigorous standards applied to them. Children generally who become too involved in participation activities risk being accused of becoming 'professionalised', placing them in a perverse no-win situation – if they lack the skills and knowledge of the 'rules of the game' they may be ineffective in influencing but to demonstrate such skills and knowledge makes them unauthentic and thus dismissible (Faulkner, 2009). They may also alienate other children, who perceive the child researcher or participant as 'different' (see Barker and others, 1996). Overall, the claim for expertise and its problems can arise from an implicit assumption that children are somehow being *representative* when they act as researchers (Brownlie and others, 2006). But

this is a nearly impossible goal to achieve, whether in being statistically or democratically representative, in a research context – and one that adults are not typically required to meet. It ignores alternative means of judging (qualitative) research, which favour criteria like credibility, dependability, and transferability rather than validity and reliability (Lincoln and Guba, 1985). It ignores other forms of participative democracy, which may be more suitable, productive and meaningful for all involved (Cairns, 2006).

Similar problems have already been articulated for disability studies, such as a series of writings by Oliver (e.g. 1997, 2003). His solution was not to emphasise disability researchers but rather to ensure the whole range of research resources were put at the disposal of disabled people's organisations. (For discussion of the conceptual benefits and problems with focusing on disabled researchers, as a mechanism for emancipatory research, see Mercer (2004).) But there are very few child-led organisations and even fewer disabled children's ones, at least in the UK. Some disabled people's organisations have recognised the younger generation and reached out (e.g. AccessAbility Edinburgh – notably no longer existing) but this remains limited. Oliver's answer of using research resources thus lacks the infrastructure, of children's own organisations, to proceed.

The above discussion leaves considerable questions. Questions like:

- What is the place of research in the intertwined areas of emerging academic areas and rights/political movements?

- What types of research are appropriate for different agendas? Are there some types of research that are always inappropriate or does it depend on the contexts and the applications?
- What is the role of supporting research 'experts', who are not easily classified into a disabled or young category?
- What expertise do particular disabled people and/or children bring to particular types of research?
- What are the range of roles possible in any one research project and how might these be utilised by children and/or disabled people?

Conclusion

Arguably, early leaders of both the disability and childhood studies movements had to fight tenaciously and vociferously against the dominant paradigms to establish and legitimise these areas of study. What might need to be promoted stridently at the start may not need to be once the principles have been established and benefits demonstrated. There certainly has been a great need to argue for the pertinence and value of children and/or disabled people's perspectives; including their carers in research may be productive and valuable as well, but carers' perspectives are not synonymous with those of children and/or disabled people. There has been a need symbolically and intellectually for children's and/or disabled people's communication (and images and activities) to be taken seriously, to identify the responsibility for effective communication lying with the researcher and not research participants, and for different sets of research agendas. The long tradition of psychological and

rehabilitative research needed to be juxtaposed with different kinds and foci of research. There still is too little research that adequately and systematically puts forward the viewpoints of children (and/or disabled people?) and values their contributions fully. There is too little research, and particularly too little large-scale and sustainable models of research, that involve children as researchers or other deep levels of involvement. Disabled people remain too few in formal research institutions but the barriers are even higher for children to become mainstreamed within research, with practical problems of employment law further limiting this.

Equally, this paper argues for a continued re-balance in childhood studies. Part of this re-balance is to explore, consider and re-develop the underlying assumptions and commonly accepted activities, on both their strengths and weaknesses. The paper argues that the phrase 'children's voices' has distinct disadvantages and exclusionary aspects, and is frequently a camouflage for what actually happens in the research process. The reasons for involving children as researchers, on an adult-initiated project, need to be examined and articulated for each particular research project. Practical barriers need to be dismantled so that more children can indeed follow their own lines of inquiry and produce evidence that will impact on policy and practice. Theoretically, we need to advance childhood studies, to move away from the dichotomies of adulthood versus childhood and take even more seriously the social construction of childhood in our own as well as others' work. We need to welcome insights from

other academic areas, such as disability studies, and continue to question our own paradigms creatively and critically.

Research with disabled children can illuminate, add to and challenge this agenda. It encourages researchers to understand and utilise multiple communication methods, to access, analyse and present research data. It suggests being reflexive about the various constructions of 'researcher' and 'participant', testing them for their presumptions and assumptions of competency, expertise and agency, encouraging more nuanced constructions applied to the particular questions at hand. It underlines that research with disabled children should not be perceived as a specialist activity but rather one that has wider lessons for research methods and analysis. By questioning effective communication, research claims, and ways of participation, research with disabled children adds to research more generally.

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