# Research with Disabled Children: Tracing the Past, Present, and Future

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This chapter does not provide a toolkit or a ‘how to guide’ for conducting research with disabled children. Rather here the trajectory of disability research in relation to children and childhood is examined within the complex and dynamic social structures in which such research is situated. We trace the general direction of travel that has taken this research out of the institution and the domain of the medical profession into the field of social science, interpretivism and rights. Wider methodological trends, the emerging interest of the social sciences in children’s lives and social agency along with the progression of disability rights and activism has transformed the landscape of contemporary research. We therefore take readers from the imposed passivity of disabled children to their agentic participation in research and highlight the ways that these ideas have been, and can continue to be, applied and interrogated. An exploration of the ways in which disability research is facilitated, conducted and published cannot be extricated from the social context in which ‘disability’ and ‘childhood’ sit. Therefore this chapter does not shy away from the ongoing debates which research in this field generate. We consider here not only changing methodologies and the positioning of participants in research but touch upon ongoing, unresolved social and political debates about who can research, what can they seek to know and what purpose such knowledge should serve. To that effect disability studies is similar to other academic disciplines that interrogate the ways in which social research is conducted. As such, readers (as well as the authors) of this chapter enter an ongoing debate about the characteristics of research with disabled children and at its end should not seek simple and complete answers to what constitutes ‘good’ research. Rather readers should aim to recognise some of the dynamic complexities and opposing positions that influence social research in this field.

## The Past

Throughout the majority of the 19th and 20th centuries the lives of disabled people were sequestered within institutions; the workhouse, the asylum and the special school, being the most predominant (Richards 2017 – this volume). Professional specialisms such as medicine, psychiatry and education emerged within these institutions (Borsay 2005) as part of the disciplinary and professional control and ownership of knowledge about disability and the disabled (Foucault 1975). As such, knowledge and expertise in this field focussed almost entirely on developmental and medical perspectives to diagnose, classify, prevent and manage the bodies and minds of the disabled (Clark 2017 – this volume). Research was thus governed by a model from the natural sciences which emphasise positivistic traits such as objectivity, measurement and the expertise of the researcher over those of the researched. Such knowledge generation thus reinforced the structural marginalisation and dominant social values associated with disabled people at the time – marginalised, vulnerable, passive, irrational and incompetent. This deficit model came to dominate almost all areas of law making, policy, education and approaches to health. A hegemonic discourse, which also shaped how research was undertaken and can be emphasized by bell hooks' critical discussion of social inequalities where there is 'no need to hear your voice when I can talk about you better than you can speak about yourself' (1990:151).

The initial development of the standardised test, the 'Binet-Simon scale' (1905) provides a pertinent example of the values and approaches embedded in research at this time. This intelligence test was developed to measure and identify those children in need of special education. In consequence generating three categories where mental age and chronological age intersect to provide classifications to divide children between 'advanced', 'average' and 'retarded' (Strong 1915). Such mechanisms of measurement were appropriated by the emerging Eugenics movement to reify ideological beliefs about both disability and race (Rioux and Bach 1994). To existing hegemonies was added 'a new faith in the explanatory powers of measurement' (Rioux and Bach 1994). Much of the academy actually participated in, rather than challenged the production of such dogma about the unsuitability of particular disabilities and ethnic groups to participate in the social world (ibid). This research, like much of the time, participated in the social construction of the 'other' (Said 2003) rather than challenged its 'Imperialist' production (Fanon 1993). The prevalent social anxiety was about how to ensure the reproduction of a supposedly 'ideal' human species; the able-bodied, intelligent, racially pure uncontaminated by intellectual and physical 'deficiencies' (Rioux and Bach 1994). Academic and clinical research provided empirical, objective, measurable evidence to legitimise these socially relative, highly prejudicial 'truths' of the time. Summed up by Goodley and Runswick-Cole (2012: 215) when they claim 'research is an imperialist, disablist and heteronormative peculiarity of modernist knowledge production'.

The demise of the institution in the late 20th century and the rise of alternative epistemologies that challenged the dominance of positivism and the natural sciences gave rise to alternative ways of doing research, which prioritised the social. The increasing popularity of the interpretivist paradigm is referred to by Denzin and Lincoln (2000) as the 'qualitative revolution'. In contrast to positivistic methodologies these approaches to research emphasise the role of the individual experience (Sarantakos 2013) including paradigms such as social constructionism, phenomenology and symbolic interactionism. These perspectives promoted methodologies which constructed an alternative research subject. This participant was more than an object to be studied under a microscope and rather an individual to be engaged with as knowledgeable of their life experiences and social worlds (Oliver 1992). Thus the methods of research shifted from nomothetic experiments to idiographic interviews.

Despite the shift described above, methods which began to ask individuals about their lives, carried with them the values and assumptions which were embedded in earlier approaches (Hunt 1981). Participants therefore continued to see research as oppressive, a violation of their experiences, irrelevant to their needs and failing to improve their circumstances (Oliver 1992). For example, an early attempt to capture the knowledge and experience of individuals with disabilities in the UK was the Office of Population and Census Survey's 1988 National Disability Survey (Martin, Meltzer and Elliot 1988). This large scale quantitative survey sought to understand the life experiences of individuals with disabilities but maintained the pathologised assumption of disability as a problem with the individual to be fixed. The first question on this survey thus reads 'Can you tell me what is wrong with you?' (Abberley 1992; Oliver 1992). Readers are here encouraged to consider the extent to which this is a leading question and the values which underpin the structuring of such supposedly objective questions.

## The Present

Emancipatory research emerged among oppressed groups in the 1970s with an aim to challenge the social relations of research production (Barnes 1996; Oliver 1992). This approach can be associated with fields such as feminism (Haraway 1991), critical race research (Hall 1997) and critical ethnography (Madison 2012) and as such privileges particular value positions about the role of the researcher and the purpose of research. For example an influential series of seminars by Joseph Rowntree Foundation beginning in 1991 provided a forum for developing new approaches to disability research (Barnes 2008). Such examples paved the way for more recent studies emblematic of emancipatory research concerning independence (Barnes and Mercer 2006), social care (Beresford and Hasler 2009) and sex and relationships (CHANGE 2010). It is not coincidental that such approaches gained traction within a wider social and political context in which wider disability activism and rights discourses (Goodley 2017; Ayling 2017 – this volume) evolved (see for example Disability Discrimination Act 1995; the

Equality Act 2010 and the 2006 United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)). Making this ‘qualitative turn’ (Hammersley 2016) of raising the voices of the marginalised (methodologically) inextricable from wider emancipatory agendas of the late 20th century (women, children, disabled, race and ethnicity, class, majority world perspectives). Within this approach research must be seen to elevate the voices of disabled people, the social positioning of the disability community and enhance the structural and material conditions of the lives of people with disabilities, specifically those actively involved in the research process (Barnes 2014). This revised position for research and the researcher is inevitably contested and controversial as it moves research from where it has been traditionally situated. Here, it steps beyond neutrality and objectivity and into the realms of social and political justice (Becker 1967). Thus contemporary disability research is extensively politicised, making it as much a political endeavour as a knowledge endeavour.

This approach is thus characterised by participatory methods which position the participant as a powerful knowledge holder and the researcher as a seeker of knowledge. This can be easily contrasted with previous power relations in the research process (Hunt 1981). As such, methods were used and designed to encourage agentic contributions from participants rather than their positioning as objects of passive experimentations. These methods include semi-structured and conversational interviews (Lewis and Porter 2004; Green 2016), focus groups (Smith Rainey 2016), storytelling (Atkinson 2004), visual methods (Booth and Booth 2003; Lorenz and Paiewonsky 2016), ethnography (Boggis 2011; Boggis forthcoming; Davis, Watson and Cunningham-Burley 2000; Hammer 2016). The emphasis is on the creative use of methods to reflect the changed value positions and ensure that the perspectives and experiences of disabled people are central. Diverse strategies and tools can be applied in innovative ways to support the participatory methods now more commonly used (Germain 2004; Clark and Moss 2001; McSherry,D. Larkin, E. Fargas, M. Kelly, G. Robinson, C. MacDonald, G. Schubotz, D. and Kilpatrick, R. 2008; Berger and Lorenz 2016; Goodley and Runswick-Cole 2011)

The wider social context in which this shift in research takes place should not be ignored and therefore research with children must be recognised as taking an equally transformative journey. Perhaps later than other emancipatory approaches the recognition of the subordinate positioning of children in the social world as problematic emerged in the late 1980s and 1990s (Cunningham 2005). Children’s position, like that of disabled people, was one premised on subordination, vulnerability and marginalisation (Hendrick 2005). Research with children was thus dominated by developmental models of maturation models of how to ensure ‘good’ future adult citizens (Raby 2014; Clark and Richards 2017). The rise of children’s rights discourses and legislation (Mayall 2000; Wyness 2001) and the development of the new sociology of childhood (James and Prout 1997) required the active participation of children. As with disability research, this prompted a shift in how research in childhood was conducted, from research *on* children to research *with* children (Moran-Ellis 2010). This development meant that methodologies and methods that attempted to hear the voices of the marginalised became increasingly popular with childhood scholars (see Montgomery 2007, Phoenix 2008, Twum-Danso Imoh 2009).

Despite all of the developments described previously many have argued that attempts to undertake participatory research with children with disabilities has yet to be fully transformative and therefore disabled children's experiences remain marginalised (Franklin and Sloper 2009). We can celebrate the notable examples that are available (see for example Curran and Runswick-Cole 2014; Hammer 2016; Goodley and Runswick-Cole 2011). However it is argued that much research still relies upon the perspectives of more powerful individuals, such as parents and professionals (Stalker and Connors 2003) and remains focused upon service provision and evaluation (Abbott 2013). In this context, the stories of those with disabilities can often be told by service providers rather than disabled people themselves (French and Swain 2001). Thus research rarely extends beyond the experience of disability as its focus to all the other aspects of children's lives. Like the emerging criticism in Childhood Studies (see Uprichard 2010; Richards, Clark and Boggis 2015), whereby children are only asked when the research specifically relates to aspects of childhood, i.e. education or wellbeing, disabled children's participation, where it is elicited, often remains restricted to a narrow set of particular topics related to disability.

Such a restriction is not confined to disability studies, we find similar boundaries in research with children more generally, whereby certain topics such as play, healthy food and aspects of education and learning are profligate (Richards et al 2015). Topics beyond these constraints are more scarce in their production and problematic at each stage of the research, such as sexuality (Clark 2013), death (Coombs 2014) or alternative family formations (Richards 2013). Such sensitive topics (Sieber and Stanley 1988) are not static but are in fact relative and culturally produced (Hydén 2008) thus it is the discursive construction of disability and of childhood "manifest in structural regulations…which render particular topics problematic' (Richards et al 2015: 27). That is to say, that exploring the topic of intimate relationships with able-bodied adults might be considered significantly less problematic than discussing this with disabled adults, and even more so with disabled young people (Smith Rainey 2016). The impediments in front of researchers wishing to explore these topics can play a role in compounding the existing marginalisation of their potential participants. The result being that the normative life experiences of particular groups deemed vulnerable are excluded from this kind of research focus. Thus as we have asked elsewhere 'for whom is this a sensitive topic and what role do such assumptions play?' (Richards et al 2015:27).

Despite the above criticisms there has clearly been a rise in participatory research methods with disabled children which have produced knowledge hitherto ignored or neglected, which shed light on the capacities and capabilities of children with disabilities. Such alternative approaches are supported by recent rights developments including notably the UNCRC articles 12 and 13 and the UNCRPD articles 7 and 21 which articulate the right of the child to have their voices heard in areas of life pertaining to them and that we, as adults, have a responsibility to facilitate their active engagement. Such perspectives contradict previously dominant medical and deficit models which constructed the disabled child as passive, incapable, irrational, incompetent and unknowing. For example Davis, Watson and Cunningham-Burley (2008) use ethnography to examine the active participation of disabled children in cultural production and their creative negotiation of social structures and intergenerational relations. In addition, Brunnberg (2005) using interviews, highlights the capacity of children with disabilities to select and construct friendship narratives and Boggis (2011) illuminates the voices of disabled children that use Augmentative and Alternative Communication Systems (AACS).

In order to conduct such participatory research with children with disabilities certain key hurdles must be successfully navigated. The following areas being particularly pertinent: ethics committee requirements, access and gatekeepers, informed consent and researcher positionality.

## Ethical Governance

Formal protocols and frameworks exist to regulate and guide the ethical conduct of human research and have seeped from governing medical research into other disciplines such as the social sciences, where contemporary disability studies predominantly sits. This has led to the establishment of formal procedures for the ethical governance of research, including Research Ethics Committees (RECs) (sometimes known as Institutional Review Boards (IRBs)) in a range of institutions including universities, research councils and the UK's National Health Service (NHS). The aim of RECs is broadly to guide and support sound ethical research practices and to safeguard both participants and researchers. RECs will make use of institutional guidelines including the Economic and Social Research Council (ESRC) Framework for Research Ethics 2012, British Educational Research Association (BERA) Ethical Guidelines 2011 or British Sociological Association (BSA) Statement of Ethical Practice (2002). Such frameworks outline key principles which govern the research process and aim to protect both participants and researchers from harm. Ethics committees can be particularly vigilant concerning research with children (Kelly 2007). Researchers must submit a comprehensive research proposal which is appraised by REC members for its methodological and ethical suitability. It is only after approval has been granted through REC procedures that the research can begin. Within the approval process researchers must often negotiate the contradictory motifs of both the agentic and the vulnerable child (Richards et al 2015). Within research proposal documentation in childhood, methods must commonly be shown to be inclusive and promote the expertise of participants. In contrast, researchers must also demonstrate awareness of the socially constructed vulnerability and dependency of 'the child', perhaps even more so when seeking to research with children with disabilities (Siebers 2008). The articulation of both these contradictory images of 'the child' is required in order to be considered ethically informed enough to be given permission by often cautious institutions (Monaghan, O'Dwyer, and Gabe 2012). Notwithstanding the general critique of ethical processes in contemporary social sciences (Hammersley 2009), one of the consequences of this paradox is that those wishing to engage in emancipatory research with children must construct an entirely different child in order to gain ethical approval to conduct their research. This is particularly problematic in the field of disability studies where researchers are often required to engage with the activist community (Goodley 2017) and demonstrate ways in which they empower their participants and indeed can sometimes be critiqued or even condemned if they do not do so (Stone and Priestley 1996).

## Gatekeepers

Having negotiated the gatekeepers in the ethics committee (McDonald, Keys and Henry 2008) the researcher must negotiate access to their participants through a variety of gatekeepers in the field. This requires careful management of power relations, trust and rapport and can be complex to manage in the realities of different research fields, particularly with children with disabilities. Gatekeepers can function as both an asset and an impediment to conducting research. The gatekeeper relationship is complex in research with children (Punch 2002) because embedded within it are the inherent power relations of the adult-child dichotomy. This is perhaps complicated further when seeking to do research with children with disabilities (Stalker and Connors 2003). It is incumbent upon the researcher to establish how the gatekeeper is constructing their own role in the research process. Do they view themselves as the holder of consent, required to give a yes or no answer to the researcher about institutional or family access or do they consider themselves a facilitator supporting participants in the provision of their own informed consent? The implication of this difference is that in the first scenario the researcher is faced with adults making decisions about the involvement of children before children have the opportunity to determine this for themselves. This may pose significant contradictions for those seeking to undertake emancipatory and/or child-centred research.

Despite this, gatekeepers hold a vital safeguarding role (see also Boggis 2017 – this volume) and cannot be avoided within research with children with disabilities. Nind (2008) argues that researchers may have to convince gatekeepers of the likely benefits for participants (see also Tuffrey-Wijne et al 2008) as caregivers can position themselves as advocates and perhaps protectors for the children in their care. They can however, enable effective access to the field. For example, Munford et al 2007, found the relationship between the parents with intellectual disabilities in their research and their care workers to be trusting and supportive one, which proved beneficial in gaining access to participants and supporting informed consent. One parent, for example who spoke English as a second language was very enthusiastic about their participation but the researchers were concerned about the extent to which the focus of the research was clear. As such, a trusted care worker was able to clarify the purpose ensuring that the researcher felt confident about the resulting informed consent. This highlights the importance of the gatekeepers having sufficient information about the research (Nind 2008) to support participants in making their own decisions about taking part and the importance of ongoing consent (Richards et al 2015) that researchers must acknowledge throughout their time in the field. In addition, Davis, Watson and Cunningham-Burley (2008) identify how reliant they were on gatekeepers in the initial stage of their ethnographic research in a school. While establishing confidence and rapport with participants they were obliged to rely upon adult staff in the setting to interpret behaviour and communications of participants. This provided vital time and space for the researchers to establish trust and rapport with the participants themselves, an important and sometimes complex element to navigate in fieldwork (Montgomery 2007).

It is important for us as researchers to acknowledge and reflect upon the power relations embedded in gatekeeper contributions (Clark and Richards 2017) as well as the ethical implications of using such existing relationships for their own purpose. It can be tempting to fall into hearing and prioritising the voices of those more articulate (the teacher, the carer) rather than stories that are more difficult to untangle and more time consuming to share. Whilst it is appropriate to recognise the co-production of such stories, care needs to be taken to ensure that these are not given precedence over those of disabled children. As highlighted above, gaining informed consent to hear any of these stories in the first place is complex nevertheless it is an essential element of all research endeavours, it is this issue that we consider next.

## Assent and Informed Consent

Informed consent broadly includes three principles. First, the provision of sufficient knowledge to prospective participants, second the initial and ongoing voluntary giving of consent and third that such decisions are made by competent individuals choosing freely (Brooks et al 2014). It is important to recognise that historically individuals with disabilities, notably those with intellectual disabilities have been considered unable to make such decisions for themselves. The right of the individual to be self-determined emerged in part as a result of the human rights violations documented within World War II and in early research studies such as the Tuskegee syphilis study from the 1930s to the 1970s and Stanley Milgram's obedience research in the 1960s. Responses to these include the Nuremberg Code (1947) and the Convention for the Protection of Human Rights and Fundamental Freedoms (1953) (latterly the European Convention on Human Rights (ECHR)). The underlying principles of such historical conventions is that individuals have rights and that their involvement in research should only come about as a result of their agreement and permission. These developments occurred in a socio-political context where social rights, such as the responsibility of the state towards the individual, were prevalent but where the rights of the individual were gradually taking precedence, emblematic of neoliberal principles such as autonomy, which govern contemporary minority world societies. Despite this groundswell of emphasis on rights and self-determination the disability communities remained excluded and marginalised. The principle of informed consent as required to be freely given by the competent individual was initially emphasised to provide protection for certain less powerful groups from abuse in the research process. In practice however, it has also meant that those deemed less able to provide such consent have been overlooked or consent has been sought elsewhere by the associated 'capable' adult such as carers, parents, teachers and social workers.  Ableist discourses located the disabled individual as one incapable of living up to the autonomous, controlled, capable, responsible, independent, self-actualising ideal of the neo liberal citizen (Siebers 2008; Hammersley 2009). As such, initial research on individuals with disabilities, particularly children and young people, was much slower to adopt fundamental principles of research, such as informed consent and still often relied on 'assent', premised on an assumption of incapability, irrationality, vulnerability and dependence (Archard 2004).

Assent has been defined as permission or affirmation of agreement given by the child to participate in research (Broome and Richards 1998). It is not a legally mandated process (Twycross 2009) but is regarded by some researchers as an alternative to full informed consent whereby children assent to parent's, caregiver's or professional's consent (Powell and Smith 2010). Informed consent is defined somewhat differently with emphasis on the capabilities of the individual to understand the information being presented, to have the capacity to make the choice and to do so free from coercion (Curran and Hollins 1994). These traits of capability and capacity are often assumed in the case of 'able' adults but contemporary discourses on both childhood and disability mean that they are not often attributes assigned to children with disabilities. Watershed moments in this regard came with both the Gillick-competency test and the Mental Capacity Act 2005. Both these events offered opportunities for recognising the possibilities for children (with and without disabilities) to consent and dissent from medical treatment, decisions about living arrangements and indeed research participation. Nonetheless it remains important for researchers to be aware of the role of others such as family, carers and professionals, many of whom act as gatekeepers to open up or close down opportunities for the active participation of disabled children in research. As discussed previously, gatekeepers can be both problematic in their inclusion in research projects as well as valuable assets to support desired participation. A common problem identified in research in this domain is the potential reliance on the approbation of these influential others. Furthermore the desire to please powerful adults can complicate research relations whereby participants may feel the compulsion to provide what they think is the right answer for the adult asking (Mitchell 2010). This isn't restricted to research with children but rather a prevalent theme to consider across research relations more generally. Careful design of information and consent materials that are accessible to the specific groups and individuals being sought is an ethical imperative. Recent research has demonstrated the value of creative uses of written, visual or auditory tools to assist with the provision of information as well as for the recording of consent (see for example Boggis 2011; Booth and Booth 2003; Germain 2004; Lorenz and Paiewonsky 2016). Such an approach is congruent with an increasing desire in wider social research to recognise that informed consent is both contextual and ongoing throughout the research process (Richards et al 2015). Such an approach to informed consent also corresponds with the move towards greater emphasis on participant as expert, not just in their own lives and experiences but in the research process itself (Atkinson 2004).

## Power Relations and the Child as Expert

A general shift towards qualitative and participatory methods occurred in the latter half of the 20th century. The decline of grand political narratives in the 1980s also generated the political space through which emerged new social movements including the second wave of feminism, environmentalism, anti-war and civil rights movements. Many individuals were increasingly detached from these all-encompassing political narratives choosing to pursue more personal narratives that were more meaningful in their life experiences (Alcock 2014). Such endeavours were linked to activism, social justice and the empowerment of previously marginalised individuals, groups and causes. It is in this context that disability rights emerged as political and where the rise of the social model, particularly in the UK, took hold. The impact of these shifts upon social research within the disability community was profound. The disability rights movement challenged some of the fundamental assumptions upon which dominant research perspectives were situated (Barnes 1996; Oliver 1992). Such methods became open to extensive critique through the absence of the research participants playing agentic, empowered roles beyond simply notions of informed consent. It is here we find demands on the part of disability rights groups for greater control in what topics are researched, how the disability community is constructed and also how such research is funded, designed and managed (Barnes 1996). As Apsis (2000) claims, "nothing about us without us". Therefore an important principle of any research endeavour is that it must have benefit not only for those taking part but for the disability community and movement more generally (Oliver 1992).

These stances fundamentally shifted the relationship between the researcher and the researched. Calling into question the motives of the researcher and their legitimacy in engaging in such research. In a similar vein to previous feminist debates and those in critical race and ethnicity studies, the researcher's own dis/ability status has become key to the debate. It is not unusual in many articles to read of the 'expertise' of the researchers not in their methodological fields but rather their subject positions as disabled or having experiential knowledge (e.g. through mothering or profession) of disability (Tuffrey-Wijne et al 2008). Such an approach is considered to ensure the generation of authentic knowledge about and for the disability community. This stance has generated a significant volume of participatory and emancipatory research with individuals with disabilities but it does also pose potential problems for the field. Here participants are constructed as powerful yet there still remains the underlying assumption that the researcher is the most powerful of all. This reification of the researcher as powerful enough to make these decisions for their subjects fails to recognise the need for researchers to navigate the demands and expectations of others i.e. research funders, academic institutions and publishers. Here the researcher is not the most powerful. In addition, in advocating this stance there is a risk of continued reification of the separation of those with a disability from the rest of society through this sustained emphasis on difference. Academia and academics are thus inextricable from the politicisation and activism of disability rights and in this context, of children's rights. They are thus vulnerable to accusations of appropriation and inauthenticity. We, as authors here, are not currently disabled under standardised categorisations and nor do we hold professional or personal caring or support roles for individuals with disabilities in our families or otherwise. Thus we recognise our potentially vulnerable position within these debates and despite our expertise in the field of research, notably research with children, we cannot authenticate ourselves in this way and thus we tread carefully in this politicised domain.

This positioning of participant as expert also dominates in childhood studies and is extended to a place whereby children are positioned as researchers themselves, actively involved in research design, management and fieldwork (Cheney 2011). This perspective is open to interrogation (Clark and Richards 2017; Hammersley 2017) whereby participatory methods have conflated participant as knower with participant as researcher. Despite its increasing popularity such positions have not been as dominant in research with children with disabilities where positioning them as expert researcher has been much slower to emerge. This is arguably a result of the lingering legacy of the medical model which contributes to the discursive construction of the disabled child as vulnerable, difficult to communicate with, dependent and unknowing. Perhaps this is also related to the domains of research which disabled children are frequently situated within (or outside of); cast as the pupil, the service user, the subject of an intervention. None of these positions easily comply with the child as agentic, powerful, rights holder and/or expert researcher.

## Final Thoughts: The Future?

How we involve children with disabilities in research is simultaneously celebrated, contested and controversial. The issues and opportunities highlighted in this chapter could serve to deter students or researchers away from such controversy into safer waters. It is not unusual for academics and students alike to be encouraged by supervisors and senior colleagues to be cautious in this field, to choose easier to reach populations, pursue theoretical alternatives and thus avoid the pitfalls that inevitably come with such politicised and polarised arenas. This is not our intention. Rather we wish to encourage the further development of emancipatory and participatory research in the fields of disability studies and childhood studies and this can only be achieved by the 'doing' of it.

Despite these issues, the road that's being travelled is heading in the right direction. There are pitfalls along the way but the field is moving away from the notion of 'done unto' whereby academics and clinicians seek to appropriate and retell in their own voices the stories, knowledge and experiences of children with disabilities. This move towards participatory approaches is a result of wider change in social research, the development of disability studies as a distinct academic discipline and from the powerful calls of disability activist groups for more emancipatory approaches. However, there remains a potentially problematic ideological divide (Oliver and Barnes 2012) which calls into question who is this research for and what does it aim to do for those involved? It is difficult to manage the embedded tensions of any given research project where different interest groups each call for alternative positions to dominate. The researcher is compelled to comply with funding regulations; the activist is motivated to ensure the prominence of rights discourses and the elevation of the participant; and the research itself is often required to be empowering, not just for the individual subject, but for the disability community as a whole. Navigating these competing expectations is no easy task and can impact on the quality of the research that is produced. We thus argue that attempting to reconcile these sometimes polarised positions would be emancipatory for disability research itself.

A potential way of doing this is to recognise the fluidity and negotiated status of power relations within research relationships (Richards et al 2015). Simplistic assumptions that the researcher was all powerful are now being replaced by an equally simplistic assumption that the child can be positioned as all powerful. We argue elsewhere that this leads to tokenistic understandings of participation and power relations in research (Clark and Richards 2017). Instead of a straightforward dichotomy of powerful and powerless what we need to recognise is that power is far more complex. It is negotiated interdependently within research relationships and cannot be assumed nor simply handed from one party to another. An alternative way forward in research with disabled children is to recognise the researcher and researched as both powerful and powerless. The research encounter should thus be constructed as a meeting place where the knowledge and expertise of both not only come together but are actually required for good research.

We celebrate the general trajectory as one where the voices of disabled children are given greater prominence and such populations are now constructed as experts in their own lives. Disabled children are now more involved in participatory research than ever before. However, rarely do we find their inclusion and participation outside of their disabilities and into the realm of childhood more generally. Even more scarce is research where disabled children are asked about topics not related to childhood at all. As Uprichard (2010) argues only when we include children in research as a matter of course and about topics unrelated to childhood itself can we claim that children are actively involved in research about the social world. We therefore argue that only when disabled children are asked about issues beyond their disability and the associated services and interventions can it be claimed that the rhetoric of inclusive research is being realised.

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