



# THE ETHICAL MAZE

## Finding an inclusive path towards gaining children's agreement to research participation

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In the UK, the ethics of engaging in sociological research directly involving children have primarily been shaped by definitions of 'competence'. While this has been a crucial guideline for researchers in shaping the concept of informed consent, it has also acted, perhaps inadvertently, as a way of excluding particular children from the research agenda. This article discusses the problems of informed consent that were encountered in research with children with learning impairments. It proposes that the process of seeking 'assent', when used within an ethical framework, is a more comprehensive method of gaining the agreement of children in research, which transcends language, ability, cultural, social and international borders.

Childhood sociology within the UK emerged in the last two decades of the 20th century as a result of the ontological repositioning of the child. This sociological questioning of the nature of childhood was a direct reaction to the individualization of children and problematizing of their condition that is evident in much medical, psychological and pedagogic research. By the beginning of the new millennium, childhood sociology had succeeded in promoting the perception that children are agentic (James and Prout, 1997) and exist within a structured childhood (Qvortrup, 1991). The outcome of these theoretical developments has been research that is primarily concerned with portraying the ordinary experiences of children within the structure of their lives. Thus the focus of empirical work has been on the main categories of childhood structures that mainstream children are believed to experience: health and welfare, pedagogy, family and home life and peer interactions. This increase of research into childhood and children's lives has resulted in discussion about the ethical implications and considerations within such endeavours.

It is important to recognize that this ethical reflection is situated within a much wider discussion within the social sciences about ethical practices

within research. Within the UK, the introduction of the Research Governance Framework for England (DoH, 2001), which applies to all research within health and social care from December 2005, heralds a new era of scrutiny within research. Parallel to this, the Economic Social Research Council (ESRC) recently commissioned the development of a Research Ethics Framework (Webster et al., 2004) and while the outcome of this is yet to emerge, it perhaps reflects an increasing concern among the social sciences to address the ethical and moral aspects of research.

These debates concerning ethics are further informed and influenced by the legal and moral aspects of human rights on a number of levels: global, European and British (Woodiwiss, 2005). These moral arguments are reflected in legislation directly concerning children both locally and globally. On a global level, the UN Convention on the Rights of the Child, which was ratified by the UK government in 1991, highlights the importance of listening to and respecting children's experiences and voices (Articles 12 and 13). This has been credited as the catalyst for new legislation, policies and institutions within many of the signatory states (International Save the Children Alliance, 1999).

Within England and Wales, the primary piece of legislation focusing on children is the Children Act 1989. This represents the formal structuring of the position of children within society and indicates how on a national level children are viewed. The main principles of the Act place the welfare of the child as paramount, and clearly require the wishes and views of children to be considered within legal proceedings; although there is a caveat that states that this should take into account the age and understanding of the child.

More recently, the UK government has been reviewing and addressing the way in which children's voices are heard. In England, where the research discussed here was carried out, the documentation for 'Every Child Matters', which is a direct response to public and state concern about services for children, considers how to improve upon current participation of children and young people in the development of and delivery of services. This is formalized within the Children Act 2004, which introduces the role of the Children's Commissioner for England, who will 'act as an independent voice for children and young people, to champion their interests and bring their concerns and views to the national arena' (DfES, 2005).

This move to include children and young people's voices has resulted in a growth in the quantity and focus of research being conducted that directly explores and encourages children's involvement in the process. For example, the ESRC programme '5-16; Growing into the Twenty-First Century' (ESRC, 2001) funded a wide range of research at the end of the century focused on raising the voice of children and exploring children's experiences of childhood. More recently, the newly established and innovative Children's Research Centre at the Open University focuses on assisting children to

design and direct their own research; the results of such endeavours can be found on the centre's website (<http://childrens-research-centre.open.ac.uk>).

In carrying out research with children, researchers have tended to draw on guidelines of informed consent as described by Priscilla Alderson (1995). Although this has been discussed and critiqued by some within childhood sociology (Christensen and Prout, 2002; Edwards and Alldred, 1999; Punch, 2002), it still remains a key tool in gaining children's consent to research.

The research reported within this article focused on a group of children who occupy a liminal position within childhood and who are not always included in childhood research: children with moderate to severe learning impairments. Because of the unique nature of the groups of children involved, the more traditional ethical beliefs and methods used within childhood research, most specifically informed consent, presented problems relating to the inclusion of *all* children participating within the process of gaining children's agreement to participate. In resolving these issues it was necessary to look beyond the concepts within informed consent and consider the potential theoretical and practical implications of defining 'assent' when used within an ethical framework.

This article begins by examining how 'informed consent' is conceptualized in the light of discussions of children's 'right to be heard' and sociology's belief in children as 'agents'. This leads to discussion of recent developments and criticisms of what is viewed, by some, as an essentialist interpretation of 'competence' (Lee, 1998). This is an especially poignant argument when considering children with learning impairments as assumptions about competence, maturity and their ability to participate within research has led to their exclusion from research. These factors encouraged reflection on whether there might be a suitable alternative. From this evolved an understanding of 'assent' that, when embedded in an ethical framework, opened a way forward that would include all of the children who attended the research settings.

The latter part of this article therefore introduces 'assent' and its definition within this research. By drawing on the principles and practices used by social care practitioners with people with learning impairments and communication difficulties and the recent work of Alderson (2000) with young children, it is possible to find an ethical way of gaining children's assent to participating in research. Examples are provided of how this was successfully applied within the research. There is also a discussion of how 'assent' cannot be in itself sufficient in ensuring ethical integrity, rather it is complemented by the researcher operating reflexively and within a framework of ethical reflection. In concluding, the article proposes that this method of accessing children's agreement to participating in research offers researchers a path forward through the ethical maze that can accommodate differences between cultures, language, ability, competence and international boundaries.

### Researching the lives of disabled children

The research referred to within this article set out to explore and identify the peer culture of children with learning impairments who spend time in specialist, segregated settings away from home (Cocks, 2005). Disabled children in the UK are seen to be marginalized and underrepresented within both society (Sharma, 2002) and research (Morris, 1998a, 1998b). There is little knowledge about how many children receive care away from home, where these children go and what they experience (Morris, 1995; Morris et al., 2002). This research therefore responded to concerns that further, more detailed research was needed to fully appreciate the nature of disabled childhood(s) (Watson et al., 1999). The specific interest in peer culture among this particular group of children had its origins in the researcher's own previous experiences as a social worker working with learning impaired children who visited respite care settings.

Children in these particular settings, primarily for reasons of health and safety, experience high levels of adult supervision. Indeed, the average ratio of adult to child recorded throughout the research was 1:3. Also, some of the children observed within this research were allocated 'one to one' support. This meant that, either because of a child's need for high levels of personal care, or because of behaviour creating risk of harm to self or others, a child would be accompanied by an adult at all times during their visit. The researcher set out to explore if, given these circumstances, children were able to establish a peer culture as defined by Corsaro as 'a stable set of activities or routines, artefacts, values and concerns that children produce and share' (Corsaro, 1988: 3).

The research was carried out in two settings that offer provision for children outside school hours. Both were run by non-governmental organizations, one operated within a county town and the other in an outlying village. The services they offered were allocated on a 'needs' basis, measured by the manager of the setting through reference to the severity of impairment and degree of stress perceived to be within the family. The village setting offered day and overnight respite care to children aged between 5 and 18 years of age, while the town setting offered play-days and after-school clubs, to the same age group. The staff in the village setting focused on 'care' as their primary role, while the town setting staff perceived their role as twofold: offering play opportunities, while also meeting defined care needs.

The research design was qualitative in nature with participant observation being the primary form of data collection. The researcher adopted the least adult role (Mandell, 1991a) as a way of interacting with the children and young people. This enabled the researcher to avoid being viewed by the children as a healthcare or educational professional assessing either their abilities, disabilities and/or needs. Data were further supplemented by written materials provided by the service providers, group interviews with staff

from the settings and a detailed research journal. Forty-eight observations were carried out over a period of 1 year, each one lasting between 2 and 8 hours (my own visits mirrored the scheduled visits of the children). Each observation was recorded in note form at regular intervals while in the field, then recorded fully within 24 hours.

The children who visited the two research settings had a wide range of learning impairments; some also had physical impairment. The difficulties the children had were assessed by the service providers as being on a scale of 'moderate' to 'severe'. While some children used language effectively, others had limited vocabularies. A number of the children used makaton, a modified version of sign language that is used alongside verbal communication, while others used pic symbols, which are a visual set of pictures designed to assist communication. There was also a significant group of children, approximately 25 percent, who did not use any form of recognized communication method.

The majority of the children were unable to maintain attention or concentration for periods of time: either walking away to move onto something else or changing the activity. Hyperactivity is fairly common in children with learning impairments and there is an increasing number of children whose disabilities are specifically associated with relational and social activity: for example, challenging behaviour, autism and attention deficit hyperactivity disorder (Ellis, 1990; Happe, 1994).

The children also represented a mix of class, gender, race and culture that reflected the wider community as a whole. There was a notable under-representation of children from ethnic minorities, which perhaps mirrors the concerns about a lack of service uptake by families from these groups (Shah, 1995). This diversity was further compounded by the extent of the age range of children visiting at any one time, which was 5–16 years old.

Two of the primary aims at the outset of the research was to be totally inclusive of all the children who used such settings and to reflect the principles of the social model of disability. These aims arose from a review of the retrospective commentary of researchers who have previously explored the lives of disabled children (Watson et al., 1999) and the critiques offered by those within disability studies of previous social research that has related to the lives of disabled people (Barnes and Mercer, 1997).

One of the main challenges within the design stages of this research was how to gain the voluntary participation of such a wide-ranging group of children. The primary issues being how to engage with children who used a variety of different communication methods and whose levels of comprehension were below that expected within informed consent and definitions of 'competence'.

However, before exploring 'informed consent' in detail, it is important to explain the conscious decision to use the title 'subjects' when referring to the children who took part in this research. To use the word 'participants'

implies degrees of involvement that in reality were not present (Alderson, 1995). Neither were the children merely objects, clients, cases or anything else. Rather they were actively involved in the gathering of data, assisting and providing me with details of their lives. They were not involved in the planning, progress and interpretation of this research, as the word participant can imply.

### **Disabled children and informed consent**

As research into the lives of disabled children is becoming more commonplace, attention is turning towards issues of ethical integrity (Costly, 2000). The introduction of the Children Act 1989, promoting the voice of the child, provoked some in childhood sociology to turn their gaze towards children's rights (Alderson, 1993, 2000; Archard, 1993), as it did those within disability studies (Morris, 1998c; Ward, 1997), using legislative changes as their primary justification for the increase in research and subsequent discussion of ethical integrity. This urgency to explore children's voices was compounded by the ratification of the UN Convention on the Rights of the Child (1991), in particular Articles 12 and 13, which relate to the right of children to be heard within their respective societies.

The specific vulnerability recognized among disabled children as research subjects means that researchers are seeking ways to ensure that their rights and innate humanity are not violated by the research process (Alderson, 1995; Morris, 1998c; Ward, 1997). Discussion surrounding the ethics and methods of researching with disabled children stresses the importance of reflexivity (Davis et al., 2000) and the inclusion of children (Morris, 1998c). Social researchers are advised to seek 'informed consent' as a formalized method of gaining children's agreement to participating in research (Graue and Walsh, 1998; Greig and Taylor, 1999). In recent research with disabled children, this has not always been achieved. For example, in a project exploring disabled teenagers' access to inclusive leisure, Murray (2002) chose to seek 'informed consent' from the parents of those participants under the age of 16, while seeking consent from the older children. Thus a number of children were involved in the research although their personal opinion and agreement had not been sought.

Davis et al. (2000) also explain the difficulties they met when intending to gain 'informed consent' from disabled children. While the researchers were motivated to ensure they gained informed consent, they had difficulty convincing the adults caring for the children that this was possible. As Davis et al. explained, the attitudes of the staff working alongside the children meant that they could not conceive the possibility that the children would be capable of consenting, thus it was the adults who were with the children that 'appeared to reject the promise that the children would know what was going on' (Davis et al., 2000: 209).

It therefore seems reasonable to suggest that researchers, while claiming to have resolved ethical tension by gaining 'informed consent' from one party or another, have had difficulty reaching this point. In exploring the common understanding of 'informed consent', it seems that the tensions explained by the researchers have their origins in the original concept and in its definition.

### *Defining informed consent*

The accepted definition of informed consent relies on a specific set of interactions: (1) presentation of information, (2) understanding, followed by (3) a response. These then result in either the consent being given or withheld (Morris, 1998c). This also relies on the information being presented in an appropriate format and on the child being able to assimilate information and respond to it. Essentially, the child is required to indicate at least some degree of competence (Ward, 1997).

Within the UK, 'competence' has been legally defined through the Gillick decision (Alderson, 1995; Archard, 1993: 78), which arose from a case heard in the British courts that sought to establish a girl's competence in consenting to a medical decision. The outcome based judgement of competence not solely on the age of consent (16) but also on notions of 'maturity', 'understanding' and 'intelligence'.

The search for further understanding of 'informed consent' is primarily discussed in terms of ensuring presentation of material that is understandable to the child (Alderson, 1995; Beresford, 1997; Morris, 1998c; Ward, 1997), of ensuring that parents do not feel overlooked in the process (Ward, 1997), that the children do not respond positively purely because this is what they feel is expected of them (Alderson, 1995; Beresford, 1997) and of ensuring that children know they can refuse (Alderson, 1995; Beresford, 1997). There has been little discussion on an ethical context of 'competence', how it is measured and assessed by a researcher.

This definition of informed consent has evolved from an understanding of childhood that remains focused on the mainstream child, who is presumed to have some age-appropriate channel of communication that adults know and understand. This is reasonable when the children researched demonstrate sufficient understanding of appropriately presented materials in order to consent. Indeed, this happened with some of the children within this research. On first introduction and subsequent meetings I would talk to the children about the research, its aims and objectives, likening it to carrying out a 'school project' where work undertaken is shared among children, adults and teachers on completion. This proved successful since it elicited conversation about the focus of the work and gave me an opportunity to include the children in my thinking. The only difficulty that arose was that as time went by the children were less interested in me and as one boy said to me one day 'it's a very long project'. For the children I think this was the

most frustrating aspect – that the results were not instant.

However, for a significant number of children it was not possible to gain their agreement to participation through informed consent. This was primarily due to the way in which agency, and more specifically ‘competence’, is defined within childhood sociology. On a more practical level, there were also challenges posed by the multiple communication methods utilized by the children. As the aim of the research was to ensure total inclusion, it therefore became necessary to seek another way of enrolling children’s voluntary participation. The first hurdle to overcome was that posed by childhood sociology’s definition and conceptualization of ‘competence’. It was therefore necessary to explore in further detail the way in which childhood sociology has conceptualized competence.

### *Children’s competence*

Within sociology the recognition of the concept of children as agentic has raised the profile of childhood studies and served to validate the growth in research in the area (James and Prout, 1997; James et al., 1998; Prout, 2000; Qvortrup, 1994). Children are perceived to be active within their life experiences rather than passive recipients of adult social worlds. They are portrayed as dynamic in assessing, altering and contributing to the societal circumstances they find themselves in (Corsaro, 1997; Hutchby and Moran-Ellis, 1998; James et al., 1998). Central to this is that children are generally situated as socially competent who are either immersed in their own worlds (Corsaro, 1997), negotiating meaning (Mandell, 1991b) and sharing cultural knowledge (Kantor et al., 1998) or occupied with making sense of adult worlds (Waksler, 1991). They are no longer objects of research but rather subjects with contributions to make (Christensen and James, 2000). In recent years, however, this approach has been criticized for failing to recognize the existence of dependencies and immaturity within agentic action (Lee, 2001). It is this issue that requires further exploration.

Lee argues that the concept of agency that is generally applied within the sociology of childhood implies the pre-existence of agency in each individual (Lee, 1998). He also claims that, by focusing on the successful deployment of agency, researchers then privilege competence and completeness. This leads to the next thread of his argument, which is that a reliance on assuming a perception of agency based on completeness and independence fails to recognize ‘the dependencies that underlie even the most mature performance of independence and a sensitivity to the incompleteness of social order’ (Lee, 1998: 460).

It seems that an outcome of adopting these essentialist notions of agency is that those children who live outside the mainstream perception of childhood have at times been inadvertently excluded from studies of childhood. Children who have dependencies that are beyond those commonly associated with children; for example, those in care, refugee children and

disabled children, are on occasion omitted from explorations of children's demonstration of agency. This is not to dismiss the work already done, rather to highlight that perhaps these groups would benefit from further focus. There are those within disability studies (Davis et al., 2000; Priestley, 2003; Sharma, 2002) and those in childhood sociology (Roberts, 2000) who have commented on the lack of recognition of disabled children within childhood sociology and research about children in a general sense. For disabled children assumptions about a child's 'competence' poses limitations and creates exclusion. As Alderson explains, in reference to very young or disabled children:

They challenge assumptions that children's competence relates to their measured intelligence, reading and maths ability, and placid compliance. Children . . . may be misperceived as inevitably very dependent when they do not have the chance to show their potential strengths. A further mistake is to assume that disadvantaged children are even less competent than sheltered ones. Competence grows through experience rather than with age or ability and very young children can have profound understanding. (Alderson, 2000: 131)

I would argue that the children within this research, although some may not have communication as adults define and understand it, and they may not be perceived as competent, do possess a profound understanding: of themselves, of the presence of others and of their environment.

#### *Accepting incompetence and dependence*

This leads to the need to incorporate incompetence, dependence and immaturity in such a way that they are not portrayed negatively or misunderstood and thus left open to misuse. Lee proposes a radical solution to addressing the independence/dependence dichotomy. He suggests that sociologists move away from an essentialist stance of agency towards an acceptance of 'immaturity' and 'incompleteness' that embraces ontological ambiguity. In doing this, Lee is proposing a fundamental shift in the way in which sociology as a discipline views both children and adults, as he explains:

To disturb the model of agency as self-possession is to disturb maturity as the standard model for sociological actors. If we can so disturb agency it would be no longer necessary to 'mature' children by deciding that they are agents. Childhood would open the door for sociology to see beyond its desire for completeness. (Lee, 1998: 469)

While this uncertainty may be daunting for some, it provides the researcher with an clear lens through which to explore the social world. It facilitates lateral thinking and an openness to new thoughts about adulthood and childhood, and disabled /non-disabled.

The idea that agency may not be an essential possession therefore encourages exploration into a range of issues such as when and how it occurs, what facilitates its use, and whether it is influenced by macro-level factors such as economics, policies, culture, institutions and social

structures. This links into the discussion within childhood sociology about 'situating children's social competence' (Hutchby and Moran-Ellis, 1998), which positions agency and associated actions in relation to context. As Hutchby and Moran-Ellis explain:

The social competence of children is to be seen as a practical achievement: that is, it is not something which is accorded to children by adults, like a right, and thus can be redefined or removed. Rather, social competence is seen as something children work at possessing in their own right, the display of which is an active, agentic achievement. But it is an achievement that is bounded by structural features of the milieu in which children live their lives. (Hutchby and Moran-Ellis, 1998: 14)

From the perspective of a researcher this raises a critical question – if agency is not always a static characteristic or 'possession' of the child then is it possible to judge or measure a child's 'competence' in consenting to research as there are so many contextual factors? For example, the researcher themselves, the circumstances of the request being made, where the research is taking place, who else is present when consent is requested, the time of day, the mood of the child, ad infinitum. Given that competence is perhaps not so straightforward, I suggest that researchers need to move away from the restrictions of defining competence in order to find an inclusive method of gaining consent.

To those working within research with people with learning disabilities, the aforementioned issues are familiar and continual sources of concern that this causes the exclusion of those with learning disabilities (Walmsley, 2001). The result is rigorous, continual and challenging ethical reflection by a small number of researchers (Stalker, 1998; Swain et al., 1998). It is this approach to research that, combined with understandings of ethics generated within childhood sociology, has informed and enhanced this ethical reflection.

The arguments against using 'competence' as a measurement of a person's ability to consent to research are further strengthened when considered in relation to developments within the study of the lives of adults with learning impairments. The social model of disability has been criticized for its focus on material factors and subsequent reluctance to explore definitions of impairment (Goodley and Rapley, 2002). While there has been discussion about the level to which the body should be considered within the social model (French, 1999; Morris, 1991), there has been less discussion about the actual definition of impairment. Some believe that this has resulted in a hierarchy of impairment where people with learning disabilities occupy a liminal position in the research agenda (Goodley, 2001). As Goodley points out:

The epistemological point being made is classically Cartesian: some elements of humanity are open to sociological investigation ('mild learning difficulties'), while some are left in the realms of static, irreversible, individualised biology ('severe learning difficulties'). (Goodley, 2001: 213)

This builds on axiomatic assumptions about competence, as suggested by Jenkins (1999). He claims that competence is assumed in the absence of proof of the contrary. However, this is turned full circle by Booth and Booth (1996), who suggest that people with learning impairments are assumed incompetent unless they can prove otherwise. This leaves people with learning disabilities rigidly compartmentalized: either striving to prove they are not incompetent, or who are labelled incompetent, regardless of their actions.

More recently, Goodley and Rapley (2002) have addressed these concerns through a postmodern perspective. Similarly to Lee (1998), they suggest a deconstruction of the discourses of dependence and incompetence that surround people with learning disabilities. In doing so, they propose a focus on revealing and exploring the interdependencies that feature in daily life. The point being that people do not operate independently in isolation of society but rather they engage in social interactions *interdependently*. This becomes particularly important when related to people with learning disabilities since they tend to be assessed according to their own dependence and perceived competence, rather than the interdependent social structures of which they are a part and in which they have a role (Goodley and Rapley, 2002).

The idea of considering the interdependence of the researcher and the researched thus offers a way of achieving voluntary accord – through very careful and detailed awareness of the ongoing interaction between the persons involved and a continual monitoring of the ‘assent’ of the research subjects.

### **Assent**

‘Assent’ is not an entirely new concept, it is something referred to within childhood sociology by a number of researchers (Alderson, 2000) and professionals (Caldwell, 1996), yet it has not been formally defined. Within the research discussed in this article, ‘assent’ was foregrounded as the sensitizing concept in gaining children’s agreement and has thus gained a concrete definition within the research process. Assent is represented within the relationship between the researched and the researcher, by the trust within that relationship and acceptance of the researcher’s presence. It removes the reliance on the child demonstrating adult-centric attributes such as maturity, competence and completeness; rather, it accepts the child’s state of being. It is also something that relies on the successful reflexivity of researcher and is most effective when placed centrally within an ethical framework, as I shall explain.

Seeking assent requires the researcher to remain constantly vigilant to the responses of the child at all times: it is not something gained at the beginning of the research then put aside. It requires time and constant effort

on the part of researchers, who need to attune themselves to the child's unique communication in order to know when to remove themselves. The following extract from my journal illustrates the time spent building a relationship and shared understanding of each other with Tim, an autistic boy with no speech and limited intellectual capacity. He was assessed by the staff as requiring one to one attention the whole time because of his often loud and aggressive behaviour:

For most of this afternoon I have spent time with Tim. I began by sitting nearby, watching the other children and sometimes watching him. As he did not react to my presence and indeed began to look at me I watched him more closely. After some time I moved closer to him and was eventually sitting next to him. He appeared to accept my presence where I have seen him forcefully push others away. He was sitting playing with some fluff, I felt very rewarded when he let me have some of the fluff – I had requested a piece to see if he would part with it – something else he is reluctant to do. We then proceeded in a game of passing the fluff between us, he directing how long I could hold it for. At times he would look directly into my eyes, I really felt that, although he has no concept or grasp of why I am here, I do feel that he knows that I intend him total respect as a person and therefore he is happy with my presence here. (Play Setting/journal)

Over the time I spent with Tim, I discovered that he rarely shared his fluff or any other object that was the focus of his attention with staff or other children. Staff reported to me that he would only share with people well known to him whom he appeared to trust. They also expressed their surprise that he allowed me to remain within such close proximity, when usually he remained at a distance from others. I understood Tim's response to me to be assent. If he had not wished me to be nearby, he would either have physically removed himself from me or not looked at me. If this was simply 'not dissent' then I believe that he would have allowed me close – however he would not have shared his fluff, which was his focus of attention. From conversation with the staff on duty this was also their opinion.

Generally, I assessed children's assent through their actions and reactions towards me. In one instance, a boy, whom I had met on a number of occasions but had not yet connected with, approached me. He signalled to me to follow him through the outdoor play area. Over the course of 10 minutes he beckoned me to follow him over a climbing frame, swinging through monkey bars, crawling through wet sand and finishing with sliding down a very wet and muddy slide. At the end of this he was laughing and from that moment on, whenever I met with him he would lead me to whatever he was doing and guide me in how to join in. I believe that he was testing me, to see how I would respond and whether I was to have access to his activities. I understood his subsequent invitations to join in as assent to my presence in his proximity.

There were other times when gaining assent was not so easily achieved and I was clearly pushed away by the children. Whenever this happened, I

would not question their action but remove myself from their space. I cannot deny that there were times when, from a data collection perspective, this was frustrating; however, when considered within the context of the total research and ethical framework, it seemed a positive experience. What I had not expected was the outcome of removing myself as soon as I sensed a child's discomfort. In the majority of instances the child or group of children subsequently approached me directly, asking me to join in. This left me with the impression that through the action of respecting their choice and by not acting in a particularly adult-centric fashion, I was opening channels of trust and interaction.

### **Embedding assent within an ethical framework**

As I have indicated earlier in the article, assent did not stand on its own within the research, rather it was embedded in an ethical framework. This stemmed from the belief that even with assent as the access tool to children's agreement, researchers must make themselves as transparent and accountable as possible. This was important for a number of reasons: first, to minimize researcher subjectivity within the whole project; second, to avoid relying on only one tool to judge ethical integrity; and lastly, to provide 'ethical symmetry' as explored by Christensen and Prout (2002).

The ethical framework for this project was shaped by Hammersley and Atkinson's (1997) identification of core issues to be addressed within any research project: informed consent, privacy and autonomy, harm, exploitation and consequences for future research. While it was designed and defined at the outset, it was something that was reviewed regularly throughout the research. This assisted in overcoming potential problems regarding the impact of the research that can and do arise when assent is the predominant way of gaining the children's trust.

#### *Privacy and autonomy*

Issues of privacy and autonomy were particularly pertinent due to the vulnerability of children within research. This is something which Hammersley and Atkinson believe is due to 'the assumption that children's private lives are legitimately open to scrutiny in a way that those of adults are not, especially professional, middle-class adults' (Hammersley and Atkinson, 1997: 267).

The recognition of privacy within the research lies in the sensitivity of seeking the children's assent. If a child did not wish me to be present, I removed myself. If I was uncertain, I would remove myself; so rather than assume a positive response to my presence I assumed a negative one.

What became difficult was protecting the children's privacy when they were interacting with me. On one occasion, a girl had been trying to tell me something for the entire length of my visit – each time she began to talk the

staff would position themselves within hearing range, regardless of the girls request that they 'go away'. This highlighted the fact that children have the right to choose who they share their privacy with, and I felt privileged that the children trusted me to do this.

### *Harm and exploitation*

This is seen very clearly in the work of Goode (1991), who gained assent through building a trusting and complex relationship with Christina, a deaf-blind child at the centre of his research. When the research ended, it was with negative consequences for Christina, who had flourished as a result of such a rewarding relationship, as Goode admits:

My departure from State Hospital was an unhappiness for Christina and me. The implications for her life were great. Without the benefit of her ally, she quickly regressed to a point where her behaviour was indistinguishable from that of the other residents. (Goode, 1991: 157)

The potential for this problem occurring has been recognized in research with adults with learning disabilities (Stalker, 1998) and was recognized from the outset within this research. If you purposely work at gaining trust and building friendships with those who rarely experience this level of intimacy, you must prepare them for your departure when the work is complete. Throughout I made clear to the children the regularity and duration of my visits. On a lesser scale, if I had spent a lot of time with one particular child and was aware of their growing attachment, I would never just up and leave. I would always make sure that they either joined an activity or that a staff member remained with them, in order to avoid them sensing abandonment. However, I cannot deny that problems did occur and although they were solvable they were unfortunate and left me with a sense of acute sadness at the speed children would attach themselves to me as a 'friend', as if this relational opportunity was rare. Sometimes the children would become possessive about who would play with me next, excluding others from joining in by telling them to go away or that I was their friend. On the whole though, I was able to extract myself by moving to another part of the setting or asking if we could all be friends.

The question of whether the research was exploitative remains with me even now. The research was and remains valuable in various respects: it has informed providers of the impact of their services, it has revealed the nature of relationships among children experiencing a form of social exclusion and it has contributed to the development of childhood sociology. In another respect, it could be seen as exploitative as it was also the source of material for a PhD thesis, so was also carried out with an element of personal gain. As a researcher this needs to be considered in order to ensure that a balance is achieved that acknowledges the vulnerability of the children but rejects the view of them as passive and unable to participate in research by

sharing their experiences. This would then avoid the scenario described by Alderson (1995) where:

Traditional ethics . . . rightly stresses the importance of non-interference, and of avoiding deliberate harm. Yet little is said of the harms of protecting children so much that they are silenced and excluded from research. (Alderson, 1995: 53–4)

### *Consequences for future research*

The consequences for future research was another aspect of the ethical framework that required consideration. The research settings rarely engage in research activities, indeed for one of the settings this was the first time they had allowed a researcher to work among them. This therefore required sensitivity in working alongside the children. If the manager or staff within either setting had felt that I was communicating with the children inappropriately or unethically, not only would I have been asked to cease my work, but then also others following behind me might be denied access. This in turn risks increasing the exclusion of these children from further research.

To have sought informed consent from certain children would have risked derision from the staff, instead the process of assent gained their respect. This resulted in one particular comment from a senior member of staff in one of the settings that ‘the researcher spends more time getting to know the children than the staff’. While this was intended as a joke, I felt both embarrassed at the discomfort of the staff and complimented that my efforts had not gone unnoticed.

Each of these dimensions of the research framework thus relied on my own efforts to engage with the issues, and on my tenacity in pursuing the most transparent path I could find in what many people view as a maze. It reflects the continuous efforts to embrace reflexivity within the research process.

### **Reflexivity**

In exploring the position of ethics within research, particularly within this work, it became increasingly clear that ethical frameworks, tools and methods cannot merely be a posture assumed in order to satisfy the requirements of academic and professional research; rather it is a position that should be declared by the researcher. It is the beliefs of the researcher that influence the ethical nature of a piece of work and impact on the final product. Therefore, flowing through each of the core issues of the ethical framework, particularly through the application of ‘assent’, is the reflexivity of the researcher.

The role of reflexivity within sociology has experienced a degree of scrutiny and debate (May, 1999; Slack, 2000) that have left its meaning open to interpretation and vulnerable to misuse. Imperative therefore in avoiding

confusion is the clarification of the definition, application and position of reflexivity within this research.

Reflexivity is an approach researchers can apply to bridge the gap between themselves and the researched. This is seen in the call within disability studies to move towards emancipation by using reflexivity to address the imbalance of research relations (Barnes and Mercer, 1997; Davis et al., 2000), and within the sociology of childhood to widen the scope of the researcher to hear the voice of the child (Davis, 1998). However, there lies a danger in subscribing to this call as it may serve to falsely raise reflexivity to a privileged position as the *only* route to ethical rigour that can withstand academic examination, without its process or meaning ever being defined or explored.

Initially my concerns about the value of reflexivity focused on the potential difficulties existent in the relations between researcher and researched, especially concerning the production of power and knowledge. I was drawn to the claim that reflexivity has the potential to reduce the power relation between myself and the researched through recognizing one's own personal vulnerability (Stone and Priestley, 1996). Within this there remained a nagging doubt that if used incorrectly it might as easily widen the power relation if I were to claim an epistemological high ground over the children. In order to overcome this, I consciously chose to parallel reflexivity and assent within the research process. I believe that the two complement each other in maximizing the ethical practice of researchers.

I was aware that as I have different narratives at work in my life, such as academic, private and social, so would the children. As Davis explains, self-reflection on the part of the researcher leads to recognition of the potential for 'many different cultural voices' among the researched (Davis, 1998). Engaging with reflexivity in this way thus allows for the existence of uncertainty and the possibility of multiple explanations and experiences caused by the complex interplay between the material and individual. Rather than perceive the existence of these multiple explanations as problematic I worked with them, positioning them squarely in the centre of research, accepting that the children would perceive me and the project differently from each other, that while some would be keen to partake others might be reticent.

But what is reflexivity? An honest answer to this question might be that it is something easier to do than define. (Davis et al., 2000: 201)

On a personal level, the process of reflexivity was not always a comfortable process. It required continuous consideration of my conduct, a review of my questioning of prejudices held at the outset, and their subsequent dismissal as insubstantial and subjective judgements. I explored my own biography in order to appreciate the events and motivations that led me to the point of embarkation on the project. It required me to suspend my own

experiences of a privileged childhood within a middle-class family unit and my interaction as an adult with children currently in my private life. My journals are testament to the fact that this is merely the tip of the iceberg and trace the development of the research, my relations with the children and my own personal journey. It is not possible to extract reflexivity from within the project as it is intertwined with, and has seeped into, the very fabric of the research. Rather I highlight its presence, and in the record that is my research journal, make the research transparent to the reader.

It is difficult to identify when this process begins and ends as it is part of my identity as a researcher. Indeed even now, as I write this article, I am considering questions about my actions, the main one being 'Why?' Why am I making the effort to put this into print? Is it because as an academic in the early stages of my career I require further publications in order to progress, or is it because I promised the children to tell as many people as possible about the research, or is it because I feel that the lessons learnt have a truly valuable contribution to make to mainstream childhood sociology? Perhaps this article is motivated by each of these factors!

### **The potential of 'assent' within childhood sociology**

The focus within this article has been on the ethical processes that were engaged in within a specific piece of research. It introduces the use of 'assent' as a method of gaining children's agreement to being part of a project seeking to explore the peer culture(s) within specialized settings that provide services for children with learning impairments. While 'assent' was explored and developed in the context of research with children with learning impairments, I propose that it could also be used in research with other groups of children, in a variety of contexts and in more 'mainstream' research with children.

In reducing reliance on 'competence', which in many ways prioritizes language and definable methods of understanding between the researcher and the researched, 'assent' increases the accessibility to research for children for whom these measures are difficult to achieve. This would include children for whom language is problematic, for example asylum seekers whose first language is not that of their host country, children within the care system who do not feel empowered to consent to research, young children who have not yet developed the skills to agree to research and children with learning impairments who are not considered to be competent. This would assist researchers in moving towards a resolution Roberts observes, that 'There are some groups of children literally or metaphorically without a voice' (Roberts, 2000: 236).

As I have demonstrated within this article, 'assent' can be a powerful tool in the quest for ethical transparency and integrity. Yet, I believe that this

is only achievable when the researcher embraces reflexivity in every aspect of their work and embeds it within an ethical framework that is defined and formalized within each and every project they embark upon.

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