

Title: Editorial: Researching the Lives of Disabled Children and Young People

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Editorial – Researching the Lives of Disabled Children and Young People

Why a Special Issue of *Children & Society* dedicated to disabled children and young people?

The simple answer to that question is 'because disabled children are children first and foremost'. The vast majority of disabled children and young people in the western world live at home with their families, most attending mainstream schools, and disabled children and young people worldwide have rights to inclusion and equal treatment enshrined in national legislation and international conventions. Yet they often remain left out – from generic children's research, from policy-making about children's services and, in their everyday lives, from inclusion in friendship groups and social and sporting activities. Having a Special Issue focusing on disabled children and young people within a generic children's journal, rather than a disability-specific publication, provides an important opportunity to highlight that their needs, preferences, priorities and aspirations are in many ways the same as those of any other young people, albeit many disabled children will need additional support to achieve their goals. This issue therefore aims to increase awareness of disabled children and young people's views and experiences and of a range of ways to seek their opinions. It aims to present cutting edge research about disabled children and young people, explore relevant theoretical frameworks and examine current issues and debates at policy level. We hope that in the future many more 'mainstream' children's studies will include disabled children and that there will be no need for a Special Issue dedicated to this group, in the same way that it would now be

considered inappropriate to have a Special Issue devoted to researching the lives of children from Black and minority ethnic communities.

In addition, as John Carpenter and Roy McConkey suggest in the concluding paper in this issue, the way society treats disabled children and young people can be seen as a 'touchstone' or marker for its treatment of children and young people more broadly. Calhoun and others (2002) go further, arguing that one aspect of critically examining and theorising perceived difference is to think about the role which the ideas attached to certain social categories (such as race, gender, class) may play in structuring society itself. Thus, the extent to which a society perceives and treats disabled children and young people as similar or different to others can tell us something fundamental about the nature of that society.

The ESRC Research Seminar Series - Researching the lives of disabled children, with a focus on their perspectives

This Special Issue features selected papers from a seminar series funded by the Economic and Social Research Council (ESRC) in the UK. The impetus behind the seminars sprang from a desire to explore and promote innovative ways forward and address gaps in current knowledge relating to research with disabled children and young people. Many studies in this area have focused on families, notably family functioning, stress and coping, aspects of caring, parents' relationships with professionals and the availability and quality of services and support. Nearly 20 years ago, Baldwin and Carlisle's (1994) review of the literature highlighted a gap in knowledge about disabled children's own views and experiences, noting a reliance on parents' or professionals' 'proxy' views. Considerable progress has been made

since then: there is now an increasing body of research involving disabled children themselves. Nevertheless, some important aspects of the field remain relatively unexplored.

First, theoretical frameworks for social research about/with disabled children are not well developed. A good deal of research has tended to be atheoretical, with a strong applied focus. Some studies make passing (often uncritical) reference to the social model of disability. A number of researchers have brought together insights from Childhood Studies and Disability Studies, eg: Watson and others (2000), Connors and Stalker (2007), Wickenden (2010). Notions of decision-making and choice (Beresford and Sloper, 2008) or Bourdieu's concepts of habitus and cultural capital (Hale 2010) have been used but are not common.

Secondly, the majority of research has taken the form of small-scale qualitative studies, often involving interviews and sometimes focus groups with disabled children. Using a wide range of visual and technological aids and supporting activities to engage children's interest and facilitate communication, such studies have yielded rich and valuable data. Arguably, however, the focus on developing techniques has outstripped attempts to develop research designs more broadly. There have been few large-scale surveys of disabled children's views, (although see Dickinson and others, 2007), ethnographies (although see Cocks, 2008) or longitudinal work (although see Ytterhus, 2004 and in this issue).

In terms of substantive topics, research exploring disabled children's views has tended to focus on their experiences of formal support, thus identifying them primarily as service users in need of care and assistance. Increasingly however, young people's views have been sought about other aspects of their lives including

friendships and social life, participation, interests, aspirations, transition to adulthood and sense of identity. Less attention has been paid to children's views about good experiences in decision-making, child protection issues, risk management, gender issues including sexuality, or appropriate research priorities. It is also important to know more about the impact of the Equality Act 2010 on disabled children and young people and the effectiveness of different strategies for tackling disablist bullying.

Certain impairment groups, including children with multiple and complex needs or communication impairments and those facing additional disadvantage, such as disabled children from Black and minority ethnic communities or from poor backgrounds, remain relatively neglected (see also Cavet and Sloper, 2004). In addition, although disabled children are disproportionably represented in the 'looked after system' (Baker, 2007), relatively little research has been conducted with this group, especially from their perspectives.

The ESRC research seminar series, held between January 2010 and May 2011, involved five day-long seminars held across the UK, focusing respectively on theoretical, methodological, policy and substantive issues, the fifth being a synthesis and 'look forward.' Invited presentations were given by leading international scholars, early career researchers, PhD students, voluntary organisations, a government policy maker, a senior service manager and two young disabled people's groups. Unfortunately, limited space meant that it was not possible to include all the seminar papers in this Special Issue. Other presentations can be seen on the seminar website -

<http://www.strath.ac.uk/humanities/schoolofappliedsocialsciences/socialwork/esrcseminarseries/>.

Introduction to the papers

The two opening papers each present a particular theoretical perspective for researching disabled children's lives with a focus on their views and experiences. These are far from mutually exclusive. First, Kay Tisdall reviews some of the core tenets of Childhood Studies and examines how these might link with ideas from Disability Studies. Both areas, she argues, point to a need to reconsider concepts of normality, competency and interdependence. Tisdall warns of a risk of stagnation within each field, with people wary of questioning certain 'mantras' for fear of censure. Tisdall goes on to unpack and challenge two mantras within Childhood Studies - the 'reification' of children's voice and the view that 'ideal' research necessarily involves employing or involving child researchers. She explores the implications for research with disabled children. The benefits of continuing reflection, creative critique and mutual learning across Childhood and Disability Studies are highlighted.

The impact of Disability Studies on research with disabled children is reviewed by Nick Watson. The social model of disability is critiqued in terms of its primary focus on social and material barriers, homogenising of disabled children and neglect of both the implications of impairment and the role of personal experience. Watson examines two alternative approaches – Carol Thomas's relational understanding of disability and post-modernist approaches embraced by Critical Disability Studies. While acknowledging their respective strengths, both are considered inadequate to the task of fully understanding and/or transforming disabled children's lives. Watson

points to critical realism as a fruitful way forward because it allows recognition that disabled childhoods arise from complex interactions between a child, his/her impairment and the material and social environment.

The following two papers discuss studies using designs seldom employed in research about disabled children. Borgunn Ytterhus presents the longitudinal ethnography she conducted over 12 years, exploring interactions between disabled and non-disabled children in Norwegian nurseries and schools. She describes her own semi-participant role, the use of respondent validation, involvement of child advisors and the ways in which methods were adapted and developed over the years to maintain age appropriateness. Ytterhus identifies a series of informal interaction rules created and negotiated *by children for children* in peer groups. Using two case studies, she demonstrates how these rules appear to militate against the inclusion of young people with intellectual disabilities but can be mastered by those with mobility impairments.

As already noted, social research about disabled childhoods is dominated by small scale qualitative studies. Eric Emerson's paper demonstrates what can be learnt from population-based studies. Using examples from large scale data sets in the UK and Australia, his findings challenge some commonly held assumptions about disabled children and their families. For example, Emerson questions the widespread view that the association between children with learning disabilities and family poverty is caused by the 'burden' of care per se. He also shows that there is little difference in parental well-being and mental health in families with and without a disabled child when exposure to common environmental adversities is taken into account. Emerson highlights the strengths and limitations of large scale surveys, but

argues that they offer a valuable opportunity for researchers to understand more about the circumstances and impacts of disabled childhoods.

The following paper focuses on policy, particularly in relation to disabled children and young people's rights. Janet Read and colleagues consider recent legislative and policy developments affecting disabled children internationally and across the four jurisdictions of the UK. These increasingly promote participation in the mainstream. There is a risk that including disabled children in universal provision can disadvantage them unless additional supports are available when required. At the same time, there is a risk that 'special' arrangements become seen as an alternative rather than an addition to generic support. Families' social circumstances can do much to reduce or exacerbate disability. The authors suggest that lifting families with disabled children out of poverty is 'arguably the most important and difficult issue for social policy', not least in the current financial and political climate.

The next three papers can be described as 'reflection' pieces. For the past five years, Bryony Beresford has been meeting a group of disabled pupils attending a secondary special school to seek their advice about various research studies. She and colleague Wendy Mitchell worked with the group to produce an audiovisual presentation about subjective well-being which was shown and discussed at one of the ESRC seminars. In her paper, Beresford reflects on the experience of collaborating with the young people on this project and the lessons learnt. Some members expressed satisfaction with their lives but this was at odds with the researchers' perceptions of poor living conditions and restricted opportunities. Some pupils denigrated themselves in the presentation, apparently reflecting low self

esteem. The author discusses the ensuing dilemmas about how to present such views in a public performance which the young people could feel proud of, and in ways which would highlight the need for policy change.

Next, David Abbott offers a thoughtful account of 'the co-production of talk and meaning' during and after interviews with 40 families who had a son, aged 15 or older, with the life-limiting condition Duchenne Muscular Dystrophy. Some families chose to have joint (parents and son) interviews; other opted to talk to Abbott separately, partly reflecting parents' differing approaches to talking about DMD and sharing the prognosis with their sons. Although the bonds between parents and sons were very strong, Abbott sometimes detected unspoken, even conflictual, concerns beneath the apparently consensual responses to his questions. He calls for researchers examining disabled childhoods to pay more attention to the context in which interviews are conducted, their own role within it and to wider ethical and methodological developments in qualitative research from which they could usefully learn.

John Carpenter and Roy McConkey, looking back over contributions to the ESRC seminar series, present a schema that conceptualises the role and nature of future empirical enquiry in relation to disabled children's voices. They summarise the interrelationships among theoretical frameworks, research methods and research themes. These endeavours need to be contextualised within other research into children's lives and located within policy, practice, family and societal priorities. The authors argue that, as researchers, policy-makers or practitioners, we all face moral, practical and conceptual imperatives for listening to disabled children's voices.

The Special Issue concludes with a 'practice piece', an example of a young disabled people's group which has influenced policy and practice at local, regional (Northern Ireland) and international level. This is the 6th Sense advocacy project, part of a Barnardos Disabled Children and Young People's Participation Project. It supports members to contribute to planning and decision-making about children's services within a Health and Social Services Board in Northern Ireland. The young people gave a presentation at one of the ESRC seminars and the paper is written by Rosemary Murray, Project Manager, who sets out the group's origins, aims and achievements. Their experience suggests that success factors for disabled young people's participation include having a strategic and structured framework, a person-centred approach offering different levels and types of involvement, and trusting relationships with peers, facilitators and professionals. However, participation is not all plain sailing: young people may not always achieve their desired outcomes when negotiating with policy makers and providers.

The global context

The papers in this Special Issue relate to the Minority World. This reflects the largely UK and Western European focus of the ESRC seminars series but, in addition, most research about disabled children and their families has been conducted in countries with advanced welfare and educational systems. It is important to place this within the wider global context. Estimates of the number of disabled children world-wide vary between 93 - 150 million (WHO, 2011), with 36% of all recorded disease and injury involving children aged less than 15 (WHO, 2008). Childhood disability is more common in low and middle income countries (WHO, 2008) and in the Majority World

much impairment is the result of poor living conditions, socio-economic exploitation, war or natural disasters (Barnes and Mercer, 2005). The World Health Survey of 51 countries in 2002-04 found that disabled children were less likely than their non-disabled peers to start school and had lower rates of staying and progressing at school, especially in poorer countries (WHO, 2008). Basic service infrastructure in many countries is rudimentary and may be particularly hard to access for families with disabled children, while welfare benefits may be non-existent. In addition, cultural understandings of health, well-being and ability differ internationally (Barnes and Mercer, 2005), families with disabled children being shunned in some countries (eg: Al-Krenawi et al, 2011 re. Bedouin-Arabs, Buckingham, 2011 re. India). On the other hand, children with intellectual disabilities are less likely to be marginalised in societies where literacy and numeracy skills are not considered essential for everyday life (Rao, 2006 re. Bengal).

Disability is not high on the research agenda for most Majority World countries, where studies of poverty and gender equality take precedence (Singal, 2010; Mji and others, 2011). There are exceptions, however, with some qualitative studies seeking the views of disabled children and young people in the Majority World: see, for example, Singal (2010), Reiser (2008), Carrington and others (2007).

Across Central and Eastern European (CEE) countries and the Commonwealth of Independent States (CIS), (former members of the USSR), recorded rates of disability have more than doubled following the collapse of communism, due to improved reporting. However, the Soviet ethos of 'defectology' – whereby disabled children were viewed as inherently defective (Grigorenko, 1998) - still holds some sway, with at least 317,000 disabled children living in institutions, often with no family contact, less than a decade ago (Dowling and others, 2005). Many disabled children

in Eastern Europe still have no schooling (WHO, 2011). However, Romania's achievement in reducing the numbers of children in state institutions from 100,000 in 1999 to fewer than 11,000 in 2011 (Foulsham, 2011) shows that the situation can be radically improved. (Not all those children were disabled).

Given these circumstances, it is not surprising that research about the experiences of families caring for a disabled child in the CEE/CIS region is at a nascent stage (although see Kaplan and others 2007, Bridge, 2004; Dowling and others, 2005). Few studies have asked disabled children about their views and experiences. However, Dowling and others (2005) conducted focus groups and one to one interviews with children with physical impairments in Russia, Latvia and Bulgaria, with the aim of understanding what it means to be a young disabled person in these countries. A 17 year old girl living with her family in Bulgaria commented: *I want you to write down that I don't consider myself ill. On the contrary, it is good to be alive when you are young.* In contrast, a 12 year old girl in Latvia said *I need more [love and affection]. I am in a boarding school. I see my parents rarely.* Poverty, segregation and discrimination were prominent features in many of these young people's lives. A Quali-TYDES project funded by the European Social Fund (2010-2013) is currently examining the impact of new policy developments on the lives of disabled young people, using life story methods (see <http://quali-tydes.univie.ac.at/>).

The World Report on Disability (WHO, 2011) found some encouraging signs of progress in Eastern Europe, with education systems moving from a medical to an interactional approach, and environmental barriers rather than individual deficit becoming identified as the cause of disability. This reflects the ethos of the United Nations Convention on the Rights of Persons with Disabilities (UN, 2006) which

requires participating countries to ensure that disabled children enjoy the same human rights and freedoms as others. Further, Article 7.3 asserts:

States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

Although there is still a long way to go before these goals are achieved for all disabled children and young people, the CRPD provides an agreed international framework for working towards full social inclusion and equality. This has far reaching implications for the rights and opportunities available to disabled children, the welfare services which must be provided to support them and, ultimately, for the kind of society we live in.

Kirsten Stalker

On behalf of the Guest Editorial team - David Abbott, Bryony Beresford, John Carpenter, Roy McConkey, Kirsten Stalker and Nick Watson

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