Disabled Children's Childhood Studies: a distinct approach?

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Abstract

This paper suggests that the emergence of disabled children's childhood studies as an area of study offers a distinct approach to inquiry; it represents a significant -shift away from the long-standing deficit discourses of disabled childhoods that have dominated Western culture and its reaches. On the one hand, contemporary childhood studies contest normative, Eurocentric mantras around the 'standard child' while, on the other, disability studies critique the medical discourses and the scope of its authority. However, while drawing on these two approaches, disabled children's childhood studies provide more than this combined critique. In disabled children's childhood studies, disabled children are not viewed as necessarily *having problems* or *being problems* but as *having childhoods*.

Introduction: The emergence of disabled children's childhood studies

This article examines the emergence of disabled children's childhood studies and discusses the potential in developing this new approach to inquiry. Disabled children's childhood studies draws on the traditions of both new studies of childhood (James and James, 2001) and disability studies but we

argue that disabled children's childhood studies can be considered to be a distinct approach to study. It is premised on three distinct premises. First, disabled children's childhood studies offers a different starting point for discussion that shifts the focus away from discussion 'about' disabled children which is so often conflated with talk of impairment, inequality and abuse; the second is an approach to ethics and research design which positions the voice and experiences of disabled children at the centre of inquiry and, the third, is a contextualised agenda for change that seeks to trouble the hegemony of the 'norm' (Davis, 1995). The aim of disabled children's childhood studies is to enable disabled children to step outside of the 'normative shadows' that so often cloud discussions of their lives (Overboe, 2004). This also entails re-thinking children's relationships with parents/carers, family members and with communities. The studies do not originate from policy directives, service outcomes or professional practice debates, although the links and impact of those are salient in disabled children's childhood studies. This is the case not only at the level of direct intervention, but in generating, sustaining and changing wider cultural practices.

Disabled children's childhood studies are written by disabled children and young people, disabled scholars and activists reflecting on their childhoods, as well as parents/carers of disabled children, allies and academics listening directly to disabled children and young people's voices. The main collection of studies discussed in this paper is by authors who formed links and networks through conferences and projects, teaching and policy consultations

in the UK and internationally including Iceland, Guatemala, South Africa. Disabled children's childhood studies has emerged through these inter/national networks and also through the relationships built at a series of Child, Youth, Family & Disability Conferences held in the United Kingdom (2008 onwards). This conference has developed partnership between researchers at Manchester Metropolitan University, The University of Sheffield, Sheffield Hallam University, The University of Manchester and the University of the West of England, The University of Toronto, The University of Iceland and The University of Zimbabwe. Networks have also emerged from the Economic and Social Research Council seminar series about the lives of disabled children that has led to the UK Disabled Children's Research Network (Abbott, 2012). There has been a high level of personal engagement in the emergence of disabled children's childhood studies by disabled children, young people, parents/carers, allies, activists and academics. This commitment may explain the passionate nature of the criticism leveled at studies that present disabled children in problematic terms and without any expectations of 'development' or, even, of having childhoods at all. The insights from disabled children's childhood studies extend beyond service-based research and beyond impairment based 'problems' and illustrate the impact of the deficit and managerial preoccupations of the global North. The authors' personal engagement might also explain the care taken around ethics throughout the research process. This includes the recognition of the need to avoid making generalized claims and the exploitation of disabled children as sources of 'data' for the 'greater good' (Naseem, 2013). Children and young people's words are used to reflect authenticity.

Personal engagement might also show how a shift in approach can occur. In our discussion of disabled children's childhood studies and its contribution as a distinct approach to study, we reflect on the relations and conditions within which disabled children's childhood studies have emerged. Regrettably, disabled children's childhoods are largely invisible in historical accounts of childhood and, where disabled children are present, they are visible primarily in deficit terms with a focus on individualized, medicalised and tragic children and childhoods associated with welfare institutions. These practices assume vulnerability and, paradoxically, take attention away from the experiences and concerns of disabled children and their families themselves. We outline the different starting points for discussion of disabled children's childhood studies and explain how the studies contest practice initiatives for disabled children that continue to privilege medical and child development discourses in order to identify and to manage disabled children's lives.

The studies discussed draw on both the new sociology of childhood studies and on disability studies that advance research and change processes that are built on personal and collective experiences. However, disabled children's childhood studies respond to the specific dominant discourses around disabled children with the ethical considerations, accessibility of research activities and strategies used to maximize the impact of their contributions. Disabled children's childhood studies' agenda for change rejects the mythical status of the 'normal' child as an end point, and promotes, instead, on-going action against poverty, and a recognition of the distinction between disabled

children's 'ordinary' and productive childhoods and their experiences of inequality, and attempts to widen understandings of children's identities in a global context. The agenda for change entails: developing understandings from the perspectives of disabled children and young people; the recognition of disabled children's diverse experiences in local environments as part of a wider global context and engaged sustained action by and with disabled children and their families and allies. As we have seen, disabled children's childhood studies are also concerned with debates beyond the global North, and consider critically the part that discourses of childhood and disability play as an important part of geo-political relations.

While we argue the case for a distinct approach to inquiry categorized as disabled children's childhood studies, we are also mindful of the risks of forging a distinct area of study without a continuing collaboration with both childhood studies and disability studies. To do so would be to risk losing their existing advocacy relationships and connections. Following Goodley (2011: 157) who argues that "critical disability studies might start with disability, they never end with it", we suggest that, similarly, disabled children's childhood studies starts with childhood and disability but never ends there.   Critical research engaging with disabled children and their experiences calls us to a wider theoretical debate that can also contribute to childhood studies and disability studies.

Disabled children and childhood studies

Academics engaging in childhood studies in the global North generally open with a discussion of the 'emergence of childhood' and how this occurred through Western industrialization and its impact on home and work spheres. When and how childhood became a distinct life stage and to what degree this signaled a significant change in family relationships continues to be debated (Clarke, 2010). Nonetheless the notion 'childhood' opened the way for theories of 'child development' and techniques to define stages and expectations. Burman (2007) deconstructs the 'normal distribution curve' as a technique that distributes 'normal' and 'abnormal' characteristics in a way that appears to have a scientific claim to authority. She argues that this normative curve is an arbitrary construct generated through auto replicating categories so that what a child is doing at a certain age is neither reflective of 'normal' age or 'normal' act. Child development creates a set of norms that simultaneously creates the 'problem' of the disabled child (Davis, 1995) and situates disabled children outside of 'normal' development itself (Moore, Beazley, & Maelzer, 1998). Discussion of disabled children is dominated by deficit discourses that concentrate attention on the impact of impairment (Oliver and Sapey, 2006). Further, emotional development becomes a concern about parents/carers; the need for parental adaptation. When given a diagnosis, parents are thought to become 'over protective' or, if they fail to 'adjust' and 'adapt' to form 'insecure attachments' and disabled children themselves are then deemed to form 'insecure attachments' (Howe, 2006). These concerns are presented as 'natural' responses to childhood disability that elicit sympathy for parents and children. Oliver and Sapey (2006) explain how these cultural practices have serious impacts: they overshadow the lived

experience of disabled children and families' need for supporting resources and social change. The dominance of accounts of 'normal' development and 'normal' childhoods, by mainstream childhood studies researchers, individualizes all children's needs in ways that erase the social contexts that produce them.

The focus on diagnosis and parental adaption produces an enduring cultural dynamic relation demonstrated by institutional, charity-based service provision. Indeed, the perceived 'tragedy' of disabled children's impairment has distracted professionals from direct engagement with disabled children themselves and, in some cases, this has meant that the identification of some serious and fatal institutional and family abuse has been missed (Murray and Osbourne, 2009). Stalker, Green Lister, Lerpiniere, and McArthur (2010) found that disabled children were let down by therapeutic services and the criminal justice system that often failed either to take account of their needs or to seek the views of disabled children experiencing abuse. The level of cultural acceptance of this tragedy dynamic is far reaching. For example, with regard to the adoption of disabled children, deficit discourse is likely to influence prospective adoptive parents unless they benefit from direct experience of full relationships with disabled children and can counter negative stereotypes (Bunt, 2013). Disabled children's childhood studies reject these deficit understandings and start with different questions about parents and families as we discuss below.

Sustained campaigns for equality and disabled children's participation

emerged in policy and childhood studies literature. Participation and voice are endorsed in The UN Convention of the Rights of the Child 1989 (United Nations, 1989) and in the principles underpinning the legal framework for children include a focus on the child, family-based care and the need to ascertain the wishes of the child in decision-making (Department of Health (DoH,1991; DfES, 2004). However, although disabled children are included in the UK legislation, their position is more precarious than that of their non-disabled peers. Disabled children are characterized as being 'children in need' and 'disability' is defined in terms of impairment and function (DoH 1991). Despite legislative principles have been developed with the aim to encompass all children (DoH, 2003), disparity between disabled and non-disabled children continued. Research shows that disabled children in the UK are more likely to experience poverty, institutional segregated forms of care and all forms of abuse (Read, Clements and Ruebain, 2006). In the 1990s, studies asking disabled children about their experience of services were undertaken and continue to chart significant disparity and inadequacy of provision (Morris, 1998; Beresford, Sloper, Baldwin & Newman, 1996; Franklin & Sloper, 2006; Clarke, 2006).

'Rights' and 'risks' have been treated as if they are separate and as having different priorities. Child protection in the UK has the priority and is regarded as 'statutory' whereas right to voice and participation are more associated with voluntary sector. These are different literatures. In effect 'rights' and risks' can been viewed as opposites with service areas operating in opposition and hierarchy regarding resources. With regard to disabled children these

discourse dynamics are compounded by the link made between disabled children's impairment and vulnerability and 'need'. Murray & Osbourne, (2009) in the *Safeguarding Disabled Children Guidance*, refer to serious case reviews that show how disabled children are put at risk when they are not heard or involved, and when the professionals focus on parents' needs or on impairment. The guidance brings together 'rights' and 'risks' recommending models of service where disabled children's safety, needs and community presence are understood as co-requisite rights and are all to be prioritised. However despite further initiatives to address the inequalities disabled children are likely to face (DfCSF, 2007), the official discourse of 'disability' is more tightly bound to fixed categories of impairment status than ever. For example, the new Children and Families Act (HMSO, 2014) continues to locate special educational needs and disability as a within-child deficit.

The move from studies 'about' children towards studies 'with' children has been advanced within childhood studies advancing children's rights (Alderson, 2008). The 'new sociology of childhood' studies focus on the child in a social context and so 'childhood' is considered a social construction rather than a process of 'natural' maturation. Children are seen as active with fluid, multiple and complex identities in contrast to the earlier concepts that assume fixed identity, passivity and vulnerability (James and James, 2004). Within childhood studies, the 'standard child' has been critiqued as a discursive strategy of governance that makes those children deemed different invisible or 'other' to the Eurocentric norm. In colonialism, Wells (2009) argues, the 'standard child' discourse has been *the* mode of installing Western norms and

culture. Debates in new childhood studies recognise diversity and analyse the intersections of gender, age, and ethnicity (although disability is often the missing dimension here as discussed below). According to Mayall (2002), childhood is relational, children are a group living in relation to adults in the same way that other minority groups are subject to the dominant culture. The imperative for children's participation in decision-making is strengthened by these understandings of children's identities and lives.

Despite these welcome developments in childhood studies, we question how far they have contributed to understanding disabled children's childhoods, their diverse and full identities, and relational experiences? For instance, the appeal for disabled children's inclusion continues, within policy and research, to be based on a 'child first' basis (Stalker, 2012). At first, this 'child first' approach seems to be uncontrovertibly welcome, as 'children first', disabled children will then benefit from the recognition, participation and decision-making that is now imperative for all children. This construct stresses commonality and implies a standard of expectation which is important in terms of quality of life, however a homogenous view of children obscures difference and different needs and for disabled children risks disembodying their identity or, paradoxically, reinforcing a negative view of the body from which we should somehow rescue the child. Where there is a stress on diversity, such as is favoured in childhood studies, categories still tend to be normative. Studies of 'other' groups of children and young people such as trafficked young people, adopted children or teenage parents, do not readily consider disabled young people as part of those groups (Watson, 2012). Disabled

children are members of families yet the dominant discourses make disabled children invisible as active in relationships. For instance in the literature 'about' disabled children 'siblings' generally refers to 'siblings of' disabled children yet disabled children contribute as siblings to their brothers and sisters (XXXXX).

The gap between the 'child first' ideal and the realities of hostility and exclusion disabled children face is both a paradoxical and a potentially productive space. Disabled children's experiences have much to contribute to understanding embodiment and identity. In disability studies, embodiment is discussed as a social practice. The dominant class is produced as 'godlike' and 'disembodied' and atypical bodies are 'other' (Corker and Shakespeare, 2002). The oppositional fixed or fluid practices of embodiment operate in interplay that impacts beyond the welfare encounter into public culture, language, local and global relations. The effects of policy on family and community life are everyday life-long experiences (XXXXX). When disabled children are situated outside the standards of 'normal', abuse goes unrecognized and 'ordinary' community activities remain inaccessible and unresponsive, if not hostile towards disabled children (XXXXX). The concerns around welfare are not limited to the more affluent global North, but influence funding priorities worldwide and normalize limits on immigration eligibility regardless of official family based principles of legislation (Meekosha, 2008).

Theories of childhood have not simply described disabled children, or children in general, but they also emerge alongside the policies, institutions and

services, shaping childhoods. In the UK, these studies highlight the links between institutional charity care, a public culture of sympathy and stigma and heroic/tragic forms of subjectivity. As we seek to illustrate below, disabled children and their families and disabled adults are not passive within these contexts, but refuse imposed limits and resist exclusion.

While we wish to recognize the contribution that childhood studies have made to understanding children's lives and, in particular, promoting the voice of children within research, we have argued that disparities between the lives of disabled and non-disabled children remain and that childhood studies, in positioning disabled children as 'children first', has either ignored disabled children's embodiment and lived experience or positioned disabled children's bodies and lives as 'other'. In the next section, we consider the contribution that disability studies have made to the study of disabled children's lives.

Disability studies and disabled children

Disability studies researchers take a very different starting point from studies 'about' disabled people questioning theory, policy and social practices. Over the last forty years, British disability studies has been premised on the view that disability, including childhood disability, is a sociological issue rejecting any understanding of disability that locates disability as a problem originating *within the person* (Albrecht, Seelman, and Bury, 2001). In this way, disability studies distinguishes itself from childhood studies that so often focus on individual, typical, child development. Disability is constructed as a social

issue that must be tackled by removing the barriers to participation that people with impairments experience in the social world. This approach, known as the social model of disability, is a Marxist materialist account of disability (Oliver, 1990). As such, proponents of the social model of disability view the emergence of disability as a social issue linked to the spread of capitalist society in which the emergence of capitalist commodity production and exchange has resulted in the "repression of certain forms of social embodiment" (Gleeson, 1999: 39 cited in Thomas, 2007: 54). One of the criticisms of the Marxist materialist account is that a distinction has been maintained between 'public issues' and 'private troubles', with the consequence that the social model of disability has failed to pay attention to the gendered (and, indeed, raced and classed) nature of disability (Thomas, 1999). However, advocates of the social model do state that societal barriers are best understood and challenged by those with experience and it has inspired experience led activism (Shakespeare, 2006) as well as being applied to recognise diverse experiences (Oliver and Barnes, 2012).

Disability studies have played an important role in critiquing childhood studies that have excluded disabled children from participating in research on the grounds that their impairment makes it impossible for them to participate. The aims and approaches of emancipatory disability research (Barnes, 2003) compliment participatory approaches developed within childhood studies in research with children (XXXXX). Disabled children's childhood researchers have considered the complexity and diversity of their lives using a wide range of innovative and accessible methodologies (e.g: Watson, Priestley, & Barnes,

2003; Davis and Hogan, 2004; McLaughlin, Goodley, Clavering & Fisher, 2008; XXXXX).

In the current economic context in the United Kingdom, research that focuses on the material conditions of disablement in the lives of disabled children is certainly important and necessary. Research has consistently shown that poverty has a major negative impact on the lives of disabled children in the UK (Read, Blackburn & Spencer, 2010). Social model approaches have also made a huge impact on the lives of disabled children in access to education and leisure (XXXXX). A focus on disability as a sociological issue, rather than an individual problem, has underpinned advocacy for the right for inclusive education and play for disabled children (Barton, 1997; John and Wheyway, 2004). Shah (2013) shows the links between policy and disabled children's childhood in her narrative study with disabled adults from three generations. She asks them about their family life and charts the policy developments and it is plain to see how opportunities for family life are impacted making the point that personal and public life are entwined.

Both new childhood studies and disability studies have made important contributions to the study of the lives of disabled children. However, we suggest that disabled children's childhood studies offer a distinct approach that can contribute to the study of disabled children's lives. In the section below, we seek to 'locate' the approach drawing on examples of work in the field by children, young people, and their allies.

Locating disabled children's childhood studies

As we argued above, disabled children's childhood studies is premised upon three distinctive approaches to disabled lives: first, the call for such an approach comes from disabled children and young people; second, is an approach to ethics and research design which positions the voice and experience of disabled children at the centre of inquiry and, third, is the particular agenda for change that seeks to trouble the hegemony of the Eurocentric 'norm' (Davis, 1995) and to consider disabled children's childhoods outside of the 'normative shadows' (Overboe, 2004). We consider each of these distinct approaches below.

i) Openings

Disabled children's childhood studies offers contributions to the field that move beyond discussion of impairment, inequality and abuse have often come from disabled children and young people. Examples include Stevie Tyrie a disabled child. Her story touches on impairment, she tells us 'I was born early' but it does not stay there, rather she quickly moves on to remind us that disabled children's childhoods are not synonymous with inequality and abuse. So she talks about family and friendship, likes and dislikes and in a way that demands recognition and celebration of her 'non-normative' life. Reflecting on her life as a disabled child, Frejya Haraldsdóttir , a disabled adult, also reflects on her impairment but her account differs starkly from the

tragic and deficit discourses that are so often captured in studies 'about' disabled children:

> I didn't realize about my impairment, or at least found it as normal as having glasses, blond hair or brown eyes. I even thought that breaking a bone a few times a month was what everyone did. (Haraldsdóttir , 2013: 14)

Accounts of disabled childhoods reveal that it comes as a surprise to children to learn that their lives are considered to be 'non-normative'. As Tyrie (2013: 11) tells us: 'I used to think that our family was the same as every other family and they all had a disabled child.'

Disabled children's complex relationships with the norm are revealed throughout their accounts of their lives. Freyja Haraldsdóttir 's story is woven through with the aspirations of a child that, outside the context of a disabled childhood, would be seen to be 'normal' hopes and dreams. Haraldsdóttir discovered that her aspirations were seen by some as 'unreasonable' and this discovery led her to keep her wishes secret:

> … when I was playing dolls with my friends when I was little I was always the father. Somehow it became a matter of fact that I couldn't be the mom because she had to dress the baby, feed it, put it to bed, give it a bath and hold it. But the dad, he just went to work, watched television and told off the kids when they were misbehaving their

mother. That I could do….I secretly played the mother when I was playing on my own. I used to have small dolls that I could hold and remember wishing that real babies could also be so small. I needed mom to help me dress it but I thought that would be fine, she wouldn't mind dressing my babies when I was a grown up. Obviously, since I knew no babies were so small in real life, I decided I was not fit to be a mother. I really wanted to, but that was *my* secret. (Haraldottir, 2013: 17)

Disabled children learn that their bodies are 'bad', 'asexual' and that they are not expected to become parents (Skitteral, 2013). In accounts of disabled childhoods, children describe their parents' as playing crucial roles in their lives; they are allies, teachers, facilitators and advocates (XXXXX). Yet the experiences of those children not living in families or with parents/carers who are unable or unwilling to represent their views are often ignored in research and practice. There are inherent dangers in valorizing the role of the family in disabled children's lives without recognizing that this may also perpetuate a mythical and unattainable ideal in many disabled children's lives. Friendship, love, sexuality, conflict and ambivalence; parents, friends, neighbours; contexts of home, school, work are complex and disabled children's childhood studies demands us to re-think and appreciate these relationships outside of the contexts of 'care' and 'normativity'.

ii) Ethics and research design

Disabled children's childhood studies demands an ethical research design that seeks to position the voice and experiences of disabled children at the centre of the inquiry. This is a particularly sensitive issue for a group of children who already experience heightened levels of surveillance from the professions (including teachers, social workers, psychologists, doctors - among others) (XXXXXX). In suggesting that researchers engage in imaginative and sensitive approaches to the study of disabled children's lives, it is important to acknowledge the risk that researchers will simply become more expert at invading disabled children's private worlds for their own purposes as adult researchers (Clark, McQuail and Moss, 2003).

Tensions also arise between the imperative to listen to disabled children, rather than their proxies, while at the same time recognising that disabled children live within families and communities. XXXXXX (2012) reflected on their aim to give ethical voice to disabled children in research by using a distributed methodology where they sought to combine ethically, sensitively and carefully the perspectives of the child with those of significant others in their lives.

Abbott (2013) gives a thoughtful, sensitive and honest account of research with disabled children and young people living at home. He discusses the challenges of being a 'good guest' in the home of a stranger alongside meeting the parents' expectations of him to be someone they could trust, while needing to meet the young person's expectations that he would not be 'too boring'. The ethics of research with disabled children is messy, complex

and challenging. The use of the researcher's self and own experience,

deciding how and whether to intervene is demanding and risky but these

concerns are not presented as reasons to continue exclusion, rather ethics

are considered throughout the research design and process and are never

completed and never, perhaps, fully resolved. Involving children in the

research process, including telling their own stories and engaging with

analysis is also part of this ethical approach (See for example Tyrie, Tyrie,

Tyrie & Tyrie, 2013; Tyrie, 2013).

iii) Beyond the normative shadows

The fixed and fluid practices of childhood embodiment make an impact

beyond the welfare encounter into public culture, language, local, global and

historical relations affecting all people. Disabled children's childhood studies

seek to trouble these practices in their local, historical and global locations. In

paying attention to local practices, an emerging strategy has been to turn the

gaze away from scrutinizing the lives of disabled children and to analyse

instead the reactions of non-disabled people to disabled children's lives or 'to

pathologise 'the normals' among us' (Goodley & Lawthom, 2013:176). Slater

(2013: 191) also argues that to be a critically young ally to disabled youth

there is a need to question 'adulthood normativity'. Moving beyond the local,

Cooper (2013) exposes the historical locations of disabled childhoods. Her

rationale for her decision to historicise the notion of the 'normal child' is to

reveal the hegemonic power of the 'normal child' in Anglo-American culture

and to trace the emergence of contemporary anxieties about normalcy. At the

same time, Chataika and MacKenzie (2013) seek to disrupt the dominance of global North accounts of disabled childhoods. They reveal the importance of disabled children's participation within family *and* community and they contrast this with the individualistic preoccupations of the global North. There is a need for an open dialogue between global North and South in order for a truly *global* disabled children's childhood studies to emerge and to flourish (Chataika and MacKenzie, 2013). As Disabled Children's Childhood Studies offers different starting points for inquiry, it also offers a different approach for analysis, one in which norms are troubled and historical and global locations are made visible.

Discussion

The contribution to understanding disabled children's childhoods is considerable. The contradictions and paradoxes highlighted above are made clear in studies that begin by attending to disabled children's experiences. Oppositions between child/adult, non-disabled/disabled child, child/parent are considered as serious problems of normative theory. Davis & Watson (2001; 159) are critical of an approach that promotes an unquestioning acceptance of the distinction between the 'disabled/non-disabled child' suggesting that this bifurcation has only served to marginalize disabled children in services, policy, practice and research.

We saw that disabilitiy studies have struggled to respond sensitively to the relational contexts of disabled children's lives. Non-disabled parents of

disabled children have continued to face criticism from within the disabled

people's movement and disability studies (XXXX). Although there have been

calls for 'alliances for change' (Tregaskis, 2004: 91) between disabled people

and non-disabled people, family members have been positioned, like

professionals, as somehow outside the disability community, as 'allies'. Yet

parents/carers and other family members' intimate, enduring and loving

relationships cannot be recognised by the use of the term 'ally' (XXXXX).

Tremain (2006) shows how the social model of disability has been taken up

and used not to advance social action but to limit the focus to one of welfare

entitlement despite its liberatory origins. The distinction made between

'impairment' and the 'social' is itself a social as if the 'natural' is somehow

outside of the social and cultural (like the practice of separating of 'sex' and

'gender'). This dualism also reflects a Eurocentric context. She advances an

approach that resists such identity politics and asks 'what do we want?'. Here

we suggest disabled children's childhood studies are a starting point for 'what

we want', the space, the methodologies, the gathering together to resist, to

write and speak back (Fanon, 1993). Grech (2013) suggests that disability

studies remains critically disengaged with ideas from the global South. This

lack of engagement takes place despite the fact that disabled children are

experiencing poverty in 'disproportionate and multidimensional ways in the

global South' (Grech : 89). Grech describes the limitations of analysing the

experiences of disabled children in isolation, and without paying attention to

the spatial, social, cultural and economic dimensions of their lives. For Grech,

an unwavering attachment to any one model of disability, whether it is a social

medical or other model, is highly problematic in the study of disability and childhood in the global South. Crucially, any assumption of a unified global model, particularly when such an approach is premised on western individualism, is problematic for disabled children's *global* childhood studies.

Conclusion

Childhood studies and disability studies have recognised the need to include disabled children, but the question remains of whether the offer of 'inclusion' is enough? Is there a need to move beyond including disabled children as the focus of 'special issues' of core journals in childhood or disability? What might be gained from seeing disabled children's lives as the starting point, or opening, for the discussion about disabled children's lives? Is the disabled children's childhoods studies we have outlined above a distinct and a specific approach and is it needed? These questions are about the approach to understanding, the links to policy and support arrangements and the basis for authority. Do disabled children's childhood studies count and if so how is their impact to be identified? What might be the impact of these studies in professional education and practice? The College of Social Work consulted people in disability and disabled children's childhood studies for the development of new for the Curriculum Guide: Disability as part of the development of the new social work degree and it states:

'Some disability related terminology carries strong negative connotations. Disabled children are sometimes described as 'children first' to avoid this but their identity as disabled children needs to be confident to convey clear

expectations for their childhoods' (Lunn, 2013:1).

In this article, we have examined the emergence of disabled children's childhood studies and outlined what we see as the potential in developing this new approach. In exploring the potential of disabled children's childhood studies, we are not suggesting that it is necessary to sever the ties with 'new' childhood studies or, indeed, with disability studies, rather we see disabled children's childhood studies existing in productive dialogue with both disciplines. However, we seek to move beyond analytical approaches that focus either on disabled children's disembodied futures or on disabled children as embodied but 'other'. Where practitioners are involved in research that also involves children and young people, their own confidence to shape change is high (XXXXXX). We suggest that through a programme of research, creative activities and gatherings, disabled children's childhood studies can be helpful in thinking about all children's lives (disabled and non-disabled) in positive and productive ways.

In the global North practices of embodiment in health and welfare are mobilised through concerns about disabled children's futures, whereas the non-disabled child, on the other hand, is expected to achieve autonomy as a disembodied intellectual or to be a body perfect performer. Further, disabled children are excluded from new childhood discourses in which children are constructed as active, agential and entrepreneurial (XXX). Disabled children's childhood studies seek to disrupt the taken for granted opposition produced between the 'vulnerable disabled child' on the one hand, and the 'developing

active entrepreneurial child' on the other (XXX).

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