Children's Experiences as Hospital In-patients: Voice, Competence and Work

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Submitted in Partial Fulfilment of the Requirement for the
Degree of Doctor of Philosophy
November 2010

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ABSTRACT

There is growing evidence that children's subjective interpretations of events may differ significantly from those of adults; yet children's voices and children's knowledge regarding hospital care remain largely unexplored.

This study was undertaken to determine what counted as voice in work with hospitalised children, and explore children's subjective interpretations and knowledge as in-patients.

Influenced by critical ethnographic methods, the study was undertaken in two phases with children who had been in-patients in one English tertiary referral children's ward. Phase one involved reconnaissance with 6 children to explore what mattered most to them regarding their in-patient experience. Phase two involved field work undertaken over six months, on a nephro-urology ward, and included in-depth work with nine children.

Voice became manifest in what the children said but also through the non-verbal mechanisms of resisting and being silent. In this study, the children chose which voice to present when they participated in the study and that voice was accepted without question.

Inductive analysis revealed that the children shared the experience of being in trouble. While they were in-patients, recognition of their competence was fluid=and contingent on structural and material factors. When their competence was denied, some of the children fought hard to re-establish their claim as authentic and knowledgeable individuals. However, while all of the children who participated in this study, regardless of ability, were capable commentators on their experiences, their capacity to work in their own best interests was sometimes challenged. During these episodes, they relied heavily on supportive adults. In the absence of supportive adults they often became marooned and subject to routinised care.

The children's interpretations of their experiences enabled new insights regarding what counts as voice in research work with children, the nature of child-adult relations and the fluidity of children's competence in the context of a children's hospital ward.

CHAPTER 1

INTRODUCTION TO THE STUDY

My first appointment as a qualified children's nurse was as a staff nurse in a tertiary referral centre intensive care unit. Since then I have worked in a number of hospital contexts that include a children's general medical ward, and children's isolation unit, a children's renal unit and as a peripatetic hospital based clinical nurse specialist for intravenous therapy. I had always considered it a privilege to work with children and families at times in their lives when they faced, what seemed to me, unimaginable situations related to the children's health and well-being.

When I started this study I had experience of being a mother of children admitted to hospital. Much of what happened during these periods of hospitalisation was unremarkable and is difficult to remember, but three episodes stand out. The first event occurred when my oldest son was admitted to hospital for a tonsillectomy. After leaving him overnight I returned early in the morning to find his face stained with blood. I wondered how long he had been left alone.

My second son was also admitted to hospital. During his admission he lay very still, each time a nurse passed by his bed he would close his eyes until they were gone. It was as though he was making himself invisible. The third event involved my youngest son. He was admitted to hospital with a breathing problem. He was 'prodded, poked and stabbed for blood', weighed and measured. When we left the hospital my husband casually commented on his surprise that the children's nurses did not speak to the children. Although the centre of attention my children had seemed surplus to events. I had no idea what, if any, sense they had made of their experiences.

I have clear memories of feeling dismissed, panicked, shocked, ignored, told off and being grateful. Yet I knew little regarding how my children made sense of what had happened to them or why they behaved in the way that they did.

I now work as Senior Lecturer in Children's Nursing. I often use my personal and professional experience to help students make sense of what might be going on for the children and families that they meet in practice. Working with students to identify legitimate sources of knowledge sparked my interest in trying to find out what was known about hospitalisation from the perspective of children. There was very little. Having completed research work on the perceptions of staff and parents, I turned my attention to the perceptions of children in hospital.

To make more sense of what was going on, and, to understand the experience of children in hospital from the perspective of children who had been in hospital, I needed to establish a critical standpoint. This was essential for two reasons. I needed to establish a platform or theoretical standpoint to justify and defend the ontological, epistemological and theoretical foundations that underpinned this work, and, make transparent my position as researcher in this work.

The Research Journey

What follows is an honest account of my research journey. This is presented and catalogued using conventional chapter headings as follows:

- Chapter 2 serves two purposes. It provides the justification for the ontological, epistemological, methodological and theoretical framework on which the work is founded. It also provides a critical overview of what was known regarding the experiences of children as hospital in-patients when I started this work.
- Chapter 3 presents the research question, aims and objectives and the philosophical foundations that underpin the methods used. It also offers an account of how the research focus and questions were refined between phase 1 and phase 2 of this work.

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- Chapter 4 focuses on elicitation of children's voices and the meaning of voice in this work.
- Chapters 5, 6 and 7 present the findings
- Chapter 8 draws together the final discussion and conclusions
- Chapter 9 presents the recommendations for practice and research

However, it is important to point out that my experiences, insights and developing knowledge did not follow the linear and sequential path that the chapter headings suggest. There was no simple progression from the literature review, to the methods to the findings. Rather, I experienced the research journey as one of constant interplay between these different but inter-related research processes.

For instance, the time I spent with the children and their repeated attempts to help me understand what they meant helped me to see more clearly that they had unique and subjective insight into their experiences. They demonstrated their agency and they helped me to understand what voice meant in the context of this work. I have included a pictorial representation of the research journey (figure 1) to convey not only the iterative research design but also the complexity of my reflexive journey and how my understandings were continually contested and refined throughout the work. While this is portrayed as a linear research process the work involved a far more complex and reflexive component that was central to the success of this work.

Figure 1 Pictorial representation of study design
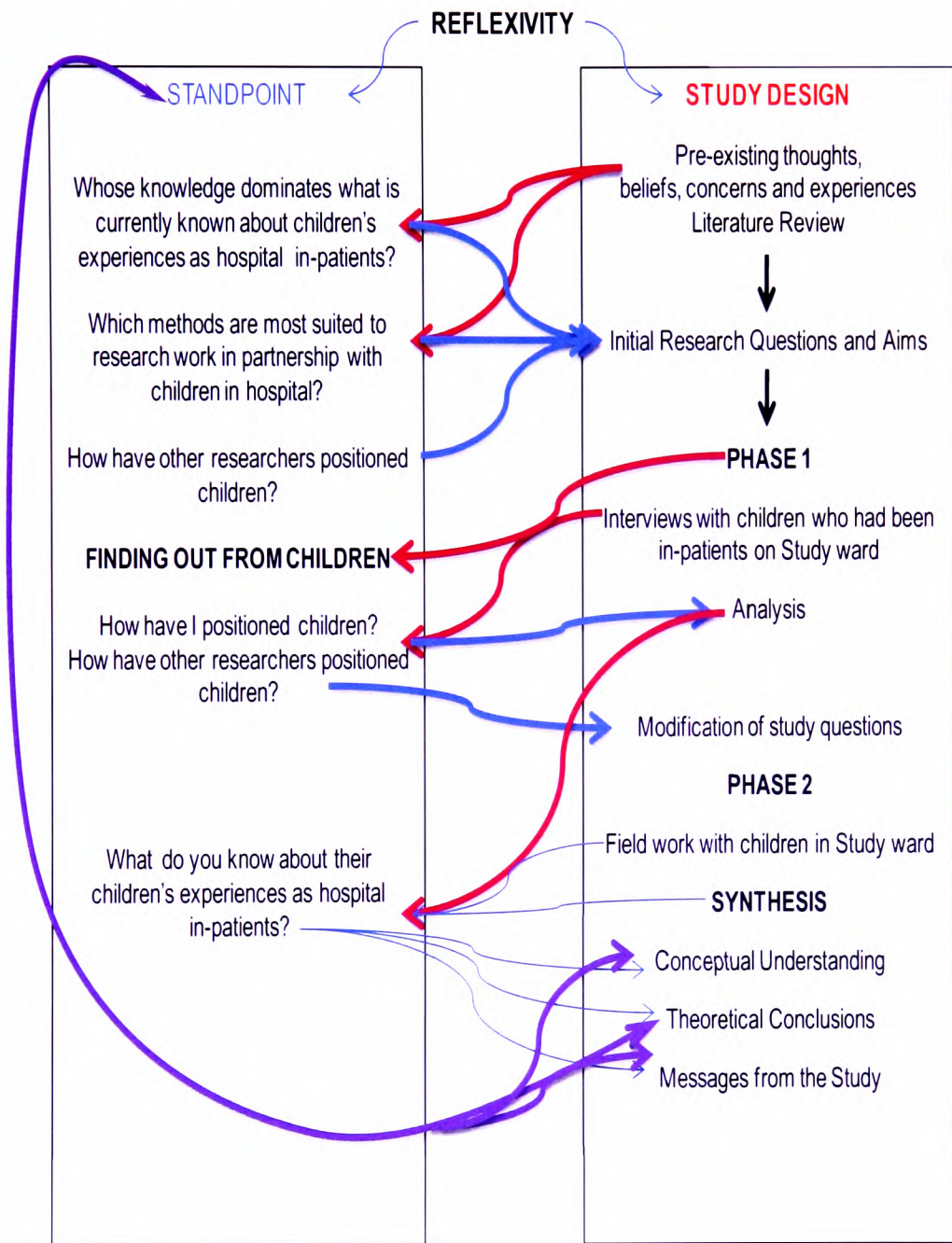
Finally, in this section I want to explain my deliberate choice of the word 'work' to describe the efforts of the children with whom I worked. As figure 1 portrays, the time I spent with the children was critical in helping me to understand more fully that it was the children who had to work hard in order to engage with the hospital staff.

CHAPTER 2

LITERATURE REVIEW

Socially constructed meanings given to the terms child and childhood imply that being a child means being in transition, or on a predetermined trajectory dominated by the purpose of becoming an adult. In other words, childhood is situated somewhere in-between being and becoming with the emphasis usually placed on the transition to becoming an adult (Mantle & Leslie et al 2006, Prout 2005, James and James 2004, John 2003, Mayall 2002, Prout and James 1997). Although popular and at first seemingly in keeping with the natural order of things, accepting the concept of childhood as little more than a phase of transition was insufficient for my purpose. As Punch (2002) noted, the way in which any researcher sees a child will ultimately affect how they listen to that child. In academic terms, understanding what it means to be a child as a phase of existence dominated by becoming something else is both limiting and inadequate.

My work with the children in this study helped to advance my understanding of the key concepts from contemporary childhood studies (for example, agency, voice, and participation). In turn this enabled me to understand more fully that the construction of childhood and what it is to be a child were both fluid and subject to constant reproduction; always contingent on place, space, time and culture.

Given this, the aim of this chapter was to make transparent the critical standpoint for this work. This was achieved in two ways. The first involved a critical examination of the contemporary debate regarding the social construction of childhood and what it is to be a child. This included a critical review of work published from the early 1900s onwards. In brief, what follows in the first section of this chapter highlights the ambiguities in the theoretical construction of children as, personal and professional, public and private, and, individual and collective beings. Once

established, my standpoint was used to critique the research concerned with children's experience of being hospital in-patients.

When I started this work, with few notable exceptions, knowledge relating to children's experiences of being hospital in-patients had been derived from adults; either through the interpretation of children's observed behaviour or gleaned from interviews with proxy adults. Given this, the second section of this chapter presents what was known about children's experiences as hospital in-patients when I started this work. Since then, publications related to children's experience in hospital have burgeoned (for instance, see Coyne, Hayes and Gallagher 2009 and Lambert. Glacken and McCarron 2008). This is considered and applied selectively throughout the findings chapters.

To begin, I set the context of being a child in Britain against the backdrop of the construction of childhood. I then consider the problems associated with historical accounts of childhood by presenting two competing views; that of discontinuity and change and that of continuity and evolution. I then draw on the construct of social panics, the sexualisation of children, the reporting of children's deaths and the notion of children as a threat to illustrate that (in the UK at least) competing and complementary constructions of childhood, even those that appear to be in direct opposition to each other, are accommodated along different dimensions of the same theoretical position. This section then turns to consider the UK policy context for children and that dominant discourses have influenced the positioning of children in society and continue to do so. This review concludes by examining how children's voices are increasingly seen as important to the future development and delivery of services

Constructions of Childhood

The last 30 years have seen a tremendous upsurge in scholarly interest and publications related to the concepts of childhood and what it maybe to be a child. Legitimate academic interest in childhood and children is a relatively modern phenomenon. Unlike other marginalised members of society, children have relied on

adult advocates to advance their best interests and develop structures that enable their voices to be heard. As Hendrick (1992) noted,

"...Unlike women, black people, and the working class, children are not in a position either to write their own history, or to ask awkward questions of those who exercise power and control over them. Nor do they have a political movement to raise public consciousness of their condition and their grievances... Until recently conceptualising childhood has been deemed hardly necessary..." (pg 4).

Interestingly, and despite common use, neither the term child nor the concept of childhood has an agreed definition (Alanen 2001). Despite this, any written account concerned with children or childhood must use these terms in order to distinguish the nature and focus of the work. This problem is most usually solved by recourse to social construction. At a simple level social construction implies that members of a group in any given society will invent constructive understandings to arrive at a consensus of what particular terms mean. However, Guba (1990) notes that this is also problematic: reality, and thereby conceptual meanings, can exist only in the context of a given mental framework (page 25). That means that any social construction will always be limited and shaped by the values and mores of the group contributing to the construct. In turn this means that constantly evolving interactions and contestability lead to shifting constructions that are easily destabilised when they are subjected to rigorous critique. This applies to the concept of childhood (Prout 2005). My understanding of this is that these changing constructions allow for and enable accommodation of new ideological patterns and herald paradigm[1] shifts (Kuhn 1996). Guba (1990) argues that constructivism requires a subjective epistemological stance and that subsequent methodologies need to take account of hermeneutics (individual constructions) alongside dialectics (comparing individual constructions against those of others). Consistent with what Guba (1990) refers to as the *'basic human condition'* the search for consensus leads to constantly shifting reincarnations of mental representations. Deconstructing these shifting reincarnations enables the accommodation of different mental representations. This means that competing and complementary constructions, even those that appear to

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[1] Here, the term paradigm is used to represent a world view. It concerns the underpinning assumptions that inform researchers ontological, epistemological and methodological standpoints. For Kuhn, a paradigm shift represented radical challenge to the dominant scientific paradigm.

be in direct opposition to each other, can be accommodated along different dimensions of the same theoretical position.

Discontinuity and Change

A number of classic texts have been published that offer a critical and historical review of the concept of childhood. In general, the work falls into one of two camps; discontinuity and change or continuity and evolution. Aries' (1962) work fits into the first. His book, 'Centuries of Childhood', declared childhood to be a modern concept that came into being after the Middle Ages. He claimed that the growth of interest in the concept of childhood was evidenced through increasing concern for the welfare of children and their need for protection. He also claimed that the upper and middle class families were the first to imbue childhood with intrinsic value with working class families doing so much later. Aries' work has been extremely influential for two reasons. First, he heralded a new era of debate as to the nature of childhood arguing that there were discernible changes over time. Second, his work created the right conditions for other scholars to question his assertions and conclusions. Since publication, there have been a number of academic challenges to Aries' contentions; not least his assertion that prior to the Middle-Ages children were not valued or seen in any real way to be different from adults.

Aries' drew his conclusions from interpretation of historical artefacts, especially art and early literature. His over-reliance and interpretation of historical, educational and moral texts was considered by some to be highly subjective and for others little more than speculative (Hendrick 1992 and Pollock 1983). In the main, these scholars focused on four key areas of Aries' work; that his sources of evidence were unreliable; that he overused atypical cases; that he over-relied on moral and educational sources; and that he failed to understand the limitations imposed on the artistic methods and artistic artefacts of the time. In keeping with Guba's (1990) argument that social construction was essentially framed within contextualised and temporal limitations, Hendrick (1992) pointed to the cultural limitations that would have framed the production of art and writing at the time. He claimed that the artefacts used by Aries as evidence would have led to misinterpreted and invalid

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representations of childhood and perhaps more importantly, children. In this way, Hendrick considered Aries' conclusions to be speculative.

Continuity and Evolution

Pollock (1983) had previously contended that there were other sources of evidence that pointed to more ambivalent values concerning childhood across the centuries. Pollock noted in particular that Aries has overemphasised the strength of culturally and socially specific socialisation. She also noted the lack of attention paid to material factors. These she argued, would have meant that families had no choice but to use children's labour to meet the needs of the family group. In fact, there is robust evidence that this continues today (Becker 2007) and that in many situations adults rely on children (Komulainen 2007). In other words, and in keeping with the modern world, both the material and structural conditions of the families in the Middle-Ages would have had a tremendous and enduring influence on the treatment of children. While it is possible that upper and middle class families could afford to educate their children, protecting them from the rigours of child labour, families living in poverty would have relied on the work of children, whatever form that took, for survival. It is often stated that the greater the distance between the history, geography and culture of children, the more difference there will be in their individual social realities (Buchanan 1996). However, Prout (2005) and Hendrick (1997) have pointed out that children who live in poverty may well have more in common with each other than those who are economically better off in the same geographical location. Benedict (2005) identified levels of responsibility, the dominant or submissive role expected of children, and the sexualisation of children as distinct markers that distinguished the experience of children in industrialised and non-industrialised countries. She argued that these 3 markers could be used to differentiate and explain the nature of adult-child relations in any given cultural group.

I have many reservations about the imperialistic attitudes predominant at the time of Malinowski's (1916) work, not least regarding the colonial interpretation of his findings and the positioning of other cultures as subordinate to those of the west.

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Yet, in anthropological terms his work is still considered pioneering, and I use it here first to illustrate an application that reveals the usefulness of Benedict's formulation. Malinowski (1916) revealed very different attitudes towards the sexual behaviour of children living in the Trobriand Islands, New Guinea. Studying the Trobriand people over a period of 16 months (1915-1916), he reported a high tolerance for sexual play and investigation by children and a laissez-fair attitude to the correction of any sexual activity in which the children engaged. Malinowski (1916) reported that at that time the Trobriand people held a universal belief in re-incarnation and refuted any physiological causes of pregnancy (Malinowski 1916).

Although dated, his work makes an important contribution to my own for two reasons. First, it is considered to be one of the earliest studies to demonstrate the importance of anthropological (and later ethnographic) accounts in revealing the inner workings of cultures (Faubion 2001). Second, it was the first study to highlight that, cultural expectations, culturally embodied knowledge, and socially constructed meanings were used to make sense of day-to-day ordinary events. In this way his work made a very early contribution to the understanding of the social construction of the concept of childhood in different contexts.

However, it is still not possible to assume, even when categorised in this way that the experience of children is collective. Nor do Benedict's distinct markers work in other situations. An example of this can be drawn from the work of Solberg (1997). She discovered that levels of responsibility varied widely between individual families. Solberg, who sought to examine the changing constructions of age in Norwegian children, identified the prominence of self-fulfilling parental prophecies. Parenting practices reinforced parents' perceptions of their own children's capabilities. Solberg (1997) reported that perceived success in handling responsibility was used by parents to judge the 'rightness' of their decision to give their children responsibility. Similarly, when responsibility was withheld, the resulting behaviour was used to justify the reasoning behind the decision to withhold responsibility in the first place (Solberg 1997). Nonetheless, in keeping with Becker (2007), Solberg (1997) noted that the structural demands on the family, especially

the working arrangements of the parents, were an important indicator of children's delegated family responsibilities. The cultural aspects of family life in Norway were also apparent. Children are not only more likely to be left on their own without supervision after school at home than their counterparts in the UK; when after-school care is arranged it is usually the children who take the decision to stop using the service. Solberg's work demonstrated the difference between children in different countries and the difference between children within countries. What seems to matter is the extent to which parents construct children's competence, and this seems to be contingent on family circumstances. Whilst Benedict's work provided a pragmatic model against which the experiences of children in very different cultural contexts could be analysed, Solberg's work pointed to the importance of giving consideration to the context of individual families, especially in unequal societies such as the UK where enduring and worsening inequalities exist between families (Prout 2005).

There is little doubt that children from poorer families have qualitatively different experiences to children from better off homes (Marmot Review 2010). In the UK, current statistics reveal that 3 out of 10 school age children witness domestic abuse, 1 in 10 cares for adult relations, and 2 in 10 suffer from mental health problems. Children from poorer families are consistently over-represented in these groups (DCSF 2010).

Situating their views of childhood within the continuity camp, James and James (2004) claim that

"...as a social space [childhood] does remain both constant and universal...[though] its character... changes over time shaped by changes in the laws, policies, discourses and social practices through which childhood is denied..." pg 20).

As such, the concept of childhood is fluid and subject to constant reproduction contingent on place, space, time and culture. That said, some commentators claim that differences between children and adults are immutable. This most often rests on biological and physiological differences which in turn have enabled the medicalisation of childhood. If, as is commonly done, childhood is defined as the

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time between birth and the 18th birthday (Her Majesties Revenue and Customs 2010) it is indeed a time of rapid growth and development (Chamley 2005) for most but not all children. Children's physiology is different to that of adults (Chamley 2005); their intellect is developing, and they have specific psycho-social and emotional needs (John 2003). These differences are reinforced in the UK as elsewhere, by according different legal status to children (Children Act 1989, Children Act 2004) and maintaining differentiated social positions (Mayall 2002, Prout and James 1997). Children are most often (but not always) part of a family and usually (in Britain at least) reliant on adults for physical and emotional care and support (Mayall 2002). Yet, none of these facts are immutable; some children do not develop intellectually or grow, some children cannot rely on adults for either physical or emotional care (Howe 2005) and the corollary is that some adults are reliant on children (Komulainen 2007). It seems that even within the dominant view of children as little more than on a journey to becoming adult, understanding children as a homogenous group does not hold up to scrutiny.

Lee (2000) suggested that the development of children's bodies had been taken over time as a more reliable indicator than '...*their spoken testimony*...' (p. 149). He argued that they have been understood as being closer to nature than adults and therefore investigated as objects; a pertinent observation given the research review presented previously. While there will always be children whose physical, emotional, cognitive and social development fits with latent-age developmental norms, there will always be those children whose failure to do so will be taken as a sign of pathology.

Cunningham (2006) contended that contemporary British parents existed in a state of high anxiety, more concerned about the welfare of their children than any previous generation. Central to this anxiety was the felt need to think about children as potential victims. However, Madge and Barker (2007) noted that parents did not necessarily worry about matters that posed the most risk to their children. Cunningham (2006) argued that the British subscribed to a romantic and innocent view of childhood; with children seen as a vulnerable group which needed

protection. According to Cunningham (2006) romantic images of childhood portray children as well-behaved and keen to achieve on their journey to adulthood (as noted in Beuf's 1978 findings) yet childhood is no guarantee of adulthood. Still, it is not unusual for the concept of childhood to be understood and differentiated from adulthood through recourse to innocence (Meyer 2007).

Innocence and Evil

Innocence is a provocative term as it conveys a moral imperative; the need to ensure a sense of purity or freedom and to protect children from moral wrong-doing. Derived from the Latin term *nocere* (to harm) innocence invokes blamelessness, lack of sophistication and ignorance of evil. The view of childhood as a time of innocence is not new (James and James 2004; Jenks 2005) nor is it static. This can be illustrated by revealing innocence and evil as shifting and unstable characteristics that are both accommodated along the same theoretical position in contemporary constructions of childhood. For instance, when children commit murder or when children are sexually abused, sensational media headlines proclaim the loss of innocence or even the loss of childhood (Meyer 2007, Cunningham 2006, Prout 2005, Postman 1994). Yet, the construction of concepts such as innocence and evil are as contingent on social, temporal, cultural and material factors, as is the concept of childhood (see Luk-Fong 2005 and Devine 2002).

Children and Sexuality

Cree (2008) pointed out that, while some spheres of sexual activity have become increasingly liberated (such as homosexuality), the sexual activity of children and the act of having sex with children has been subject to increasing state intervention, legislation and control. The UK Sexual Offences Act, 2003, declared the sexual touching with any '*child*' aged 15 years or younger a criminal offence; albeit that there was no intention to prosecute every case of underage sexual activity (Cree 2008). Sexual intercourse with any person aged 15 years or younger constituted statutory rape (Sexual Offences Act, 2003). In addition, children under the age of 16 years can not legally consent to any form of sexual activity as they were deemed to lack the capacity to do so. However, they can seek contraceptive advice and

support from voluntary and statutory agencies and can seek a termination of pregnancy without their parent's or guardian's consent. The medical practitioner whom they consult must deem them to have the capacity to understand the consequences of their requests; legalised through Fraser Guidelines[2] (House of Lords and Department of Health and Social Security 1985). In part this guidance has been constructed as a professional defence against prosecution, but it attests to the ambiguous construction of children engaging in sexual activity

More recently, Solberg (1997) Glauser (1997) and Hart (1997) have reached similar conclusions from their work in Norway, Brazil and developing countries. Malinowski's (1916) work has been used to argue that sexual activity with children is natural. De-contextualising his work in this way is not only disingenuous but demonstrates scant regard for the cultural influences on the construction in disparate geographical locations.

Given the culturally and contingent nature of childhood, it is not surprising that there is a degree of ambivalence and ambiguity. To further this discussion I apply the concept of social panics to paedophilia and children's safety to demonstrate the construction of children as innocent incompetents. I then provide evidence of the contradictory position that constructs children, especially teenagers, as a group perceived to be out of control and a threat to the rest of society.

Social Panics

Social or moral panics arise when a growing social concern elevates a social problem to the category of a social panic. Cohen (1972) characterised social panics as "...*a condition, episode, person or group of persons which emerge to become defined as a threat to societal values and interests...*" (pg. 7). Agreed criteria for social panics include the presence of five conditions, concern; hostility: consensus, disproportionality and volatility (Zgoba 2004).

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[2] revised guidance available at
http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Publicationsandstatistics/Press releases/DH_4086804

The first of these, concern, relates to a consensus that a collective value or ideal is threatened. The second, hostility, relates to the hostile reaction of the public to the group perceived to constitute a threat to the collective and shared value (Goode and Ben-Yehuda 2009, Cohen 1972). The third category is consensus. Consensus indicates a shared acceptance that the perceived threat to a collective value by a particular group is real (Goode and Ben-Yehuda 2009, Zgoba 2004). This is followed by disproportionality whereby the response to the threat is disproportionate to the threat that actually exists. Finally, volatility refers to the sudden eruption of the perceived threat. These eruptions may be somewhat unstable over time, but repeated episodes serve to reinforce the threat as being real (Goode and Ben-Yehuda 2009, Zgoba 2004). In an extensive analysis of 3 highly publicised social panics, Goode and Ben-Yehuda (2009) revealed how each emerged from a '...social foundation, a dynamic...revealed in the inner workings of the society in which it took place...' (page 11). According to Goode and Ben–Yehuda (2009) moral panics are related to a collective perception of deviance associated with a particular section of the population that threatens a basic and shared value. An unintended consequence is that some adults become wary of working with children (ITV 2008, Roberts 2008, Piper, Powell and Smith 2006).

Concern

Paedophilia is an ill-defined concept. Listed as a psychological disorder that leads adults to have a sexual preference for pre-pubescent children, it is also used in every day parlance as shorthand for any adult who sexually abuses children. Paedophiles have become a cause for concern as they threaten children.

Hostility

Public reaction to the sexual abuse of children has undoubtedly changed over the last century (Cree 2008). Commenting on the changing attitudes to sexual abuse, Woods (2005) stated that:

"...children in the 1970s (as throughout British history) were more or less expected to look after themselves in matters sexual. Men who "fiddled with" schoolboys and under-age girls were still called child molesters, as they had been since I was a child. We were warned, darkly but vaguely, to robustly fend off any dialogue with the

kind of funny men who might offer to "show you something" as you walked home from school... [T]here seemed to be a distinction made then between low-level molestation ("fiddling") on the one hand and vicious sex crimes against children (rape and/or murder) on the other. There was also a distinction between "incest" and non-domestic sex crimes. Now everything is "paedophilia", the blackest crime on the books..."

It is against this background that I contend that those labelled as paedophiles have come to represent a deviant group in society which is perceived as a threat to the innocence and the future of childhood.

Consensus

As noted earlier, in order for a social concern to become elevated to a social panic the perceived threat needs to be accepted as real by other members of society. Often, the threat is promulgated by lobbyists or those who are considered to hold influential positions in a community such as leaders of religious groups and law enforcers (Goode and Ben-Yehuda 2009). These lobby groups garner public anxiety to gain support for action and often legislative control of the deviant group. More recently, the media (both print and broadcasters) has been implicated in the promulgation of public anxiety and public panic regarding crimes against children. As Zgoba (2004) noted: *"...the media captures hold of (sic) the story and continuously escalates the sensationalized aspects, bringing the occurrence from the ordinary, to the extraordinary..."* (pg. 388). In the United States of America, during one summer, high profile child abductions received constant press attention.

"... The media frenzy surrounding these publicized cases has created a 'fear factor' among parents and caregivers, begging the question as to whether the incidence of child predation has increased or whether the nation's heightened sensitivity is a result of increased media reporting. Nonetheless, the fear of child abductions and molestations has captivated the nation..." *(Zgoba 2004 pg. 386).*

In this situation, the media had promulgated the stories of child abductions to such an extent that the summer became known as the summer of abductions, creating high levels of public anxiety regarding what had been termed as an epidemic of crimes against children. Most people consider the death of a child to be a personal tragedy for the parents and other members of the family and community. The death of any child is considered to be a death out of time and considered as a significant

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loss of one of the most vulnerable and innocent members of any society. Arnold and Gemma (1994) have described the death of a child as the ultimate deprivation. Yet, not all child deaths receive the same scrutiny or press attention.

Disproportionality

It is worrying to note the scant attention paid to discovering the cause of death of many children and the under-reporting of children's deaths in industrialised nations. In 2001, the National Society for the Prevention of Cruelty to Children [NSPCC] (2001) published a study (an update of the, 'Out of Sight' report – NSPCC 1999) into the reporting of children's deaths between 1980 and 2000. The study highlighted a sharp decline in the media coverage of children's deaths caused by a family member, which in part was explained by a key change in news values; taken to mean that which was interesting or newsworthy. In addition, interviews with journalists revealed that the social class of murdered children (with those from lower social classes considered less newsworthy), the involvement of stranger danger or an element of horror were additional factors that would often result in intense media attention. Following this, the NSPCC commissioned a study into the attribution of cause of children's deaths in UK hospital settings (May-Chahal, Hicks and Tomlinson 2004). Undertaking non-participant observations in one city centre Accident and Emergency Department over a period of 3 months, the authors (social workers) reported a failure to learn from the deaths of children (whether they occurred within or outside the hospital environment); a lack of any systematic inquiry to exclude maltreatment as a cause or contributory factor in the death; and that when children survived maltreatment they become equivalent to those who did not experience life-limiting or life-threatening events. Although the scale of the tragedy seems heightened when the death of a child is the result of deliberate harm or neglect, May-Chahal, Hicks and Tomlinson (2004) highlighted the tangible difference in the public response to the death of children murdered by those considered to be deviant and the death of children in other circumstances.

The United Nations Children's Fund [UNICEF] (2003) published a report that drew attention to the gross under-reporting of children's deaths across industrialised

nations. The report revealed a startling 50% under-reporting of children's deaths in the UK. In addition, the report highlighted that 80% of people responsible for the abuse of children were biological parents. Other material conditions, such as poverty, stress, and drug and alcohol misuse, were highlighted as significant risk factors for abuse, yet these do not provoke public outrage.

This overt lack of attention and interest underlines the disproportionality in the media coverage given to the death of children who are murdered by a stranger considered to be deviant than to those murdered by a member of their family. This seems challenged only when the story contains an emotional twist such as when a father murders his children to punish an estranged wife or when the child is failed by safeguarding services. Recently, a report that was commissioned by the UK Government (Rose and Barnes 2008) to analyse more than 150 children's deaths between 2001 and 2003 that had been subject to a serious case review received scant press attention. Despite the number of deaths and subsequent investigations there was little evidence of any improvement in effective safeguarding practice (Rose and Barnes 2008).

In contrast, sensationalist headlines were used to portray and sustain a sense of public outrage when Jessica Chapman, Holly Wells and Sarah Payne were abducted and murdered. In each case, police enquiries unearthed a link between deviant adult sexual behaviour and the resulting violent attacks on the children. Daily blanket media coverage in newspapers, television and radio meant that the public was constantly bombarded with new hypotheses and speculation. In keeping with the five criteria for moral panics specified by Goode and Ben-Yehuda (2009), these murders (concern) added impetus to the calls for legislative powers to address growing concerns related to the threat to children from those constructed as deviant to the general population (consensus and hostility). In the cases of the children mentioned, the notion of paedophilia (deviance) coupled with sensationalist headlines and blanket media coverage appear to have combined to ensure that being murdered by a stranger sustained public anxiety and fear and therefore was

news-worthy (social panic). However, most children who are murdered are killed by a family member (disproportionality)

It seems that when safeguarding systems fail, blame is attributed to named workers who have failed to act on suspicions. In other words, blame is apportioned to front-line professionals charged with safeguarding children. Importantly, this blaming culture enables other members of the community to side-step any responsibility (Frost 2005). It seems that public inquiries into the murder of children are more newsworthy when there is an element of perceived madness (DH Inquiry 2003a), miscreant behaviour (DH 1994), sexual deviancy (Zgoba 2004), professional inadequacy (Rose and Barnes 2008), or horror (NSPCC 2001). Since then, the Children and Young Persons Act which received royal assent in 2008, has set out statutory procedures whereby all registered deaths of children (those aged less than 18 years) must be reported to the Local Safeguarding Children's Board; whether or not this will increase the public profile of all children and more importantly, lead to better practice, remains uncertain.

This discussion provides evidence that the construction of children as innocents is deeply embedded within the public psyche. However, it also points to the lives of some children being valued more highly and considered more newsworthy than others. In stark contrast to the perceived threat to children from paedophilia, concern that young people are out of control is also evident.

Children as a Threat

In a similar way to that of paedophiles, it appears that children, most notably teenagers, are increasingly feared, perceived to be out of control and in need of regulation (Morrison Gutman, Brown et al 2010). Madge and Barker (2007) assert that the media has played a prominent role both in pointing out the risks that children face and highlighting the risks that children present. Just as young pre-pubescent children are portrayed as being innocent, so too, young people are perceived as being innocent until they commit a criminal offence (Meyer 2007).

To explain further, there are some serious misgivings surrounding the issue of criminal responsibility as this can be used to determine the extent to which children are protected from prosecution. In the UK, criminal responsibility is used in two ways. It not only legislates the age at which children are considered to have the mental capacity to commit a crime but also legislates for the age at which children can be subject to adult prosecution and punishment. The age of criminal capacity and capability in England has been debated over the last century with many changes being made (Hendrick 2008, Cunningham 2006, Jenks 2005). It is also worth noting how the age for criminal responsibility differs around the globe. For instance, in England, children aged 10 years or more are considered to have the capacity for criminal intent, while in Scotland, children aged 8 years and above are considered be capable of criminal intent (though this is currently subject to review by the coalition conservative/liberal democrat government).

Prior to 1998, the presumption of 'doli-incapax' was used in England to convey the notion that children age 13 years and younger were incapable of criminal intent. It was incumbent on the prosecutors of any case to prove beyond reasonable doubt that children aged 10 to 13 years who were accused of criminal offences, had the capacity to differentiate between right and wrong. Importantly, knowing right from wrong was considered different to knowing that something was mischievous or naughty. Despite lobby groups pressing for children to continue to receive the full protection of the law up to the age of 14 years (Bandalli 1998), royal assent of the Crime and Disorder Act 1998 removed the presumption of 'doli-incapax' for children between the ages of 10 and 13. This meant that it was necessary for the defence team of any child aged 10 to 13 years to prove that the child did not understand the difference between right and wrong acts, and, puts the Crime and Disorder Act 1998 in direct conflict with legislation (notably the Children Act 1989) giving precedence to the welfare of children, and government policy claiming to champion children's welfare (Chamberlain and George et al 2010, Department for Education and Skills 2003). In addition, it failed to offer children the full protection of the law and was at odds with the drive to improve the family welfare system (Gillen 2006). Further

confusion and ambiguity was added when the law governing sexual offences (Sexual Offences Act 2003) set the age of capacity to consent at 16 years.

The legislative differences governing the age at which children can be held to account and give consent are evidence of the current ambiguity that surrounds childhood and the confusion that exists surrounding the categorical organising framework of age. It appears that an obsession with youth offending has taken precedence over the policy of promoting children's welfare (Pitts and Kuula 2005, Pitts 2003).

Overall, these examples lead to a pessimistic view of childhood in contemporary Britain. A view supported by the recent UNICEF (Ansell, Barker and Smith 2007) report into child wellbeing in member states of the Organisation of Economic Co-operation and Development [OECD]. Britain's children ranked in the bottom half in all 40 indicators purported to represent a matrix of children's well being. Children in Britain were ranked at the bottom of the league for happiness. According to Ansell, Barker and Smith, (2007), the UNICEF report highlights economic inequality as a key factor in the experience of many children in Britain. The findings paint a picture of neglect for many of Britain's children.

Added to this, Britain is one of only five European countries that legislate for corporal punishment. In 2008, the UK Parliament failed to endorse an amendment to the Children and Young Person's Bill that sought to outlaw smacking. In a ministerial statement[3], the then Minister for Children, Beverley Hughes justified this, stating that,

When we reviewed this issue...and surveyed parents, we found that while fewer and fewer of them are using smacking as a form of discipline, the majority said they wouldn't support a ban. This reflects the common-sense view that while smacking isn't a good thing, it should not be a crime... We are 100% committed to giving children the protection they need. We have already tightened the law to give children greater protection against assault in the Children Act of 2004, which removed the defence of 'reasonable punishment' to any charge of assault occasioning actual bodily harm or worse. Around the same time the bar for a charge

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[3] Available at http://www.childcare-matters.co.uk/cmblog/2008/10/why-the-government-thinks-it%E2%80%99s-ok-for-parents-to-hit-their-children-2/

of Actual Bodily Harm against a child was lowered because of their extra vulnerability.

Hughes' account is consistent with the government strategy of improving the plight of children by working with parents. As Balls (DCSF 2010) stated: '...*government does not bring up children, families do...*'. Still, this runs counter to the stated government philosophy of listening to and acting on the views of children (DCSF 2007). In contrast, Willow and Hyder (1998) were commissioned by Save the Children and the National Children's Bureau, to explore the views of 4 to 7 year old children with regard to smacking. Working with 70 children, Willow and Hyder (1998) reported that being smacked left them feeling 'horrible inside' and 'feeling worse' about their parents. The children also expressed their view that smacking did not work, and they suggested more appropriate punishments such as withholding pocket money or being sent to their bedrooms. A note of caution is needed here. The alternative suggestions given by the children convey the sense that the children which were included in the study had their own bedrooms and were in receipt of pocket money; not the case for all children. The findings of this study are consistent with the UNICEF (2003) assertion that adopting the principles of non-violence towards children would in turn help to remove the ambivalence towards children. They claim that ambivalence is in part fuelled by legislation that supports the use of corporal punishment (smacking) to discipline or correct children. Still, recent reports suggest a continuing tolerance for smacking children in the UK (Children's Society 2010, Singlet 2010).

In summary, it appears that public reaction to the murder and death of children, the assumptions on which the cause of death decisions are made, legislation that supports corporal punishment, and the criminalisation of youth behaviour all attest to the underlying values that are brought to bear on a pessimistic view of childhood in contemporary Britain. It is evident that there continues to be an uneasy relationship among the State, parents, the general public and children. At a time when there is a growing emphasis on participating with children and taking their views seriously (United Nations Convention on the Rights of the Child [UNCRC] 1989, Rose and Barnes 2008, DCSF 2007) there is a growing moral panic and public anxiety around

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children. This anxiety fits with Goode and Ben-Yehuda's (2009) and Cohen's (2002) criteria for moral panics, fuelled by lobbyists and resulting in exaggerated and disproportionate responses.

A consequence of this is that some people, especially men, are concerned that having a preference for work with children may render them guilty by association and there seems to be a growing reluctance on the part of adults to intervene with children thought to be in need of help (ITV 2008). In a paradoxical turn, this is fuelling public anxiety about the future of childhood (Darbyshire 2007, Cunningham 2006, Prout 2005, Postman 1994). This paradox is not new but reflected in historical analyses that have sought to catalogue the concept of childhood and children's experiences over time.

Child- Adult Relations: The UK Context

A central plank of the New Labour's government policy relating to children was that parents, not governments, raise children (DCSF 2007). The ideology that parents know best sits comfortably with the British tradition of the family as a private place, free from state interference (Fox-Harding 1997). Indeed the context of the family has provided the context against which historical artefacts related to children have been interpreted. The primacy given to parents' rights with regard to their children is important because it is the parents who have a particularly significant role to play in childcare, child-rearing and ultimately the decisions related to children. It is not surprising then, that the family is a highly-contested arena of government policy; especially when that policy is concerned with children and childcare. There has been a tendency to subsume the best interests of children within the women's rights movement, but there is increasing unease relating to the notion that all women and all mothers work towards the best interest of their children. This is perhaps most prominent when women are portrayed as 'standing by' or 'failing to protect' their children from harm caused by male partners. While a full review of the relationship between violence and control of women and the abuse of children is beyond the scope of this work, it is important to acknowledge that some mothers are rendered incapable of protecting their children (Howe 2005).

The abuse of women often precedes the abuse of children in the same home, and rather than being a place of safety, the home can become a risky place (Howe 2005). It is also known that women who suffer abuse from male partners also have a predilection for high stress and anxiety, mental health problems, social isolation and low self-esteem (Howe 2005). Combined, these factors render them either emotionally unavailable to their children or incapable of offering protection. There is also evidence that when children attempt to intervene and protect their mothers from abuse, the result is that they become a victim of the abuse themselves.

There is no unified critical theory; rather there is a constantly shifting understanding arising from dialectics (Burman 2008, Freire 1970). Yet, a common strand in critical work is that it attempts to reveal those things that matter to groups or individuals who have been silenced or oppressed by the interests of those who are more powerful. So, just as understanding and revealing gendered power relations has been essential to feminist critiques, understanding and revealing generational power relations is essential in work aiming to give precedence to the voices of children. Critical approaches that have been used so successfully to reveal new insights related to the lives of oppressed groups can be used to achieve similar results for children. A key difference is that adults will always be involved. Children's subordinate position to adults has been maintained through a number of structural mechanisms. Many underpinned by the seemingly natural order to the family, developmental psychology and the concept of chronological age. My discussion now turns to consider each of these.

For some authors the word child has largely been understood as a relational term (Mayall 2002). This means that it helps to distinguish between the relationship (relations) that individual children have with other children and adults (most often family members) to denote family relationships (through genetic descendancy, legal adoption, and, in some cases socially agreed arrangements). For instance, I am a sister, a mother, a daughter-in-law, a cousin, and an auntie. It is also quite usual for parents to continue to speak of their progeny as a child or children beyond adulthood, until the parents' death (Mayall 2002). Used in this way, the term offers

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little insight into the nature or quality of that relationship. It is possible that the emphasis placed on the relationship between parents and their children in western democratic societies; especially the relationship between the mother and her children; reinforces the emphasis on family and family relationships (a key criticism levelled at Bowlby's work by Burman 2008).

The children's rights movement, underpinned by the UNCRC (1989) supported the contention that children, if not oppressed, had been seen and treated, not only as the property of their parents but also as a subordinate group in society. This subordination had in part been reified by the dominant position given to the discourse of cognitive psychology. Other academics have reached similar conclusions (Fox-Harding 1997).

Children and Cognitive Developmental Psychology

Psychological cognitive development has been a pervasive and influential branch of academic research with regard to understanding children's development. As such it has had an enduring influence on both lay and professional understandings of what is to be a child.

It was during the 1950s that the groundbreaking work from psychologists such as Piaget became popularised. Piaget (1976) is considered by some as the founding father of cognitive development theory. He sought to discover the relationship between:

- the biological age of children and different stages of cognitive
- development
- the necessity of meeting current needs to protect future development
- the importance of a stable family.

Attempting to establish a grand theory relating to the development of children's thinking, he suggested different stages that egocentric infants would traverse on their journey to becoming sophisticated and more socially capable thinkers; according to Piaget, the marker for this achievement is the ability to engage in abstract conceptualisation. His work was instrumental in pointing out the similarities

in cognitive development amongst children of similar ages. Piaget was quite insistent that intellectual development was a universal and continuous process separated by discrete stages; each distinguished by different behaviours (Donaldson 1978). Donaldson (1978) points out how Piaget's intention was to:

"...discover and explain the normal course of development. For he believes that there is (sic) a normal course, a sequence which we all follow though we go at varying speeds and some go further than others..." (pg. 130).

Drawing on the concepts of 'assimilation' and 'accommodation' he attempted to establish that children did not simply react to their environment but rather that they took action in order to change. Piaget emphasised human re-activity. For Piaget then, accommodation and assimilation were indissoluble and resulted in the necessary adaptive changes to survive (Donaldson 1978). In this way he cast children as reactors. Donaldson selected two interesting exemplars presented by Piaget to further her critique of Piaget's meaning. In the first, make-believe play is offered to illustrate the concept of assimilation, whereby a child can use something - such as a piece of wood - and, through imagination uses it to represent a different thing, like a doll (Donaldson 1978 p134). By comparison, the concept of accommodation is illustrated through recourse to imitation. For this, a child will attempt to copy the behaviour of others that they have observed in the same environment (such as copying someone who is ironing). The importance of these constructs to Piaget's final thesis was that they explained the processes through which a young infant develops cognitively in order to de-centre themselves from the rest of the environment.

A central feature of Piaget's argument was the notion that each stage of cognitive development followed on from the previous one and that all children followed the same pattern of development. According to Piaget, the completion of a lower-level stage was necessary before reaching the next which was considered to be more complex along a hierarchy of thinking as the following excerpt illustrates.

"...If we divide behaviour into three main systems, organic hereditary structures (instinct), sensori-motor structures (which may be learned), and symbolic structures (which constitute thought), we may place the group of sensori-motor displacements at the apex of the second of these systems, while operational groups and groupings of a formal nature are at the top of the third..." (Piaget 1952 pg.132)

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In this way his work provided a seemingly natural order to the development of cognition and understanding; his main thesis that development must precede learning.

In contrast to Piaget's theory, Vygotskiĭ's (1962) work on intellectual development contended that learning preceded development. Although Vygotskiĭ's work developed around the same time as Piaget it was only published posthumously in the west in 1962. A central tenet of Vygotskiĭ's work was the *more knowledgeable other'*. For Vygotskiĭ, the age of the *'more knowledgeable other'* was of no concern. What mattered was that they were more knowledgeable with regard to what the child wanted to or needed to learn. Vygotskiĭ is credited with developing social learning theory. Social learning theory recognises culture and social interaction as fundamental to cognitive development. Vygotskiĭ (1962) pointed out the need to 'scaffold' children's learning and interaction by matching tasks to their current competence. Importantly, Vygotskiĭ's work is often cited in support of the need to use talking strategies and to hold conversations with children. He also stressed the importance of play and allowing children the opportunity to follow their own interests and ideas. In contrast, Piaget's research approach has been criticised for casting children as research subjects, limiting the possibility of any acknowledgement that they contribute to their own development (Burman 2008).

That Piaget's work made a valuable contribution to cognitive developmental theory is clear. Piaget (1976), Donaldson (1978), and others working in the field have made significant scholarly contributions to modern thinking about children. What is questioned here is the dominance that this work has had in influencing structural components that are used to control and manage the day-to-day lives of children in the UK.

This enduring influence is such that many of the constructs included in Piaget's work have been popularised to such an extent they have become almost taken for granted, naturalistic and biologically determined. Piaget's work in particular and later

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Donaldson's (1978) adaptations have been extremely influential in casting children as a homogenous group. Despite this, Piaget's work has been criticised for being too dominated by western constructs and lacking in techniques sufficiently sensitive and more suited to the abilities of the children with whom he worked (Burman 2008, John 2003). Other criticisms point to the lack of contextually appropriate experiments (Burman 2008, John 2003). When tested using experiments designed around familiar objects and experiences, many children proved to be far more capable than Piaget had reported (Donaldson 1978). Nonetheless, Piaget's work has in part, ensured that age continues to be the dominant category by which to organise the lives of children (see Mantle and Leslie et al 2006).

Developed from evolutionary biology, the notion of a hierarchy of thinking that develops over time had become strongly associated with chronological age. As already noted, Piaget's (1976) work had been instrumental in conveying the sense that the stages of cognitive development are invariant and naturally determined. The enduring influence of Piaget's work can be seen in educational principles that are used to organise school systems and the dominant teaching and learning approaches used with children of different ages. Developmental psychology is used by health visitors and public health nurses in the UK to assess and judge the adequacy of children's attainments. Despite the cited ages by which each child would progress through each stage of intellectual development being intended as averages, (Donaldson 1978) these have become established as milestones against which children's development is judged. Perhaps more importantly, failure to demonstrate the required behaviour by a certain age is often used as an indicator of possible pathology and evidence for being cast as being different to other children. In the context of this work, initial nursing assessments of children and subsequent communication and intervention may rely heavily on Piaget's framework. In addition, Piaget's work underpins many of the UK nursing models and frameworks for work with children (Casey, 1988, MacDonald 1988, and Clarke 1988).

Burman (2008) and John (2003) have published rigorous critiques of developmental psychology, the associated experimental research techniques and generalisations

founded on what they termed culturally blind observations. John (2005) argued that children are much more than active-reactors trying to adapt to environments. She asserted that children interact, influence and shape the world in which they live. She argued that if adults listened more to children's views, gave more importance to their interpretations, accepted them as different but equal in their claim to rights and protection, the lives of many children would be improved. She is not alone in this assessment (Roberts 2008, Cunningham 2006, James and James 2004, Mayall 2002, James and Prout 1997). The importance of this analysis is that it highlights the way in which the discourse of cognitive development has been sustained through modernity and exerted a powerful influence on many current policies and processes concerned with children (John 2005, Prout 2005).

Despite recent changes and the emergence of a new orthodoxy acknowledging children's agency and their right to be involved in all matters that affect their lives (Prout 2005, James & James 2004, UNCRC 1989), many researchers continue to rely heavily on age to differentiate between children. Such is the dominance of age as a category by which to structure the lives of children, that it seems perverse to question its functionality as an organising framework. However, as a one-dimensional concept, age offers little more than a simplistic way of understanding children. On its own it provides an inadequate conceptual model to direct effective work with children.

Age as an Organising Framework

In keeping with European and other western democratic countries, age is used in the UK as a dominant category to organise and shape the lives of children. Terms such as newborn, infant, preschool, school-age, adolescent, and young adult are just some of the common labels or categories used to structure many aspects of the social world for children. The inadequacy of age as an organising framework is easily established by demonstration of the controversies that surround its use. In legal terms, the term child is used to distinguish between those who have reached the age of majority (right to vote). This separates them from those who are still (in law at least) minors; albeit the age of majority differs between countries. In England

and Wales the age of majority was changed from 21 years to 18 years, while in Scotland it was changed to 16 years (Her Majesties Revenue and Customs 2010). While useful, for some purposes, such as the right to vote, age is at times unhelpful as it denies the reality that children progress, develop and mature at different rates and at different times. This is especially pertinent in relation to the children's experience of chronic health and repeated admissions to hospital (Alderson 1993).

Despite being little more than a numerical index, chronological age subordinates alternative socially constructed and historically significant concepts (Aaopola 2002). Taking a critical view of chronological age, Aaopola (2002) invited 88 young Finnish people aged between 15 and 16 years to write essays on their experiences of growing up. Using a discourse analysis she was able to illustrate how the young people used many varied, competing and complementary concepts for age that were often interrelated but also oppositional. The final analysis revealed the importance of subjective and contextually embedded experience and that age was experienced as a shifting phenomenon influenced by cultural, social and temporal structures. Age emerged as a concept that was fluid and contextually related to place, space, time and the others involved in the event or interaction, and subjectively interpreted. In their essays, the young people drew on different constructions of age in unique and complex ways that made it difficult to separate out clear distinctive categorical concepts. Despite this, Aapola (2002) was able to organise the identified concepts into a series of dimensions; cultural/social; biological/physical; experiential; and symbolic (with the latter including ritual and functional sub categories). In fact, the young people in the study acknowledged the necessity of using chronological age as a marker to restrict their access to certain activities. For instance, some of them understood the necessity to restrict their access to alcohol by using age to inform law. They understood this as promoting their safety and health, and protecting them from unwanted consequences. The addition of symbolic age incorporated notions of the ritual and functional aspects of growing up.

However, despite the rigour of her arguments, the contradictions inherent in her work are immediately apparent. Given her appeal to the necessity for alternative organising concepts, she is a victim of her own critique. Using chronological age as an organising framework for her own study and describing her participants by age turn her own arguments against her work. That said, and given my own experience, the dominance of chronological age as an organising structure is so pervasive that it is almost impossible to communicate meaning or speak about children without recourse to it. It is possible that the use of the term young people offers a useful alternative to convey a different set of assumptions than those conveyed by the term child. However, I would sound a note of caution as this may do little more than make it more difficult to work with all children. Age is an inadequate tool for the purpose of assessing children's competence, knowledge and understanding. Nevertheless, key stakeholders and gatekeepers to children and young people are often firmly wedded to chronological age as an organising framework.

To conclude this section, UK legislation in support of corporal punishment (Singlet 2010), the criminalisation of youth behaviour (Gillen 2006), and the public response and media reporting of children's deaths (NSPCC 2001) attest to the underlying values that are brought to bear on the construction of childhood and what it is to be a child in the UK. This analysis underlines the ambiguous, ambivalent and fluid positioning of children in the UK as elsewhere. However, the emerging orthodoxy, that of children as social agents (Christensen and James 2008, Prout 2005, James and James 2004) is increasingly visible in policies generated to support the notion that children should be consulted, listened to, taken seriously and have their views acted upon. From the 1980's onwards, the theoretical position of children as social agents has been gaining support but more recently, research evidence has been providing a strong foundation on which a new sociology of childhood is being constructed (for examples see Hart 1992, Mayall 2002).

The view of children as social agents is enshrined in the UNCRC (1989) and is clearly evident in the current policy directing the care of children in hospital (Department of Health [DH] 2003a). A central tenet of this policy is that all children,

regardless of their ability, age, ethnic background or social class, have the right to express their views on what happens to them and to have those views taken seriously by the adults delivering services. It is contended here that participation[4] and involvement with children can be used to help nurses improve the experiences of children in hospital. The benefits that accrue from participation are evident. Mantle and Leslie et al (2006) note how children's participation in the care system is thought to provide a means of improving their safety. Badham (2004) found that participation enabled leadership for disabled children and Dev Griesel, Swart-Kruger and Chawla (2002) reported that children's participation had a positive impact on their environment and living conditions in South Africa. Hill, and Davis et al. (2004) go further by asserting that there is a strong positive relationship between children's participation and social inclusion. It is reasonable to assume that participating with children in hospital to discover and understand something of their experience may benefit other children in hospital.

Children in Hospital

The initial search for research evidence for this section was limited to that published in the English language from 1950–2005. CINAHL, Psych-Info and PubMed databases were searched using child; children; paediatric, pediatric, hospital; experience, children's nurses; voice; views; perspectives as key words to identify relevant literature. In addition, citation-tracking and hand searches of journals not identified by the electronic databases were performed.

This section of the literature review begins with consideration of the number of children admitted to hospitals in the UK each year. I then consider the work begun in the 1950s by John Bowlby and James Robertson related to attachment and loss. Fifty years later there has been some rigorous academic criticism levied at their work (see Burman 2008). That said, their insights led to a radical re-thinking of child adult relationships. This had an enduring impact on policy directing the care of children in hospital. I then turn to consider the development of policy directing the care of children in hospital. Finally I present a critical discussion of the research

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[4] A consensus on the definition of participation remains elusive, in this work the term is used to represent the involvement of children at any level

regarding the experience of children in hospital; highlighting the lack of knowledge derived from children's subjective insights.

In the UK, children and young people[5] account for 19% of the total population. Each year, 20% of children attend accident and emergency departments, 700,000 have at least one overnight stay, and 300,000 attend for day surgery (National Statistics Online [ONS] 2003). In addition, many children admitted to hospital have complex healthcare needs with a significant proportion requiring highly technical interventions. Regardless of the appropriateness of the hospital environment, some children stay in hospital wards for lengthy periods of time (Health, Social Services and Public Safety 2007, Noyes 2000). It has been argued (Coyne and Livesley 2010) that children in hospital are particularly vulnerable because of their illness, their stage of physical, intellectual and emotional development, and because they have so little control over what is happening to them. Given this, it is important that those who work with children in hospital understand the consequences and potential impact of hospitalisation from the perspective of children and their families (Healthcare Commission 2007a).

Attachment and Loss

Trying to understand children's experience of hospitalisation can be difficult as it rests upon a series of complex and inter-related factors. However, John Bowlby's theory on human attachment and loss offers insight and explanation as to why hospitalisation can be so traumatic for children and their families. Attachment theory was the life work of Bowlby (1975-1990). Bowlby, an eminent psychologist, examined the impact on growth and development into adulthood of how young children experienced the relationship between themselves and their attachment figures. In other words, he studied child-adult relations. Attachment theory is particularly useful in the context of this study as it is considered to be universal and applicable in different contexts. In addition, it provides theoretical insight into the experiential impact of attachment behaviour and the way in which children may signal a need for care. To fully appreciate the importance of attachment theory to

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[5] Hereafter in this work the term children is used to denote children and young people

children's experiences as in-patients in hospital, the theoretical constructs on which the theory stands warrant further discussion.

An attachment figure can be defined as any person with whom the child has an emotional bond. Attachment figures are most often the child's care-givers. An important facet of the relationship between a child and their attachment figures is how the child will seek out or search for their attachment figures when they are feeling fearful, frightened or anxious (Ainsworth 1989, pg.711). This means that the child will seek out physical and emotional closeness to their attachment figures when they are faced by strangers, strange places or strange situations (Ainsworth 1989, pg.711). Admission to hospital potentially confronts the child with all three.

Understanding the relationship between an attachment figure and a child is a central part of attachment theory, however, it is also necessary to understand attachment behaviour. For Bowlby, attachment behaviour was activated when a child was confronted by a stranger, strange place, fear, darkness or separation from their attachment figure. Active attachment behaviour focused the child's attention of seeking and maintaining proximity to their care-givers. In other words, attachment behaviour was the term used to describe how the child signalled a need for care. Should the child's attachment behaviour remain ungratified (or unfulfilled) by the close proximity of their attachment figure, the child may 'collapse into distress' (Bowlby 1975, pg. 209).

The three terms used to identify adaptive styles of attachment behaviour were secure; ambivalent and avoidant. More recently, a fourth category, disorganised, has been added to describe the attachment behaviour of children who have been unable to do anything to provoke the required response from their attachment figure (Howe 2005).

For my work, observing how the children interacted with and gained the attention of adults when they were on their own became an important element of understanding their experience of hospital. Perhaps the greatest limitation of Bowlby's work was

the inattention paid to the relationship, and how this developed over time, between children and care-taking adults and those who care for children during separation from their attachment figures. This later became the focus of Robertson's work (Robertson and Robertson 1989). Understanding this relationship, especially when children feel threatened is particularly important in the context of children in hospital as many of them are alone and distressed when inpatients (Roberts 2010, Cleary 1992, Hawthorn 1974). It is also important to note that physical presence is no indicator of the emotional availability of care-givers (Howe 2005, Bluebond-Langner 1978, Bowlby 1980) and that emotional support may be what children need most.

Sroufe (1998) explained that children's experience of their relationships with their attachment figures or care-givers can exert a powerful influence on their concept of 'self' and in turn their 'self value' in relation to others. According to Sroufe (1998), these internal working models (or mental representations of self) enabled children to construct mental representations or working models of how they perceived their value to others. In turn, this translated into how they valued themselves and set the course for how they would grow and develop a sense of self. In this regard Bowlby's work was ahead of its time. The concept of internal working models or mental representations acknowledged the child's social agency (the ability to act independently and make choices). This meant that these working models were organised by the children rather than the other way around. Because of this central tenet in Bowlby's formulations, his work is easily reconciled with Vygotskiĭ's (1962) concepts of developing cognition. Vygotskiĭ also considered children as active social agents that influenced their environment.

Whilst criticism can be been levied at Bowlby's work, the recognition of children's agency was an important facet of his work; in other words, his recognition that children actively participated and influenced what happened to them (Howe 2005). Attachment theory became pivotal to understanding the needs of hospitalised children as it provided a powerful theoretical lens for the critique of hospital practices in the 1950s.

Subjective evidence in support of Bowlby and Robertson's work is apparent in the personal stories told by many adults admitted to hospital as children; as one 40 year old man who had been in hospital as a child and needed to endure painful aspirations of pus recalled;

"...looking back on this experience from a distance of forty odd years it is surprising how serene my memories of it are compared with the memories of the rest of my childhood. I endured many discomforts of weekly aspiration of pus... but this has not left a mark...I remember my mothers first and only visit far more vividly...I returned home an alien. I held a passport but it had ceased to be valid..." (Cleary 1992 pg.11)

It is clear then, that any event that disrupts a child's mental representation or inner working model of attachment may go on to exert a critical influence on how children trust or mistrust their attachment figures. Hospitalisation is one such event, and attachment theory, especially Robertson's work, was fundamental in the campaign for better standards of hospital care for children. In addition, attachment theory offers some insight into individual children's ability to signal their need for care.

Impact of Hospitalisation

Even short periods of hospitalisation are known to have adverse effects on children, their siblings and their families (Shields 2001, Callery 1995, Sylva and Stein 1990). Specific factors that heighten these risks include age (with younger children far more likely to suffer adverse effects of hospitalisation) and the duration of stay in hospital (Wright and Stewart et al 2007). The exact impact of duration of stay is contested, with some researchers reporting that children with stays of 2 to 3 days exhibit more statistically significant negative behaviours after discharge than those with shorter or longer stays (Wright and Stewart et al 2007). These research estimates suggest that as many as 60% of children suffer from negative impacts such as nightmares, separation anxiety, aggression towards authority, and an increased fear of hospitals and doctors (Kain and Ming Wang et al 1999, Wright and Stewart et al 2007). Whilst these negative effects are thought to diminish over time and to have largely disappeared by 2 weeks, some researchers have noted much longer impacts for some children (Kain and Ming Wang et al., 1999). Since, Rennick and Johnson et al (2002) and Nichols (2004) have reported that children discharged from intensive care units exhibit signs of post traumatic stress and that some show

diminished intellectual and social functioning and possible immunological incompetence.

Most of the work in this field has been undertaken by anaesthetists in an attempt to discover interventions that would not only diminish the negative effects of hospitalisation but assist in successful induction of anaesthesia (Wright & Stewart et al 2007). A common feature in all of the studies cited was the use of validated instruments such as the Post Hospital Behaviour Questionnaire, the EASI Instrument of Child Development; the State Trait Anxiety Inventory; and the Modified Yale Pre-operative Anxiety Scale (for an example see Kain & Ming Wang et al 1999). These instruments have been used as observational tools by researchers or used as self report instruments by parents. None of the cited researchers reported any attempt to elicit the children's perspective on their behaviour or experience.

Similar quantitative research approaches are notable in work undertaken to assess hospitalised children's coping strategies (for example Savedra and Tesler 1981). The work of Savedra and Tesler (1981) involved non-participant observations using a pre-determined checklist of children's behaviour, during which they adopted some techniques that are difficult to reconcile with ethical practice. For instance, they reported that observers were to ignore children who attempted to talk to them or to give non-committal answers to questions.

Working some 13 years later, Spirito, Stark and Tye (1994) were among the first to elicit first hand from children what mattered most to them. This was then used to examine their coping strategies. Similarly, Board (2005) sought to elicit children's subjective responses on discharge from a children's intensive care [CICU] to a general medical ward, regarding anxiety, stress and coping. For this reason, both studies are considered in more detail later in the literature review section of this chapter.

Concern for the Welfare of Children in Hospital

Concern for the welfare of children in hospital is not limited to the UK. Attempts to improve the experience of children admitted to hospital is evident in many countries including Sweden, Australia, Canada, United States of America [USA] (for examples see, Runeson, Martenson and Enskar 2007, Shields and Nixon 2004, Espezel and Canam 2003, Burns 1994, Beuf 1978). There have also been attempts to influence the care of children in hospital across national boundaries. In 1998, 12 voluntary organisations from different European countries held the first conference concerned with the care of children in hospital. During the conference held in the Netherlands, a rights-based charter, consisting of 10 articles, was agreed. In 1993, the European Association of Children in Hospital[6] [EACH] an umbrella organisation concerned with promoting the best interests of children before, during and after hospitalisation was formed. This organisation adopted the charter (since known as the EACH Charter for children in hospital). EACH is made up of 17 associations and 8 members from 20 European countries (plus 1 association from Japan). The EACH Charter was updated in 2001, and is consistent with the UNCRC (1989). The charity, Action for Sick Children (formerly National Association for the Welfare of Children in Hospital) is a listed member from the United Kingdom. NAWCH was instigated by James Robertson; his work and the contribution and influence it has had on the care of children in hospital is considered in the literature review of this chapter.

The most recent international collaboration is the International Network of Health Promoting Hospitals and Health Service. The Task Force on Health Promotion for Children and Adolescents in and by Hospital and Health Services, [HPH] (2010) has recently published their final report on the implementation process of the self-evaluation model and tool on the respect of children's rights in hospital. The report detailed the progress made over 6 years to develop a self-assessment tool based on the theoretical components of non-discrimination, the best interests of the child, life, survival and development, and the respect for the views of the child. The four-phase tool (mapping, planning, making improvement and evaluating change) is a

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[6] Information about EACH is available at http://www.each-for-sick-children.org/about-each

rights based transformative model that places the views and opinions of children at the centre of the assessment and change process. Although the pilot work is encouraging it is worth noting that none of the participating organisations felt able to engage with children on the statement concerned with the right to a dignified death. Adoption of the tool across the range of children's hospital services is as yet uncertain and many challenges remain. Not least working towards full participation with dying children (and those who are acutely and critically ill) to ensure that their voices are central in the shaping of care and services they receive.

In the UK, concerns for the welfare of children in hospital has led to education programmes specifically designed to equip nurses with a raft of skills and competencies that enable them to assess, plan and evaluate care interventions (Smith and Long 2002, Price 1994) in line with the UNCRC (1989). Originally developed to support paediatrics as a special branch of medicine, children's nurses emerged to provide effective care of sick, hospitalised children (Miles 1986). Sick children's nursing, renamed as registered nurse (child) in the UK, emerged as one of the four pre-registration branches of nursing in the overhaul of nurse education (commonly referred to as Project 2000). The recent review of pre-registration preparation has also determined that children's nursing should remain as a specific branch in

undergraduate nursing programmes (Nursing and Midwifery Council for Nurses, Midwives and Health Visitors[7].

Regardless, the National Commission of Inquiry into the Prevention of Child Abuse [NCIPCA] (1996) identified institutions charged with caring for children as a significant risk factor for child abuse. Hospitals, along with children's homes and schools represented particular concerns, with the inquiry pointing to the *continual emergence of scandal of child abuse in such centres*'. Drawing on work undertaken in the United States of America [USA] by Gil (1982), Kendrick and Taylor (2000) defined this in terms of programme abuse, whereby standards that fall below those normally acceptable are tacitly accepted and remain unchallenged. Unfortunately,

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[7] Available at http://www.nmc-uk.org/About-us/Policy-and-public-affairs/Politics-and-parliament/PMs-Commission-on-the-future-of-nursing-and-midwifery/Review-of-pre-registration-nurse-education/

the factors that contributed to the tacit acceptance of unacceptable standards remain unclear. Still, the lack of appropriately prepared nurses in particular continues to be cited as an important contributory factor in child health care scandals (Healthcare Commission 2007, DH 2003b and 2001c). Yet inspections of hospital services for children continue to report failings in the services provided (CQC 2010a, 2010b). The CQC (2009) has recently reported the findings of inspections of 2 children's tertiary referral centre in England. They identified that the trust was failing to keep children, their visitors and workers safe from hospital-associated infection and that the standard of education update for nurses in the management of basic and advanced life support was declining. Shortfalls from another inspection of children's tertiary referral centre (CQC 2010) reported further shortcomings. This suggests that little has changed, and for some, this is tantamount to child abuse (Kendrick and Taylor 2000, Hobbs and Heywood 1997).

Children's Experience as Hospital In-patients

Van der Horst and Van der Veer (2009) have been instrumental in challenging the notion that Bowlby and Robertson were the sole and first pioneers to lobby for improved conditions for children in hospital. The evidence they present in support of this is valid. However, their work is limited as:

"we decided to ignore the various nursing journals (e.g. Nursing Times, American Journal of Nursing, Nursing Research) because they were difficult to access and only seemed to repeat the arguments in the medical journals. Also, it seems probable that it was the medical doctors, and not the nurses or sisters, who made the decision to experiment with different hospital practices..." (pg. 36).

What follows here highlights not only the inadequacy of their approach but that their analysis is incomplete and therefore flawed. Following on from the tradition of observing children in hospital (Robertson and Robertson 1989) nurses' research concerned with the experience of children in hospital has been dominated by field work studies.

Concern for Unaccompanied Children

In the UK, Hawthorn's (1974) classic field work study drew attention to the experiences of children who were alone in hospital. Adopting a non-participant

quantitative field work research approach, she used 4 observers to code nurses' and children's activity against a pre-determined, structured schedule in one London children's hospital ward. Hawthorn acknowledged that codes relating to children sitting on beds, or standing up were of limited value and those more meaningful codes for happy versus discontented children defied definition. There are other limitations and weaknesses inherent in her work. For instance, sleeping children were coded as content. It is no longer accepted that a sleeping child is content or pain free. In addition, confidence limits were not computed as the necessary data to calculate these was unknown. Suspect inter-rater reliability of the observers also calls the findings into question. However, she concluded that children were observed alone for 38% of the time, with older children spending more time alone than youngsters. Children who were alone were observed as 'miserable and alone' for nearly 10% of the time they were observed. Significantly, children with parents were categorised as miserable for less than 1.5% of the time (p=0.001). In spite of the limitations of Hawthorn's work, her findings provided further evidence in support of allowing parents to stay with their children in hospital. Yet, insight from the children's subjective experience regarding this is neither considered nor sought.

Cleary (1992) published the findings from a quantitative study that sought to evaluate a care by parent scheme in Wales. As part of this she also used non-participant observations of children in hospital to examine how they spent their time. She categorised children into either, a non-resident parent group, a resident parent group or a care by parent group and; using 5 minute activity sampling and 20 case studies of children watched continuously for 5 minutes in every hour; she reported that children without a resident parent spent up to 60% of their time alone. In comparison, in the group classified as having a resident parent, 1 child was observed alone for 50% of the time. In the care by parent group, children were alone for between 20% and 42% of the time. Cleary's findings revealed that many children spent a significant amount of time alone. Her work also suggested that relying on parental residency was insufficient in ensuring that the needs of all children were met. More alarming was the reported observation that when alone, children were considered to be distressed for 30% of the time. Limitations of Cleary's work include

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the difficulty of defining the concept of 'alone' in the context of a multi-bedded ward and a failure to elicit the children's perspective on what was going on. Nonetheless, qualitative diary entries made by the observers revealed that some children struggled to get the attention of nurses, especially when they needed the toilet, with several children becoming quite distressed. Again the children's insights were neither sought nor considered. Although Cleary's work was published 18 years after Hawthorn's study, it seemed that little improvement had been made.

In a recent rigorous phenomenological study that sought to explore the experience of parents who stayed with their children in hospital, the need to help unaccompanied children emerged as an important part of the parents' experiences (Darbyshire 1994). Similarly, Callery's (1995) study into the experiences of nurses and parents working together revealed resident parental concerns for unaccompanied children. Still, neither Callery nor Darbyshire sought to elicit the views of the children who were the subject of these observations.

In the UK, Kari, Donovan and Taylor (1999) sought children's views on hospital services. They reported a 58% response rate to a survey of children (aged 12–18 years) in 3 north London state secondary schools. A key strength in their work was that the children completed the questionnaires themselves. They reported that 30% of the respondents had been admitted to hospital after the age of 13; 58% of these were admitted to a paediatric ward and 20% to an adult ward. More than 50% of those admitted to a paediatric ward and 75% of those admitted to adult wards were unhappy being accommodated with either younger or adult patients. Beyond this no findings relating to their experiences as inpatients were reported. Nonetheless, this work signalled a shift to the consideration of children's views.

Children's Views on Being Hospital In-Patients

Spirito, Stark and Tye (1994) had previously sought to discover what worked well in what circumstances for chronically ill and acutely ill hospitalised children, focusing on stressors and coping strategies in the USA. They recruited 54 chronically ill children and 71 acutely ill hospitalised children. All were told that the researchers

were '...*trying to find out how children deal with different problems when they are in the hospital.* They asked the children to think about a situation that had bothered them since they had been in the hospital. The children then described the problem to the researcher before being asked 3 additional questions; did the situation make them nervous or anxious; sad or depressed; mad or angry? Replies were recorded using a 5 point Likert scale.

The children were then asked to complete the Kidcope questionnaire (Spirito, Stark and Williams 1988) that had been designed to evaluate 10 cognitive and behavioural coping strategies. Of note was the finding that older children (adolescents) selected illness related problems and that younger children selected pain related problems. A lack of privacy and disrupted sleep was noted by the children in the chronically ill groups. Although dominated by the interpretation of adults, this work indicated that there may be important differences in the ways that children with chronic and acute illness experience hospital.

Board (2005) recruited 21 children aged between 7 and 17 years who had been admitted to children's general medical unit following discharge from a children's intensive care units in to large metropolitan hospitals in the USA. Using Lazarus' theories of stress and coping as a theoretical framework, her study asked 4 questions, each answered by data collected in one of three ways. The first question involved recollections of being in the children's intensive care unit (structured interview using open ended questions developed from her personal experience of working in children's intensive care unit and Lazarus' theoretical perspectives and previous research with hospitalised children). The second was an examination of the frequency and effectiveness of school-aged children's coping strategies immediately after discharge from the CICU (administration of the Schoolagers' Coping Strategies Inventory developed by Ryan-Wenger 1990). Of note in this was the inclusion of the item – do work around the house. The explanation for including this item was that it was necessary to '*preserve the integrity*' (rather than validity) of the instrument. That said, all children answered 'never' to this item suggesting it that it did not skew the findings. The third question attempted to establish the children's

level of anxiety immediately following discharge from the CICU (the children were asked to draw 'a person in the hospital' that was later assessed using Clatworthy, Simon and Tiedeman's (1999) assessment tool to measure the emotional status of hospitalised school-aged children) The fourth related to the identification of relationships between variables such as demographics, emotional status, hospital experience and recollections (statistical analysis). Whilst these instruments all pre-determined what mattered to children, Board (2005) attempted to elicit a firsthand response from the children. The children's parents chose whether or not to stay with the children during the data collection activities but they were 'instructed' not to talk to their child or comment during the process. Both Spirito, Stark and Tye's (1994) and Board's (2005) studies went someway to elicit children's perspectives but this was tempered by the use of adult constructed instruments to assess the children's reports and a failure to report any qualitative insights derived from the work with children.

In contrast, some researchers had undertaken research to elicit the subjective views of children about hospital care Curtis and Liabo et al (2004) and Carney and Murphy et al (2003). Carney and Murphy et al (2003) used 1 of 4 randomly allocated questionnaires to collect the views of 213 school aged children immediately prior to discharge from 2 district general hospital. They concluded that the verbal structured was the most useful and elicited the most meaningful data. They reported that the older children identified the environment as most the most important factor, and that younger children identified continuity with care givers as most important. They suggest this is due to their separation anxiety though no further evidence in support of this is given. Curtis & Liabo et al (2004) undertook a qualitative study working with 92 children, (57 of whom were consulted in hospital wards or out-patient departments) suing interviews. Commissioned by a UK London Borough, Curtis and Liabo et al (2004) highlighted the importance that the children accorded to communication, relationships, environment, courtesy and respect. These were considered to be fundamental aspects of what worked well and what needed to be improved in the care of hospitalised children. Of particular note were the researchers' comments that feedback to hospital clinicians and managers indicated

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that they had long known of the issue raised by the children but had yet to act on any of this knowledge. This suggests that the work had been commissioned as a token gesture to seeking the views of children. Battrick and Glasper (2004) analysed the results of questionnaires from 50 families following the discharge of children from a children's acute unit. While there were a number of limiting factors to the trustworthiness of the findings (for instance a low response rate and difficulty in ascertaining how many children completed the questionnaire alone), the researchers reported that the parents were very positive and complimentary regarding the care that their children received. In contrast to the findings reported by Carney and Murphy et al (2003) that the children who participated in their study were more positive than other findings reported in the literature, Battrick and Glasper (2004) reported that the children were more candid in their views than their parents. This suggests that children's interpretation of their experiences differs from that of their parents. None sought to work with children during hospital procedures or during the children's acute phase of illness.

In contrast, Beuf (1978) and Bluebond-Langner (1978) had both sought to align themselves with children in hospital by undertaking field-work in the context of hospital wards in the USA. Beuf's (1978) qualitative ethnographic study of children in hospital was underpinned by her contention that '...*the treatment of a child in the hospital is, in part, a crystallization of the ways American children are treated in general...*' (pg. 2). Her stated intention was to raise important issue rather than put them to rest. Arguing that not all children in the USA were considered to be incompetent,[8] she stated that generally they were considered to know less than adults. Setting her work in the context of Goffman's (1961) treatise of asylums as total institutions (Beuf 1978), she undertook field work participant observations in 2 hospitals between 1971 and 1972. Importantly, Beuf positioned herself as an adult visitor and a worker with the play therapists. Claiming that lack of information sources left children ignorant of what went on in hospital, she highlighted episodes of parents being corralled by staff to force children's compliance. She also pointed out that parents located the responsibility for getting well within the sphere of the

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[8] Sioux Indian reservation public health officers were horrified to discover that Sioux mothers left to the children the choice of whether or not they would be hospitalised (Beuf 1978 pg 7)

children's work. In addition she constructed a typology of '*kid*' (sic) patient types. These were; *the wild kid* (these children sought to obstruct the work of the hospital and were demanding and loud); *the gregarious kid* (these children were considered eager to please); the kid that embraces the sick role (staying in bed and trying to align their needs with the hospital demands); *the junior medical student* (these children are authorities on their disorders and use the hospital slang with some accuracy); *the withdrawn or depressed kid* (these children were considered to be withdrawn from social interaction). Beuf described these terms as a typology of coping strategies that had been inductively derived from observation of children. She also noted that individual children could and would assume different types of coping at different times. Interestingly, her conclusion that children develop different types of coping strategies in different situations set her work apart from those who relied on pre-determined instruments hospitalised children's coping behaviours. Unfortunately, Beuf did not report on or include any of the conversations that she had with the children regarding their views on why they behaved in the way they did. This conveyed a sense that the children were simply objects being used to illustrate and highlight not only the shortcomings of hospital care but the overall position of children in the USA. In this way Beuf's work is an example of an authorial ethnographic account in which those that were the subjects of the account are silenced. Nowhere in her work is the children's agency recognised as a force for transformation in what happens to them. This means that her recommendations focus on changes to medical and nursing practices with no indication that these should be informed by the children's views.

That said Beuf's work was important as it was one the first attempts by a researcher to move beyond developing understanding of children's experience as something that could be measured using objective, pre-determined, deductive, instruments. In this way it was innovative and creative and it made a scholarly contribution to knowledge of children in hospital. Yet, in some ways her work is limited not least by the use of Goffman's theory as an organising framework. This is because it appears to offer more insight into the usefulness of Goffman's theory as an explanatory

framework for the expression of emotion than an inductive account of the children's experiences of being in hospital.

In contrast Bluebond-Langner's (1978) ethnographic study of children in hospital placed children's subjective experience at the centre of the research work. She spent 9 months working as a researcher in a children's oncology ward in the USA. There was a subtle difference in the way in which the research questions were constructed. Rather than seeking to illustrate the ways that American children were treated (as in Beuf's work) Bluebond-Langner (1978) wanted to explore how children *"became aware of their world and their place in it..."* (pg 196). She drew heavily on Glaser and Strauss's (1965a, and 1965b) seminal work on dying awareness contexts, in which they argued that the behaviour of people can best be understood within the awareness context in which the death occurs. From the field work observations she concluded that the hospital ward could be understood as '*mutual pretence*' context, governed by tacit but fixed rules of engagement. Central to this was the culture of knowing and concealing what was known. A culture in which the children, their parents and families and the staff engaged. She argued that this world was visible to others through observation. However, I would add that Bluebond-Langner's subjective interpretation of what she observed was a crucial element in discovery of children's knowledge, in particular the discovery of the children's perception of and compliance with the '*mutual pretence'* context. The children emerged as sophisticated knowers who moved through 5 stages of the disease process from '*it's a seriousness illness*' to '*a series of relapses and death'*. Their knowledge was derived from their subjective interpretations of their experiences of the social world of a hospital ward. The children's impending death was rarely discussed yet this had not limited their understanding of what was going on. In the absence of frank discussions they maintained their social agency by resorting to rebellion and silence. A similar trend was noted by Noyes (2000) in the context of her qualitative work with children who were ventilator dependent. Noyes' work stands out as she used determined efforts to include as many children as possible by drawing on innovative and creative methods to engage children regardless of ability. Setting her findings in the context of the UNCRC (1989) she

concluded that the children in her study had their rights denied, their competence ignored and their wishes and concerns unheard. The ultimate insult was that they stayed in hospital for lengthy periods of time and long after the time they were fit for discharge.

The Needs of Hospitalised Children

Whilst most of the studies cited so far allude to the notion that children's needs during hospitalisation require specific and special attention, and Runeson and Hallstrom et al (2002a) sought to identify the extent to which children participated in decisions regarding their care. They also (Runeson and Hallstrom et al 2002b) sought to identify the specific needs of boys during an observational study of children in a Swedish university hospital. Working in the tradition of non-participant field work observation, the focus on boys was not justified on gendered grounds; it simply came about as only 2 girls were recruited into the study and subsequently left out from the analysis. They defined needs as '*what ought to be met to enable a person's normal existence...*' (pg.159). However, no attempt to define a normal existence in the context of a hospital ward was made. They set out to observe the children over a period of 120 hours. They reported that the observed boys' needs emanated from 2 distinct situations; those arising from non-threatening experiences and those arising from threatening situations. The first included; a need for activity, a need for new experience, a need for information, a need for participation; and a need for praise and recognition; The second included; a need for control; a need to have parents nearby; a need for what was familiar and a need for integrity. Again this was a scholarly piece of work but the voices of the children were systematically excluded (and the experience of girls ignored with no theoretical explanation). The researchers interpreted and gave meaning to the children's observed behaviour. No consideration for the children's own interpretations was sought.

A consistent strand in the work presented hitherto is the exclusion of the voice of children and findings dominated by adult interpretations of children's social worlds. Adult ways of knowing have been dominant meaning that children's insights have been subjugated and their knowledge denied. Consistent with these conclusions,

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obsessive research attention has been paid to nurse-parent relations, driven by the dominant discourse of family centred care.

Family-Centred-Care

As noted, the UK government had responded to the needs of children in hospital through the dual strategies of encouraging parents to stay in hospital with their children and the employment of specially trained nurses. In the UK, 2 models or frameworks for nursing children were published in 1998 (Casey 1988, MacDonald 1988 and Clarke 1998). They are included here as both were used on Study ward. Casey (1988) and McDonald's (1988) and Clarke's (1988) models for nursing children identified the nurse-parent relationship as critical to the success of the children's experiences. This was not surprising as family-centred-care and parental participation had become a Rubicon. In the UK at least, and elsewhere, partnership working with parents had become deeply embedded within the psyche of children's nurses (see Jolley and Shields 2009, Franck and Callery 2004, Savage and Callery 2000, Callery 1995, Darbyshire 1994).

In a rigorous phenomenological study of resident parents of hospitalised children, Darbyshire (1994) drew attention to the tensions inherent in the parent-nurse relationship and concluded that it was like parenting in a goldfish bowl. Callery's (1995) ethnographic approach to his research with parents of hospitalised children rested largely on the analysis of interviews away from the field. While there is much overlap in writing on qualitative and ethnographic methods, Sherman Heyl (2001) suggested that ethnographic interviews are those characterised by a well established rapport between the interviewer and interviewee that has been developed over time to enable a genuine exchange of views. In other words, they are characterised by a duration and frequency of contact. Callery's interviews met neither criterion; yet his work revealed that nurses experienced parental presence as an additional burden and that the parents of hospitalised children were exposed to additional costs.

Savage and Callery (2000) identified that 36 studies into nurse parent relations had been published between 1984 and 1998. This trend has continued (see for instance Shields and Pratt et al 2007, Hallstrom, Runeson and Elander 2002). Yet, the extent to which this enduring focus on nurse-parent relationships has improved the experience of children in hospital remains questionable (CQC 2010, CQC 2010, Healthcare Commission 2007a and 2007b). Both structural and material factors are implicated in this (such as the availability of parents and an insufficient number of children's nurses). Regardless, parental presence and the specific preparation of qualified nurses as strategies to improve the experience of children in hospital have both been inadequate. Not least because the delivery of care to hospitalised children in partnership with families is a complex and contingent matter (Franck and Callery 2004). The complexity of family centred care is heightened further when the needs of individual children, parenting styles, cultural differences and health beliefs and values are taken into account.

Nurses Relationships with Hospitalised Children

While few researchers had focused directly on the children's interpretation of their experience in hospital, some had sought to discover something of the meaning of nurse-child relations from the perspective of nurses (Bricher 1999, Totka 1996, Burns 1994). For instance, Totka (1996) undertook a phenomenological study in America with 5 qualified nurses. The findings reported nurses' struggles to establish interpersonal boundaries between themselves and the children. Limitations for Totka's study rest on the ill-defined concepts of over-involvement with children and what 'crossing the line' meant. Nevertheless, the findings point to nurses caring and empathic intentions. Similarly, Bricher (1999) undertook a phenomenological study into the experiences of 5 children's nurses in Australia. Trust was identified as an important concept with nurses placing considerable value on the development of trusting relationships. Bricher (1999) noted that little was known about the strategies nurses use to develop and maintain trusting relationship with hospitalised children in the face of having to undertake painful treatments, and called for further research into this. Yet she did not question the need to discover children's knowledge with regard to trust. The development of trusting relationships with families also emerged

as a significant concept for nurses in Ford and Turner's (2001) phenomenological study of 4 Australian paediatric nurses' caring for hospitalised children with special needs. For Burns (1994) the phenomenological study the meaning of engagement for 8 American nurses working with hospitalised children and their families was creating a safe passage through the hospital experience. Inherent in this is the need for trust. Cultural differences in nursing practices related to children in the USA, Canada, Australia and England mean the findings should be treated with caution. Nevertheless, each of these studies reports the emotional labour involved in work with children in hospital, yet the children are treated as silent characters, as though their experiences act as the backdrop to the unfolding stories. Their testimony remains undiscovered.

Summary

The first section of this review points to an uneasy relationship among the State, parents, the general public and children. At a time when there is a growing emphasis on participating with children and taking their views seriously there is a growing social panic and public anxiety around children. This position is not new, but it is reflected in historical analyses that have sought to catalogue the concept of childhood and children's experiences over time. Still, children are considered to be in need of more protection and viewed as a particularly vulnerable group in society. However, their developing status alone does not explain the current high levels of anxiety and social panic that exist around children in the UK; especially with regard to their safety. Psychological cognitive development theory continues to be the dominant discourse that naturalises age as a valid category to organise children's lives and determine their capability.

In spite of academic criticism that centred on feminist dissatisfaction with seemingly naturally ordered gendered implications of Bowlby's work (Burman 2008) its influence on UK policy concerned with children in hospital has endured. Likewise, Robertson's legacy lives on through the work of Action for Sick Children. Unfortunately, the care of children in hospital continues to give rise to concerns and there is recent evidence of continued shortfalls. Setting standards and measuring compliance with these has so far failed to provide more than patchy progress with regard to improving the care delivered to children in hospital (CQC 2010, CQC 2009, Healthcare Commission 2007a and 2007b). A main concern of researchers has been to identify measure and evaluate the effectiveness of hospitalised children's coping strategies or to infer understanding of their experience from field work observations (for instance Cleary 1992, Beuf 1978 Hawthorn 1974). Overall, the research focus relating to children in hospital had been dominated by adult interpretations and adult proxies or focused on nurse-parent relations and parents' participation (Savage and Callery 2000, Darbyshire 1994, Callery 1995,). While some researchers had sought to focus on what mattered to the children, the use of deductive and pre-determined instruments tend to fix the children's concerns into pre-existing, adult determined concepts such as anxiety, stress and coping (Board

2005, Spirito, Stark and Tye 1994). Yet, there is growing evidence that children's interpretations of events may differ significantly from those of adults (Battrick and Glasper 2004).

When I started this work, children's voices were largely missing from the knowledge and evidence related to children's experiences of being hospital in-patients. Since, there have been concerted efforts to engage children in order to determine their views on hospital services. However, few researchers have worked with hospitalised children, during episodes of acute illness, contemporaneously, to discover their unique knowledge and insights. Nor has any published study with children in hospital established what counted as voice in work with hospitalised children.

CHAPTER 3
METHOD

As a professional who had been socialised into the bureaucratic, cultural and adult-dominated order of a hospital ward, I knew less than children about the experience of being an in-patient on a children's ward. I wanted to redress this imbalance through work with children. In particular I wanted to address those factors that related to children's knowledge and those factors that related to the methods that would best support the discovery of children's knowledge.

AIMS

My aim in this research was discover something of children's knowledge regarding their experiences and interpretations of being in-patients in Study ward (a schematic is provided Appendix 1) at City hospital[9]. This aim was pursued through two research questions regarding children's knowledge and my research methods.

STUDY QUESTIONS

Question 1 Children's knowledge:

How do children interpret and give meaning to their subjective experiences of being hospital in-patients on a children's ward in one tertiary referral centre?

Question 2 Methods:

What methods would best enable the discovery of children's knowledge?

Objectives

These questions gave rise to 3 specific research objectives:

1. To discover, explore and reveal something about the children's subjective interpretations of being hospital in-patients.
2. To work in partnership with children.
3. To examine critically the extent to which the research methods used enabled children's participation.

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[9] Study ward and City hospital are pseudonyms used throughout this work for the ward setting in which the research was undertaken

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PHILOSOPHICAL FOUNDATIONS

As noted by Williams and May (1996) the purpose of any research is

"...to seek answers that involve explanation and understanding... the credibility of its outcomes will rest heavily upon the conduct of the investigation..." (pg. 7).

From the outset researchers have to consider the coherence between their ontological[10], epistemological[11] and methodological position. My transformative intentions led me to reject idealism founded on claims that the *'real'* world exists only in the minds of those who perceive it (Williams and May 1996). In contrast this work was founded on a realist ontological position, that children experience a real world that exists independently of their experience of it, and that children interpret their world through individual, unique and subjective realities (Mayall 2008). In turn this led to the epistemological assumptions – that children are knower's who can participate in research concerned with the discovery of their knowledge. Yet, participating in the discovery of knowledge alone was too simplistic and incomplete. My work had additional moral and transformative intentions, that children had a right to participate in research, and that change derived from children's unique perspectives was justified. For these intentions to be realised I needed to select a philosophical framework that enabled a transparent, reflexive and critical scrutiny of the power and generational issues inherent in social relations with children (Alderson 2008, Christensen & James 2008, Gigengack 2008, Roberts 2008).

Critical Realism

Kincheloe and Mclaren (2005) argued that the label 'critical' indicated an overt intention to confront injustice and power relations. Understanding my own research aims in this way was consistent with the overall aims of this project. This was also consistent with Hanley's (2005) assertion that academic research benefits from a critical review by those who were experiencing what was being researched to

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[10] Ontology is a branch of philosophy concerned with the nature of existence and that which exists (after Williams and May 1996)
[11] Epistemology is a branch of philosophy concerned with how we know what can be known and the justification for the claims made (after Williams and Mays 1996)

ensure that academic priorities and definitions reflected those at the centre of the experience.

This methodological position concurs with Benton and Craib's (2001) notion that realist intentions are opposite to fantasy, escapism and non-representational forms of expression. They argued that although reality is socially constructed through day-to-day interactions between people and is therefore, value laden; reality is grounded in a 'real world' that exists outside the perception of those who experience it. Benton and Craib's (2001) features of critical realism were applied to this study in the following way:

- *Sense was made of cognitive processes accepting that they were about something which existed independently of those experiencing them.* In this study this meant that the Study ward and the procedures and practices therein existed independently of children experiencing and interpreting them, but that children who were admitted to Study ward would interpret and give meaning to their subjective experiences, and they would develop unique and individual insights and knowledge.

- *Reflexivity was used to acknowledge social processes that contributed to any representation.* By this I mean that the representation of the children's knowledge presented in this work was socially constructed and so relativist. In particular, it was necessary to locate myself as the researcher throughout the study to make transparent how my personal history and experience acted as filters through which co-constructed understandings were reached.

- *It was necessary to get 'behind' misleading appearances.* For me this meant that there were systems and structures that framed the experiences of children in hospital that purported to be in their best interest. However, these were to be critiqued and contested to reveal the ways in which these structured the experiences of the children admitted to Study ward.

- *Theory is always fallible, open to contestation and reformulation.* I interpreted this as meaning that my theorising and insights are open to contestation by others who will bring to this work their own life world filters.

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Further reflection and theorising will give rise to different formulations.

I acknowledged then that there could never be a single explanation or one authentic true voice, nor could the experience of being in hospital be completely understood or predicted. What emerged from this study would be a co-constructed reality that reflected how the children and I worked with the construct of their experience in hospital through a value-laden lens that mediated the inquiry (Guba 1990). It also meant that the findings presented here are contestable and will be open to re-interpretation by others.

METHODS

As noted, all researchers have to consider the congruence of their ontological, epistemological and methodological framework. For me, the starting point was to consider how I had constructed the problem for investigation.

As an adult I had partial knowledge regarding children in hospital from a variety of personal and professional experiences. I had worked for 25 years as a children's nurse; I had been a lecturer of children's nursing for 10 years, and I was a mother of children who had been admitted to hospital. What I lacked was knowledge derived from children's subjective experience of being in hospital. This deficit takes on greater significance in the context of children who reflect, interpret and know something of what they experience (Lewis 2010, Prout 2005, Mayall 2002, Roberts, Smith and Bryce, 1995). To date, children's voices had been stultified in the development and delivery of hospital services and the development of knowledge used to nurse children. I intentionally set out to redress this imbalance by using my power as an adult researcher to give precedence to the voices of children. As Perry (1987) noted, it was no longer acceptable to understand that social systems and structures existed outside those who experienced them. As social systems and structures are co-created by the individuals who at the same time experience and reproduce them, it became necessary to incorporate the insight of children to move closer to a more authentic and different understanding of what was going on when they were in hospital and what mattered to them about their experience.

I knew that I could never achieve a full emic perspective, but I wanted to communicate a novel, external perspective (Long 1999). I wanted to discover this by being aligned as closely as possible to the children. As the relationship between structure, children's experience and action was reciprocal, children's ways of knowing and children's voices were the starting point for the discovery of knowledge about their experiences (Mayall 2008). This meant that the research design had to take heed of the importance of children's subjective perspectives and embrace them as partners in the research endeavour (Kirkby 2004, Hart 1992). This seemed particularly important in respect of research that purported to see from the standpoint of the children.

Ethnography

Understanding hospital admission as a social rather than scientific event led me to reject scientific methods. This rejection was not based on a rejection of causal relationships; rather, it was based on the premise underpinning scientific method that seeks to separate the ontological from the epistemological or the known from the knower. It was also based on my understanding that knowing what worked had traditionally driven health research agendas, particularly those concerned with hospital services for children (chapter 2) at the expense of understanding what mattered to those who used and needed services.

As established in the literature review, as both human and organisational systems were implicated in the experiences of children in hospital, the methods chosen needed to:

1. accommodate the ontological and epistemological frameworks set out
2. be internally consistent and coherent with the needs of the study
3. enable an inductive approach to elicit how the organisational structures and inter-personal dynamics were represented in the minds of the researchers (the children, me). These needs were consistent with Schön's (1991) assertion that individuals' behaviour in relation to organisations may be

best understood through the exploration of their subjective mental frameworks.

According to Deegan (2001) the goal of ethnography is to engage with contextual particularities in order to see from the standpoint of the other. Hammersley and Atkinson (1995) interpret the term ethnography as:

"...referring to a set of methods [that require the researcher to] participate, in people's daily lives for an extended period of time, watching what happens, listening to what's said, asking questions – in fact, collecting wherever data are available to throw light on the issues that are the focus of the research..." (Hammersley and Atkinson 1995 pg 1)

Ethnography is concerned with meaning rather than laws (Guba 1990) and seeks to determine both tacit and propositional knowledge in the pursuit of meaning. For Guba (1990) ethnography rests on six salient features that are closely related to a constructivist methodology in that it:

1. is involved with understanding subjective interpretations of the experience of reality

2. is bounded by the context within which the experience had meaning

3. is undertaken in social situations and contexts that occur naturally rather than being contrived

4. gives reflexive consideration of the complexities of time, socio-cultural and geographical influences

5. relies on field work methods with the researcher as the instrument of the research

6. uses inductive analysis

Burgess (1984) concurred that the social world is constructed and interpreted by social beings. He appealed to Becker and Geer et al's (1961) classic description of ethnography as involving a researcher observing others in the situations that they ordinarily meet before writing up a convincing account of what has been observed. For Geertz (1999) ethnography requires the researcher to 'deconstruct the piled-up structures of inference and implication' through thick description of the context to derive rigorous interpreted meanings. However, sometimes traditional ethnographers appeal to detached authorial accounts of reality that portray social

groups as homogenous; by doing so, they silence the voices that point to alternative constructions (LeCompte 2002). Koro-Ljungberg and Greckhamer (2005) added to this criticism by highlighting that traditional ethnographic accounts resonate with Bourdieu's notion of

"...constructs of the second degree because they are constructs of the constructs made by the actors in the social scene..." (pg290).

Moreover, ethnographies have been portrayed in a pejorative sense as a-political accounts of what happens to others:

"...the ethnographic account was supremely ex post facto...the silences and enforced secrecies of the method are ultimately political silences... It was a refusal as well as an enablement...condescending and patronising with researchers assuming a right to a position of power over those researched..." (Willis 1981 p. 194).

I wanted to collaborate with children, recognise their agency and incorporate their unique insights to expose the power relations that existed between the children and adults who inhabited the ward. This was consistent with the requirement to get behind potentially misleading appearances (Benton and Craib 2001). I was not fully convinced that a traditional approach to ethnography would have enabled the ideological component of children's competence to feature in the day-to-day experiences of children in a children's ward and ensured that the children could speak for themselves (James 2001, Gubrium and Holstein 1999).

Some researchers have attempted to transform ethnographic practices in line with critical perspectives; particularly in terms of which voices are privileged in the accounts that were written and disseminated (LeCompte 2002). The crisis of representation (Denzin and Lincoln 2000, Gill 1997) challenged ethnographic researchers not only to study individuals in their social environments but take political decisions with regard to how and whose voice would be privileged. Nonetheless, ethnographers continue to report observer 'blind spots' especially in work with children, pointing out the danger of concentrating on active events, especially those that are both visible and audible at the expense of passive events such as being silent (Gordon, and Holland et al 2001, Gordon, Holland and Lahelma 2005). This is discussed further in chapter 4. This warning had special resonance

for work with children in hospital as those who are quiet and still are often wrongly perceived to be settled, pain free and content (Cleary 1992, Robertson and Robertson 1989, Hawthorn 1974, Robertson 1952). So any methods that I used needed to accommodate more than the spoken word or active children. I needed to reveal the meaning of passivity and silence from the children's perspective.

Field Work

Gubrium and Holstein (1999) suggested that ethnographers could deal with this epistemological dilemma by managing what they described as the border between narrative accounts and fieldwork observation. They argued that those usually silenced in research could speak for themselves. In this way they claimed that researchers could:

'...profit from the inherent tension found in the interplay between voice, social conditions and our own authorial aspirations' (pg 571).

Denzin (1997) had previously critiqued this position by claiming that standpoint ethnography was essentially a critical realist ontology that sought to transform through emancipatory principles. Denzin cited Smith's (1992) criteria for:

'...good social science' in the critical realist tradition as that which reveals the 'invisible structures of oppression in [social] worlds..."

This meant that my work concurred with these criteria in two ways. I had explicitly stated my intention to privilege the voice of children. I had intimated a desire not only to privilege their voices but to reveal, if I could, if children's voices were subordinated[12]. I wanted to do this by highlighting when it was apparent that adult understandings and constructions of the children's competence shed light on how the children realised their agency. In so doing I have to admit to a personal and research bias but defend this as political action.

Incorporating children's voices from the start and attempting to maintain a reflexive awareness in the field went some way to ensure that my observations were focused on what mattered to the children. I now know that I was right to find a space in which

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[12] The subordination of individual children's voices relates not only to a preference for adult's ways of knowing but giving precedence to articulate children or those most often favoured by adults (Stafford, Laybourn and Hill 2003)

the voices of all those children who participated could be privileged. As Hart (1992) noted,

"...children are undoubtedly the most photographed and the least listened to members of society, there was a strong tendency on the part of adults to underestimate the competence of children while at the same time using them in events..." (Hart 1992 pg 8).

That said I am also aware of the inherent contradiction in this. While I am critical of the hegemonic stance that has rendered children's knowledge as less important than adults' knowledge, I defiantly situate myself in this work as a powerful adult. Throughout, I drew on my adult and professional authority, and at times, blatantly sought support from those who were deemed even more powerful (supervisors) to ensure that I got my own way in privileging the voice of children. It was not always an easy journey. At times it was arduous and, after 18 months of refused entry, I almost gave up. Tenacity, if not downright stubbornness kept me going; if only because in this small way I had experienced something of what it felt like to have my views dismissed by others who thought they knew more than I did, or that what they knew was in some way superior. I do not claim that the children in this study were empowered as equal partners in the research endeavour, or that this study freed children in hospital from the domination of adult control. Rather, in keeping with the notion of children as active knowers, I wanted to discover something about children's interpretations and meanings. I participated with them to get to know something of their experiences of being in hospital as in-patients in order to reveal their knowledge and insights with the intentions of developing new knowledge and understanding. This framed my work within the traditions of critical ethnography. The insights are grounded in the experiences and interpretations of the children, and the children spoke for themselves.

STUDY DESIGN

I now set out how the research was designed and demonstrate how my original formulations were modified by direct work with the children during phase 1 (reconnaissance) resulting in changed to the questions for phase 2.

My initial intention was to work in partnership with children to provide a detailed account of their experiences of being in hospital. To begin this it was necessary to

find out from children what mattered to them when they were inpatients. In order to keep the children's priorities at the centre of this work I adopted a 2- phase approach.

Phase 1

This was designed as the reconnaissance phase. I used it to engage children in conversations about their experiences in hospital.

Phase 2

This was designed as field work and involved me spending time on Study ward observing and talking to the children who were inpatients.

An in-depth discussion of both phases follows, highlighting the subsequent changes to phase 2 that came about from my work with the children during phase 1.

Negotiating Access to Work With Children

Getting In

As my work was concerned with the experiences of children who had been in-patients I knew that I needed to identify and agree access to children who had been in-patients on a children's hospital ward. I began this process by presenting the research proposal to a meeting of the Royal College of Nursing Research in Child Health network. Following this I was invited to present the proposed work to a clinical team of urologists working at a northern England tertiary referral centre. Serendipity had some part to play in the initial success of these negotiations as the hospital clinicians explained that they were searching for a way to extend their portfolio of research to include the voices of children. They agreed that I could work with the children admitted to Study ward. This presented me with the opportunity to work with and observe children in hospital (subject to research governance and ethical approval) in a surgical ward.

Callery (1995) identified that the advantages of working on a surgical ward included fewer seasonal influences on the number of children admitted as well as access to

children admitted for both short and long-term stays. I add to these that working on a children's urological ward afforded me access to research partners who had a substantial body of knowledge and expertise regarding children's experience of hospital; the children who had been admitted there. I also now contend that working with children who required longer term or repeated stays in hospital enabled a more in-depth exploration of their subjective interpretations, and I was able to explore how these developed and were modified over time. In addition, it helped me to get behind misleading appearances.

Phase 1

Reconnaissance

Shatzman and Strauss (1999) used the metaphor of 'mapping' to explain the reconnaissance required by ethnographers to establish boundaries and identify gatekeepers in order to get to know something of what was is going on in the field. To do this they suggested that it was necessary to move beyond the immediate locality of the field. Some researchers have used the reconnaissance phase to get to know something of the location. For instance, Callery (1995) attended ward hand-over on Sunday afternoons and periods of waiting to set up interviews to gain insight to what was happening in the field. This was followed by in-depth interviews with staff and parents. The end result was a scholarly contribution to the knowledge of how parents contributed to the care of hospitalised children. Similarly, Street (1992) revealed how she observed and had discussions with nurses engaged in different types of nursing, generally understood by the context in which they practiced (for example community health nurses), to decide on the final location for her acclaimed work on clinical nursing.

I wanted to use the reconnaissance phase of my work in a different way. I wanted to engage with children who had been admitted to the Study ward by inviting them to tell me something of their experiences focusing on what mattered to them. Whilst rich descriptions of context and participant accounts are fundamental to the success of any ethnographic account (Geertz 1999), I contend that the greatest challenge lay in explicating this from the perspective of the children who had been in-patients in

Study ward. In order to do so I needed to devise a pragmatic means through which I could invite children who had been in-patients in Study ward to work with me. Although the children were not their own gate-keepers, they were knowledgeable. Having decided to find out at first- hand from children, the next step required a decision regarding who would be invited to participate.

Participant Sampling

Traditional probabilistic sampling owes much to the dominance of hypothetical-deductive reasoning in research designed to arrive at generalisable conclusions. However, in my work, the focus was on discovery and description rather than predictive outcomes. The challenge was to arrive at a sampling strategy that would enable me to answer the research questions, work within a moral and transformative framework, and take account of the practical day-to-day real world issues that framed the children's experiences. Purposive sampling acknowledges that knowledge and insight reside within those who experience the subject under scrutiny. Studies drawing on purposive sampling make no attempt to generalise findings; rather they attempt to shed light on the subjective interpretations of the participants (Denzin and Lincoln 2000, Field and Morse 1998, Streubert and Carpenter 1999).

The sample size in quantitative studies is pivotal to reliable and valid conclusions but, in qualitative work, meaningful comparison that helps to develop explanations and theoretical understanding means that a sample size of 1 may be sufficient (Mason 2002). In contrast, the exact sample size needed to answer research questions in qualitative work can never be known in advance. In addition, as noted by Mason (2002) *"qualitative samples are usually small for practical reasons to do with costs and especially in terms of time and money..."* (pg 96). As this research was not externally funded and was time limited I wanted to derive a sample that reflected the diversity of children admitted to a hospital ward without selecting large numbers of children to be involved. In discussion with my supervisor, a target sample of 5 to 10 children in the first instance was agreed upon with an understanding that, if necessary, I could try to recruit more children later. This did

not deny the interactional nature of sampling (Mason 2002). Rather, it meant that I could develop a sampling strategy that was consistent with the ontological and epistemological foundations of this work and make transparent from the outset the decisions that I had made, and take account of available resources. In turn this meant that others would be able to read this work and follow my decision trail (Koch 1996).

Mason (2002) noted the precarious nature of qualitative research whereby one case (participant) with particular characteristics can be presented as a representative of similar cases. While I was not claiming to be in search of a single authentic truth or a single authentic voice I certainly wanted to make a determined effort to include those children who had traditionally been excluded from research. This included children who were disabled[13] and those from ethnic minority groups (Shaw, Brady and Davey 2011, Hanley 2005). I was aware that special arrangements would have to be made to include children for whom English was not a first language, children with special physical or learning needs, and children who used augmentative communication aids. I began by constructing a sampling frame. This involved devising the following inclusion and exclusion criteria.

Inclusion Criteria

Children who met the following conditions were invited to participate in the study:

1. They had been admitted as in-patients to the Study ward in the last 18 months and had been an in-patient for at least 24 hours. This meant that the children who agreed to participate would have shared the common experience of being an in-patient and staying overnight. As I wanted to explore the experiences of children who had lengthy or repeated hospital admissions, starting my work with children who were in-patients was reasonable.

2. They were between seven and seventeen years of age. Scott (2008) asserts that from the age of seven children can not only give an account of what they have experienced but, they have also mastered impression-

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[13] The term disabled is used here in the social sense after Oliver (1983), in that it involves the loss of opportunity to take part due to social or environmental barriers.

management, can respond to standard questions, and are *'adept at controlling what they reveal'* (p 91). In addition to this, I had taken into account the children's potential age on admission, the time I would have to spend with the children, and the need to develop a rapport with them rapidly I was also unsure that I had the time and resources available to elicit useful accounts from younger children.

3. They were admitted under the care of the urology team with which access had been negotiated.

Exclusion Criteria

Children were excluded on the following grounds;

1. They lived greater than 1 hour's driving distance from the hospital. As it was necessary to take account of the resources I had available to undertake this study, I agreed with my supervisor that I would exclude any children who lived beyond this distance. This would still allow me to consider living locally versus having a significant journey as potentially influential factors.

Sampling Frame

The ward admission book listed the date of admission and discharge, the children's names, addresses, their type of admission (list or emergency) and admitting consultant. I identified all the children aged between 7–7 years listed under the care of the urology team during the previous 18 months from the ward admission book. This resulted in 157 children being identified as potential participants and this represented my sampling frame. I then constructed a table that included the children's names, addresses, ages, gender and reason for their admission. From this I was able to select some attributes that could be expected to present a diverse group of children. For instance, I concluded that the children's names offered some indication as to their gender and ethnic heritage. Their address provided a means of selecting children from different geographical areas. While I knew that these represented only crude indicators it did demonstrate my intention that my work would be inclusive. It was not that I knew or thought that these characteristics would impact in any way on the children's experience of being in hospital; it was that I

wanted to reach children from populations that were usually excluded. This is consistent with the principles of theoretical sampling whereby the researcher attempts to account, when possible, to achieve a sample that includes people who have those characteristics that may impact or influence the work (Mason 2002). In all 59 children were invited to participate.

Accessing Children - Designing the Logo

As I was committed to working with children from the outset I wanted to design invitation materials that would be especially appealing to potential participants. I successfully negotiated access with a local after-school club to consult with children on a design logo for the study. The after-school staff agreed to work with the children on my behalf. The children were invited to participate in a logo design and title competition.

They were told that I wanted to find out about what it was like for children who were admitted to hospital. The children who attended the after-school club were familiar with entering competitions. In the event, 5 of the children agreed to participate. They were supervised by the after-school club staff for an hour during which they sat together and drew pictures of what came into their minds when they thought about children in hospital (see fig. 1). I do not know if any of the children had been in-patients but they worked together in a group, chatting, sharing ideas and looking at each others' work. Collectively, they agreed that Safe and Sound should be the title of the work. At the end of the session the children voted for the winning logo (see figure 2).

The winner received a letter telling his parents that he had won and asking permission to reward him by sending a high street gift voucher to the value of £10. They replied stating that they and their son were very pleased that his

Figure 2 - The winning logo

work had been chosen. This logo was then used on all invitation and consent materials connected with the research to provide an indication that the children's views were important. It also created a readily identifiable and visual badge for the project.

Consultant Letter and Information Leaflets

The senior urology consultant agreed to write a letter of introduction for me. This legitimated both the research and me. In addition parent/carer information leaflets, children's question and answer leaflets, parents agreement forms and children's and parents' consent forms (see Appendices 2,3,4,and 5) were sent via the post to the children's home addresses. Each leaflet had the logo designed by children attending and after-school club to give some indication of the importance that would be given to the views of children. Arrangements had been made to ensure that the information leaflets could be made available in different languages (for example, Urdu and Punjabi) and in different formats (Maketon, Braille and audio) if requested by families.

Parent Permission to Access Children

The parent information leaflet was written in plain English to provide as much information to parents as possible in a simple but honest format. Those parents who agreed that their children could be approached to take part were asked to read the children's information leaflet to their child or to pass the information leaflet to their child for them to read.

Children's Information

Two children's information leaflets were prepared; the first was aimed at children aged seven to eleven years (junior school). The second was written to appeal to young people aged twelve to seventeen years (secondary school). While I had asked that the research logo be used as the main image on the information leaflets the publishers advised that using images they had commissioned from a market research company to appeal to the different age groups should be used in preference. The compromise was to use both. Despite my efforts to produce children-friendly and age appropriate materials it was possible that some of the children in younger age category could have felt patronised by the leaflet intended to appeal to them. Likewise, some of the older children may have preferred the style of the leaflet aimed at the younger children. This simply reflects the inadequacy of using age to judge children's preferences and needs. However, it provided a pragmatic solution to an enduring problem and fitted the advice of the time on providing information to children about research (Consumers in NHS Research 2003, Lightfoot & Sloper 2002).

Once agreement had been reached with the parents and children that they wished to take part in the study they were asked to contact me by telephone, email, voice-mail or text message. Offering a range of contact mechanisms was deliberate as I wanted to make it as easy as possible for the parents and children to contact me but had no prior knowledge of their preferred communication mechanism. In particular SMS text messaging has been reported as an effective method for communication in research studies (Bexelius and Lof et al 2010, Fry and Neff 2009, Anhøj and Møldrup 2004).

Family and Children's Responses

A total of 8 families responded to the invitation to participate in phase 1 of the study. One mother left a voicemail message to say that her daughter was too ill and that she wanted no contact with the research project. Her daughter's contact details were deleted from the study records on receipt of the voice mail. Another parent sent an email to say that while he wanted his son to take part his son was reluctant.

He asked me to telephone him to discuss a way forward. During the conversation he asked if I would go and talk to his son to try to persuade him to take part. I explained I would only talk to his son if he initiated further contact. No further contact was received. However, it is worth noting here that I had no way of knowing if there were children who wished to take part but were prevented from doing so either through their parent's disinterest or their parent's decision to decline permission for them do so. In spite of my determined efforts to include as many children as possible, I could no more than provide information in an attempt to influence powerful gatekeepers who control access to children. In all, 6 children participated in phase 1. Of these, 2 responded by text message, 1 by email, 1 by voicemail, and 2 returned the parent agreement form by post.

The demographic characteristics of the children who participated in phase 1 (see table 1) demonstrates the diversity of the children who agreed to participate on the grounds of ethnic heritage, age, gender, physical disability, learning disability, address, school type and the reason for admission. As my intention was for the children to tell me something of their experience, I had not intended that they would represent or speak on behalf of other children who were admitted to Study ward.

Once the response from the family was received, I made contact with them to arrange a mutually convenient time and place to meet. All of the children elected for the meeting to take place in the evening in their own homes. Given this, it is worth considering the arrangements that were made to reduce the potential risks encountered in field work undertaken in family homes.

Safety and Fieldwork

Fieldwork can be a risky business, and, as noted by Liamputtong (2007), personal safety may be jeopardised. As the named principal investigator I was responsible for the safety of families and myself during field work (Social Research Association (SRA 2001). As recommended by the SRA, and in order to fully understand the issues of fieldwork safety, I attended a researcher safety workshop. This workshop was instrumental in helping me to appreciate the need for rigorous safety

procedures, including thorough risk assessments before, during and following home visits.

During the workshop, two researchers with recent fieldwork experience shared what had happened during one of their home visits. Towards the end of the research interview the male participant began to talk to an imaginary friend about killing people. This man had martial arts weaponry openly displayed throughout his flat. When the researchers (a team of two) tried to leave the flat they found he had locked the exit door without their noticing. The leaders of the workshop (two ex-police officers) explained the importance of undertaking a visual risk assessment on entry to any house. Visible displays of weaponry were to be weighted highly for risk. They also advised watching carefully for the interviewee locking any doors and advised that researchers should always position themselves between the interviewee and the exit. It was also considered necessary to undertake field work in pairs.

However, this is not always practical or possible, especially in the context of personal studies. Accepting this, the workshop leaders suggested several different strategies that could be adopted in order to minimise risk. These included giving a detailed itinerary to a designated colleague; informing participants that others know the itinerary and the location for the interview; that others are expecting a call upon completion of the interview; access to a fully-charged mobile phone; a pre-programmed quick dial number for the designated colleague; and an agreed codeword so that help could be covertly requested. These procedures were adopted along with those detailed in the Salford Institute for Health and Social Care Research policy on researcher safety. The policy required that I telephoned an external partner to advise them when I arrived at the property and when I had left. They were asked to contact the police if more than 90 minutes elapsed between calls.

In retrospect, I was completely hopeless at abiding by these rules. While I always alerted my colleague (supervisor) that I had arrived at the correct location and was

about to start the interview, I often forgot to let him know when the interview concluded. This meant he contacted me before contacting the police as agreed. In addition, I was usually so relieved to have found the house and grateful that the children had agreed to talk to me that I took no notice of what was on display, nor did I position myself near an exit door. I think this is because I consider my work with children and families to be a privilege and respected their gift of inviting me into their homes. In one house I removed my shoes as was expected, in another I was offered a mountain of biscuits and chocolate. In every house, I was offered coffee or tea. I was also fascinated by the children's accounts. I had not realised the extent to which I had focused on these until I was transcribing the recorded conversations. I had been an unwitting witness to dogs sliding across wooden floors, clocks chiming and personal telephone conversations. In one house, the interview continued while a member of the family pulled cushions off the sofas and chairs in search of a mobile phone.

Name	Age	Disability/life long illness	Gender	Resident Adult/s	Distance from Hospital (miles)	Admission Type	School Type
Sarah	15	Physical disability life long illness	F	Mother Father	50	**List** Spina-Bifida illeostomy	State Secondary
Aarif	9	Life long illness	M	Mother Father	5.9	**Emergency** Renal insufficiency & urine infection	State Primary
Fion	10	-	F	Mother Father	4.1	**Emergency** Abdominal Injury & haematuria	Public
Joe	11	-	M	Mother Father	16.5	**List** Circumcision	State Primary
Seb	9	Life long illness-	M	Mother Step Father	28.6	**List** Repair of ureter	Public
Kamran	10	Learning difficulty Life long illness	M	Foster Parents	16.5	**List** Hypospadias repair	State Primary

Table 1 Characteristics of Children Phase 1

Data Collection

The popularity of interviews in qualitative research is pervasiveness. I wanted to listen actively to the children's accounts and I wanted to avoid beginning with a list of questions or relying on the more usual forms of interviewing that had been devised largely for adults. That said, it was still necessary to engage in conversations with the children.

Greig, Taylor and MacKay (2007 p.157) highlighted the importance of listening to children during research endeavours as:

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'...the understanding of any speaker is not just a question of hearing but of being compelled to listen to what is being said...'

According to Gadamer (1975) understanding implies that *'...two people...understand one another...'* and most often, language is the medium through which understanding can be shared. Gadamer used the term 'disturbance' to explain how the life world of another can become accessible to others through shared traditions and language, or hermeneutic conversations. For my work, disturbance related to my desire to be open and prepared for my own understandings to be challenged and modified by those of the children. For these reasons I elected to undertake *'...conversations with a purpose...*" in a place chosen by the children (Burgess 1984). As for shared traditions, it seemed to me that the children would all be used to playing and taking part in craft activities. As already discussed, the purpose was to get to know and understand something of what mattered to the children about being in hospital. However, undertaking interviews with children required some special considerations. Christensen and James (2008) listed language use, literacy, cognitive development, concern with the quality of elicited data and scepticism regarding the reliability and validity of children's accounts as particular concerns. In addition, they highlighted work with children as that which presents particular ethical issues. In spite of these concerns, Gigengack (2008), Mayall (2008), Scott (2008), Greig, Taylor and MacKay (2007), INVOLVE (2004), UNICEF (2003), and Morrow (2001), amongst others, continue to advocate for inclusive, participatory research with children through creative and enabling mechanisms. Further discussions of the methods used to engage the children and elicit their accounts, and to reveal their knowledge and interpretations are considered in detail in chapter 4.

In keeping with Mason's (2002) advice, I had undertaken some preparatory work for the interviews; but largely my preparations centred on safety in field work. For the purpose of the interviews with the children I had decided to use focused conversations; the focus was on the children's experience of being in hospital. Beyond this I had no questions but wanted to work spontaneously with the children, following their lead to discover more.

On completion of each interview I undertook a rapid analysis to identify the topics and issues raised by the children. For me, the most important message and the learning I took from my work in phase 1 was to be courageous in challenging adult assumptions about children's worlds.

Developing Insight

As Phase 1 was the reconnaissance phase of my work I had intended that what the children revealed would help me to keep children's voices at the centre of my work. They revealed a great deal, and some used many different stories to illustrate their points. Finally, I agreed with my supervisor that using modified framework analysis (Ritchie and Spencer 1994) would provide a pragmatic solution and avoid my arriving at superficial conclusions or fixed theoretical interpretations too soon. At this point I simply wanted to be able to elicit some of the tangible mechanisms related to the processes and events that were described by the children. While the children described experiences and their interpretations of these from unique subjective positions it was possible to determine those things that worked well for them and those things that did not.

The modified framework approach required me to begin by repeatedly listening to the recordings while reading the field notes I had written in my car following each visit to the children's homes. I then read the transcribed interviews while listening to the recorded conversations and made notes indicating my initial interpretations.

The first challenge came with my assumption that the children would accept my agenda and be willing to tell me about their experiences on Study ward. Although the children all engaged with me with regard to their experiences in hospital, they did not do so in the way that I had anticipated. Rather, in order for them relate to my agenda, they had first to find the meaning that the experience had for them. They did not take my knowledge for granted and would often ask if I had understood what they meant or if I knew what they were talking about. They deconstructed their experiences spontaneously into three discrete but inter-related and inter-dependent elements:

- things that led to their admission
- their admission to hospital and induction into the ward
- things that happened to them and others while they were in hospital.

They had deconstructed their experience in this and by doing so they had helped me to construct the framework for the initial analysis. To begin I developed a thematic framework based on the deconstructed elements presented by the children. The data was then indexed and labelled using these initial themes. Each theme was then compared with the others and the data was interpreted and arranged to help me reconsider my approach for phase 2.

For instance, those children that had experienced hospital for the first time had, it seemed, used a number of strategies both to predict and make judgements about their experiences. These included talking to friends who had been admitted to hospital. Those with more experience of being hospitalised drew on different experiences in an informal way to audit, rank, reconsider and refine how they made sense of what had happened to them. Excerpts relating to these aspects of the children's experience were listed under 'things that led to their admission'. Taken collectively, the insights gained from trying to understand the nature of the children's individual experience and the subjective meanings that they constructed from them left me with an optimistic perspective on children. They had, indeed, been able to make sense of what had happened to them from individual perspectives. They helped me to understand that their whole experience was continuously refined and reconsidered in the light of new experiences.

Outcomes from Phase 1

Rather than present the outcomes from phase 1 as a fixed set of findings, I offer an account of how this work was used to re-formulate and modify my understandings of children in hospital and how it provided insight into what mattered to them.

I had determined to begin this work by focusing on safety. As Glaser (1992) pointed out:

'...a 'thought up' problem may sound juicy but the preconception leads nowhere...the research problem is as much discovered as the process that continues to resolve it...They are integrated...' (pg 21).

As suggested by Glaser (1992), it was during the initial analysis that I began to understand something more about the problem. I was able to step back and reconsider my explanations and how these were different to those of the children. My analysis pointed to the children's knowledge regarding child-adult relations and the recognition or denial of their competence. It seemed that their experiences were always mediated through adults. Child-adult relations were a prominent feature in negotiating their admission, their experiences as in-patients, and their experience of the ward and hospital environment. In the light of this, I reconceptualised the problem for investigation. While I did not have any answers, it meant that during the field work I wanted to explore the children's experience of child-adult relations in more detail. I also wanted to explore the contribution that the relationships between children and adults made to the construction of children and their perceived competence or incompetence.

Inherent in this was an understanding that the complex concepts of social capital[14] and practical agency were intimately related to individual and collective circumstance, perceived competence and material and structural factors (Morrow 2005, Alderson 1995, Harrè 1983). Although there is no agreed consensus on the exact meaning of social capital, in this work my understanding of the term has been influenced by the work of Morrow (2005) John (2003), Grotberg (1995) and Harrè (1983). In addition, the children had helped me to understand that no one adult could meet all of the needs that the children had.

Phase 2

Getting In

Gaining access to undertake work in the field was a particularly difficult task. Ethics approval was granted in October 2004. The NHS trust research and governance

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[14] Although there is no agreed consensus on the exact meaning of social capital the use in this work as been influenced by Morrow 2005 and Grotberg 1995

approval took a further six months (April 2005). Further delays caused by the determined and persistent obstructive behaviour of one key gate-keeper and a catastrophic event (embargoed for the purpose of confidentiality) meant that phase 1 of the study was delayed by a further seven months. The interviews for phase 1 were completed between November 2005 and January 2006. Substantial delays to phase 2 then followed. Again the delay was caused by the same gate-keeper. It was not until this person left the Trust that I was able to negotiate access for phase 2. The field work was completed between November 2006 and April 2007.

Once permission to undertake fieldwork on Study ward was granted, staff information sheets (Appendix 6) were made available to all staff. In addition, a general ward information poster, as approved by the local ethics committee was placed in key public areas and in the parent and child information section of the ward folder placed by each bed space. The purpose of the information literature was to inform the children, parents and staff that the study was taking place on the ward and that if they wished to know more or discuss any aspect of the work they could contact me. They were also advised that if they requested, they could be excluded from the research and that I would discard any data pertinent to them or their child.

Participant Sampling

I could find no specific guidance on the sampling strategy or any way of determining the exact size of a sample needed for qualitative research. However many 'types' of sampling have been identified. Flick (1998) included extreme, intensity, primary, secondary, typical, critical, maximum variation and convenience. Holloway and Freshwater (2007) identified a similar list of sampling types but added homogenous, heterogeneous, opportunistic, chain referral, theoretical, total population and random. Unfortunately, some of these types appeared to appeal to quantitative traditions whereby mathematical formulations such as power calculations and confidence intervals help researchers to establish generalisable findings. As I was not intending to claim that my findings would be generalisable most of these suggestions were unhelpful. As Miles and Huberman (1994) noted,

the sample needed to enable depth and detail rather than size. It was also necessary to recognise the interactional nature of my work and to be flexible as the sampling criteria might have to be changed as the study progressed (Tuckett 2004).

Although the concept of saturation (sampling until no new insight is achieved, Glaser and Strauss 1967) had been recommended by some commentators, it was not possible to state with certainty that the next participant would not offer something new or novel. Mason's (2002) notion of sampling to understand rather than represent, was a little more helpful. Yet still, the next participant could always add something to create a different or alternative explanation. As Flick (1998) noted, as there were:

'...theoretically unlimited possibilities of integration of further persons, groups cases etc., it is necessary to define criteria for well founded limitation of the sampling...' (pg. 65).

Regardless of the label attached to the sampling *'type'*, what mattered most was that the sampling strategy was consistent with the requirements of the research question, and, in my work, inclusive. According to Flick (1998) sampling strategies focused either on comparative groups or focused on specific individuals. In my case the focus was on specific children. Taylor (1999) offered what I considered to be the best advice with regard to the sample size:

"...the question of when to conclude a study cannot be answered definitively, only arbitrarily. A study is done when you have gained an understanding of the setting or slice of social life that you set out to study. Because our understanding of the social world is necessarily incomplete and imperfect, representing an approximation and oversimplification, no study can ever be considered finished. There are always deeper levels of understanding to be achieved. Yet if we do not withdraw from the field every once in a while to try to make sense out of what we have seen, heard and experienced, we would be left with piles of data with no understanding of the social world at all... The question to ask is not when is the study finished but when does the field work yield diminishing returns..." (pg 277).

Using the notion of diminishing returns meant that it was no longer necessary to specifically identify in advance an exact number of participants. However, for the ethics committee I agreed with my supervisor to work to a target of 10 children in the first instance over a period of 6 months. These children were selected from

any children who were inpatients in Study ward during my field work visit and who met the study criteria for phase 2

Entry Criteria for Children Phase 2

- They had been admitted as in-patients to the Study ward under the care of the urology team that had agreed access.

- They were between 4 and 17 years of age. While children younger than 7 years may have found it difficult to describe their experiences in detail, it was possible to work with them to help them to communicate their views on what was happening to them, and they are able to make informed decisions in their own best interest (Alderson 2007). Importantly, children's competence and knowledge is related more to their experience than their age.

The only exclusion criterion was that their parents did not consent to their involvement, or that they did not wish to be involved. Children who did not speak English, those who had communication impairments, those considered disabled or from ethnic minority groups had already been too often excluded from research (Kirkby and Lanyon et al 2003). In addition, researchers who had worked with children in hospital had often excluded children thought to be too sick or too vulnerable to take part in research. Their exclusion was often justified on ethical grounds (Coyne and Hayes and Gallagher 2009, Lambert, Glacken and McCarron 2008, Carter 2002, Callery 1995). Bluebond-Langner (1978) has persistently taken the opposite position pointing out that those children considered most vulnerable and thereby most often excluded are often the most silenced but the most in need of being heard.

Apart from identifying inclusion criteria, I had agreed through governance procedures that the field work would last for a period of up to 6 months; that I would work with no more than 2 children at once; that periods of observations would usually last between 2 and 4 hours and that I would work with individual children on 1 to 5 separate occasions. These criteria reflected my intentions to work effectively with children while avoiding my presence becoming burdensome or wearing. It was

also agreed that I would renegotiate my work with the children at the start of every episode of field work and respect their wishes to decline at any time.

It is possible that some will consider this to be a convenience or opportunistic sample. However, I contend that the careful consideration I had given to devising inclusive sampling criteria was more robust than either convenience or opportunistic sampling suggests. After all, any research work that draws on ethnographic methods is a contingent mix of '...*insight, coupled with chance...*' (Fine and Deegan 1996). Fine and Deegan (1996) go on to identify three distinct components of ethnographic work that relate to chance; temporal serendipity, serendipity relations and analytical serendipity. In other words, chance rather than science is central in determining how the mundane can be transformed by a researcher who is prepared to contest taken-for-granted explanations and to get behind common sense understandings. By doing so, the detail inherent in the single case can be become more meaningful than searching for a collective understanding derived from the involvement of many.

Working with the children in the context of Study ward not only enabled direct observation with the children but also allowed me to consider how child-adult relations and the ward environment and culture impacted on the children's competence. This was especially important given the outcomes identified from what the children had told me in phase 1.

Identification of Potential Participants

I devised a practical routine that helped me to identify children who met the inclusion criteria. On arrival at the ward I would identify those children who had been admitted under the care of the urology team. I would then obtain information about their age and type of admission from the ward admission book. If the parents were present, I approached them, introduced myself and offered them the parent and children's information leaflets. I then left them to read the information and asked them to let me know if they would consent to their child taking part. Everyone that I approached consented, and all the children agreed to participate. This meant that the children

were recruited into the study at different times during their hospital journey. Although everyone I asked agreed to take part, the children sometimes declined to work with me on subsequent visits. This was not only important in relation to respecting the children's wishes; it demonstrated that the children were in control of the decision related to their inclusion. On two field work visits there were no children that met the inclusion criteria. Despite my best efforts; I never met any children who did not speak English or any with communication impairments. In total, nine children participated fully in phase 2 (see table 2).

However, the sampling strategy meant that I recruited many vulnerable children. 3 of the children were accommodated; all but 1 had life-long or life-limiting illness. All but 2 had some form of physical disability. 2 of the children had learning difficulty and few had the same surname as their mothers suggested that they were members of reconstituted families.

Table 2 Characteristics of children in phase 2

Name	Age	Disability/life long illness	Gender	Present Adult/s	Admission Type	Number of admissions during study period	School Type
Ben	9	Physical disability life long illness	F	Mother	**List** Mitrofanoff	One	Special School
Peter	9	Life long illness	M	Mother	**Emergency** Dislodged urinary catheter	One	State Primary
Kelvin	12	Physical disability	M	Father	**List** Bladder studies (1) Repair of urethra (2)	Two	Public
Celeste	12	Life lone illness	F	Mother Father	**List** Removal of kidney and tying off ureter	One	State Secondary
Caron	14	Physical Disability	F	Mother Father	**List** Pelvic surgery	Two	Private Church School
Ged	5	Life Long Illness	F	Mother Father	**List** Epispadias repair	One	State Primary
Jo	13	Life Long Illness	F	Mother	**Emergency** Urinary Tract Infection	One	State Secondary
Sam	9	Learning difficulty and life long illness	M	Mother Father	**List** Mitrofanoff	One	Special School
Lauren	8	Physical disability	F	Mother Father	**List** Mitrofanoff	One	State Primary

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Staff Participants

Four interviews were also undertaken with members of the staff team. One health care assistant, one play worker and two staff nurses agreed to be interviewed. The staff participants were selected as they had been involved with 3 of the children. The interviews focused on their work with these children as I wanted to explore the dominant discourses used by staff and to examine the extent to which the staff version of events coincided with or differed from those of the children. In particular, I was keen to discover whether or not the children's competence featured in the staff accounts. The interviews were not undertaken to validate or discredit the children's accounts; rather they helped me to explore further the importance of child-adult relations and to conceptualise further what I thought was going on. This was not only consistent with Tuckett's (2004) acknowledgement of flexibility with regard to sampling, in part it was consistent with Hammersley's (1999) assertion that ethnographic methods help people to see events in new ways and that in turn this contributes to public knowledge. He emphasised that the methods used should *'...emphasise diversity, complexity and creativity...'* (pg. 59).

Participant Observation

According to Hammersley (1999), relying on what people say they do without observing them and observing what people do without asking for their explanations neglects the need to discover meanings and risks misinterpretation. For Becker and Geer (2003) participant observation happens when:

'...the observer participates in the daily life of the people under study, either openly in the role of researcher or covertly in some disguised role, observing things that happen, listening to what is said and questioning people over some length of time...' (pg. 294).

Denzin (1997) adds to this the need for introspection. The importance of introspection was notable in the work of Davis, Watson and Cunningham-Burley (2008), Gordon, Holland and Lahelma (2005), Savage (2003) and Gerrish (2003). Gordon Holland and Lahelma (2005) positioned themselves as non-participant observers in schools to observe boys and girls in the classroom. They discussed how their presence had sparked different interactions, and their field notes revealed that their attention was most often drawn by audible and active events. In turn, this

led them to turn their attention to those children who were silent and passive. This enabled them to understand more fully the gendered relationship between resistance; an unstable and shifting concept; to that of power relations in high schools. Gordon, Holland and Lahelma (2005) work is particularly pertinent as they describe the context of a school as an intersecting web of gazes. Similarly, Savage (2003) and Gerrish (2003) highlighted the importance of witnessing events. Both had positioned themselves as nurses in the field and undertaken observational studies of nursing practice. Savage (2003) opted to wear a nurse's uniform and participated in some core nursing activities such as bathing patients. This level of participation led to a number of transformations in her understanding of what she saw. For instance, having reported an initial unease at witnessing the nurses' use of touch with patients without obvious reasons for doing so, she became aware over time that she had begun using touch in the same way. Davis, Watson, and Cunningham-Burley (2008) studied the experience of disabled children and how they negotiated their own social worlds in the context of a special school. They reported that some teaching staff were resistant to the notion that the children with communication impairment could participate actively. A further difficulty related to the field workers' concerns about the expectations that both the children and the staff would have about his behaviour. In his words he:

'...didn't have a clue how [he] was expected to behave...and found it extremely difficult to understand if the children were happy with [his] presence in their class...' (pg221).

Over time he discovered that the children did not associate his role with that of other adults in the school but that they still used his status as an adult to achieve their best interests.

Study ward was inhabited by a myriad of actors, each with a different position. The staff, visitors and children turned their gaze on each other, each using different and multiple frames of reference. I entered into Study ward with a different gaze, that of a researcher with a personal history of being a children's nurse, and a mother of children who had been inpatients. However, I was not trying to discover a deeper understanding of nursing. I had positioned myself as a researcher who was there to

work in partnership with the children. This meant that though my work related to that of Savage (2003), Gerrish (2003), and Gordon, Holland and Lahelma (2005), in that I wanted to use ethnographic methods in order to discover something about the social world of children in hospital; it was also distinct as I was neither participating as a staff member nor working as a detached observer. The approach that I had taken had more in common with that reported by Davis, Watson and Cunningham-Burley (2008). While I read their work after completion of my own field work, their warning that adults who enter adult dominated children's institutions are often expected to engage in supervisory and surveillance activities was consistent with my experience. I certainly had to manage the duality of being both a researcher and an adult participant with a nursing background in the social world of a children's hospital ward.

Some authors have argued that researchers working with children can choose to position themselves as a friend, non-authoritarian adult, least adult or detached adult (Davis, Watson and Cunningham-Burley 2008). What mattered most to me was that I worked effectively with the children to discover something of their knowledge and insights. As the children would have different needs, abilities, capabilities and communication preferences, it was important to take a flexible rather than fixed approach. Central to this was the need to consider power relations as this is an essential component of generational issues. This is discussed in greater depth in chapter 6.

I began my field work by spending my time sitting at a table in the middle of the ward, using all of my senses to 'get a feel for the natural flow of events...' (Taylor 1999 pg.276). As I did so, I became aware that the children, visitors and staff watched me. Although inactive, I was not a passive observer. I was influencing what other people did. In this position I was vulnerable to the expectations that I would 'watch over' the children. Over time, I moved to work with individual children, sitting by their beds. Most often we played games. It was during these episodes that I discovered that the children experienced their competence as a fluid and unstable characteristic. This mirrored my own experience as an adult visitor to the ward.

I used those things (both structural and material) that were available to the children and used by them to help me to understand and discover something about the children's experiences. As Davis, Watson and Cunningham-Burley (2008) note:

'...there is much to be gained from using the everyday cultural artefacts and structural processes of children's worlds...' (pg. 235).

Throughout my work, I drew on the everyday cultural practices of children (for instance, play), and the everyday material artefacts (for instance, bed rails), and the structural processes inherent in Study ward (for instance rules governing access to resources) to discover more about children's experiences of being inpatients on a children's ward. In doing so I positioned myself next to the children in order to discover and reveal a more authentic understanding of what mattered to them.

Data Analysis

Inductive analysis has been described by many authors (Holloway and Freshwater 2007, Creswell 1998, Flick 1998, Field and Morse 1998) yet the process still lacks transparency or consensus. Generally, the tools and techniques used are associated with particular methodological approaches (Paley 2005, Paley 2000). For instance, grounded theory has a strong association with constant comparison and theoretical sampling (Glaser and Strauss 1967) to derive theoretical formulations of what is going on. In contrast, phenomenology leans towards thematic analysis of which many variations exist (for instance, see Field and Morse 1998) and involve searching for the saturation of themes in order to arrive at the essence of the phenomenon from the viewpoint of the participants. These approaches to inductive analysis were reconciled with the philosophical foundations from which they derived, notwithstanding that even the original proponents had often modified their approaches. For an example, see Glaser (1992). Other authors have tended to interpret and re-interpret these approaches in less consistent ways.

I dismissed analytical frameworks that manipulated the language of philosophical constructions. Not only did these fail to reconcile important philosophical differences from which main constructs were derived (see, for example, Burnard 1991), they reduced the complexity of the interactive processes of analytical induction to a set of

linear and forced stages (Glaser 1992). As Johnson (1999) notes, many methodological approaches are abstract constructions that reflect the nature of complex constructs within highly theorised methodological positions. It is not good enough for other authors to re-interpret methods for analysis but fail to reconcile key components of the method with the core constructs of the philosophical position. Although popular, some of these approaches deny the unique nature of subjective experience and the potential for differences to be accommodated rather than managed out of the final analysis.

For instance, Cresswell (1998) advises researchers to explore if the participants' essential meanings emerge in different contexts. This suggests that inductive analysis requires some form of validation whereby a single interpretation could be derived from multiple occurrences. Similarly, others argue that researchers should search for a single constitutive pattern that holds the interpretation of the data together. Common in both approaches is the need for a team of analysts to meet and discuss emergent patterns before reaching a consensus. By appealing to consensus and agreement, individual subjective meanings are subordinated to a collective way of knowing. This denies critical realist notions of socially-constructed, subjective interpretations, and appeals to idealist notions of phenomena that emerge as facts amenable to the senses and derived through agreement. The literature had presented me with a confused and confusing plethora of analytical methods; each one slightly different and each one placing emphasis on a different aspect of the process. Yet none were consistent with the ontological and epistemological basis of my work. However, reproducing the children's accounts as they were told would have limited my role to that of scribe (Flick 1998).

One notion that I entertained was applying Labov's (1982) six categories of structure for fully formed narratives. The appeal of this was an attempt to reveal how children constructed meaning from the interpretation of experience. Additionally, it would have ensured that the children's voices remained central. However, the children's narratives were not fully formed and sometimes little more than utterances and non-

verbal communications. In addition, I needed an approach that enabled the analysis of many types of data. Relying on the spoken word was insufficient.

Whilst accepting that the individual subjective interpretation of the analyst lies at the centre of any inductive analysis it was also important to remember that the children, even those who were silent, were also active participants in this work. Many of the prescribed methods for analytical induction appeared to assume that interpretation began with the reading and transcribing of interviews and field notes. As Reismann (1993) noted, this denied the subjective process and interaction that was discernible at five levels of re-presentation whereby:

- Attending to the experiences requires the participant to remember and recall events and to recount the story
- The teller selects how the story will be told to reveal how they wish to be known to the listener
- Telling the story requires the teller and listener to enter into a process of interaction and interpretation
- The listener attends and interprets the story from their perspective
- Other readers then bring to the work their interpretation.

In this my work is consistent with the arguments presented by Rolfe (2006) and Koro-Ljungberg and Greckhamer (2005) that qualitative researchers should embrace epistemological diversity. In particular Rolfe (2006) argued that qualitative research could not be subsumed within a single paradigm as it is neither epistemologically nor ontologically coherent. In conclusion he proposed that:

- Methods and methodological slurring is not a problem but should be justified in the context of the study
- Validity criteria should be resisted
- The quality of a research study is revealed in the writing up
- The validity of research reports are subject to the wise judgement and keen insight of the reader
- Responsibility for appraising research lies with the reader.

This was consistent with championing different forms of knowledge, privileging different knowers and celebrating diverse voices. As Gadamer (1975) noted, data analysis was itself an embodied experience that was dynamic and continuously interpreted for meaning. I had also accepted that the children with whom I worked would share the experience of being an in-patient on Study ward but that they would interpret their experiences in uniquely subjective ways. As noted by Koro-Ljungberg and Greckhamer (2005) it was important that I resisted what they termed the dialectical move to subsume difference into sameness (p298). This meant I was committed to managing rather than managing out difference. To do otherwise would have challenged the ontological and epistemological foundations on which this work was predicated. In other words, acknowledging children as experts in their own lives meant that I had also decided to respect their agency in selecting the message that they wished to convey (Reissman 1993).

However, there is an important point that I wish to make regarding the involvement of children in the analysis of the data. Literature on the ways in which children can be involved as full partners in each aspect of the research process is burgeoning. This involves consideration of recruitment and retention, training in research processes, costs and sustainable engagement. Moules (2009), Kellet (2006) and Smith, Monaghan and Broad (2002) have argued that involving children in the analysis of data has benefits not least in ensuring that the resulting findings are embedded in children's insights, and, Coad and Flay et al (2008) have offered a pragmatic model to help researchers plan for effective participation with children. While Cavet and Sloper (2005 and 2004), and Coad and Evans (2008) have evaluated the value of including children in service delivery in health care and hospitals. However I contend that the practicalities and validity of doing so would have been questionable. The permission to work with the children that I had received through ethical approval prevented this; though I would have been prepared to challenge this had I thought it appropriate. What mattered most was that I had promised the children, using process consent, that they could decide when they would step down from being active participants. None of the children contacted me following the initial interview (phase 1) or after discharge from hospital

(phase 2). I took this as an indication that they had decided that their participation was at an end.

There were other considerations. The children with whom I worked had not been trained or prepared to be involved in the research. I had also always accepted that it was my responsibility to enter their world rather than to expect them to enter mine. In addition they had not been recruited as a participant cohort who came together at regular intervals to undertake the research work. Their participation and agreement was carefully negotiated and related to the development of the research questions, and bringing to my attention what it was that mattered most to them as hospital in-patients. I had sought no mandate to ask them to become involved beyond this. I had also given them an undertaking that access to the raw research data would be limited to my supervisor and me.

However, it seemed that while some research approaches are well suited to the participation of children throughout, significant challenges to the participation of children, especially in field work studies remain not least because field work studies rely heavily on the researcher's interpretation of what is witnessed in the field (Fine and Deegan 1996). For now, significant challenges to the inclusion of children in the data collection and data analysis phase of field work studies remain.

Having decided that I would not involve children in the analysis of the data, it seemed that the starting point was to trust induction as a method of deriving meaning (Fine and Deegan 1996). It was also important to acknowledge the serendipitous nature of ethnographic work (Fine and Deegan 1996).

Fine and Deegan (1996) coined the term "analytical serendipity" to describe how ethnographers 'establish linkages without being certain of why they make sense'. They suggested that 'ah-ha' moments represented developing insights. For me, the decision to subordinate knowledge derived from the literature or from professional and parental insights helped to reveal important links and patterns to enable me to make sense of the context as the children made sense of it. For me, the 'ah-ha'

moments sometimes came during my field work but they were revealed most often during my analysis and through the use of concept mapping.

While I did not conduct a grounded theory study, I did draw on the constant comparison techniques described by Glaser and Strauss (1967) and on Glaser's (1992) thoughts on retaining the contextual integrity of data during analysis. According to Long (1999), Glaser and Strauss's (1967) principles of grounded theory analysis involve the following principles:

- that the theory must be more than a collection or list of concepts,
- that there must be a clear relationship between the subsidiary categories
- that there must be a visible story line, and,
- that patterns or connections claimed to have significance must be validated against the data.
-

In other words, there must be a move from a synthesis of the component parts to a final 'coherent entity' (Long 1999).

The following explanation demonstrates that adherence to these principles enabled me to move from lists of the prima-facie concepts to conceptual attributes that were central to the development of stable subsidiary categories. This involved working towards a higher level of conceptual understanding to produce a visible story line and emergent theory. Throughout, the patterns and connections thought to have significance were validated against the data; in other words, constantly compared with each other and the data. What follows demonstrates how I followed Long's (1999) example of using concept maps to juxtapose Mason's (2002) 3 levels of analysis (literal, interpretive and reflexive) with the strategy of constant comparison from Glaser and Strauss's (1967) principles of grounded theory analysis.

Lists of Concepts

The process of induction had begun during my initial conversations with the children during phase 1. What I needed to do was to transform the children's accounts and my field notes through the process of substantive discovery. This can be more simply expressed as the need to ensure that my analysis and subsequent insights were significantly influenced by what the children had said and what I had witnessed to reveal an interpreted understanding of what was going on (Hammersley 1998).

I realised that I needed to sort, organise and index the data before I could engage in any meaningful interpretation and reflection. Consistent with Mason's (2002) suggestions, I began by working with the data in a literal sense, listening to the tape recorded conversations while reading and re-reading the transcripts and my field notes. As I did so, I highlighted key statements and made notes and memos regarding what I thought might be going on. From this I derived a list of prima-facie concepts that were grouped together in a literal sense. Table 3 demonstrates a number of prima-facie concepts later attributed to the subsidiary category '*child-adult relations*' and which is reported fully in chapter 6. Had I been using thematic analysis it is possible that I would have been content with the development of themes and understanding based on this literal way of working. However, from an early stage these emerging concepts could be seen not to exist in isolation. Glaser and Strauss (1967) were emphatic that a theory that is grounded in data must be more than a collection or list of concepts. Yet, this was an important starting point.

Once completed, the prima-facie concepts were then grouped together using concept maps. A worked example from the subsidiary category of '*transition to patients who are also children*' (chapter 5) is presented here to explain this further.

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Data	Initial Concept
Mums and Dads "Can I say something please, this is very important. This is VERY important for mums, dads and children. You need your mum, and your mum wants to look after you, and you need your mum to look after you, because when your mum's there you know nothing is going to go wrong."	**Mums and Dads**
"This is a bit weird but...well, mum went to get a coffee and I wondered where she'd gone. I got a bit frightened. That's why you need your mum to look after you, I don't know why, but mums your mum, you need someone with you 'cause you feel warm, you've always got something to do, there's always someone there...it helped me to manage... you want an ice-lolly, there, gone, got it. Because you ask your mum but you have to shout the nurses...the nurses can't just stay with you can they, they have other people to attend..."	**When Mum's not there**
"[kind nurses] don't rush about to get to other people, 'cause if one thing goes wrong... they make a mistake and they think it's good, but it's bad, and [I] could die..."	**Nurses** **Taking time**
"This other nurse who I'd asked came up and said yes, she's on her way but she didn't come for quite a long time. You can ask for tablets sometimes and they say oh, I'll be 2 minutes and you have to wait about half an hour. They're probably just really busy but sometimes you really need them. It was awful that time, when she did come to get me out I was in such a state 'cause I'd been in there for such a long time and in that much pain, ...I hadn't had my pain relief 'cause she hadn't been to see me, by the time I got out I couldn't get settled even sitting in my wheelchair.."	**Busy Nurses** **Having to wait**

Table 3 Illustration of initial list of concepts

The children had explained their admissions as being planned and unplanned. However, they knew that their planned admissions could be unexpected and that their unplanned admissions were often expected. The children also understood that their admission was often complicated by the competing demands of other children. They placed great emphasis on being expected and understood this to be related to their being welcome. In turn, this contributed to their feeling safe. However, this security was set against a perturbed background. Their admission to hospital and transition to becoming hospital in-patients was dominated by a working culture of conflict and deceit. My understanding of the cultural context of the children's admission to Study ward was used to frame the findings. The concepts highlighted in green are those that became the stable conceptual attributes critical to the subsidiary category of '**transition to patients who were also children**' (expanded upon in Chapter 5).

I used these early concept maps to re-examine my developing theory and ensure that this was derived from and fitted with the data. In this I had selected the term 'entrée' to label the conceptual attribute relating to the children's experience of admission to hospital.

Figure 3 Early concept map
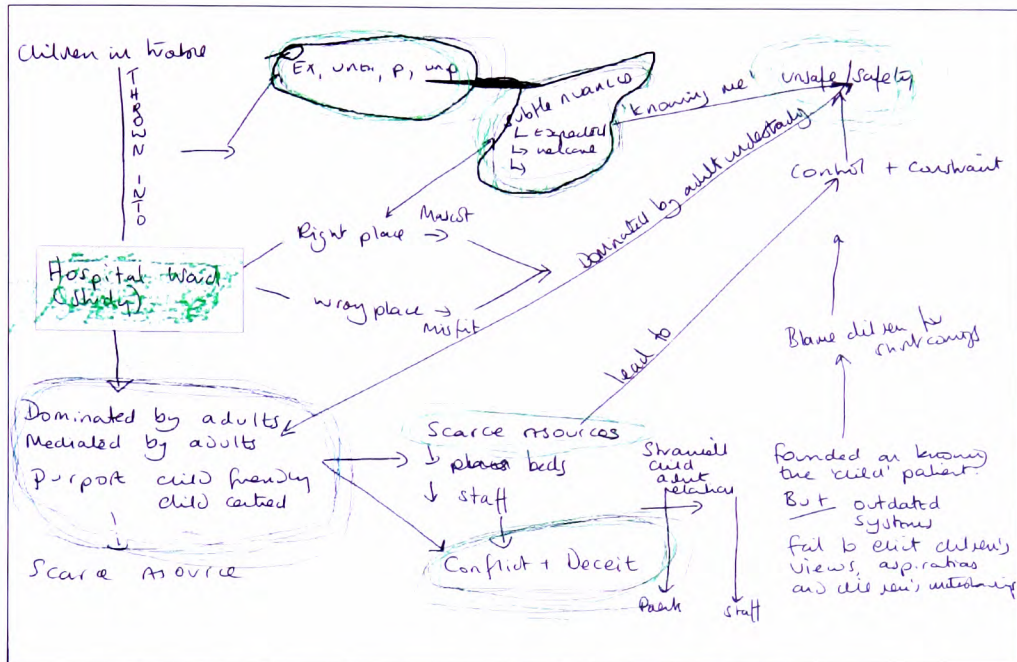
The use of concept maps meant that I could establish a clear directional and significant relationship between the interpreted working culture of the ward, the children's status as mascots or misfits, and how these combined to impact on their entrée to the ward (see figure 4). This also meant that I had derived findings that offered new and different insights grounded in the children's experiences as hospital in-patients.

Figure 4 Concept Map Subsidiary Category 1

A series of extra-ordinary events - transition to patients who are also children

Children's Entrée to Study Ward

unplanned welcome

planned feeling safe

entrées

unexpected expected

Interpreted Culture

Disruption to social, home and family life

Outliers

Managers

Diagnostic labels Negotiating admission

Deception ———→ Mascot or Misfit? ———→ Tug of war ⟶ Conflict

Special entrée privileges

Claiming space

Poorer experience Ward staff

IT

Allocation of a bed

Uniquely Identified

Subject to different rules

A series of extra-ordinary events

TRANSITION TO PATIENTS WHO ARE ALSO CHILDREN

Although the term 'entrée' was not used by the children, it was chosen by me as it conveyed more fully the nature of the intense negotiations in which the children, their families, the ward staff, and management often engaged to decide who had legitimate access to the ward.   Using the term entrée meant that I could demonstrate a key difference in how the children interpreted and understood the admission process and it offered a alternative to the more usual professional terms of list and emergency.

Although painstaking, the use of concept maps helped me to establish a stable conceptual system (figure 5) consisting of a core category and 3 related subsidiary categories (figure 6 and 7). Study ward as a place where children's children struggled to find a space for their voice and competence.

Figure 5: Pictorial representation of the relationship between the core and subsidiary categories.

Study Ward
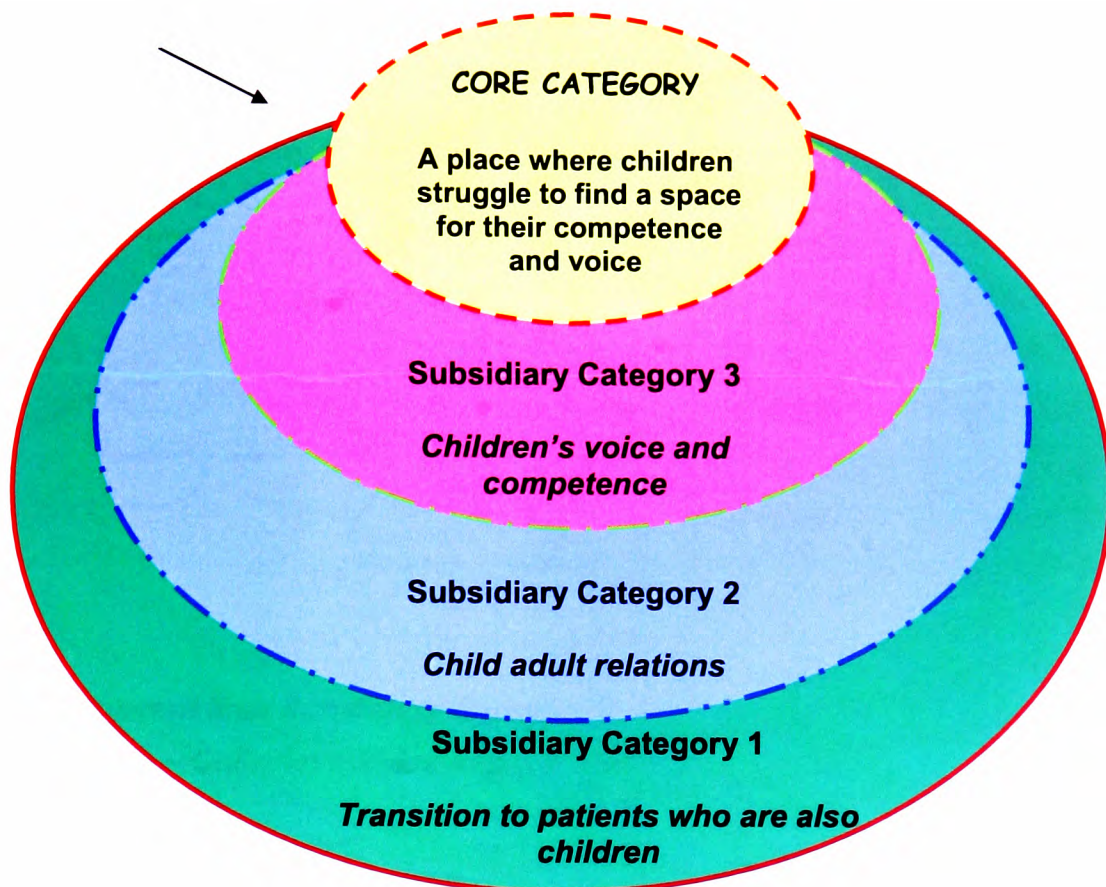
A detailed concept map for subsidiary categories 2 and 3 is also presented here to demonstrate and validate the relationships between the conceptual attributes that related to each (see figures 6 and 7).

Figure 6 Concept Map Subsidiary Category 2
Different Worlds - Child-Adult Relations

Freaky nurses

Difficult children

Strained relations

I'm here

Disrupting staffs work

Invisible as individuals

dehumanised

Children's bodies as objects

depersonalised

mothers

Protective Adults

Stroppy children

fathers

Disrupting staff's work

secrets

Reducing stigma

Emotional labour

Competing priorities

Getting the Job done

Too many demands

Being more like other children

Adults as instruments Sympathetic to others

Reducing difference

Needing to know children as individuals

Assessing children's needs

I have

children

competence

Resilience

agency

Inhabiting Different Worlds

Staff

Knowing children As surgical patients

I am

I can

Child-Adult Relations

Different Worlds

Figure 7 Concept Map Subsidiary Category 3
The Challenge – Children's Voice and Competence

position on the ward

cry

Getting attention

call

Rebellion

pester

Islands of distress

Marooned

Over bed rails

Into chairs

shout

Vigilance

bored

distressed place of work

silenced

depleted strength

Escapees

articulate

emotional needs

Confined to bed

initial post operative

going out

Into wheelchairs

sick

having to wait

pain

the light

emotional containment

controlled

Contested resources

the play room

Solace in Bed

Control of pain

Alone

staff

the food

Children's voice and competence

The Challenge

dependent

Routinised care

While this at times this was more in keeping with Corbin and Strauss's (1990) refined and staged approach to constant comparison, it was not inconsistent with Glaser and Strauss's (1967) original writings. In pragmatic terms it worked, and not

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only represented my attempt to constantly compare the developing theory against the data (Glaser and Strauss 1967), it helped me to reflect constantly on the theory that was developing and therefore in keeping with Mason's (2002) third level of analysis, reflexivity.

I concluded that my analysis had made transparent novel and compelling theoretical insights that Study ward was a place for children in which they struggled to find a space for their voice and competence. This was the core category to which each of the subsidiary categories related.

I have used a number of devices in this work to attest to the validity of my theoretical abstractions. However, for me, the most important of these is presenting my findings using verbatim data extracts taken from the conversations that I had with the children. In a similar way, I have reproduced my field notes to demonstrate the importance of not only listening to children but also noting their silence and observing children's behaviour, even when they appear to be inactive. For me the final test of coherence came in the writing up of the thesis. Yet, as noted by Fine and Deegan (1996), in the final stages of my analysis I had to consider what other researchers had discovered to *suddenly see relevance where none was noticed before*. However, for others who read this work, the final and most important judgement on coherence will come from their interpretation of what they read.

ETHICAL ISSUES

While children's participation in some countries is considered unremarkable and their competence and capacity to understand is often greater than expected Hart 1992), in other countries, such as the UK, mechanisms and acceptance of children's involvement in research is less well-established and in need of further development (Coyne 2010, Alderson 2007, Hill & Davis et al 2004). Although there has been some reported progress in the inclusion of children in matters that affect their lives (Coyne 2010, Murray and Hallett 2000), progress in health and youth justice services has been considerably slower (Carnevale and Macdonald et al 2008). Fuelled by scandals published widely in the media (Royal Liverpool Children's

Inquiry 2001, DH 2003b, DH 2001c), the NHS in England and Wales has been subject to increasing regulation and control (Long and Johnson 2007). This has done little to ease the process of gaining access to children for the purpose of research (Stalker and Carpenter et al. 2004).

The ethical considerations concerned with access for research work with children are different because of the fundamental need to consider the power and generational issues inherent in child-adult and child-practitioner relations (Punch 2002). These relationships are even more complicated in work with accommodated children (Bogolub and Thomas 2005). In particular, the concepts of confidentiality, consent, assent and permission, anonymity, risk of harm, and the legal requirements governing the conduct of research with children need careful consideration.

The Legal and Professional Framework

There is no single specific law that determines the appropriate conduct of research with children or adults in England; rather there are a number of statutes that apply in certain circumstances. These include the Family Reform Act (1969), the Children Act (1989, 2007), the Data Protection Act (1998), the Human Rights Act (1998), the Freedom of Information Act (2000), the Human Tissue Act (2004), the Mental Capacity Act (2005), the NHS Act (2006) and the NHS Consequential Provisions Act (2006). With regard to older children, the Family Reform Act (1969) legislated that young people aged 16 and 17 years could consent to medical treatment without parental consent, but this legal provision does not apply to non-therapeutic research. In addition, the common law principle (based on precedent laid down in court cases) has established that *'there is an expectation of confidentiality between 2 parties, that confidence will not be broken without the explicit consent of the patient'*. Still, anonymised and de-personalised data can be used for the purpose of reporting research. Yet, drawing on laws governing the NHS, the Research and Governance Framework for Health and Social Care (DH 2005) stated that:

"...Care is needed when seeking consent from children and from vulnerable adults, such as those with mental health problems or learning difficulties. Arrangements must be made to ensure that relevant information is provided in appropriate written

or pictorial form and that the role and responsibilities of parents, carers or supporters are clearly explained and understood..." (DH 2005 pg 7).

In addition, despite being at odds with its own guidance on children's competence (DH 2003a), the DH (2009) has recently stated that:

"...for consent to be valid it must be given voluntarily, by...someone with parental responsibility for a patient under the age of 18".

Alongside the legislative and policy framework (DH 2009)[15], there is professional guidance, for instance, the Royal College of Nursing (2009), the Economic and Social Research Council (2010), the British Sociological Association (2002) and the Sociological Research Association (2001). All seek to provide guidance on high ethical standards throughout the conduct of research.

While adults can self-determine whether or not to consent to research, the need to gain permission from parents, carers or legal guardians to approach children to participate in research studies remains a contested matter. According to Alderson (2008), respect for children's views is closely linked to their right to be heard. This is embedded in the (1989), in particular article 12 (*children's views should be given due weight in accordance with their age and maturity*) and article 13 (*the right to freedom of expression*). However, these rights are conditional and are tempered by the capacity of children, responsibilities and rights of parents, and national legislation (Alderson 2008).

Coyne (2009) has challenged the current position by pointing out that most of the published arguments are wrongly concerned with issues of power between children and adults rather than focusing on children's rights. Drawing on the self-determination principle set out in the (1989) she argues that it is children who should be consulted first rather than seeking access to them through gate-keepers.

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[15] DH (2009) Reference guide to consent for examination and treatment superseded earlier guidance published by the DH 2001a and DH 2001b and includes specific guidance on seeking consent/assent from children for the purposes of research

A discernible tension is evident between the inherent ideological view of children as active participants in their own social situations and the traditional construction of children as 'pre-competent or developing in competence' (Danby and Farrell 2004 pg 36). In spite of the growing acceptance in the UK of children as social agents and the right of children to be involved in matters that impact on their lives, research activity with children in England, as elsewhere, has been subject to increasing control and governance (Danby and Farrell 2004). Some progress has been made and advocacy groups such as INVOLVE[16] and Participation Works[17], together with the appointment of a children's commissioner for England, have provided further impetus in driving forward children's right to be heard. However, it is apparent that in the UK children are most often positioned as the 'property' of their parents.

Improving the lives of children by working with their parents (a central tenet of the former New Labour's children's strategy) has been described by Aynsley Green, the former commissioner for children in England as a *"courageous experiment"* (Beckford 2010). Nonetheless, he cautioned the recently elected coalition government against retreating to seeing children too often as 'chattels'. At the time of writing this thesis, targeting interventions at parents rather than individual children remains the preferred approach to the improvement of children's lives. For now this remains unchallenged by the newly elected coalition government. This means that any research with children requires careful consideration of the need to seek and gain the parent's or the legal guardian's consent for permission to approach children to participate in research before doing so.

In keeping with this I sought consent for permission to approach children to take part in the study from their parents and legal guardians (in the case of one child a social worker). It has been argued that children have the right to be self-determining of whether or not to take part in research. Of note, however, are the findings from research with children undertaken to establish their preferences regarding seeking their consent to participate in research. The findings indicated that they wanted to be involved in any discussions but had a preference for their parents to take the

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[16] Available at http://www.invo.org.uk/
[17] Available at http://www.participationworks.org.uk/

responsibility for signing the consent form (Alderson 1993). In agreement with Coyne 2009 and Coyne and Hayes et al. (2006), I agreed with my supervisor that seeking consent for permission to approach children from parents and legal guardians offered a pragmatic solution. Other researchers have reported taking a similar course (Coyne, Hayes and Gallagher 2009, Coyne 2006, Balen and Blyth et al 2006).

It appears that Alderson's (1995) assertion that seeking parental permission is the safest course of action still applies as the existing gate-keeping systems are adult-focused and founded on constructions of children as becoming adult, incompetent and in need of protection. There were also practical implications in my decision. For phase 1, I had access only to the name and address of the children. I had no other way of contacting them. Arriving unannounced at their home addresses would have seemed at least impolite if not bizarre.

I accept that my decision means that some children who may have been interested in taking part may not have received the information from their parents, or that their parents may have decided to refuse permission for me to approach them. As reported previously, one mother left a voice mail message stating that her daughter was too ill to be involved and that she wanted no further contact from me. Her wishes were respected. I was unable to influence her decision other than doing what I could to present the study in a professional manner offering as much information as possible (see information leaflets Appendices 2 and 5). However, I was able to be more proactive with respect to resisting parent demands that their children should take part when their children expressly stated that they would rather not. As Coyne (2009) notes, parents may exert considerable pressure on their children to participate in activities regardless of the children's wishes. This was evident when the father of one child asked me to persuade his son to be involved. I was able in this instance to refuse to do so. Just as adults have the right to decline consent for research, children also have the right to decline to do so (Alderson 2007). This right was reflected in the research design and participatory approach taken with the children throughout.

Process Consent

The principle of process consent was used throughout the study, with all asked at each stage of their involvement if they wished to continue. Great care was taken to ensure that no child was coerced at any stage of the research process. All participants were guaranteed that they had the absolute right to withdraw from the study at any time. However, seeking consent from children is also a contested matter. It is generally accepted that once parents have given permission for their children to participate, consent or assent from children should be sought. Some researchers have made brave attempts to develop specific techniques, such as games, to help children understand what is proposed and their role in it, and to elicit their assent and or consent (Runeson and Elander et al 2000, Bray 2007). Others have argued that seeking assent offers a more comprehensive and inclusive framework than consent for gaining the agreement of children to participate in research, especially those with special needs (Cocks 2006). Cocks' (2006) arguments regarding this seems to rest on the understandings of adult carers who argued that while children were incapable of giving informed consent they could assent. However, Bray (2007) and Cocks (2006) imply that seeking assent relates to a once and for all process. This is of limited value in field work research that takes place over time. In addition, as Coyne (2009) notes, the terms assent and consent are sometimes used interchangeably and give rise to different interpretations. Balen and Blyth et al. (2006) defined assent as:

"an agreement by a person that something be done to her or him, even where she or he does not understand the purpose behind the act".

English (1995) suggested that assent was:
"... the affirmative agreement of the child to participate in the research". In this study, although I was not involved in '*doing*' something to the children, I was involved in eliciting their views. In phase 2, my work with them took place over a number of days, or, in some cases, weeks.

Given this, I decided to follow Alderson and Morrow's (2004) and Coyne's (2010) lead and use the term consent to communicate those procedures that I used when seeking permission from the children to work with them, regardless of their age. This seems reasonable as assent has no status in English law (Alderson and Morrow 2004) as any agreement to participate based on assent is based on incomplete

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information. Assent may also be used to cover children's refusal. According to the DH (2009), consent is valid only if it is given on the basis of sufficient information and given on a voluntary basis. However, consent remains valid for an indefinite duration unless withdrawn. While the children had the absolute right to withdraw from the study at any time, I did not accept that their consent to participate was given once and for all. Rather, throughout the study, the principle of process consent was used. This meant that children were asked at each stage of their involvement if they wished to continue. It also meant that they could take control of the amount of involvement that they had, and that their refusal or consent to participate was flexible at any time. This was especially important during the observational stage of the research when the children might have felt particularly vulnerable and evident during phase 1 when some of the children declined to comment on some aspects of their experience.

The concept of process consent was particularly visible in my work with Fion. On two occasions during our conversation she became upset and started to cry. On each occasion I switched off the recorder and expected that she and her parents would want to end the interview. However, that was not so. Twice she asked me to switch the recorder back on. It was the first time that she had been able to tell someone about her experiences in hospital. By acceding to her request I enabled her to take control of the extent to which she would be involved. Her parents had been with her for most of the time that she was in hospital. Still, they had not realised which aspects of her experience had been the most upsetting. At the end of the interview Fion's parents expressed their gratitude. I had advised them that they could seek a consultation with the psychologist who had agreed to talk to any of the children or families who became distressed during or following the interview. They declined, but said that they would continue to talk to Fion and seek help if she continued to be upset. Regardless, I decided to telephone her mother the following day. She explained that she thought Fion was 'fine'. Having given Fion the power to decide to continue with the interview, I had little choice other than dealing with her parents at that point as the legitimacy of my direct access to Fion had expired.

It is possible that some readers may interpret Fion's distress as an indication that the research had caused harm. While I agree that the encounter was not comfortable, the interview allowed the issue to surface. It was apparent that what had mattered most to her parents regarding her time in hospital (getting Fion the right drugs, (see page 187) had mattered less to Fion. Her concern was the insertion of the urinary catheter. The interview had helped her parents to understand this a little more and given Fion the opportunity to bring this to the fore. This demonstrates the benefit to children that can follow the sharing power, especially the power to decide what to disclose during a research interview and to continue with the interview even when distressing events are being disclosed. It also underlines the balance that has to be found between causing harm, giving a voice to children and letting children lead on what to disclose and when to discontinue the discussion.

The benefit of process consent was also evident in my work during phase 2 when the children turned away as I entered their room, stated they did not to work with me, or signalled that they had had enough. This meant that I was able to respect the decision of the children to decline to work with me at specific times. In keeping with Bluebond-Langner, Bello Bellasco and Wander's (2010) assertion, it also meant that the decision to participate and work with me during most acute phase of their hospitalisation enabled them to have their voices heard at times and about things they found particularly hard. It is possible that many other researchers would have excluded these children from research and denied them the possibility of having their knowledge discovered (for example see Coyne 2006).

Balancing Risks and Benefits

My experience with Fion brought to the fore the risk of unintended harm that may be caused to children from by research encounter. I had considered the risk of harm to any participant in this study to be minimal but had taken the precaution of negotiating with a psychologist for open access to services should any of the children become distressed. In addition, I had acknowledged that the children's participation may have added to the children's and the family's burden over time.

However, I contend that this burden was offset by the children knowing that their involvement could lead to proposed changes to the delivery and organisation of the services that they received as in-patients. Children and parents who had participated in other qualitative research into the services they used had reported benefits in being listened to and having their views taken seriously (Bluebond-Langner, Bello Bellasco and Wander 2010, Hill 2006, Alderson 1993). Listening to children, whatever their circumstance was key in this work Morrow 1996). As noted by Bluebond-Langner, Bello Bellasco and Wander (2010) children facing adversity and those in situations that adults may find hard to contemplate want their views to be known. It is intended that similar benefits will attach to participation in this study and that the children will have contributed to the discovery of knowledge that can be used to benefit other hospitalised children in the future.

In keeping with the Children Act (2004, 1989) and professional guidance (Royal College of Nursing 2009) I considered the safety of the children as paramount. There was a clear statement in the information leaflets of my intention that should any of the children disclose that someone was harming them, or that they intended to harm themselves or somebody else, I would break confidence and report this to the necessary authorities. However, I also had to consider the extent to which I would intervene should I witness potential or actual harm (whether intended or unintended), and the basis on which I would disclose information that the children shared to a third party (other than my supervisor). Kendrick and Taylor (2000) had previously brought attention to the potential for unintended harm to children in hospital through the complicit and tacit acceptance of structural and material shortcomings (Kendrick and Taylor 2000). One of the children who participated in the study was known to social services and had been accommodated. The others were not; at least there was never any indication that they were. However, I had to acknowledge that there was possibility that the children would disclose that they had been unintentionally harmed whilst in hospital.

Williamson and Goodenough et al (2005) had reported that the ethics review of their proposal to undertake research work with children resulted in a condition that they

remove the statement *'you tell us you are being hurt'*. It was considered inappropriate. Although they complied, they began every interview by re-iterating that they would tell someone else if the children disclosed that they had been or were being harmed. Nevertheless, they questioned the extent to which the term 'hurt or 'harm' would have been understood by the children and noted that failing to inform the children adequately on the limits of confidentiality meant they were assuming power as adults on decisions related to safe-guarding. They concluded that much more debate is needed of the limits of confidentiality that are applied to research relationships and disclosure of information. This also needs to incorporate the views of children.

In my work none of the children disclosed that they or anyone else was being harmed. However, they did tell disclose what I considered to be suboptimal care. For instance, Sarah disclosed that she had been held down by 5 nurses against her will when her Jackson Pratt drain was removed. Seb told me that a nurse had hurt his ear when measuring his temperature. Kamran explained that he was confined to his bed and bored throughout his stay in hospital. The children found these events remarkable enough to tell me about them. In turn, I considered them to be unacceptable. In addition, complaints about the food were commonplace. These examples illustrate that it is not easy to find a balance between harm and poor practice. I had decided that my obligation to intervene to help children on the ward took precedence over my wish to complete uncontaminated field work. I had no doubt that my presence was a form of contamination, and, as already noted, I never assumed a position of an inactive or detached observer. Throughout the findings Chas I have illustrated some of the many occasions when I intervened for the benefit of the children. However, I also note the times when structural factors left me complicit in the children's suffering. Qualitative research is never without risk, but it can provide rich rewards (Morse 2001).

Anonymity and Confidentiality
While it is acknowledged that it is impossible to predict all of the consequences for participants or host organisations involved in any research study, special

procedures had been designed to ensure that the names and addresses of participants were stored separately from transcribed discussions and field notes. Pseudonyms were used throughout and any special features that could lead to identification of participants through verbatim quotes or detailed descriptions have been changed. Access to the raw data was restricted to myself and my supervisor. A locked secure archive of original tapes, field notes and transcriptions will be kept for a minimum of 10 years, and then destroyed.

Arrangements had also been made for the research data to be accessed via a password protected computer. I had also agreed with the children to use pseudonyms and if necessary, make some changes to the description of their presenting needs to protect their confidence and maintain their anonymity. However, not all of the children agreed with these measures. Some requested that I use their real name. At least they told me there was no reason not to do so. Yet, I was concerned that could not be certain that at some time in the future they would change their mind. Once submitted, this thesis becomes a fixed text document that will available to the public through the library. In addition, conference presentations and publications may follow. However, it was not only the legal framework and professional guidance that was implicated in my decision. Some years ago I was involved in the care of young women who subsequently died. She had agreed that her photograph could be used to illustrate a professional article. Some years later, following her death, the image was used again on the front cover of a professional journal. This experience has always served to remind me of the importance of setting out the limits of confidentiality and consent. This is further compounded by the exponential increase in electronic media and my understanding that it can be impossible to remove an electronic footprint. Given I will be unable to control the dissemination of this work once submitted I took the decision to decline the children's offer to use their names and elected to use pseudonyms throughout. By doing so I was aware that I was contradicting my standpoint in letting the children lead. However, I have remained faithful to the children's accounts and there words are given precedence throughout.

So far, I have focused my analysis of the ethical issues on my work with the children. However, throughout the study I was cognisant of the need to maintain high ethical standards with the staff who were also involved. I had to pay due regard to their involvement and consider in some detail their consent for permission to observe their practice, their anonymity, and their confidentiality. I also took account of the need to protect them from harm and to reduce the perceived risks that their involvement had.

I also considered the ethical issues related to the observation of staff. According to Murphy and Dingwall (2007), the ethics of field work are closely related to the researcher's ontological and epistemological stance. Given that I had made determined efforts to include as many children as possible I knew that I was going to spend a great deal of time working on the ward. This meant that I would be regularly observing staff. While the distinction between overt and covert field work appears clear, given the interpreted nature of data analysis, it is possible that the research report and subsequent publications could,

"...disrupt the assumptions that participants make about their world...and break down protective silences'" (Murphy and Dingwall 2007).

In turn this could lead to unintended personal distress for which the signing of consent forms offers no protection. I decided to use an 'opt in' approach with staff and designed a poster and ward staff information sheet (Appendix 6) that were posted around the ward and left at the nurses' stations. I had also agreed with a senior member of staff that the research would be discussed during a ward meeting, that the discussion would be recorded in the meeting minutes, and that my details would be passed to anyone who wished to discuss this with me.

None of the staff asked to be excluded and many expressed their view that they were pleased that the study was taking place. Many expressed their desire to know what the children thought about their experiences. However, I sought written and verbal consent from the staff who agreed to be interviewed.

Ethical Approval versus Access

The research proposal was subject to ethics approval from the University of Salford Research and Governance Ethics Committee and the Local NHS Research Committee (coordinated through the Central Office for Research Ethical Committee (CORAC) since renamed as National Research Ethics Service and Integrated Research Approval System[18]). Favourable review was received from with the Local Research Ethics Committee judging the planned work and associated safe-guarding plan to be exemplary.

However, despite the proposal receiving positive reviews from a raft of gatekeepers I faced significant challenges in gaining access to the hospital ward. The hurdle in getting access to the children came from my negotiations with a senior nurse. Despite receiving positive responses from a raft of governance procedures on key stakeholder continued to decline permission for the work to begin (phase 1) and proceed (phase 2).

Reflecting on the difficulties encountered in gaining access to children to explore their experiences as hospital in-patients Coyne (2010) has called for a critical review of the role that key stakeholders play in refusing access to work with children in hospital

Throughout the study, I was able to maintain high ethical standards. There were many difficult decisions to be taken, and I have presented these honestly along with my own analysis of the events. This indicates something of the complexity inherent in trying to break out of the dominant paradigm of adult-focused regulation and the subordination of children as incompetent beings in need of protection and direction.

I have also admitted when I made mistakes and when I became complicit in the children's suffering. There were certainly times when I felt helpless, hopeless and incompetent and failed to make any difference to what the children experienced. My feelings are an indication of the daily struggles that the staff on Study ward faced to

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[18] Available at http://www.nres.npsa.nhs.uk/applications/integrated-research-application-system/

provide optimal care to the children with whom they worked and I remain grateful to the ward staff for allowing me access to their world.

CHAPTER 4

ELICITING CHILDREN'S VOICES

ELICITING VOICE (1)

A number of academic colleagues had indicated their surprise that work with children was challenging enough to warrant pursuit of a higher degree. Others were waiting with interest to see how I validated the children's accounts. This was, at least in part, underpinned by the assumption that children cannot speak[19] for themselves or that, when they do, their accounts lack veracity or are contaminated by adults (Fivush 2002, Vrij 2002). In spite of the growing acceptance of children as social agents, it seemed that, for some, the validity of children's voices was still questionable (Oates 2007).

I needed to find a way to establish and legitimate my claim that the children had spoken for themselves. I wanted to devise a method that would help me to determine and defend my claim that the children's voices had been given precedence. What follows supports my contention that they were. Still, before any systematic review of the processes and methods I had used to elicit the children's accounts could be elucidated, it was necessary to establish what counted as voice in this work with children. Those who accept that children are social agents with the capacity to shape and interpret their experiences may find the arguments presented in this chapter banal (Hendrick 2008, O'Quigley 2000), but this chapter is not for them. It is for those readers who are newly acquainted with the notion of children as legitimate commentators. It is also in keeping with the notion of researchers turning a critical lens on their own work to defend and legitimate the claims made.

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[19] In this work the term speak is used interchangeably with voice and represents all of the mechanisms used by children to communicate their views and reveal their knowledge

Invocation of Voice

Authorship and representation continue to spawn academic debates across many qualitative traditions, not least those influenced by ethnography (Davis, Watson & Cunningham-Burley 2008, Segall 2001, Hammersley 1998). In other words, there remained a considerable challenge to researchers who claimed that their work legitimately represented the subjective interpretations of others. Given this, the complexity of my research was complicated still further as the participants were children.

As Hendrick (2008) noted, generational relations between children and adults are complex, not least because all adults have been children and experienced childhood. However, Hendrick, amongst others (See Mayall 2008, Roberts 2008) was critical of commentators (like Jordanova 1996) who maintained that children had and would always have to speak through the dominant discourses of adults:

*"...Children are intimidated by a 'dominant discourse' but it does not necessarily follow that they **have** to speak with the voices of this discourse. It is not inevitable they may speak **through** the discourse, thereby altering it in subtle ways. All dominant discourses contain within them resistant themes. To suggest otherwise is to deny children any potential for their own voices. It refuses the oppressed the agency to impact upon 'power' and consequently make a difference..." (Hendrick 2008, pg 55) [emphasis original]*

Providing evidence that the children had spoken for themselves and that it was their voices that were represented in this final written report was an essential part of meeting the transformative element of my work.

In order to make sense of the challenge that I faced, and in order to establish my own position, I had to establish how I had interpreted the concept of voice. Although few of the authors cited in chapter 2 (literature review) had considered what they meant by voice in relation to qualitative research with children in hospital, there were notable exceptions in other disciplines. Ross, Munn and Brown (2007), Cornwall (2003) and Gill (1997) associated voice with participation. Indeed, Ross, Munn and Brown (2007) noted that voice was consistent with Freire's polemic in which participation holds the potential to disturb taken-for-granted assumptions. In other words, power was intimately associated with participation and participation was

intimately associated with voice and therefore easily reconciled with critical research methods. Understanding voice in this way resonated with my work on two levels. Not only did it challenge the notion of exclusion based on the ability to talk, it underscored the need to adapt and adopt a panoply of creative methods to enable inclusive participation; a particularly moot point in work with children.

As noted in chapter 2, few of the qualitative researchers who had worked with children in hospital or participated with children to elicit their views on aspects of health and health care, had explicitly defined the meaning of voice. Although most had at least implied that their definition of voice was associated with a right to be heard, having the right to be heard offered no guarantee that all voices would be heard. Sometimes, structural components of access to children in hospital had combined to silence children's voices (Stalker and Carpenter et al 2004). That said, on other occasions researchers appeared to assume that being heard was a one-dimensional concept in that it related to that which was spoken or verbally expressed.

When children had been involved in research concerned with their experiences in hospital, they had often spoken the first language of the researcher and had been able to communicate verbally. Indeed, many researchers who had worked with children alluded to those who participated as articulate (for an example, see Miller 2000). Although not intentional, this appeared to legitimate both the researcher's choice of participants and the participants' right to be included or to participate. In other words, the meaning of voice had been interpreted as being related to those children who could competently articulate aspects of their experience. In turn, it is possible that this will drive the notion of voice as an exclusive rather than inclusive structure. Given this, I had to interrogate my own work to discover how I had interpreted and discovered the meaning of 'voice' from the children with whom I had worked and whether I had revealed their knowledge and presented their views.

Before I present the findings of this interrogation, I need to consider the evidence relating to children's memory, recall, expression of emotion, their capacity to lie and

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the impact of stress and stressful events on children's recall and memory. This is important as in phase 1 the children with whom I worked were remembering events that had happened in the past. In phase 2, while much of my work with the children concerned contemporaneous events, they also told me about things that had happened when I was not there. Again, they were remembering. Given this, I considered next the evidence relating to children's memory, children's recall and the impact of stressful events on children's recall from memory.

Children's Memory

An extensive review of the psychological research into the development of children's memories was beyond the scope of this work. However, given my intentions to elicit children's experiences and their subjective interpretations of these, it was important that I established the evidence base for children's capacity to remember, accurately recall and verbally express their accounts. In doing so, what follows is heavily indebted to reviews by Fivush (2002) and Powell & Thomson (2002).

Psychological research on children's memory is broadly split into two camps; research into what aids children's recall of an event, and research about what hinders or interferes with memory. In both camps, researchers have made significant discoveries regarding factors relating to children's capacity for accurate recall. In her review of autobiographical memory research, Fivush (2002) asserted that memory competence, or how and what children could remember and recount, was of critical importance. Critically appraising the available evidence, she concluded that children's recall was '...*almost always accurate...*' (p. 55). While there are variations, it appears that children have enduring and often detailed memories of their personal experience from the age of 3 years. However, it is more likely that they will remember more specific detail from distinctive as opposed to recurring, mundane events. Interestingly, it seems that children's memories and their ability to verbalise these are enabled by

"...*what becomes elaborated in conversation with another...*" (pg. 61).

In other words, children are more likely to remember experiences which are also talked about with others. This work into memory had established that pre-verbal

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children were unlikely to remember events that happened before their linguistic and verbal capacity had developed (Fivush 2002).

Regardless of children's ability to remember, the dynamic nature of memory means that other influences can have either an enhancing or deleterious impact. Principe and Ornstein et al (2000) were principally interested in how intervening events in the delay between an experience and recall impacted on children's recall accuracy. In particular, they sought to examine how additional discrepant and congruent information differentially impacted on three to five year old children's accounts. With a sample of 59 three year olds (range: 33–45 months) and 60 five year olds (range: 57–69 months) recruited, the children were assigned to one of four groups; three experimental groups and one control.

The findings indicated that the five year old children were significantly better at responding to open questions (P= <0.001) and that intervening events had the capacity to impact on stored memories. In particular, the recall of children who engaged in congruent post-event experiences was heightened. In contrast, the recall of children (especially those in the aged three years age group) was deleteriously influenced by discrepant post-event experiences. They concluded that children's free recall can be inaccurate especially when discrepant information has been encountered in the period between the initial event and recall. They also cautioned against using spontaneity of recall as evidence of accuracy, especially when children had encountered erroneous information in the intervening period between the initial event and recall. However, there was some evidence that the longer it took to communicate a free narrative, the greater the number of words used and the greater the amount of contextual detail added, the greater was the likelihood that the recall was accurate (Pezdek & Hintz 2002).

The Impact of Stressful Events on Memory

Many of the children with whom I worked were recounting stressful experiences but the impact of stress on accurate recall is a contested matter. Studies of children who have undergone voiding cystograms had been used to explore the extent to which

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stressful events hindered or enabled memory development and accurate recall (Olafson 2007). At the time of writing this work there was no agreement on the exact role that stressful events had on the accuracy of recall. In a review of research findings, Powell and Thomson (2002) concluded that a one-off stressful event may be clearly remembered but that repeated stressful events may fragment memory. In keeping with Fivush's (2002) conclusions Powell and Thomson concluded that there was some evidence that being able to describe an experience verbally at the time that it occurred was a critical factor for long-term retention and accurate recall. Powell & Thompson (2002) added that from the age of four years children could not only remember but could also distinguish between similar events. Although inconclusive, these findings challenged the notion of children as incompetent commentators. They also raise questions regarding the wisdom of assuming that stressed parents, concerned for their children admitted to hospital, can offer accurate proxy accounts.

For this reason, I turn now to consider one further study that was published in 1997, before setting out why it holds particular significance for my own work. Aldridge and Wood's (1997) research sought to examine children's ability to talk about feelings. While this study lacks sufficient power to derive certain findings, I was drawn to it as it reflected on the real day-to-day work with children who had endured stressful events.

The Verbal Expression of Emotion

Aldridge and Wood (1997) sought to reconcile their analysis of transcriptions from interviews with children who had been abused with findings from studies with non-clinical samples of children. They were principally interested in the disconnection between their own findings and other research that suggested that children who met standard developmental norms could:

"...*spontaneously comment on the intentions, feelings and desires experienced by themselves and others...' (Thompson 1989 cited by Aldridge & Wood 1997 pg 122)* and

"... *from the age of 36 months can accurately identify situations that elicit simple emotional reactions like happiness, sadness, anger and fear...' (Saarni & Harris 1989 pg 117 cited by Aldridge & Wood 1997 pg 122)*

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Reflecting on their own analysis of real-life transcripts from videotaped forensic interviews with children, they reported that some children seemed to be unable or unwilling to discuss feelings regarding their personal experience of abuse. They suggested that the difference in findings between their work and that of other researchers was due an over-reliance on maternal reporting of children's ability and the use of researcher emotional cue strategies. This, they argued, led to an over-estimation of children's ability.

To examine the incongruence between their work and other research findings they drew on the concept of adult emotion prototypes (Shaver & Schwartz et al 1987) and the subsequent work of Harter and Whitesell (1989). Harter and Whitesell (1989) had identified five levels of children's developmental ability to identify and verbally express emotions; each was matched to a latent-age developmental norm. Aldridge and Wood sought to establish if these prototypes where evident in children's accounts elicited by researchers. They set out to establish whether the developmental changes in children's understanding of emotion concepts (as proposed by Harter & Whitesell 1989) were evident in the children's language used to describe emotions. In other words they were testing the children's linguistic competence in relation to the verbal expression of emotion using contrived play situations. They also sought to discover what factors, if any, would explain the differences between children's ability to express emotion in the research situations published previously compared to the real-life experiences of work with abused children. They recruited 56 children aged 5-11 years (four boys and four girls in each age category of 5, 6, 7, 8, 9, 10 and 11 years) who were monolingual and had no known communication or language development impairment. A cohort of eight adults was recruited as a control group.

Although their sample was too small (N 56) to compute statistical significance, they concluded that no child of 5 years or below, nor more than a quarter of the 6 and 7 year olds in their sample had the linguistic capacity to express fear. Whilst most children could express the emotion of fear by the age of 8 years, a significant minority could not (37.5%). There were similar findings for anger and anxiety. In

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addition, while children of 5 years could usually express positive emotions as happiness and negative emotions as sadness they had an impoverished descriptive vocabulary beyond this. No child aged 11 or younger had developed the vocabulary necessary to describe or convey the notion of coercion. This contrasted strongly with 50% of adults in the control group (aged 18 and over) who could. Similarly, the ability to express opposite valence emotions (both liking and disliking the same person simultaneously) was absent in the children's sample.

Aldridge and Wood (1997) suggested that this was due to the expression of opposite valence emotions being both conceptually and linguistically difficult for children aged between 5 and 11. However, they failed to comment on the 50% of adults who also lacked the capacity to do this. Nor was there any discussion regarding the 87.5% of adults who failed to express verbally the emotions of loneliness and embarrassment or the 75% of adults who failed to express verbally pain as key factor in the scenarios designed to elicit these emotions.

These findings have significance for my work for the following reasons. First, they challenge the often taken-for-granted assumption that adults are competent commentators (unless proven otherwise) on their emotional experiences. Second, they suggested that until the age of eleven, children may have impoverished linguistic and vocabulary skills and may lack the capacity to express verbally loneliness and embarrassment; both significant concepts reported in research findings regarding children in hospital (see for example Cleary 1992, Beuf 1978, Bluebond-Langner 1978, Hawthorn 1974). This seems to be especially pertinent for children who endure significant and stressful challenges as in-patients. This meant that verbal testimonies alone could present significant hurdles to the children in my study. It also meant that I needed to be sure that I had helped them to overcome these hurdles to reveal their meanings and knowledge. This pointed to the need for a definition of voice in my own work to be interpreted as more than verbal expression alone. I had to discover a far more inclusive and more comprehensive definition of voice. I also needed to be sure that I had not spoken on behalf of the children nor put words into their mouths.

While Aldridge and Wood (1997) suggested that mothers may over-estimate their children's ability, they seemed to see children's ability as being determined. In contrast, Mayall (2008) points to the cultural and contextual factors that may inhibit or enhance children's communicative competence. It is then possible that familiar, supportive adults could scaffold and enhance children's capacity to express emotion. Despite this, Aldridge and Wood (1997) acknowledged that children who had help from adults who used emotion cues fared better.

Children and Lying

Finally, for readers who are less convinced of children's capacity it is worth considering whether or not children tell lies. It is, of course, possible that even young children may lie (Fivush 2002), but I could find no evidence to suggest that children had a greater capacity than adults to manipulate facts and recollections or to lie about their experiences. However, it is known that loyalty towards or fear of another person could exert an enduring influence on children's willingness to talk and to tell the truth (Coulborn Faller 2007a). In this children are no different to adults. At the time of writing, testing children's capacity to differentiate the truth from a lie was considered much less important than it once was. There is no evidence that differentiating between telling the truth and telling a lie impacted on the accuracy of children's accounts of what had happened. In other words, knowing the difference between telling the truth and telling a lie did not necessarily lead to an untruthful account of what had been experienced.

Learning from Forensic Interviews

Some qualitative researchers have focused a great deal of attention on the reliability of the analytical processes used to derive rigorous findings from research (Rolfe 2006, Long and Johnson 2000, Koch 1996). While this is laudable, there had been far less analytical attention paid to the processes used to establish what had counted as the voice of participants or how their voice had been elicited. It is for these reasons that I drew on the guidance and the substantial body of evidence that had been used to validate the credibility of children's testimony in criminal courts in the UK to review and defend my own work critically.

In 1992, the Home Office and Department of Health jointly published the Memorandum of Good Practice[20]. The purpose of the Memorandum was to assist practitioners who were undertaking forensic interviews with children to derive evidence admissible in criminal courts. The Memorandum introduced a 4-phased framework for forensic interview work with children. The 4 phases were

- establishing a rapport
- eliciting free narrative
- questioning
- closing

The guidance was well received. This structured approach to interviewing children, particularly when children's disclosure of events was sought, had been refined and researched in a number of contexts and a number of countries (USA, UK, and Israel). Early research reported high levels of satisfaction amongst professionals using the framework to conduct forensic interviews with children,

"...the Memorandum [is] beneficial in terms of reducing the stress for the child witness and for improving the quality of the child's account..." (Aldridge & Wood 1997, p8).

The rest of this chapter is particularly concerned with the first, second and third phases, developing a rapport, eliciting a free narrative, and questioning.

Developing a Rapport

While children have good memories of events that they have experienced they are not used to being asked for their account of them. Additionally, some children may think that the adult with whom they are working knows more than they do. Others may be naturally reticent, shy, have verbal or communication impairments or be unable to engage in lengthy conversations (Aldridge and Wood 1998). My task throughout this work was to develop a range of strategies that would play to the strengths of individual children rather than emphasise their weaknesses or their difference from me and others, and enable them to effectively engage. In other

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[20] Hereafter the Memorandum and since superseded by Home Office 2002 and Home Office 2007

words, I needed to work with them to establish a rapport and a meaningful relationship.

Some researchers working with children had taken account of these concerns, and some had developed and reflected on a number of techniques used to engage with children of different ages effectively (Greig, Taylor and MacKay 2007, Lewis & Kellet et al. 2004, Fraser & Lewis et al. 2004). Others had relied on specific methods such as drawing (Coates 2004), story-telling (Sutton, Smith & Swettenham 2004), and theatrical techniques (Evans & Norman 2002). These strategies offered effective solutions for researchers attempting to realise the full potential of work with children, but they often relied on repeating the techniques with limited flexibility with each of the children. This meant that although creative, when used in isolation some methods could become self-limiting.

A different approach was the mosaic technique. This involved using a range of different strategies to prevent the children from becoming bored or tired of the more usual approaches taken by adults (Punch 2004, Clark 2004, Clark and Moss 2001). More recently still, attention had turned to consider the benefits of using art and craft techniques (Coad, Plumridge and Metcalfe 2009). Collectively, this literature provided a useful benchmark from which I was able to derive some confidence in the methods which I had used to engage the children. Examples of how this was achieved both in phase 1 and 2 are presented in the next section of this chapter. Although useful, this evidence did not provide me with the necessary scrutiny that I wanted to apply to my work to discover what counted as voice or to attest to the extent that the children had spoken for themselves once a rapport had been established.

Eliciting Free Narrative Accounts

According to the Memorandum, the free narrative phase of the interview was about listening to children and encouraging them to:

"provide in his or her own words and at his or her own pace an account of the relevant event(s)..." (p 17).

In other words, the free narrative phase of the interview provided a means to elicit uncontaminated accounts from children. Strategies that were known to enable children during the free narrative phase included having supportive adults present at the time of the interview and using capability-relevant language. In addition, the use of supportive utterances, comments and non-verbal affirmations such as nods were known further to scaffold[21] children's efforts. There was also an important balance to reach between giving children the time to express their views, repeating questions that children did not respond to, and pressing them into giving the answer that they think is sought.

That said, even when children offered a free narrative account, missing contextual detail and a lack of facts often limited the usefulness of what had been elicited. There was then a need for a questioning phase to probe, clarify and check understanding.

Questioning Children

Guidance on the questioning phase of a forensic interview suggested that the interviewer should progress from open to closed questions. Open questions were considered to be the most appropriate and most likely to elicit the children's accounts and understanding in their own words, but they did not always elicit information of sufficient detail. This meant that interviewers would progress to the use of closed and specific questions. There was evidence that certain questioning techniques such as providing contextual detail could be used in direct work with children to enhance their memory correspondence (accuracy) and enable them to communicate more detail (Coulbourn Faller 2007a).

However, closed questions had a greater propensity to elicit inaccurate answers and the questioning phase of any interview was perhaps the most likely to render an inaccurate testimony. For instance, there was a positive correlation between leading closed questions and erroneous answers (Coulborn Faller 2007b, Bourg & Broderick et al. 1999). In particular, tag questions were known to be particularly difficult to resist. A tag question is one in which a positive statement is followed by a

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[21] Scaffolding is adapted here from Bruner (1950) as the processes that are used to mediate and support children's efforts to communicate

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negative, or a negative statement is followed by a positive; for instance, 'he is very nice, isn't he'. Along with the intonation used, the tag question was considered to be highly suggestive and very likely to elicit the suggested answer, regardless of the accuracy of this. While negative tag questions are seldom used in day-to-day conversations, positive tag questions are more common and therefore more likely to be used by researchers like me.

Aldridge and Wood (1998) reported their alarm at discovering a 100% positive response rate from children who answered positive tag questions during an analysis of forensic interviews. This could have occurred for several reasons. One is that children often think that the adult to whom they are talking knows more about what is being discussed. Another explanation is that children are usually more familiar with supportive adults who scaffold and enable their communicative competence than those who seek to discredit their accounts (Coulborn Faller 2007a). They are also more likely to:

"...operate at their most mature level when they are socially neutral and lose their social competence when they are upset or angry..." (Dunn & Brown 1994, p121).

This underlines the need for those who work with children and those attempting to elicit their views to remain mindful of the need for supportive and complementary methods that maximise children's strengths, rather than methods that demean, supplant, or disadvantage children.

Testing Children's Capacity

The accumulation of international evidence has had an enduring influence on policy makers in the UK. This sea-change in the assumptions and positioning of children as valid commentators on their own experiences is such that the most recent guidance stated that:

"...where children are to give evidence, it is no longer necessary, as it was at one time, to persuade the court that he or she is possessed of sufficient intelligence to justify the reception of the evidence and understands the duty of speaking the truth...' (Home Office 2007 Section 2, p 4)

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To add further weight to the validity of children's testimony, some forensic guides had suggested that certain aspects of the children's ability to do some things should be tested. An example of this offered by Coulbourn Faller (2007c) is that interviewers deliberately misrepresent something that the children had said to test if the children would correct the adult's account. For instance, if a child had told the researcher that they had a brother, the researcher would reply, 'Oh, you have a sister.' Those children who fail to correct the interviewer are then coached to do so. Another example is that children may be asked to state when they did not understand a question and be told that it was acceptable to simply tell the interviewer that they, *don't know.*' Another technique is that of asking the children something that they could not possibly know, such as the name of the interviewer's dog. Again, those children who guess are coached not to do so. What is less clear is what happens when children resist attempts to coach them or change the way they answered. It seems that individual differences between children mean that there will never be a fully fail-safe mechanism for eliciting their views. That said, this is just as challenging and pertinent in work with adults.

ELICITING VOICE (2) A CRITICAL REVIEW

Having reviewed the evidence derived from psychological studies into children's memory and recall, together with that concerned with investigative interview techniques I now turn to make transparent the methods that I used to elicit children's voices and offer a critical analysis of the processes used. What follows here also provides evidence that the children spoke for themselves, that the participatory methods used were inclusive and that no participant, regardless of ability, was excluded or silenced.

To begin, I start by describing the methods that I used to establish a rapport with the children in phases 1 and 2, highlighting how the difference in context (home and hospital) had significant bearing on what the children did and how they behaved. I then present a critical review of how I was able to build a rapport with the children and their families before analysing the conversations that I had with them. This analysis focuses on how I enabled and scaffolded the children's efforts to communicate their knowledge and insights. It also provides evidence that the children corrected adult interpretations of the children's experiences that are different to those that the children constructed. I was especially keen to discover how the children dealt with what, for now, I will call adult interference.

The Beginning

In any research relationship there is a beginning and an end. My endings (or closing with the children) are considered in the final chapter. Here I deal with the beginning of my work with children and how my relationship with them was sustained and often strengthened over time.

Beginning participatory research work with children is contingent on the development of a trusting relationship. Christensen (2004) noted that adults sometimes make the mistake of using familiar contextualised mechanisms that structure adult-child relations to develop research work rather than taking the time to observe children and identify the preferred mechanisms that individual children use

to communicate. However, in phase 1 of my work, there was no time to sit and observe children prior to talking to them about their experiences of being in hospital. This meant that I had to consider in advance the impact that both time and place would have on my research relationships with the children.

Context

The importance of the context for research is sometimes too easily overlooked. The place in which any research work takes place may have a significant impact on the quality of what is revealed (Connelly 2008). As Alderson (2008) and Mayall (2008) had already observed, children behaved and responded very differently in different places. Even more important is the understanding that children's:

"...social experiences and their relative competences as social actors must always be seen as contextualized rather than determined..." (p 171).

Phase 1

For phase 1 the children had all elected for the interviews to take place at home, in the evening, after school. As I was aware that families would be involved in preparing meals and pursuing after-school and other activities I was keen to reduce any intrusion to a minimum. In all but one case the families were at home at the pre-arranged time. Aarif had gone to his class at the mosque, so I waited outside in my car for 30 minutes. When he returned, his father and mother apologised profusely that they had forgotten that I was coming.

As noted by Mayall (2008), the home is a private place, with some areas, such as bedrooms, often considered more private than others. Homes are most often dominated by adults and in keeping with Mayall's (2008) observations it was always the adults who answered the door and invited me in. It was also always the adults that suggested where the interviews should take place. In keeping with cultural traditions my conversations and interactions with the children always took place in the living room or lounge. This is most often considered to be the appropriate place for visitors to be accommodated. It also positioned me as a guest in the house and as such subject to the 'house rules'. Being invited into the families' homes was a privilege that I never took for granted. I was always overwhelmed by the welcome I

received. Cups of tea and coffee, plates of biscuits and sometimes mountains of cake were supplied. I never felt like an intruder but I was still cognisant of my guest status. In some cases some of the family members had vacated the room so that I could work with the children. Seb's step-father and sister left. Most of the children's mothers asked if they could stay. This was in sharp contrast to Mayall's (2008) observations that the mothers with whom she worked expected to stay with the children during research work. Fion's father also asked if he could join his wife during Fion's conversation. Her brother went to work on a computer in an adjoining room. Aarif's mother stayed and continued with her sewing until she was called away to deal with a telephone conversation; from then on she came in to the room and left at will. All of the families switched the television off. I took this as an indication of the seriousness that they attached to my visit. It conveyed a sense that they wanted their children's views to be heard and acknowledged. Only Joe asked to speak to me in private. In other families, family members who were not involved in my work with the children went about their usual activities, coming and going and occasionally joining in.

As noted, in phase 1 my time with individual children was short. I had agreed with the children and families that my work with the children would last for no longer than 60 minutes unless they agreed otherwise. As I had no time to observe the children at home I went to each house armed with an array of toys, books, puppets, stickers, craft activities, and recording devices. I had taken the time to select toys and activities that could be used co-operatively.

The children were asked to choose a toy or activity and they were encouraged to play with these during our conversations. Additionally, they were offered the opportunity to play with their own toys. Sarah was the only one to choose not to do so. Joe kept hold of his hand-held Portable Play Station (PSP). I always began my work with the children by introducing myself. I adopted the identity of a non-partisan researcher, telling the children that I wanted to know about their time in Study ward. I explained that I wanted to do this so that the staff in hospital could give them and other children what they needed when they were in hospital. I also explained that I

would tell the people at the hospital what they had said, but that I would not use their names so that the staff would not know who had said what. I also explained that I had been a children's nurse and that I was working as a teacher of children's nurses. Liamputtong (2007) suggested that simple explanations and the avoidance of jargon were mechanisms that sensitive researchers could use to help research participants to understand what was intended.

All the children in phase 1 agreed that my conversations with them could be digitally-recorded. They were also curious about how they sounded on the recording. I played this initial recording back to them and we often giggled about how we all came across. The children then decided whether or not to hold the digital recorder or where they wanted it to be placed during our conversations. Sometimes this took up more time than I had anticipated. For instance, Kamran and Sana wanted to sing and record their Christmas song, Prickly Hay, and then hear the recording back. Giving the children time to do such things was an important part of being sensitive to the needs of children and reciprocating the time they had already given to me.

Following each phase 1 visit I made an entry in my field journal. These notes captured my initial thoughts about the children and what they had told me. When played back, the recorded conversations captured the seemingly chaotic nature of some of the households. Familiar people, pets, friends and neighbours were going about their day-to-day business. On occasions I recognised aspects of my own family life embedded in the seemingly disordered ordinariness of children and pets disrupting adult encounters. In fact, working with children in the context of their usual home life and routine was far more important than I had anticipated initially. I was familiar with communicating with children in hospital who had been admitted as in-patients. I had expected them to be anxious and sometimes frightened. However, as they told me about their hospital experiences and as they described their experiences of being an in-patient I became increasingly aware that, in keeping with Harre's (1983) work, the children had a strong sense of self and self identity. In keeping with John's (2003) assertion, they conveyed their understanding that they

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were social agents able to impact on and influence the world in which they lived. I became increasingly convinced that they wanted their voices not only to be heard but to have their views taken into account. In other words, in the context of home they had a space that was not only "...*structured by moral and political considerations, rules and conventions...*" (p 2), it was a space that accommodated their individual identity. This was in sharp contrast to their experience in hospital (see chapter and my theoretical conclusions). I also became aware that they had developed strategies to make their opinions of certain events public in the context of Study ward yet kept other aspects hidden. As the following analysis reveals, these experiences contributed to my developing critical standpoint and provided a platform from which I could continue to question my acquisition of knowledge as derived from my position (D'Cruz 2004) as a professional children's nurse and mother of hospitalised children.

Phase 2

During phase 2, I worked with children during their time as in-patients on Study ward. In contrast to the private status of the children's homes, the hospital ward was a public place for children. Study ward was a nightingale design; the entrance door off the main hospital corridor led down a narrow passage way with toilets, store rooms and cubicles off either side. The nurses' station was situated at the end of the passage way, with the senior nurse's office opposite. Both were situated at the top of the ward. The children's beds and cots were arranged alongside either ward, to the left and right. Additional large high dependency cubicles were situated at the bottom of the ward off the main ward area (see diagram 1).

The beds were close together. Although each bed had curtains fastened to a rail that was fixed to the ceiling, when closed these would often touch the next bed. Each bed had a wall light (some with no bulbs), a bedside locker, and some had bed-tables. A chest was placed at the foot of each bed for storage. Most beds had a patient information point fitted to the wall. For a payment, this could be used to watch a tiny television screen or make telephone calls. It also provided the means for a nurse call system but this had never been used nor activated by the ward staff.

There were no patient call buttons or any alternative means for the children to signal a need for attention beyond shouting.

Access into the hospital was gained through the main entrance that was open until late in the evening. Once the main door was locked, entry was controlled by security staff. However, the Study ward door was seldom locked and there were additional entry points to the ward and corridors that visitors sometimes used to gain access. In addition these doors were left open during periods of hot weather in an attempt to cool the temperature of the ward. The double doors at the end of the ward opened straight onto an access road at the back of the hospital site. When open, a few chairs would be placed across the entrance in an attempt to stop children from wandering out. There seemed to be less concern about others wandering in. The parents sometimes used this access to go outside to smoke a cigarette.

Establishing a Rapport

Throughout phase 2, and regardless of having the parents' permission to work with the children, I began every episode of contact by introducing myself and making sure that the children were willing to work with me. This included checking if they could remember the purpose of my visit. I also always asked them to select a toy or activity from my research bag. In addition to the toys, I always carried a digital camera and video recorder. During my visits to the ward, Sam and Peter were often excited by what they might find. Kelvin was a little more ambivalent, indicating that most of what I had was really quite uninteresting. While he often made a choice, sometimes he declined. Sometimes the older children asked me to choose for them. I chose a craft activity to share with Celeste, and I selected a scented candle for Caron to take home. On some occasions the children chose the camera. One outcome of this is considered later in chapters 4 and 7..

Not all of the children in phase 2 agreed that I could record our conversations. Benjie did not want to be recorded and his choice was respected. Kelvin sometimes did and sometimes did not. In fact, sometimes Kelvin was very keen for me to switch the recording device on when he had something that he thought was important to

tell me. Sometimes the children asked me to switch the device off. For Sam in particular it seemed to signal that he was bored with answering questions and simply wanted to play, but the time I spent playing with Sam was an important aspect of my work with him.

Combined, these strategies were successful in enabling the development of a social relationship but also created a separation between me as a researcher and the other adult workers in the ward. A key benefit of asking the children to choose their preferred activity or toy meant that they were usually quickly engaged. Despite this, there were occasions (discussed in more detail in the findings chapters) when the children on the ward declined to work with me. Their wishes were always respected.

Scaffolding Children's Communicative Competence

Supportive Adults

While consideration of the methods that I had used to build a rapport with the children was essential, I needed to go beyond this and consider the extent to which I could claim that the children had spoken for themselves. I have already established the evidence base that supportive adults can scaffold children's communicative competence, but I wanted to be sure that the adults had not interfered with the children's accounts or spoken on their behalf.

During my analysis of the conversations that I had during phase 1 and during the field work in phase 2 I became aware of the degree to which some of the children had relied on their parents and siblings for support. At one point, Sarah had asked her parents to confirm her account of having a Jackson Pratt drain removed. She turned to her parents and stated: "...*they did, didn't they..?*" When they agreed with her she turned back to me, gave me a nod and smiled as though to say "I told you so". It was as though they had boosted her confidence and courage to tell me more. Sarah had also relied on her sister for support on several other occasions during my conversation with her. When she was deciding the extent to which spina-bifida was part of her identity, she turned to her sister for confirmation that her ideas were valid. It was not that she needed them to speak on her behalf; rather, she sought

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and received support from them. Fion and Aarif also sought affirmation and support from their mothers. Other children relied on their parents in different ways. One example was evident when Seb was reticent in telling me what operation he had undergone. Although his mother gently tried to persuade him to do so, she accepted and supported his initial decision to decline.

These examples illustrate that supportive adults are not those who insist that children behave in a certain way or those who expect children to do what they are told. Rather, supportive adults are those who follow the lead offered by children; affirming, scaffolding and encouraging their efforts. The value of having supportive adults present during my conversations with children in phase 1 was amplified when Joe opted to speak to me on his own. When I first arrived at his house his mother had left us in the lounge. She said she would be upstairs if we needed her. At first Joe seemed somewhat nervous about talking to me; in fact he appeared to me to be the most nervous of all of the children with whom I worked. I had gleaned from his behaviour and the way he fidgeted with his hand-held gaming device. His nervousness may have been underpinned by uncertainty; not knowing what to expect. He may have been nervous about the content of the conversation that we were about to have. Given the nature of his surgery, a circumcision, it is possible that he was simply embarrassed. Embarrassment is known to prevent some children from talking freely about their experience (Coulborn Faller 2007c). There are however, many other possibilities. Joe had not met me before nor had he been involved in any other research interviews. As he had agreed with his mother that he would be interviewed by me on his own (she returned to the room only when the interview was complete) he did not have access to a supportive known adult or advocate during our conversation. However, he may have been less comfortable talking about his circumcision with his mother present. Without further confirmation from Joe, my explanations remain speculative.

Supportive Children

Kamran's participation in this work underlines the importance of not only having supportive adults but the role that supportive children can play. In a similar way to

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adults, some children were willing to intervene and support other children to enable them to give their account and express their thoughts and feelings. An observation noted by Kamran, a 9 year old boy described by his foster parents as having learning difficulties and communication problems, presented me with the most challenging research encounter. He appeared to be especially dependent on his foster parents and his sister to enable him to communicate. Although younger, his sister Sana was familiar with helping Kamran to settle down in new situations and in helping him to answer questions. While at first Sana tended to interrupt and answer questions for Kamran, she responded positively to her foster mother's request to let Kamran answer if he could. However, she continued to sit with him and play with him throughout the interview. Being interviewed in the presence of his sister and foster parents seemed to help Kamran cope with the situation. This meant that he was able to articulate and describe his feelings during his stay in hospital. While I cannot state with complete certainty that this would not have been possible had I worked with him alone, I am sure that the interview would have been less successful had Sana not been present. Other researchers have reported similar conclusions. Mayall (2008), Roberts (2008), Maybin (2009) and Maybin (1996) illustrated the importance of children's talk in helping them to make sense of their experiences and learning.

Overcoming Hurdles

O'Kane (2008) suggests that creative methods of engagement enable children to focus on events and talk about both abstract and complex matters that are important to them. By doing so, she asserts, *'the methodological problems surrounding interpretation of children's activities'* are diminished as children are enabled to speak for themselves and reveal their unique interpretations. I would add to this the need to assist children in overcoming a significant number of hurdles that can limit rather enhance their communicative competence. These hurdles included the need to overcome adult explanations of the children's experiences that were different to their own, vocabulary impoverishment, linguistic capacity, nervousness, fear of reprisals and the difficulty inherent in the expression of emotion.

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It is also possible that the children would have spoken freely to other children, yet as discussed earlier, while there have been significant in-roads made to the involvement of children as data collectors in some situations (Participation Works 2010, McLaughlin 2005), involving children as field workers in complex social situations remains a significant challenge.

Overcoming Adult Explanations.

As noted, some adults stayed with me while I worked with the children. Many of them negotiated with me and their children if it was acceptable for them to do so. There were exceptions. Caron's mother always left so that Caron could tell me anything she wished, and Kelvin's father often took the opportunity for respite when I was working with Kelvin. However, many of the parents stayed and spontaneously joined in the conversation. An example was when Celeste's mother told me why she thought that the pain specialist nurse was particularly important for children who had undergone complex surgery. To illustrate this Celeste's Mother gave an example. She said:

CM   *"It had gone down with a jump from a 2½ to a 1".*
C   *"No, from a 4 to 2½".*

This conversation between Celeste and her mother continued until they came to an agreement that the exact detail did not matter. This encounter provided evidence that Celeste could and would challenge her mother's account when it differed from her own. More importantly, it provided the right conditions for Celeste to go on and explain how she interpreted the numbers on the pain ladder. In this way, the exchange between Celeste, her mother and me illustrated the intimate relationship between the social construction of understanding and the subjective nature of interpretation. The disagreement had provided the right conditions for Celeste's knowledge to emerge and be accepted as valid.

Similarly, Seb corrected his mother when she explained why he was so cross when a nurse hurt him while measuring his temperature. She had tried to explain to him that it had happened in the middle of the night and that as he was in pain any interference would have mattered. She was trying to persuade him that his

interpretation was wrong. He resisted her comments with some force and asserted that:

S   "No, she did it in the middle of the day, she did it once; she did it twice actually when you were out drinking coffee. Just came up to me and put it in my ear".

In turn, Seb's mother acknowledged his knowledge and accepted his explanation.

Overcoming linguistic ability

My work with Kamran also illustrated the impact of linguistic ability and vocabulary on eliciting children's knowledge. Although Kamran had communication impairments he was reliant on language to communicate as he did not use augmentative aids. He was unable to give a free narrative account of his experience. Rather, he gave most of his account through short one word answers. Given this it was appropriate to probe and question Kamran so that his views could be included. The following excerpt illustrates that using Kamran's name helped him to know that the questions were aimed at him and that offering contextual information (did you sleep in hospital?) helped him to tell me something about his interpretation of his hospital experience:

JL   "Kamran, how long where you in hospital for"?
K   "Dunno".
JL   "Kamran, did you sleep in hospital"?
K   "Yes"
JL   "Do you know how many nights you slept in hospital"?
K   "1 day"
JL   "Where did you sleep"?
K   "In a bed"

Repeating my questions for a second time was another successful strategy that helped him to communicate and share his knowledge that his time in hospital had been boring:

JL   "Kamran, what was it like in hospital"?
K   "Boring".
JL   "Boring, why was it boring"?
K   "Silence".
JL   "Kamran why was it boring"?
K   "I was watching telly all day because I had nothing to do".

This very short excerpt was typical of my conversation with Kamran. By using several different interview techniques I had helped Kamran to communicate his interpretation of being in hospital. Making sure that his sister was involved in the sticker activity meant that he was supported. Using his name helped him to know that the question was directed at him. It also meant that his sister understood that I wanted Kamran to offer his own response. This did not mean that his sister was excluded. On the contrary she joined in singing "Prickly Hay" (a Christmas song). This analysis of eliciting Kamran's knowledge and insight of his own experience is not dissimilar from the findings reported by other researchers who have reflected on research interviews with children. For instance, Aldridge and Wood (1988) gave detailed examples of children's accounts that were very short but also informative. Although Kamran was unable to provide a free narrative account, the use of short, specific, closed questions clearly assisted his communicative competence. I had scaffolded his attempt by giving him time to consider his response and repeated the question a second time when he did not answer. This was consistent with the advice offered by the Home Office (2007), Coulborn Faller (2007b), Powell and Thomson (2002) and Aldridge and Wood (1988). Overall, although I had no conscious intent of working with him in this way, my expertise derived from helping children to communicate was clearly evident.

Overcoming nervousness

As noted earlier, although Joe had agreed to work with me he appeared to be very nervous about doing so. In spite of this, I had been able to build a rapport with him and to scaffold his account by talking to him about an earlier experience of attending an accident and emergency department. In addition I had used simple closed questions to facilitate his free narrative:

JL   *"had you ever been to casualty or anything like that?"*
J   *"I've been to casualty because I have a scar here"*
JL. *" You have what?"*
J.   *" have a scar here."*
JL   *"Oh, how did you get that?"*
J   *"And I've got another one here; I went through a glass mirror?"*
JL   *"How did you do that?"*
J   *"Well, there were 2 beds like that, and a glass mirror across, and I was with two of my friends, Two girls, one of them my cousin and the*

other was my mum's friend's daughter. She jumped across it, and
then my cousin jumped across it and I jumped across it and I fell
through it [pretends to jump]."
JL   *"Oh dear, what, right through it like that? [pretend to jump]*
      had]."

However, as the following excerpt illustrated, I had also used a series of "yes-no" questions in the following sequence:

JL   *"Did you?"*
J   *Nods*
JL.   *"You didn't think it would break?"*
J   *"No."*

Closed questions that require a yes or no answer are considered inappropriate as they sometimes lead to inaccurate accounts and are considered to be leading (Coulborn Faller 2007c). However, at this point in my work with Joe I was still building a rapport and trying to earn his trust in the hope that he would be able to tell me something more about his experience while he was an in-patient on Study ward. It seemed reasonable to agree with him that he did not expect to fall on the mirror or that the mirror would break.

In my work with Celeste during phase 2 I had used a complex and leading question that could have confused her:

JL   *"When you came round, after, when your mum and dad were here, you said*
      you were quite relaxed, is that the way it carried on? Were you still relaxed all
      the time?"

Not only had Celeste resisted my attempts (albeit they were not intentional) to lead her, she went on to correct me when I interpreted her pain as 'very, very bad'

C   *"Yes. I was still in a bit of pain but I did feel quite relaxed."*
JL   *"Where was your pain?"*
C   *"There." [points to her abdomen]*
JL   *"Across your tummy, right across?"*
C   *"Yes."*
JL   *"What does it feel like, can you remember?"*
C   *"It felt tight."*
JL   *"Was it very, very bad?"*
C   *"It wasn't very bad, I would say it was just bad. Then it got a bit better."*

Again, I had used a closed question seeking a yes or no answer. This could be construed by others as me prompting Celeste. As already noted, research into forensic interviews has demonstrated that some children are particularly suggestible. Given this, it is worth considering why it was that Celeste had resisted my lead.

Children are not used to being asked for their opinions about the services that they have received, and they are often socialised into giving correct answers to authority figures. By using a tag question I could have inadvertently coerced Celeste into giving me the answer that she thought that I wanted. However, in this example, acknowledging that Celeste was in pain and that the pain had been substantial was an attempt to demonstrate empathy and strengthen the rapport I was building with her. After all, I was engaged in participatory research that was consistent with a social relations model rather than relying on a fixed researcher–subject relationship. I had set myself up as a friendly adult who wanted to know something about her experience in hospital but with no particular authority.

It is possible that Celeste resisted my suggestion in order to make sure that I understood things from her perspective. She had already corrected her mother's recall of her pain. It is possible that she was simply determined to help me to understand her experience from her perspective. Nevertheless, there are other explanations. Evidence from research with children undergoing voiding cystograms (Olafson 2007) is frequently cited to support the contention that knowledgeable children are highly resistant to suggestibility, especially when what is suggested is discrepant to their own experience. This was not only in keeping with the epistemological claims that I had made for this work but also provided further justification that what had been discovered and revealed in this work was grounded in the subjective experience of the children who took part.

Overcoming fear of reprisal

Sometimes, the children had concerns which were kept hidden from ward staff. This became clear during my work with Benjie and Caron. During one of my

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conversations with Benjie, he had signalled for me to move in close to him so that he could whisper something in my ear. As I did so he looked around the ward to make sure that no-one could over-hear and then asked: *"Will you tell them what I say?"* Caron had also asked me if the staff would find out what she had said. Both Caron and Benjie had opinions and insights that were complimentary to the staff and the work that they did. They also had concerns; both had endured experiences that had left them in pain, feeling ignored and having difficulty in getting the attention of the staff when they needed something. Despite their level of concern, they had felt unable to raise these with the staff. This illustrates that some of the children accepted their subordinate position and that they feared reprisals should they complain. It is also consistent with Coulborn Faller's (2007a) assertion that children's fear of reprisal can limit the extent of what they are prepared to talk about and disclose.

I explained to both Caron and Benjie that I would report on what they had said, but that this would be some time from when I had spoken to them and that I would change their names so that they were not recognisable. Given the nature of Benjie's problems and the rarity of Caron's congenital anomaly, it is quite possible that pseudonyms alone would be insufficient to ensure anonymity. It seemed to me that the children wanted what they told me to be passed on in order that their views could be used to influence necessary change. There was then a vague and tacit boundary that fixed my work with the children; a boundary that I constantly navigated to protect their right to inform future service delivery while maintaining their anonymity. This challenge had been noted by Bourg & Broderick et al (1999) in relation to children who disclosed their experience of abuse. While I intended no comparison between those who deliberately harmed children and the staff who worked on the ward, I did consider that ignorance of institutional abuse and tacit acceptance of structures that disempowered children in hospital were harmful to the children. Furthermore it would be naïve to suggest that no reprisals would follow had I knowingly disclosed the children's identities. I dealt with this by scrutinising the quotes carefully that I used during the initial feedback to staff, making sure that there was nothing that could have been related back to Benjie or Caron. This was

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the right decision as some of the staff from Study ward who were present for my feedback asked me to identify the children that I was quoting. When I refused to tell them they tried to guess.

Overcoming Reticence and Embarrassment

The importance of establishing a rapport and gaining the children's trust was an essential element in my work with all the children. Some of the children were certainly reticent to talk about the nature of their problems. For instance, while Joe was especially animated when he told me that he had been to the accident and emergency department following the failed attempt to jump across a mirror placed between two beds, he was much more reticent to talk about his circumcision.

J   *"I was circumcised."*
JL   *"OK. And is that because, had you had a problem?"*
J   *"I think, I had a bit of a problem, and my mum said 'its cleaner."*

He did not refer to the reasons for the need for his circumcision again. With hindsight, had I used an open question rather than a closed he might have done so. Similarly, Seb was reticent to talk about his hypospadias:

JL   *"What was it Seb, why did you have to go to the doctor?"*
S   *"Err, I had to have an operation."*
JL   *"Ok. Do you want to tell me why or would you rather not? You don't have to."*
S   *"Do you know, do you know why?"*
JL   *"I don't know, but I can find out. Do you want me to find out?"*
S   *"It's just a bit embarrassing. That's all I'm saying."*
JL   *"That's absolutely fine, OK."*

Both excerpts illustrate the boys' initial reluctance to talk about their urological problems. It seems that some things were sometimes too difficult to talk about in detail, at least initially. Talking about those things that I thought more mundane, for example the food and having access to the right television channels, was not. As mentioned previously, I was constantly navigating the boundary between probing too much and inadvertently oppressing the children, and enabling and supporting their communicative competence. It was possible that inadequate probing or insufficient recognition of cues prevented the children from communicated aspects of their experiences that were important to them.

Overcoming illness

I had visited the ward to work with Ged and was told that she was too sick to work with me. She had pus oozing from one of her catheter sites and had been vomiting. I entered her cubicle expecting her to decline my offer to play, as I did so she sat up in the bed and gave me a big smile. I took this as an indication that she wanted to work with me. She told me how she had cried when she had needed to have one of her catheters replaced. She did so by drawing a picture of her sitting in bed which we discussed together. Despite being ill, she was wanted to work with me, but she remained quiet and shy.

In my study, all of the children had urological problems. This meant that my conversations with them were directly or indirectly related to their genitalia and toilet habits. Most children are socialised into considering these subjects to be out of bounds, inappropriate or rude. Yet, genitalia are intimately bound up with gendered identity, and being continent is intimately connected with growing up and becoming independent. The potential to engage the children in conversations about subjects that they have been socialised into avoiding was certainly anticipated. I had expected some reticence and encountered some embarrassment, but, tellingly, the embarrassment was often mine and not necessarily the children's.

An instance of this occurred during field work when Sam had asked if he could use the camera. I had explained to the children that they could not take any photographs of people (other than themselves and that these would not to be used in publications or presentations). Sam always complied with this rule. However, on one occasion when I was working with him, he was very excited about his penis. It looked 'normal' and he wanted everyone to know. He threw back his bed sheets, spread his legs out wide and photographed his penis. I noted in my field work journal that I was shocked and embarrassed. I wondered what other people who witnessed the account thought and quickly covered Sam with his bed covers. I wondered how I would have justified having a digital image of boy's penis on my camera. I was later relieved to discover that Sam's aim with the camera was less than accurate and that he had

only taken an image of his crumpled bed sheets. Sam's source of pride was my source of embarrassment.

Yet, the children with whom I worked revealed their intense desire to become more like other children again and again. Other children were those whose anatomy and physiology was more in keeping with that considered to be normal. While the children considered themselves to be a member of the social class of children, they had knowledge related to their anatomy, and sometimes their physiology, that made them different within this social group. Sam's pride and desire to show off his newly functioning penis offered insight into his knowledge. It was my inability to probe still further the social meaning of this for Sam that limited his capacity to reveal the social significance of this. Still, as discussed in the findings, being more 'normal' was an aspiration for many of the children. According to Christensen (2008) and James (1993) and Alderson (1993), children regard being the same as other children important as 'sameness' constitutes a means through which children's social relations are maintained.

Overcoming Shyness

Sometimes, as with Kamran, it was not that the children were reticent; it was that they did not have the capacity or capability to reveal their knowledge without additional support. In a similar way to Kamran, Ged was shy and very quiet. As such she needed an extensive range of support to enable her participation. With Ged, I used a finger puppet, drawings, and story-telling techniques and I frequently read to her. All worked as effective strategies to earn her trust, enable her communication and support her inclusion in this work.

The finger puppet was chosen by Ged from my research bag when we first met. We agreed to call the finger puppet Princess Finger (PF). Princess Finger became important not only in how Ged communicated with me, but how she did so with other adults, including her parents. Using Princess Finger and combining this with storytelling techniques proved to be a very effective strategy in enabling Ged's communicative competence.

JL   "So what was your operation for, Ged?"
G   "Ur"
JL   "Shall I try like this ... once upon a time, a long time ago there was a little girl called Ged, and she came to Study ward for an operation. Her operation was to make something better. [PF]...'Do you know what you are making better?' and Ged said"
G   "I had my wee done."

As already noted, eliciting the children's voices meant going beyond verbal communication. For Ged, non-verbal communication was sometimes her preferred way of telling me what had happened. While she was sometimes reluctant to talk to me, she would respond to Princess Finger through a series of nods, headshakes and shrugs. Following the convention often used by Christensen and James (2008) Mayall (2008) Roberts (2008) and others, the snippet below includes Ged's non-verbal responses:

JL   "Because you had your wee done. Is it better now?"
G   Silence.
JL   "and Ged's got a tube in her tummy. What is the tube for?"
G   Smiles.
JL   "Do you know? "
G   Shakes her head.
JL   "You don't know what the tube is for?"
G   Silence.

Ged responded to the first 4 questions with silence, nods, head shakes and smiles. She then used a one word answer to tell me about her catheter before reverting back to non-verbal mechanisms. As the following indicated, this pattern was repeated during many conversations I had with Ged.

JL   "What's in here Ged?" [pointing at the urine collection bag].
G   "My wee."
JL   "Is that your wee? Your wee comes out of your tummy."
G   Nods.
JL   "You're a very special person aren't you?"
G   Smiles.
JL   "So does that tube take your wee out?"
G   Nods.
JL   "And what is in this one?"
G   "Nothing."
JL   "Why is nothing in that one?"
G   "Because it is not working."
JL   "It's not working. Will it start working when we take this one out?"
G   Silence.

JL   "Will it? "
G   Shakes her head.
JL   "No. Will it never work that one?"
G   Shakes her head.

Throughout this exchange with Ged I had not only scaffolded her communicative competence by repeating questions, adding contextual information, paraphrasing what she had said and used humour to focus my work with her, I had also accounted for her silence. As noted by Lewis (2010), researchers who work with children are often caught between:

"...the promotion of authentic 'child voice' and a context [of] limited development time and minimal opportunities for involving 'reluctant children..." (pg 3).

She continued that research work with children with special needs is painstaking and time consuming. I would add that the impetus to get research work completed on time and the amount of effort that is required to work with some children means that reticence and incapability are inappropriately used to exclude some children. Although my work was not externally funded, and given the difficulties I had encountered to gain access to the children, I was always encouraged by my supervisor to spend as much time as possible in the field and to make determined efforts to include all the children who met the entry criteria. In the end this paid dividends as I was able not only to develop effective relationships with the children but also to work with them to reveal their knowledge and insights, as the following illustrates:

JL   "Ged, do you know, when I came into your room today, you were getting a
      different catheter, weren't you? "
G   Nods
JL   "What has happened? Can you tell me? Tell me into there [pointing at digital
      recorder that Ged is holding] what had happened when I came into your room."
G   "My tube came out."
JL   "Your tube had come out. How did that happen, do you know? "
G   "Getting in the bed."
JL   "When you were getting in the bed. Where were you before you got into bed?"
G   [Points at chair]
JL   "On this chair here? "
G   Nods
JL   "This big red chair?"
G   Nods
JL   "And who lifted you back to bed?"

G   [Points towards her father who is sitting by the bed table]
JL   "Did that table put you back on the bed?"
G   Shakes her head
JL   "It didn't, did it?"
G   Shakes her head
JL   "Did daddy put you back on the bed?"
G   Nods

This short excerpt illustrated that non-verbal communication was as equally legitimate as voice in the representation of children's views. Although challenging, it was as important to derive and develop effective methods to elicit Ged's narrative as it was to work with children who had a greater capacity for verbal communication. With regard to this using the finger puppet proved to be an effective communicative strategy.

Finding Voice in Work with Children.

In ethnographic studies, the voices of key informants are most often represented through spoken words, and spoken words were most often used to communicate subjective meanings (for an example see Bluebond-Langner 1978). Key informants were usually those with whom the researcher had established a close relationship or those who seemed to speak on behalf of others who shared something of the experience in question. Central to this tradition is the notion of voice.

The meaning of voice for this study was initially discovered during phase 1 and the field with children during phase 2. It was further crystallised during the final analysis and synthesis of all my research data. During the time I had spent on the ward I had witnessed what I thought of as both ordinary and extraordinary events and I observed and talked to the children about them. My sensitivity to that which was observed on the ward had been rightly influenced by my conversations with the children in phase 1, and then further developed during the field work. However, during the analysis and in subsequent supervision sessions, I became aware that the experiences of two of the children, Kamran and Ged, were less evident than others. Being mindful of my claim that I had used inclusive and participatory methods, recognising that some of the children were less visible in the analysis than others was a problem. I determined that Kamran and Ged had communicated their

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insights but that my analysis had not been sensitive enough to hear their voices. During my time with them I had worked hard to ensure that their knowledge was elicited but working hard was not enough. They were neither articulate, effable or effusive; but they did have knowledge and had revealed this to me.

I returned to the data and attempted to discover, if I could, why this was so. In turn this enabled me to interpret their under-representation as a form of silencing and then I discovered that being silent was just another form of voice. Developing the critical framework presented in this chapter and using this to scrutinise how the children's voices had been elicited helped me to see beyond this silencing. Fortunately, I had worked hard with both Kamran and Ged to elicit their insights. It was my inability to understand what they had both told and taught me rather than their inability to communicate their knowledge that lay at the heart of this difficulty. It was through my further interrogation of the data that Ged and Kamran had provided that I discovered the meaning of voice in this work and that it was conveyed through more than spoken words. This helped me to move beyond an over-reliance on the analysis of conversations towards a more inclusive analysis of the children's actions. In turn, this enabled a greater depth of analysis which revealed that non-verbal communication was of equal importance in communicating the children's interpretations of their experiences. Once I had discovered this I was able to use their insights to further interrogate the transcripts and field notes. This then led me to discover what being quiet or silent might mean for other children in Study ward.

I now contend that children's accounts are at least as reasonable as those of adults. When children are communicating their knowledge about their lives, then their voices deserve to be given precedence. However, it is also important to acknowledge that regardless of any shared characteristics, such as age, gender and culture, subjective interpretation of personal experiences means that individual differences and variations between children always exist. As with adults, in the context of similar experiences, children bring highly subjective interpretations to bear on their accounts of those experiences. In addition, it is incumbent on researchers to be sensitive to the many types of voice that may be presented by

children. In line with (2010), determined efforts are needed, not only to recruit children who are usually excluded from research, but also to ensure that their participation is not subverted by participants with yet stronger voices or voices that are more readily heard. There is then no one authentic voice of children, nor one authentic voice for any individual child. Children's voices are contingent on time, place, space and those with whom they interact (Connolly 2008). Individual children, as do adults, have many voices, each one as authentic as any other. The challenge is to work creatively to reveal children's knowledge through the children's choice of voice.

SUMMARY

When I started this work I possessed partial knowledge of children in hospital. As a qualified children's nurse I could not discount nor disclaim bias (Hicks 2005). In the past I had used my position as a lecturer to inoculate novice nurses with professional discourses. These had given importance to the concepts of vulnerability, protection and innocence over children's competency and social agency. Although important, these concepts had offered little more than an appeal to a particular set of biases. This meant that I had objectified children as a homogenous group and had denied their social agency. I had looked at children and inoculated students into the practice of looking at children as objects rather than people. Moving to a position in which those children with whom I worked were understood as people who both shaped and interpreted their world was a challenge.

There remains a great deal of uncertainty, disagreement and contradiction in the research findings concerned with children's memory. Significant disagreements within the psychological research community are reported (Clifford 2002). However, there are some areas of agreement. Clifford (2002) also reported a considerable shift in how memory is conceptualised; from that of a storehouse metaphor concerned with quantity, towards a correspondence metaphor that is concerned with quality. However, there is some agreement that help from adults using emotion cues exerts a positive effect. While inconclusive, evidence on children's memory and the impact of stressful events on memory suggest that children are competent commentators. However, it is likely that their communicative competence and their ability to express emotion had less to do with latent-age developmental norms and more to do with enabling adults (and sometimes other children).

I am now convinced that scaffolding children's communicative competence is of benefit in supporting children. In particular in this chapter, I have argued that most children can be supported to overcome significant barriers to participation, and that it is possible for adults to use their power to help them do so. More importantly, by doing so, sensitive researchers can ensure that more children are included and that fewer children are excluded.

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Over the last two decades, a number of forensic guides had been developed, some with more or less criteria than the original Memorandum had suggested. Nonetheless, all broadly follow the 4 phases of building a rapport, eliciting free narrative accounts, questioning and closing that had been promulgated since 1992. I have presented some of the evidence that the Memorandum (2007) and subsequent forensic practice had spawned. This has had a significant and liberating impact on the inclusion of children and led to a sea-change in how children's competence to recall and recount their experiences was understood. Previously considered to be collectively incompetent, vulnerable, subject to intimidation, magical thinking and suggestibility, children's testimony had become critical to finding out what had happened to children. In other words, the Memorandum had signalled and driven the state's intention to enable rather than stultify children's accounts in criminal proceedings. Forensic work with children also provided the starting point from which to challenge the established assumptions about the capacity for children to give accurate accounts (Plotnikoff & Woolfson 2002, Esam 2002). Children's testimony is then, critical to finding out what has happened to children and critical to revealing children's knowledge. It is for these reasons that I used the evidence presented in the first part of this chapter to develop a critical stance from which to determine if I had enabled inclusive participation and let the children speak for themselves.

The guidelines on using a phased approach to interviews with children assumed the existence of a start, middle, and an end, but I was not involved in a linear process. My work with the children did not always follow the usual conventions of research interviews, nor the conventions of conversations with a purpose. Rather, my conversations with the children, especially in phase 2, were spontaneous and responsive to events that were happening at the time. I was primarily involved in social interactions. Adopting a forced, linear approach to conversations with the children would have been counter-productive and would have led to unnatural or at least unusual interactions. It could also have had a deleterious effect on the rapport that I had developed with the children and might have damaged the quality of the interactions that I had with them. While each aspect of the phased approaches is

important, in my work they were sometimes contemporaneous and at other times indistinguishable.

Children expect adults to support them. In conversations this means affirming, paraphrasing, nodding and making positive utterances. To adopt a clinical approach felt counter-intuitive. I wanted the children to tell me things but I was not there to interrogate them or discredit their views.

As previously discussed, there were a number of tried and tested methods that had been used to engage effectively with children, develop a rapport and enable their participation and voice to be heard. These included methods with which most children would be familiar and in other contexts would be labelled as play. Using mechanisms with which children are familiar is a reasonable approach to research work with children. However, using these alone did not guarantee nor validate my claim that what was presented in my work was firmly grounded in the experience of children or that the children had spoken for themselves.

It is, indeed, possible that people who read this work will wonder about the influence of researcher suggestion or adult contamination. There were certainly times when members of the children's family seemed intent on making sure that I was well-informed on issues about which they felt very strongly. It was also the case that some children had, in developmental terms, impoverished linguistic skills and vocabulary. Yet, with some improvisation, using strategies such as story-telling techniques, the children's views became accessible. Moreover, evidence in this chapter strongly supported my claim that it is, indeed, the views of the children who participated that are represented.

Despite some of the children's accounts being less amenable to representation, the absence of their voices became burdensome. The challenge was to find an effective means of representing and re-presenting the quiet - if not traditionally (in a research sense) silenced - children. The critical stance taken during the analysis of the data

ensured that views of all children who participated were represented in the final work. However, the problem of representation went beyond this.

That any individual can speak on behalf of another is a dilemma that continues to fuel discontent with qualitative methods. The conundrum at the centre of this discontent is that it is not possible to account for the individual outside a cultural context; nor is it possible to account for a cultural context in the absence of an individual's interpretation. Nor is there ever a single or fixed authentic account of reality.

The children often told me about what they had done [action] and why they behaved in the way that they did [intention]. From their explanations and over time I was able to interpret the children's behaviour, such as turning away or sitting quietly on a bed as another form of voice. Voice encapsulated what the children did or did not do as well as what they said. This meant that voice came to represent complex, inter-related and intimate relationships between social relations, action, intention and power. For these reasons, and consistent with Cornwall's (2003) explanation of voice, voice became manifest in what the children said but also through the non-verbal mechanisms such as resisting, rebelling, being silent and breaking the rules. There is no single or representative authentic voice in this work. The only claim to authenticity that I make is that the children chose which voice to present when they worked with me and that I accepted that voice without question.

My final point in this chapter is that in spite of the fact that expected latency-age developmental milestones are most the frequently cited criteria against which decisions on children's capacity to participate in research are made, they are inadequate. It is far more important to work inclusively with children on the basis of their social positioning within social contexts. It is only through inclusive methods that children's experiences and knowledge can be revealed.

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CHAPTER 5

FINDINGS (1)

A SERIES OF EXTRA-ORDINARY EVENTS
TRANSITION TO PATIENTS WHO ARE ALSO CHILDREN

For the children in this study, admission to hospital followed a series of extra-ordinary events. These often came about from ongoing health problems or an accident. Admission to hospital represented a moment in their lives when they were in trouble. Their troubles resulted in disruption to their home, school and social lives and constituted additional work for them and their families. In this chapter I present the children's experiences of becoming hospital patients in the context of the interpreted culture of Study ward. Most of the children had explained to me, spontaneously, what necessitated their need for hospital care. It seemed important to them that this was where their stories began. I determined, therefore, that it would be the right place to begin to report my findings.

Entrée to Hospital Services

Entrée is the term most often used by researchers to explain the raft of processes and negotiations that precede and frame their experience of 'getting in' to their chosen research field. These processes are not always successful and access to the field can be subject to long delays and disruption. For these reasons I decided to use the term entrée in this study to refer to those processes and negotiations that the children endured and experienced 'getting in' to the hospital. This involved having their claim to hospital services legitimated, negotiating with gate-keepers, and being signposted to the most appropriate hospital or ward.

Whilst the children's individual experiences of entrée to hospital differed considerably, they all shared the common experience of being in trouble. This trouble created a problem; the solution to which was located somewhere within the hospital. Even when the children were knowledgeable about what was needed, their

entrée into the hospital had first to be legitimated. GPs, doctors working in district general hospitals, paramedics and hospital staff at the local children's accident and emergency department were implicated in this. On occasions, the children's mothers were also implicated. Once the claim to hospital services is legitimated the children were labelled as a list or an emergency case. Those children who were listed had to wait, while those who were deemed to be in need of emergency care had direct access to hospital services.

As a mother of a sick child I was no stranger to these processes. My son had breathing problems when he slept. Over time this became serious; he had severe sternal recession, episodes when he seemed to hold his breath (sleep apnoea); he slept for long periods of time and was very difficult to wake. At the time I had recently resigned from a senior nursing post in a children's intensive care unit. In spite of my experience as a children's nurse, no professional took my account seriously. I was dismissed as an over-anxious mother who was missing work. Eventually, when I took my son to see a specialist, he asked me why I had waited so long to seek help. This meant that I knew, as a parent, that it was sometimes difficult to gain access to hospital care. What I did not know was how children experienced and interpreted this.

The children with whom I worked in this study often used medical terminology, but they never used the words "list" or "emergency" to make sense of their admission. These labels were clearly related to management, procedural and administrative mechanisms rather than to children's experience. This meant that its use had obfuscated the children's understanding. In contrast, the children spoke of expected and unexpected events, but also explained that expected events could be unplanned. This made sense to them. This reflected the nature of their on-going health needs, lives punctuated by episodes of ill-health, and bodies that needed to be fixed. This was how they made sense of their entrée into hospital. They knew that an admission could be planned but unexpected or expected and unplanned. What mattered, then, was that they had a problem for which they needed help (for example, pain, pyrexia or being different to other children), and that the people with

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the competence, knowledge and skills to resolve their problem were most often located in Study ward.

Planned and Expected Entrées

Sarah seemed to have a good understanding that her last admission to Study ward was planned and expected. She needed a urostomy, and this need determined her last admission to Study ward.

S   *"...I had to have my urostomy done..."*

Joe's admission was also planned and expected. He told me:

J   *"...I went [to be] circumcised..."*

Some of the other children were admitted because of problems related to ongoing health problems. Celeste was admitted in order for surgeons to *"tie her tube off and try to find her kidney..."*, and Caron had a pelvis that *"had a gap in the middle..."* and needed to be fixed. Benjie's admission was also planned. Born with multiple congenital anomalies, Benjie was described by his mother as having no control of elimination. He told me that he had been admitted to have his

B   *"bladder and bowels done - a Mitrofanoff[22]. I've had my long bowel cut and some taken to make a new bladder. I've had my bowels done as well...".*

Similarly, Kelvin had been admitted for surgery to correct the anatomy of his urethra. Ged, the youngest contributor to this work, had been admitted for a second attempt at bladder augmentation[23], Mitrofanoff and closure of her bladder neck[24]. While she did not explain this verbally in detail, she told me that she had come to hospital to have *"my wee done"*. She had also drawn a picture of herself in bed with her catheters attached to the bed rail.

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[22] A Mitrofanoff procedure involves the reconstruction of a urethral outlet obstruction, bladder dysfunction. The Appendix or a piece of small bowel is attached to the bladder and brought out to the surface of the abdomen as a small opening which is sewn onto the abdominal wall

[23] An augmentation is a procedure undertaken to enlarge the bladder most often using a strip of tissue from the intestine

[24] The closure of the bladder neck is a surgical procedure undertaken to improve urinary continence

Lauren, Kamran and Sam were also admitted for planned operations; they had bodies that did not function in the way that other children's bodies did. Key to this was their desire to be more like other children.

Planned and Unexpected Entrées

Seb's experience was a little different. During our conversation he had told me that he had been admitted for a second hypospadias[25] repair. Having previously been fixed, his body had broken as the fix no longer worked.

S   "...Because I already had one [hypospadias repair] when I was 3 years old but it didn't work..."

Seb's entrée to Study ward had been complicated. He first had a cystoscopy (his *"little operation"*) at his local hospital. This was to identify the cause of his problem. It also legitimated his right of admission to Study ward. Following this it was decided that his mother would catheterise him at home until he could have his *"big operation"*. Although his admission was planned, he and his mother had made deliberate efforts to influence the speed with which his planned operation took place. To me, he was also a list admission, but for Seb, his admission was planned but unexpected.

Seb had perceived himself to be directly involved in taking the decision to stop daily catheterisation and seek an earlier admission for surgery. I became aware of how he used the first person plural 'we' to represent the partnership between him and his mother during these negotiations:

S   "...Oh that was horrible, It really hurt. They showed Mum, yeah they showed Mum how to do it just to make sure. There's, like, little blue things, tiny, but it really hurt. Once I tried it without it [anaesthetic gel] and it actually felt better without it... only for about 2 days, and then we started missing a few days, then every 2 days. It upset me to do it so that's when we stopped doing it. So that's when we went back to hospital. I thought it was going to be weeks."

JL   "And how long was it?"
S   "It was only a week because we stopped..."

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[25] Hypospadias is the term used to describe a physical anomaly of the urethra in boys when the meatus of the urethra does not open at the tip of the penis

As Seb explained, their joint decision to stop daily catheterisation was instrumental in bringing about an earlier admission date for his operation. In this way, he had drawn on his social capital and practical agency. In doing so he understood that he had directly influenced what had eventually happened.

Unplanned but not Unexpected Entrées

Aarif had a long history of hospital admissions for his ongoing bladder and kidney problems.

A   "...Erm, I think it started when my ureter was connected to my bowels...and that was a problem... Yeah, that's why I've got kidney and bladder problems more than my bowel. I had another little problem when I was a baby. I had holes in my heart but I didn't have to go to hospital. It just cleared up."

On this occasion he had been unwell for 3 days and had tried to stay at home but eventually his mother had taken the decision to go to the hospital.

A   "I was like on the settee 24/7, lying on the settee, and I had to get up for my catheter every hour. I was in pain sitting up: the only position that hurt less was lying down. My mum just told me I was going to hospital..."

Peter had a similar experience to Aarif but it was not that he had become unwell; his urinary catheter had become dislodged while he was at home being cared for by his grandparents.

While these entrées to hospital were unplanned, they were not unexpected as the children were used to returning to the hospital when they needed help or could not cope at home. Yet they did not fit my understanding of an emergency. Still, Aarif and Peter's entrée to the hospital was less tortuous than that of Seb. Their mothers had only to make a telephone call to let staff know that they were coming in. They had special entrée privileges.

Unplanned and Unexpected Entrées

Events surrounding Fion and Jo's entrées were very different to those of the other children in that they were caused by medical emergencies. Fion was admitted to hospital following an accident.

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F   "I had split my kidney [while] me and my cousin were playing with a metal pole, and I slipped on some mud and I fell on the wooden spike..."

Jo had been staying with a friend for a sleepover when she became unexpectedly unwell and urgently needed to be admitted.

J   "I was at my friend's and I woke-up with pains so I had to get ready for Dad to pick me up... about 5 O'clock in the morning..."

Jo had a long history of bladder problems and had previously undergone a Mitrofanoff procedure to enable her to catheterise herself every three hours. She did not manage to wait for her father to collect her. The pain became unbearable so her friend's parents called for an ambulance. Jo was first taken to a local hospital in an ambulance where she was admitted before being transferred to Study ward two days later.

Once at the hospital the children in this study were subject to a number of inter-related, discrete and tacit processes to ensure their fit into the model of service organisation and delivery. Unfortunately, there was often little agreement between the ward staff and the management regarding which children had legitimate access to Study ward.

Negotiating Admission

Often, entrée to City hospital resulted from complex discussions or ongoing health problems. Once entrée to the hospital had been agreed, being admitted to the right hospital or the right ward was not always easy. The children were not only involved in negotiations with their parents, carers and hospital staff; on occasion, they or their parents had to negotiate or re-negotiate what interventions would be undertaken once they had arrived.

The decision around Sarah's last admission to Study ward had been made with medical and specialist nursing staff, and she had known and agreed to have the operation for some time. As she pointed out, had her need related to a bowel problem then she would have been admitted to a different hospital:

S   It's not a stoma, that's for your bowels. That's done in [another hospital]."

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None of the children took the decision lightly. Joe had been persuaded by his mother that the circumcision would both solve his problem and be cleaner.

J   *"I had a bit of a problem and my mum said it was cleaner..."*

Aarif also conveyed a sense of working in partnership with his mother to reach a decision regarding the need to go to hospital, although he seemed to have been less involved in the final decision.

A   *"...because the pain was so bad..."*

It seemed that pain was always an important factor used to legitimate the children's claim to hospital care. This was certainly the case in Jo's admission, but she was separated from her mother when she developed severe stomach pains. Jo had relied on her friend's parents to act on her behalf. Peter, whose catheter had become dislodged while he was at his grandparents' house, relied on his grandmother to intervene. She had called his mother who had told them to go directly to the hospital. The circumstances surrounding Fion's accident meant that she was unable to call directly on support from her parents. She revealed that the decisions normally taken by her parents were taken by her grandparents.

F   *"My grandma phoned my dad, my dad wasn't there so she phoned my mum, my mum was quite far away so she phoned my granddad who came with my brother who then took me to hospital."*

Lengthy Negotiations

For many of the children, the quest to be normal or at least more like other children was a key factor in their decision to go ahead with surgical operations. Caron had been involved in negotiations with a number of different surgeons across the north of England for over two years regarding her surgery.

C   *"For about two years, the consultant said that he could do the procedure in North City. And another one said he could do it, but he didn't do it in the end. Eventually, it all went ahead..."*

Disruption

Even when the children's admission was planned it was sometimes rearranged or cancelled. This meant that the carefully planned, family arrangements were disrupted, as Caron explained.

> C "...and first of all, it was on July 17th. But I didn't get done; it was cancelled because one of them had to go away or something. And partly, it was a let-down... There was so much put into organizing it all: it was set for August 14th last year. And we came in and everything, and, like, the week before I'd been having intravenous antibiotics to get rid of an infection. It came to the day and everything was set to go ahead. I'd had the scan and everything. And they came and said they couldn't do it because I had got an infection. Everything had been arranged. My brother and sister had been sent away to Lincoln to stay at my auntie's. It was a disaster..."

For Aarif, admission to hospital meant that he missed out on special social events:

> A "I missed a major disco, the Christmas disco that we have every year. And I missed the chance to see Narnia in the cinema; and I've never been in a cinema, never, but now I've missed my chance..."

Discovering Children's Knowledge

The children's understanding of the processes surrounding their entrée to hospital was somewhat different to my own. The categories of list and emergency admission with which I was familiar were inadequate for the children to distinguish their experiences. What they told me resonated much more with my experience of being a mother of a child in trouble rather than that of being a children's nurse. The children's accounts revealed that their journey as a hospital patient began well before their arrival at Study ward. The children also helped me to understand that admission to City hospital could follow any combination of unexpected, expected, planned or unplanned events. It was not a part of their lives that was separated out, but an integral aspect of their life experience. Discovering their knowledge of this helped me to see beyond the more usual construction of hospital admission as an isolated event and underlined the importance for researchers to think beyond institutional boundaries in order to understand the meanings that children ascribe to their experiences.

The Interpreted Cultural Context of Study Ward

Although complex, I likened the negotiations between the ward staff and the management regarding the admission of children to Study ward to a game of tug of war. However, both sides used deceptive tactics to win. The pull and counter-heave of this game was played out time and time again. During my field work visits I witnessed that the children were represented and reduced to patients in the conversations between ward staff and management during this tug of war. It seemed that the goal of managers was to pull patients who had neither renal nor urological needs into the ward. The official term used by staff for these children was 'outliers'. Conversely, the goal of the ward staff seemed to be to pull patients who had neither renal nor urological needs elsewhere. When the ward staff lost this game, they pointed out that the management had deceived them about the true nature of the children's medical diagnosis and nursing needs. Conversely, the managers pointed to staff manipulating bed occupancy returns such that they indicated higher bed occupancy than was the case. This was an important observation as this tug of war revealed that Study ward and the resources therein was as a contested place framed by a culture of deceit.

An important factor in the discourse of deceit related to the children's hospital identity (most often framed by the discourse of medical diagnosis). Rather than being fixed, this was continually constructed along contingent lines. Both ward staff and managers appealed to moral intentions and keeping the children safe. Yet neither spoke a common language. The managers framed the children's diagnosis as being uncomplicated and their needs as low-dependency. This was then reframed by Study ward staff who pointed out the reality of children with multiple pathologies who were highly dependent. It seemed to me that working with children with specific nephro-urology needs made an important contribution to the specific professional and somewhat unique identity of the nurses working on Study ward, especially with regard to their practice specialty. Yet, they were often left feeling inadequate and duped.

A familiar pattern of negotiation between the ward staff and bed managers was discernible. Part of the negotiations involved senior managers promising extra staff to help with the increased work load. Often, the promised extra staff never materialised. This led to ward staffing levels that were inadequate to ensure the safety of the children.

It was not unusual for children with respiratory or medical needs to be admitted to Study ward especially when there was urgent need for availability of intensive care beds and the medical wards were full. In these circumstances any ward labelled as high dependency would be expected to accommodate children with acute needs, as in the case above. This is consistent with Aldridge's (2008) contention that professional knowledge and skills (especially those in nursing and social work) are devalued in the current context of target driven and financially constrained services.

In fact, the ward staff and managers were equally implicated in a deception, each knowing they were in some way being deceived and deceiving the other. However, the consequence of this was that children, especially the outliers became dehumanised and depersonalised. The talk of children was littered with diagnostic labels and medical interventions. Ultimately they became 'it'.

S   "It had a nasal pharyngeal tube in..."

This part of my analysis pointed to competing structural processes that had a direct influence on the children's experience of being admitted to Study ward and what happened when the staff were unable or ill-prepared to meet their needs. Importantly, it was the analysis of the children's experience that unmasked how these tacit, structural processes, reproduced through staff relations, worked in opposition to the espoused child-centred and child-friendly intentions of the organisation. My interpreted analysis revealed that the culture of Study ward was often dominated by conflict and deceit. This became particularly important when viewed from the perspective of the children who told me what happened when they were admitted out of place. However, some children had special entrée privileges

which appeared to benefit the children and the ward staff through reciprocal legitimating processes.

Induction to Study Ward

The term induction is used here to frame the subjective interpretations of the children regarding their transition from children in trouble to children who were also hospital in-patients. It was evident that the children particularly valued being expected and being welcome when they arrived on the ward. This was not experienced in the same way by all of the children; rather each used different recollections and memories to explain to me why these things mattered. In fact, for some of them, being expected was directly related to their perceptions of feeling welcome, while for others, being expected was associated with their perceptions of feeling safe.

Being Expected and Being Welcome

Seb drew on his recent experience of his induction into his local district hospital to explain his understanding of this. He knew this hospital quite well as he had been admitted there when he had broken his leg.

S   *"I was on a bouncy castle. I jumped off the side of it, and everyone was still bouncing when I fell off. I fractured it."*

He described his experience of going back there and demonstrated the depth of his knowledge about the things that happened to him.

S   *"First we just waited in the waiting room, only for about 10 minutes. That's just usual. I think we went in, and they got me sorted and got me a bed. They put magic gel, not magic, gel on my hand… it's good stuff because it freezes that part of your hand so the prick doesn't make it so it's really hard, but the only thing against it that some people are allergic to it. My sister is allergic to it. They just said, "So do you know where everything is?" So I said "Yes I know", but they showed me. I'd forgotten where the play rooms were, but, they showed me to the play rooms and then, since that, I was jut playing in the play room. Then they weighed me. Then they put me on a bed; nice, comfortable. They put a prick in my hand. All I felt was a little prick."*

Joe described a similar experience:

J   *"I was shown to my bed. I got laid down on the bed. This nurse came over. She put cream on and then put a plaster on over it, and then put something*

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else on. Then later on she put this, like, it looked like an engine or something that had tubes sticking out of it. Then I went to the toilet and they took me to the room were they put the needle in. [The cream was] magic cream. I think it stops, I don't know why, but I think it stops the pain in your hand or something."

Feeling Safe

I asked Seb what it was about his bed that made it nice and comfortable. He replied:

S   *"...They've actually puffed up pillows, if you know what I mean, and they've got it all nice and folded and everything so it's all ready. [It makes you feel] welcome, you've got to feel welcome and then you know you feel safe."*

Seb told me how he had worked out that being welcome meant that he would be safe. His first experiences led him to conclude that everything would work out the way he desired;

S   *"...because everyone is prepared, so you know, if everyone is prepared then they are prepared for the operation, and then that means that it's all going to be a success...it's just going to be a complete success..."*

Being welcome and being expected was important for other children. Sarah explained why it mattered to her.

S   *"...If you don't feel welcome you just want to go home don't you. If you feel welcome you don't mind staying..."*

Aarif felt that it was important but could not tell me why.

A   *"They [always] expect me because my mum rings up. [It's] important to me, [but] I'm not quite sure actually..."*

Joe had previously attended an accident and emergency department when he had sustained a serious cut to his leg. He told me how he had been scared.

J   *"I felt scared because I thought I was going to have to have stitches, and I don't like stitches. Because I think it's like a needle going thought my skin and then up, but I just got, I think I just got butterflies..."*

Joe had mixed feelings about feeling safe.

J   *"I felt safe because it was, like, if anything was going to happen to me, if I was going to lose blood or anything, whatever happened, I was in a hospital; they could probably save me. But I felt unsafe as well. I was scared of losing blood and just scared of dying really."*

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Aarif concurred when he said that being in hospital *"...makes me feel a bit more safer...".*

In contrast, Fion had been far less concerned about the welcome. When I asked if she had been shown around she simply said *"...I was too sick...".*

These excerpts illustrate how the concepts of being expected and being welcome were interpreted in a number of different ways. Some of the children were very clear that it mattered but could not articulate why. For others, being expected and being welcome appeared to be connected with being looked after (for instance the pillow being fluffed up). Of particular interest to me was the stark contrast between my professional understanding of how to keep children safe in hospital and the children's reliance on the simple, if not mundane, hospitality aspects of their care. My own understandings were founded on the notion that keeping children safe was underpinned by an exacting assessment of need documented in accordance with professional record-keeping standards (Nursing and Midwifery Council for Nursing, Health Visiting and Midwifery 2009). I had internalised this to such an extent that time-consuming administrative processes used to admit the children to the ward had, for me, become unremarkable. Regardless, the children seemed to share the implicit assumption that they would be kept safe while they were in hospital, if not be safer than they would have been had they stayed at home.

Apart from personal experience, the children drew on different sources to determine what they might expect. Interestingly, despite hospital preparation sessions being valued by nurses, none of the children had attended one.

Seb had been shown around Study ward on the day he had visited the out patient's department but this came about following a direct request from his mother. Benjie had been visited at home by one of the clinical nurse specialists. She had taken a recorded disc for Benjie and his mother to watch in preparation for his operation, but they were unable to get it to work. Joe had talked to his friend who had attended

hospital for a tonsillectomy. This led him to have high expectations of what to expect:

J   "Well, it was alright for my friend who had his tonsils took out because... he got put in another room on his own and he got sky [TV]."

Unfortunately for Joe, his expectations of having his own room and access to Sky television were not realised.

Becoming In-Patients

During my field work I witnessed overt structural processes that involved a nursing assessment of the children's needs, ensuring that they could be uniquely identified and allocated a bed space; but this offered partial and professionally-dominated insights. The admission of the children to the ward rested on the necessary documentation being completed and them having a correctly labelled identity band placed on their wrist (or pinned to their clothing when this was not possible). In fact, these processes and procedures were so unremarkable to me that I had initially considered them only to illustrate how staff priorities took precedence over children's needs. While there was evidence that these processes were prioritised by the ward staff as vital, if mundane, activity, they were held by the children to be both unimportant and at times inadequate for the intended purpose. In contrast, it was subtly nuanced aspects of hospitality that mattered most to the children.

Admission to Study Ward

It was quite usual that the administrative procedures relating to the children's admission would to be undertaken by student nurses or health care assistants who were often asked to admit the children. This meant that they were to complete the ward documentation which included recording demographic details including the child's name, age, date of birth, address and the name of their mother or father. Although the ward staff spent a lot of time admitting children to the ward, the administrative processes hardly featured at all in the children's accounts. While many of the children seemed blasé about the administrative processes, they accepted them as being part of the hospital and ward staff work. It was Seb's recollections of the administrative admission processes and his notion of this being

the equivalent to him being "...*sorted*..." This provided the critical challenge for me to shift from my professional standpoint and attempt to reach a more authentic understanding of what mattered to the children. It seemed that the children's role was to comply.

Being shown to a bed appeared to be a significant and important factor signalling the children's transition from being a child to being a child who was also a patient. Yet, unbeknown to the children, and as discussed hitherto, other factors exerted a direct impact on their legitimate claim to a bed on Study ward. It would be considered usual that the boundary of the space around a bed was delineated by the fall of the drawn bed curtains. However, on Study ward, the beds were placed so closely together that the curtain would often touch the side of the adjoining bed when drawn. This meant that other boundary markers were needed. Additional pieces of furniture placed around the bed seemed to provide a marker for the territory that could be claimed. These included a small locker on one side of the bed; a small toy chest at the foot of the bed and a bed light over the top of the bed.

A Squash and a Squeeze

My second meeting with Kelvin was when he arrived on the ward in preparation for his corrective surgery. He had travelled from over 400 miles and had endured a six hour train and taxi journey. Kelvin had been accompanied to the ward by his father. They were both hungry and wanted some warm food, but the evening meal had already been served. The ward staff explained that they had soup and could make sandwiches or toast, but Kelvin and his father had been snacking on cold food throughout the journey and wanted something more substantial. Kelvin's father had left the hospital in search of an 'Indian takeaway' that he had been told was just around the corner. I was struck immediately by how small Kelvin seemed once by himself in the context of the ward, and I wrote my reflections in my field work journal.

Kelvin seemed tiny. Some of his belongings had been placed into the bedside locker and bedside chest. His suitcase was still full of clothes, including 15 football shirts (we had a giggle remembering which team shirts he had). Kelvin was busily searching for something. When I asked, he said that he wanted to find his electronic game. He was getting worried that maybe he had left it at home but felt sure that it must be there somewhere. I suggested that Kelvin should wait for his father to

return rather than continue his search for his game. However, he was not content with this but decided to climb over his bed to search for his game in the locker. Kelvin's bed was touching the chair of the parent with the child in the next bed; the curtain that was drawn but draped across the back of the chair and his bed. There was some room on the opposite side but another parent sitting in a chair meant that his access to his locker and bed were blocked. He climbed onto the chair, onto his bed, off the other side and looked in his locker drawer for his games. I watched in some trepidation, asking him to take care and be careful that he did not fall. I realised that I was unable to assess his capabilities and the ward staff had told me they knew little about him. He looked awkward and somewhat unsteady but told me that he was fine.

This second meeting with Kelvin reinforced the lack of space around the children's beds and how it was sometimes necessary for the children rather than the adult visitors who were with the children in the next bed to compensate for this. Kelvin had decided that he wanted his hand-held electronic game and that he wanted it straight away. He was not prepared to wait for assistance from his father. My professional wisdom was challenged as I grappled with the dilemma of wanting Kelvin to get what he wanted but being reluctant to ask the visiting adult who was with the child in the next bed to move. In part, this was because the curtains around the bed next to Kelvin's had been drawn. I had internalised this as a signal not to interrupt or disturb those behind them. It was as though the rules of the contest for space were played out through tacit but complementary processes. It seemed to me that Kelvin knew what the boundary was as he skilfully negotiated the space to claim the locker, the bed and the chest. There seemed to be an unwritten but established social contract in operation. Even the parents asked for permission for the children to come and go. In turn, the children appeared to exercise some rights over the extent of the space they could call their own.

His game was not in the locker so he climbed back over the bed, over the chair and landed in front of me. Safe? He is safe, but not content. He asked me a direct question:
K "Where's my game?" JL "I don't know Kelvin. I don't want to root through your case 'till your dad gets back."
K "It must be here somewhere."
JL "Do you want to put your slippers on?"
K "OK"
I agree with Kelvin that I will come back to see him again. He says that will be OK. I am a little relieved; tell the staff I am leaving and that Kelvin cannot find his game.

The two processes of accepting the identity band and claiming a bed space went hand-in-hand. They represented situated, ritualistic and structural components of an unwritten contract that confirmed the children's identity as legitimate hospital patients and their right to a bed and bed space. As I had noted, Kelvin had been determined not to wait for his father's return and signalled his right of ownership to the bed and bed space that he had been allocated. However, the nature of the boundaries of bed and bed space were continually contested.

Celeste's Intruder

In addition to the furniture around each bed space there was some medical equipment. The oxygen and suction equipment, additional plug sockets and patient televisions were fixed to a universal panel that was situated behind all of the bed spaces. Additional equipment, such as intravenous infusion devices, enteral feeding pumps, cardiac monitors and oxygen saturation monitors were added as needed. Most of the beds had been fitted with *Patientline* telephone and TV monitors but not all of these worked, and some of the children asked for and were given portable television sets. Most of the time, medical equipment was removed when individual children had no need for it. However, the ward was short of space, and places to store medical equipment seemed to be at a premium. This meant that the boundaries around some of the bed spaces were less easily determined. For instance, the bed space opposite the nurses' station housed the emergency resuscitation trolley; while the bed space nearest to the first transplant cubicle at the bottom of the ward housed the portable renal dialysis machine. Neither of these seemed to cause a problem until Celeste was admitted to the bed next to the transplant cubicle.

Celeste had pointed out that the dialysis machine situated at the side of her bed was plugged in and continually turning on and off. This disturbed her, and it was impossible to close the curtains so that the machine was on the outside of the space. Her mother had become so disturbed by this machine that she had switched it off not knowing whether or not this mattered. Had Celeste needed the machine its proximity would have mattered less; but she did not need it, and it was this criteria that led to her understanding that it should not be near her bed.

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Figure 8 Celeste's intruder

Celeste had told me that she wanted to talk about the machine:

JL   *"You wanted to say something."*

C   *"Take a picture of that machine, Mum."*

JL   *"You tell me about that machine while Mum takes that picture."*

C   *"That machine there, I don't even need it. It's stuck there and it can turn on and make noises and stuff. It's got nothing to do with me, and it just turns on by itself."*

M   *"She had come back from the theatre and she was on the morphine and she's out of it, it's like this noise. Obviously, babies cry and there's nothing you can do about that but you don't need that going."*

JL   *"It annoyed you then, did it, Celeste?"*

C   *"Yeah."*

The noise from the machine was a nuisance for Celeste. It was not that all noises mattered. Some, such as babies crying, were unavoidable, but the issue was that this machine was not needed by her and that it took up valuable space; it was a physical intrusion.

M   *"We are trying to wash Celeste and this, that, and the other. He's [her father]tried to get her stuff. We've got stuff everywhere, boxes full. He had to bring a lot home." [Points to the boxes around and underneath the bed.]*

JL   *"Are the boxes full of stuff, Celeste's stuff?"*

M   *"Celeste's stuff. You have to bring all sorts of things when you are here day and night. We've had to turn the chair that way, when ideally you like to be sat where I sit. Good job that we do get on because imagine if you were trapped next to somebody who was a bit [pulls face].... It would be difficult wouldn't it?*

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Obviously, the little boy [in the next bed] has got machines and Celeste had all the machines. I had to literally climb over to get her stuff to wash her."

But it was not only Celeste's mother who felt that space was at a premium. Celeste explained what had happened when she was having her catheter removed:

C   *"The nurses when the curtain was closed, when they were taking the thing out [urinary catheter], the curtains were in the way, and they couldn't get round. It was very small, about that much space."* (Indicated about 12 inches with her hands.)

Having the space used to store medical equipment felt like an imposition. To underline this, they commented on the noise that the machine made. Citing the noise as the problem rather than citing the machine as an intrusion appeared to be the basis for a more reasonable complaint. Freedom from noisy intrusions, at least some degree of quiet (or peace) was as an important resource that was expected. That said, neither Celeste nor her mother had said anything to the ward staff about the machine. Celeste's mother had been effusive in her praise for the ward staff. It seemed that when the parents had concerns they left this unspoken or tried to work out the tacit rules that would make their concerns appear to be legitimate. Although the Patient Advisory Liaison Service (PALS) has been developed to assist hospital children and their families make their views regarding their care known, no-one ever spoke about speaking with PALS. There is evidence that PALS has not yet been able to bridge this gap (Heaton and Sloper 2004, and Heaton and Sloper 2006). Rather than rely on what the organisation had made available the children knew that it was their work to enter into this strange world. By doing so they seemed to accept their position as being less powerful than the hospital staff. However, just as Celeste and her mother acted in Celeste's best interests, the other children revealed how they developed strategies to manage certain aspects of their hospital experience. This theoretical insight is developed further in the chapters that follow.

Of significance here is that both Kelvin and Celeste had specific needs that fitted well with the specialist skills, knowledge and competence of the staff employed on Study ward. However, this was not always the case and often being admitted 'out of place' had a significant bearing on the experiences of hospitalised children.

Mascots and Misfits

For Sarah, being in the right place was fundamentally important in order to achieve the right outcome, keep her safe and protect her from harm. This was emphasised by her experience of hospital staff getting it wrong when they had little or no expertise in dealing with her problem. However being in the right hospital was not enough. The children also had a much better experience when they were admitted to the right ward.

Sarah had explained to me that the origin of her problem resulted in her attending one of four tertiary referral centres.

S   *"So it's ...Hospital 1 for that specialty [bowel], Hospital 2 for Hospital the hip specialty, Hospital 3 for bladder and bowel specialty stuff...and Hospital 4 as well..."*

She went on to explain the importance of being in the right hospital

S   *"Last time I got a dislocated hip, you know, when it's like that [points to her side]. Last time I fell over, this was when I could walk about two or three years ago. I could walk then, and I'd been messing about, and I fell and my hip twisted round and came up here [points to just below her armpit] so I had to go to hospital. I got rushed in by ambulance, and when I got there [the local district general hospital] they didn't have a clue. They were getting ready to take me down theatre..."*

Sarah then explained her understanding that any surgical intervention to her hip could have resulted in serious harm as she was told it should be managed conservatively. Her understanding of this was so clear that she had interpreted and internalised the local hospital as *'wasting her time'*.

S   *"I'd rather stay here [at home] because I know at least I'll be alright then. If the worst comes to the worst then I can go S. [At] B you're just wasting your time. Sat there for 3 hours waiting to see a doctor."*
J   *"Is it just wasting your time or is there something else?"*
S   *"Yeah it's that they don't know what they're doing. I don't know if it's just they're not specialised and that, but when I had my hip done last it came out even worse. They didn't even bother trying to check my notes; they just assumed that it was like that, didn't they? [Turns to her parents for affirmation]."*

I had made several entries in my field work journal relating to a number of incidents regarding the admission of children who were regarded as outliers onto Study ward.

On one occasion I documented a discussion between the ward staff who thought that they had been forced to admit another child. They had spontaneously included me in their discussion.

> Standing behind the nurses' station there is a discussion about staffing levels. The staff nurse turns to me and states...
> *"They've known all day that we only had 3 (night staff). I knew they wouldn't find anyone [to come in and work], and they're still giving us a patient and they're sending another at 9.30..."*
>
> This is confusing. Why do they spend so much time denying admission to the ward to children who need a bed when there are spaces? The staff appear to be cross and tell me that this happens all the time.

The situation was made more difficult because there was no agreed system to help staff to allocate beds. In a study to examine the process of coordinating hospitalised children's care in Denmark, Beringer, Fletcher and Taket (2006) concluded that lack of formal coordination processes not only led to inconsistencies it limited the opportunities for staff to tailor care to the needs of the individual children. The findings presented here suggest that a similar situation exists in Study ward. This meant that children relied (albeit unknowingly) on different staff to argue for or against their admission. In other words, and without knowing, children competed with other children for access to the available but often scarce resources. As already noted, the nursing staff on Study ward spent a great deal of time defending empty bed spaces against pressure from senior bed managers to admit children who did not have renal or urology needs; often with little success. During one of my field work visits, lengthy negotiations had taken place between the bed manager and senior staff nurse. The bed manager was trying to admit a 10 month old baby who had arrived in the medical emergency unit with breathing difficulties. The bed manager explained that the baby was not very poorly (the local term for not very sick) and would need little attention. As Study ward had an empty cubicle, she argued that this was the most appropriate space in the hospital in which to admit the baby. On arrival to the ward in an incubator, the baby seemed to be quite distressed. The following excerpt taken from my field notes captured the experience for one family whose baby was an 'outlier' on Study ward:

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There have been some heated discussions between ward staff and the bed manager. The ward manager has been promised an extra member of staff if the ward takes a baby who has been waiting in the medical referral unit. His parents had arrived claiming that he was unwell, but the bed manager insists that he is fine and simply needs a cubicle. The staff agree to take him, and the baby, a 10 month old boy, is brought to the ward by the medical referral unit staff accompanied by his parents. He is put in the cubicle adjacent to the nurses' station, connected to a pulse oximeter, cardiac monitor and intravenous infusion device. The ward staff go to look at the baby then leave his parents in the room with him.

The alarm on the infusion device continues to trigger over the next hours; the ward staff seem oblivious to this. I am concerned so ask the health care assistant to check if everything is alright. She keeps going into the room, looks at the machine and silences the alarm. I ask what she thinks, and she says that he is alright. I note that she goes into the room and looks at the alarming machine not the baby. I tell the staff nurse that his alarm has been triggered several times. She nods and says it is OK. After an hour his mother comes to the nurses' station. She tells two staff nurses who are writing up nursing evaluations before handing over to the night staff that he needs a special medication to help with his breathing and the next dose is due now. They ask if she knows what the name of the medication is. She doesn't. They ask if she has any. She has at home but explains that it will take a couple of hours for her husband to drive home and back to the hospital but her son needs it now. One of the staff nurses goes into to the cubicle to look at the baby with his mother. She comes out and asks another staff nurse if she knows what the medication is. She doesn't. They both continue to write their notes.

The mother comes back to the nurses' station about 15 minutes later and repeats her request for medication. This time a different staff nurse responds. She looks in his notes but can find nothing. She promises to telephone the doctor. The night staff arrive, and the staff start to complain about the baby being admitted to the ward. He is not one of their children. Some of the night staff express disquiet, but the senior night duty staff nurse goes into the cubicle. A small group of staff (3 staff nurses) begin a conversation about the ward being haunted. I am surprised at this as they are within earshot of some of the children. They start to discuss the lady-like ghostly images they have seen on ward.

The staff nurse who had gone to look at the baby comes out of the cubicle and asks for urgent assistance. She tells the day shift staff nurse to put out an urgent call for a doctor to attend. "This baby is unwell," she states. She goes back into the cubicle and applies tracheal suction. Other nurses start to remove their cardigans; it is as though this is a signal for the end of their social chat and the start of work.

It takes 30 minutes for the on-call doctor to arrive. This is not the respiratory doctor, and she says she is confused about what she is expected to do. The parents both come to the nurses' station and ask where their son's medication is. They appear to be increasingly agitated and start to raise their voices, stating that they have been at

the hospital for a couple of hours and he is just getting worse. The senior staff nurse calls for the night sister to attend and contacts the registrar on call.

The next day when I arrive on the ward the cubicle is empty. I ask the staff what happened to the baby. They tell me he had two respiratory arrests about 1am and had been transferred to the intensive care unit where he was now ventilated.

This whole episode seems to capture the essence of what the staff had said about the misrepresentation of children's needs. I had heard the senior nurse tell the staff nurse that the baby was *'not that poorly'*, and was shocked to discover just how ill he had become. I had witnessed at first-hand what the staff had expressed. I also understood how it was far easier for hospital staff and the children and their families when there was a close fit between the needs of the children and the expertise, resources and equipment available to ward staff. The best fit was usually achieved through the assignment of a diagnostic category, but this was challenged when there were no beds in specialist areas available. The corollary was that some children who needed to be admitted to Study ward became 'outliers' in other wards. Fion had become an outlier simply by being admitted for observation when there were no beds available on Study ward. She had been transferred from one accident and emergency department to City hospital so that she could be seen by a paediatric renal surgeon. His decision was that she should be admitted for observation for at least one night. Unfortunately, the ward most suited to meeting her needs (Study ward) was full, and she was admitted on to a ward that specialised in meeting the needs of children with neurological disorders. She explained to me what happened.

F   *Erm, I went to, I can't remember what it was called, but it was for your head... they put me in a place if you hurt your head..."*

Fion's father was keen to add his perception of what had happened.

FF   *"She was very sick, so they said 'we can't see anything wrong but we'll keep her in overnight. We don't have any paediatric wards, so we'll send her over to City'. So we were sent later on in the afternoon, I went with her, and when we got there they said 'we haven't got any beds'..."*

JL   *"Right"*

FF   *"'We'll just put her in Heady ward for observation.' So we were in Heady ward just over night until the next morning when she was transferred to Study ward. The only thing I thought was bad about the whole thing was that it wasn't planned very well. We realised that she was going to have to have a catheter,*

and they realised that she was going to have to have a catheter, and we waited about three hours for a catheter to be fitted. Not a problem I can wait for the catheter. I can wait for 3 hours... We waited three hours for the catheter, that was fine. And then she had it fitted. It was horrendous. The thing was... the people on the head ward, unfortunately, they've never done it before. They weren't geared to treat abdominal injuries: it was all head injuries. And because we didn't realise how ill she actually was, because she had only been sent for observation, she was in bed and she was really in a lot of pain. So they were giving her pain relief, but then at 11 o'clock at night they ended up taking her for a CT scan because they just didn't know what it was. So we waited for three hours, we had the catheter fitted, and then the first thing they said was 'Oh, we can give you something for the pain for the catheter now'. They should have given us that three hours earlier. They knew they were going to fit the catheter, and they knew that they had something that they could give her that relieves the pain in your bladder, to stop your bladder contracting apparently. They didn't give her that, they waited until after it was fitted then tell us they could have given her something four hours earlier, so she could have had that..."

During her father's account, Fion listened attentively and was nodding in agreement, but it was later in my work with her that I realised the extent to which this experience had impact on her sense of safety and security and continued to do so. This aspect of my work with children is discussed in greater detail in the ethics section of chapter 3. For now, I have selected this excerpt to illustrate the extent to which outliers, those children who do not fit the skills and competence of the staff, are difficult for hospital staff to manage.

The situation was further complicated by a particular number of beds being allocated to named consultants. The staff often had to explain why children being looked after by one consultant had been admitted to a bed allocated to another. As in the example explained by Steph, the consultant who wanted to admit the private patient knew that he had empty beds. However, these beds had been allocated to children under the care of other consultants and to children who had been admitted from the medical emergency unit. In addition, the ward was expected to work at 100% bed occupancy. This meant that they were constantly negotiating with senior managers and consultants, and often found themselves in a hopeless situation.

Complicating this still further was the privileged entrée for some children which manifested as self-referral. This privilege was accorded to those children who were repeatedly admitted and well-known to staff. In part, this acknowledged the unplanned but expected nature of their entrée into hospital. Privileged entrée was considered to be best practice and was often ranked highly by families whose children had life-long and life-limiting illness. Yet it compromised the staff's ability to manage bed occupancy and bed availability. It was in this way that I began to interpret children like Aarif as Study ward mascots. This was because their needs provided the best fit for the specialist skills and competence of Study ward staff and thereby legitimated the skills and competencies of the staff employed to work on the ward. This led to legitimate reciprocity in that the ward staff did what they could to reserve the beds for those children with nephro-urological needs and justified doing so on moral and pragmatic grounds. Moreover, these justifications were used by the staff on Study ward to eschew managers' attempts to maintain high bed occupancy rates. That said, they were intolerant and critical of the financial motives that seemed to drive the managers' actions.

SUMMARY

The children's admission to hospital was an integral part of their life experience; they situated it in this way themselves. It was not a separate part of their lives. Regardless of the seemingly ordinariness that admission to hospital has for hospital staff, for the children, admission to hospital always began with them being in trouble. The need to go to hospital constituted an extraordinary event that disrupted the lives of the children and their families. It was always the children and families which had to accommodate the ensuing disruption.

The everyday terminology of admission to hospital that was used by hospital staff was not sufficient for the children to explain their experience of gaining entry and being admitted to hospital. Nor was it distinct enough for my purposes. For instance, the term 'admission to hospital' is typically used in two ways; to represent the processes of admission to hospital and to represent the duration of time in hospital. The meaning is contingent on the context in which the term is expressed. This limits any understanding of the children's experiences as it presumes the beginning of their experience to be different to what they reported. This was amplified by the use of the terms list or emergency that were used to record the 'type' of admission (as in the ward admission book). While these terms made sense to me as a children's nurse they made little sense to the children and did not feature in their accounts. In contrast, the children told me about expected, unexpected, planned and unplanned extraordinary events. They understood that these extraordinary events could be both unplanned but expected, and unexpected but planned.

Similar to the findings reported by Beuf (1978) the children accepted the stamp of the ward's authority by acquiescing to the wearing of the identity bracelet. They also accepted that their right to leave the ward was dependent on receiving permission to do so from a member of staff. In return, the children expected at least some control over the bed that had been allocated to them and the space around it. However, the bed space was not the only contested space, the children worked hard to establish their claims to influence what happened to them once they had been admitted to the ward. This work included attempts to influence the place and time of their admission

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and many of the children perceived themselves to be directly involved in the related discussions and processes.

Those children with 'mascot' status were afforded special entrée privileges, of note and as discussed further in the following chapters, mascot status contributed little to the children's experiences once they had gained access to Study ward. The ward staff appeared to understand that some children required open access to the ward and that this was often unplanned though not unexpected. This insight into the needs of the children, especially those with mascot status appeared to legitimate the need for specialist staff. Nonetheless, the underlying message from the children was that they expected that they would be safe in hospital and sometimes safer there than at home. However, their expectations were not always met. Of particular importance is how the competing demands of matching children's needs with staff that were competent and held a specific set of skills conflicted with the strategic aim of working to 100% bed occupancy. In spite of many hospital workers being specifically prepared to work with children, this was insufficient to provide quality care for the children with nephro-urology needs. Without clear guidance and systems in place to help staff to manage the demands for beds, it was left to them to negotiate and battle for individual children. In turn, this had led to a culture of deceit that set nurse against nurse; and children against children. This was then, the cultural context of Study ward that framed the children's experience of adult-child relations.

The consequence of this was that individual children could be diminished and their identity reduced to medical diagnoses and medical interventions. The ultimate reduction was illustrated by the use of the term 'it'. The children were sometimes engaged in preventing hospital staff from causing them harm. In particular, the children's safety was compromised when they were in hospital but out of place (misfits) but the safety of many other children was also compromised. This was not only the case for children whose needs 'misfit' the competency and skills of the Study ward staff; the safety of children with nephro-urology needs was also, at times compromised.

It seems that the concepts of being child-friendly and child-centred did little more than provide an illusionary façade for adult-centred patterns of knowing. While the rhetoric of child-friendly and child-centred approaches provided the illusion that individual children were central to the work of the hospital; structural mechanisms related to business functions. These business functions subjugated the needs of children to the imperative of maximising bed occupancy rates. While purporting to meet the needs of individual children and to match their needs to specialist skills and knowledge of staff, the children's experiences revealed that this was often an impossible task. Understanding this then helped me to unravel further the layers of complexity that impacted on the children's experience and in turn theorise with regard to what might be going on.

CHAPTER 6

FINDINGS (2)

DIFFERENT WORLDS
CHILD ADULT RELATIONS

In this chapter I draw on the words and actions of the children to narrate their constructions of child-adult relations on Study ward. The insight derived from my work with the children led to my interpretation of Study ward as two worlds. One inhabited by the children and the other inhabited by the staff. Each worked towards different goals and experienced different realities. In turn, this lead me to conclude that there was an urgent need for a more inclusive and participatory model of practice. Moreover, I argue that basing this on a resiliency framework would not only make visible and accommodate children's emotional labour but provide a means to bridge the worlds of children and adults in the context of a hospital ward.

The children often had to engage in hard labour and risk their reputations with staff to get what it was that they needed. Some children drew on their social capital and practical agency to do this by using the adults who accompanied them and the staff as instruments of persuasion and intervention. Others developed a strategy of pestering. No strategy was completely successful, but the adults' responses suggested that they found many of them difficult to handle. In turn, this not only sometimes led to difficult and strained relations between the children and the staff it led to strained relations between the children and their visitors. Of note was that the children's actions led to negative constructions of their behaviour and in turn of them as individuals. Some children were labelled as being difficult; a negative attribute that seemed to spill over and inform others' opinions of them.

To begin I present the analysis of my first meeting with Kelvin before revealing how his relationship with the adults on the ward became increasingly difficult. Kelvin told me why he behaved in the way that he did, but my work with one of the staff nurses

involved revealed that she had interpreted his behaviour differently. This seemed to leave Kelvin in limbo; he needed care but seemed to be unable to negotiate successfully for this to be delivered in the way that he thought necessary.

Reducing Difference

Kelvin was one child who had been labelled by staff and his father as being difficult. The following analysis revealed the extent to which his behaviour and actions were calculated to get what he needed, and how his desire to remain infection-free and his aspirations to be dry were behind the strategies that he adopted.

I first met Kelvin during his admission to the ward for a cystogram and bladder studies. Kelvin was 11 years old. He had multiple congenital anomalies affecting his urethra and bladder, the fingers on his left hand, and his legs (one was shorter than the other). He had a short stature for his age and a leaning gait. He was dressed in a football shirt, training trousers and trainers. He and his father had told me about his previous admissions to hospital over two hundred miles away and the two previous operations that had failed to correct the anatomy of his urethra. Kelvin's appeal to being normal was central to his purpose for coming into hospital for yet another operation; he aspired to being dry in order 'to be more normal'. Kelvin had self-catheterised throughout the day for some years.

The purpose of Kelvin's visit to City hospital was to have a third operation to reconstruct his urethra and enable him to 'pee' without the need of a catheter. For the staff, the purpose of Kelvin's visit was for him to undergo a reconstruction of his urethra and bladder neck. Both appear similar but they are not nearly the same. The medical description serves to obfuscate his real desire to be more like other children and to be able to pee normally. During my work with him he explained to me how important it was for him to be catheter-free:

JL   "So why did you change from doing that [catheterisation] to having an operation?"K "Because, well, I was trying to get the catheter to not act like... to not be there, so not to have to have it anymore."
JL   "So you don't have to be catheterised anymore?"
K   "Uh-hum."

JL	*"And what is that? Is that a good thing?"*
K	*"It's a very good thing."*
JL	*"It's a very good thing."*
K	*"Yeah."*
JL	*"Why is that? Can you say why?"*
K	*"Because you can be normal again."*
JL	*"Normal again? And so have you never done that before [pee in the toilet]?"*
K	*"Yeah, but not as I should."*
JL	*"Not as you should. And I can see from your face that that's been a bit annoying, has it?"*
K	*"Yeah, very."*
JL	*"Very annoying. How do you manage that at school, then, Kelvin?"*
K	*"The school, it's not very big."*
JL	*"Right. Is there anybody there who can help you?"*
K	*"I don't need it."*
JL	*"You just do it yourself?"*
K	*"Yeah."*

Secrets

Kelvin went on to explain how he kept this secret from his school-friends. Keeping this secret from school friends was important to Kelvin's appeal to being the same as other children, but he wanted this to end, and he wanted desperately *'to pee'* normally. Kelvin was not alone in keeping secrets. Sam had also explained to me that he had a 'secret' signal (thumbs up) that he would use at school to signal to his teacher that he was wet and needed to be changed. In a similar way, Caron had developed a particular way of walking to disguise her pelvic abnormality.

For Goffman (1968) stigma encapsulated what some people experience when particular characteristics render them different to those considered 'normal'. This stigma may be managed in such a way by the stigmatised individual that there is a discrepancy between an individual's perceived and actual identity. Arguing that any revelation of this discrepancy can lead to spoilt social identify, Goffman suggested that there were "sympathetic others' who were ready to adopt the stigmatised person's standpoint in the world and to share with them the feeling that that they are human and 'essentially' normal. According to Goffman's treatise, there are 2 types of 'sympathetic others' both termed wise; those who share the stigma (such as those with similar characteristics and other family members) and those who work in

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positions that cater for people with the stigma. They co-operated with the children in keeping secret their difference. James, Curtis and Birch (2008) have suggested that those children whose identity conflicts with the 'norm' endure stigmatised childhood. From the children's accounts, people like teachers and the staff on the ward formed members of their 'wise' community. Although the children never expressed their aspirations in relation to being stigmatised, many of them communicated their desire to be more like other children and their wish to reduce their perceived difference from other children.

Following the failure of Kelvin's last operation, the surgeon in his home country had spoken to the consultant at City hospital asking if he would intervene. It was through my work with Kelvin that I came to understand the distinction between the staff's focus on the present and the children's focus on the future.

Inhabiting Different Worlds

My work with Kelvin provided useful insight into his competence and his ability to act in respect of his best interests. I had constructed this as his being determined, which I understood to be a positive attribute. However, other adults involved with Kelvin appeared to derive more negative constructions from his behaviour. This became apparent in accounts from his father and from ward staff of their interactions with Kelvin following his operation.

During one visit to the ward to work with Kelvin I had made a reflective comment in my field work diary and transcribed a short conversation that I had with two staff nurses:

> *There are 16 children on the ward today. Five staff on an early shift and 3 on the late and night shifts. There are five doctors talking to staff and parents at the nurses' station. The ward seems busy – perhaps it's just the number of people at the station? Mandy came over to me immediately, she interrupted a conversation I was having with a member of staff and Emily joined in.*
>
> M   *"Are you here to see Kelvin? I lost or very nearly lost my temper with him this week..."*
> E   *"Yes... even his dad lost his temper with him."*
> JL *"Do you want to talk to me about it later?"*
> M   *"Yes, but I'm glad you're here, we can do nothing with him. Good luck."*

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I was shocked by Mandy's candour and wanted to know more about the event that had left her feeling so frustrated. Mandy was Kelvin's named nurse. On previous visits to the ward I had been particularly impressed by Mandy's approach to the children and had mentioned this to my supervisor. I considered her to be one the best nurses that I had met. I had also noted that the children depended on her a great deal. She had spent a great deal of time working with Kelvin during his time on Study ward. I was keen to learn more about her understanding and interpretation of what had been going on. In terms of my work, I was particularly interested to see how she constructed Kelvin and if she represented his voice in her recollections. This was critical to my developing theory of the ward constituting two worlds. During an in-depth conversation with me, she reflected on her work with him and revealed her interpretations of what had happened:

M   *"It was quite a stressful shift. I was just about to accept a patient back from HDU. I had just come in on the late. We got out of handover, and I'd been assigned a patient who is coming over from HDU and I was trying to get the room ready. Every time I walked past Kelvin's bed he kept calling me, and I said that I would be with him in a minute. When I went to him he said that he needed his pad changing. He said he'd been asking for them to do it all morning...."*

I felt that it was important to emphasise here that Kelvin had told her that he had asked earlier for his pad to be changed:

JL   *"He said that to you?"*
M   *"Yes. He said that he had told the other nurse. I think his dad had just popped out over lunch time. It was about 1.30 or 2pm. I went to do it, and when I went to do it he had his hands all in the way. I was trying to explain to him what I was doing and he was just stopping me from doing it. He was lifting his foot up into my face as well."*
JL   *"So he'd asked you to do it?"*
M   *"Yes."*
JL   *"But then he was trying to stop you. Do you know why he was trying to stop you?"*
M   *"Because he was worried that it would get in his wound. The day before he'd had his bowels open and had to go in the bath because all of his dressing had been soiled. I think it was actually the morning or the day before, I'm not quite sure which. I think he was worried about dressings having to come off, or whatever. All he had on was about four steri-strips. I was explaining to him that I was just going to clean it up. The way he was moving around was actually making it spread worse and get closer to his wounds. I had people talking to me through the curtains telling me my patient was coming from HDU..."*
JL   *"They knew you were busy with Kelvin."*

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M   "Yes. They were just telling me that they were on their way. I said that they could come [and bring a child from HDU], but I was in the middle of something. I knew that the patient was coming and would require a lot of work when they arrived. I was just a bit stressed about that. He was putting his foot up in my face and everything as well, even though I was asking him not to. I got him all cleaned up any way, but I did very nearly lose my temper with him."

JL   "Is that the closest you've come?"

M   "Yes..."

JL   "When you say lose your temper, what do you mean?"

M   "Not do anything bad, but I've been quite patient with him because I know that he does need to know what we're doing. So we talk through everything with him, but I just felt that I didn't have the time. He probably picked up on that which was why he was responding in the way that he was..."

This excerpt illustrates that Mandy understood the importance of giving Kelvin sufficient time but that the time that she had to give him was contingent on other factors. In this instance, she knew that the impending admission of a child from the high dependency unit presented her with competing demands. She went on to explain how she tried to control Kelvin's demands:

M   "It made me feel really bad, actually. I did actually have to say to him, 'Kelvin if you don't stop putting your foot in my face I'm going to go away and leave you'. I did actually have to say that to him... I felt that I hadn't given him the proper time and attention that he needed. There was nothing that I could really do about that because I had to do all sorts of other things at the same time."

M   "Sometimes I do go away thinking that I've not done that properly because I've had to do this, this and this at the same time. You do go away thinking that you've not given that patient enough attention. Quite often, if you've patients who've got parents with them more, at times they do a lot of the care. I feel that shouldn't be expected of the parents. Whether or not they do the care at home, I think that when they come into hospital if they want an opportunity for a rest, we should be able to provide that because we're here to look after their child. Sometimes if you know that they've got a parent with them, you do kind of think that the parent will sort that out and you don't need to do quite as much, which does make me feel that I haven't given my full attention."

While the literature is replete with research reports that concur with what Mandy had said, and some have speculated on what this may mean for children in hospital (for example see Darbyshire 1994, and Callery 1995), few studies have sought to elicit the children's subjective interpretations of this. My analysis suggested that, for the staff, the children's competence was not a fixed characteristic; rather it was a fluid

and unstable characteristic, subject to change in different circumstances. This added further weight to my developing theory that recognition of the children's competence was contingent on structural factors. It was sometimes necessary for the staff to deny the children's competence as a means of control and constraint so that the staff could get the work done. On occasion the effect was to limit the children's practical agency and silence their voices. That said, not all of the children readily accepted control or limits to their agency. Some developed alternative strategies that were actively pursued. These strategies underlined the children's resiliency, although some children appeared more resilient than others.

My conversation with Mandy is important with regard to Kelvin's experience and his interpretation of it for a number of reasons. During the conversation with Mandy I had told her that Kelvin had already experienced two failed attempts at reconstructive surgery in another country, and that he had told me about his intense desire to be dry and in his words *'to be normal'*. This meant that he had a great deal invested in the operation being a success; just as Seb, Caron, Sarah, Ged and Sam had. Alderson (1993) stressed the importance that children give to being the same as other children and that this usually underpins their acquiescence and consent to painful surgical procedures. Given the two previous failed attempts at corrective surgery, it was important to Kelvin that this operation was a success.

Mandy explained that she was completely unaware that Kelvin had had previous surgery for the same problem. The medical notes available on the ward were temporary and consisted of no more than the medical assessments that related to his current admissions. Mandy was shocked. She reflected on how a lack of knowledge had led to negative constructions of Kelvin as being difficult.

M   *"The thing is that we don't handover all of the background on Kelvin. I didn't know until you told me that it was his third time having this operation and that he's had lots of problems in the past. People who aren't familiar with that could actually just see him as quite a difficult patient and quite a stroppy, uncooperative patient."*

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Following my conversation with Mandy, I sought to elicit Kelvin's interpretation of the same event. He had expected that the removal of his stitches would be sore, and was clearly concerned in anticipation of this. He tried to explain to me why he had reacted in the way that he did.

K   *"I had stitches, paper stitches; and they just took them off."*
JL   *"She had to take your paper stitches off?"*
K   *"Yeah. It wasn't sore. I thought it might have been."*
JL   *"You thought it might be sore? So what did you do when Mandy came to take your stitches out?"*
K   *"Say, 'Just leave them, just leave them, just leave them'."*
JL   *"Right, and what happened?"*
K   *"She took them off, and it wasn't sore."*
JL   *"OK. So you said, 'just leave them, just leave them, just leave them'. Did you do anything else?"*
K   *"Nope."*
JL   *"No? Did she have to take your stitches out?"*
K   *"Yeah."*
JL   *"So when you were saying to her, 'Leave them alone'..."*
K   *"Well, I just pulled them, like."*
JL   *"Right."*
K   *"Yeah."*
JL   *"And do they not come off in the bath?"*
K   *"Sometimes. Sometimes they don't."*
JL   *"Right. So it was Mandy who took them off, and you were saying 'Leave them on, leave them on, leave them on.' Did you? You know when you said that to her: 'Leave them alone', what did you want her to do? Did you really want her just to go away? And what about having them taken off? How would you have done that?"*
K   *"Well, they were going to fall off themselves, they would have fallen off themselves, anyway."*
JL   *"Would they?"*
K   *"Yeah."*
JL   *"And did you say, 'Can you leave them until they fall off themselves'?"*
K   *"Yeah, but she said, 'No, there's blood on them.' So..."*
JL   *"Right."*
K   *"She took them off."*
JL   *"And why does that matter?"*
K   *"Because the blood can infect it, or something."*
JL   *"Right, OK. And what do you think about that? Is that reasonable?"*
K   *"Yeah, because then I would have to get another operation."*
JL   *"Yeah. So you said to Mandy, 'Leave them alone, leave them alone', but she didn't leave them alone. So how does that make you feel?"*
K   *"Quite happy, because then it didn't get sore and that."*
JL   *"Yeah. So you knew it had to be done?"*
K   *"Yeah."*

JL   *"But you couldn't stop yourself from shouting at Mandy?"*
K   *"I wasn't shouting exactly, but..."*
JL   *"Right. You weren't shouting. How loud were you saying it?"*
K   *"Just what I'm saying to you."*

Mandy's reflection concurred with Liaschenko's (1997) assertion that knowing the patient is moral obligation. Mandy also highlighted the importance of knowing each of the children as individual people in order to avoid negative constructions. This is underscored by Kelvin's account as it is this that serves to reinforce the importance of doing what is possible to elicit the children's understanding of what is proposed. It seemed that the additional work demands on Mandy's time meant that she had insufficient time to work with Kelvin in a more positive way. Coyne and Hayes et al. (2006) worked with 55 hospitalised children in 3 hospitals in Ireland, aged 7 – 18 years. They sought the children's views regarding their experiences in hospitals using focus groups and individual interviews. They concluded that fundamental aspects of good practice with children in hospital included trusting relationships with nurses, but that these were based on the nurses' knowledge of the children as individuals. Having sufficient time to spend with the children was critical.

Joe had also explained that nurses needed to *'take their time'* to avoid 'getting it *wrong'* as he might *'die'* if they made a mistake. Trust, developed with children over time, has emerged as a valued concept in research studies exploring nurses' work with hospitalised children (Randall, Stammers and Brook 2008, Coyne and Hayes et al. 2006, Ford and Turner 2001, Totka 1996, and Bricher 1999, Burns 1994). The children in my study concurred with this, but the findings presented here add new insights as I was present with the children on occasions when the nurses were too rushed and faced too many demands. This then highlighted the structural challenges that the children had to work hard to overcome in order to get what they needed. Yet, only Bricher has voiced her concern regarding the inevitable tension inherent in the development of trusting relationships with children, having to get the job done.

Having considered a number of incidents from multiple perspectives meant that I was able to analyse further my developing theory that as in-patients the children

inhabited a different world to the staff. Study ward as a place for children in which they struggled to find a space to be heard and have their competence acknowledged.

Steph, who, like Mandy, appeared to have a very strong child-focused attitude to her work, had also explained the importance of having insufficient time and needing to get the work done. She explained the consequences and the emotional labour that she confronted in her work with the children. She had explained to me the circumstances surrounding the removal of Lauren's Jackson Pratt drain. In spite of Steph's best efforts it had snapped:

JL   *"When you came out of the treatment room with Lauren, you said 'Oh god, that was awful'."*

S   *"I had just had to take Lauren's JP drain out. Now this has gone on from this morning, they must have been busy this morning, then it got handed over, take the JP drain out... So in the end I said 'Look, I will go and take it out. I will take the students in and do a teaching session.' I prefer to go in the treatment room because the bed space is there to relax on, you know. I do not like doing it unless I have to. So we took her in."*

JL   *"Was she quite happy?"*

S   *"Yes. I mean, she does not like things being done, but as long as you talk her through it and she is in charge, and you stop when she wants, etcetera. I took the dressings off without a problem. Talked her through it, nicked the stitch to the JP; not a problem. Then we pulled it. And there was a bit of resistance, but I said 'It's OK Lauren, we will have it out in a minute. Have a breath'. So she took another breath, and I pulled, and it snapped. Her mum said 'It snapped' and I knew. I had done nothing different to any other time. Quite a lot of the time you find resistance. And if the doctors come up they will just say 'Pull a little bit'. So I did not do anything different but it snapped. The registrar said 'It's nothing you've done, you were just unlucky. It might be us; we might have caught it with a stitch internally'. But that does not make me feel any better because I do know now that she will have to go back to theatre to have it removed."*

However, Steph did not make any attempt to tell Lauren what had happened. In fact she had tried to keep this from Lauren.

JL   *"Does Lauren know what has happened?"*

S   *"Yes, because she heard mum say it had snapped."*

JL   *"How did she react?"*

S   *"She did not really. She said 'Oh, what have you done?' I said... Well I just covered it up really. Mum does know. Mum said 'She'll probably have to go back to theatre, won't she?'*

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In this excerpt Steph acknowledges the time pressure that she was subject to and that she was trying to help Lauren removing her drain. The nurses responsible for her care had had insufficient time to do this earlier. In this way she placed Lauren's best interests at the centre of her work. Still, she acknowledged that she had failed to respond to Lauren's question "*What have you done...?*". For Steph, it seemed sufficient that Lauren's mother was aware of what had happened and that this meant that Lauren did not need to know. It is possible to interpret this as poor communication. Lambert, Glacken and McCarron (2008) and Coyne and Hayes et al (2006) have pointed out the inadequate nature of effective communication between hospital staff and hospitalised children in Ireland. The findings presented here suggest that similar shortcomings exist in the care of hospitalised children in England. However my analysis adds to this insight. Given Steph's reaction and explanation, it seemed to me that admitting to Lauren what had happened was too hard, and that emotional labour was implicated in this (Gray 2009, Gray and Smith 2009, Smith 1992). It was not that Steph did not know how to communicate what had happened to Lauren, Lauren had trusted her and it seemed to me that this was the challenge that Steph struggled to overcome. In this way, as in Mandy's account, there was a disconnection and contradiction between the implied values that the staff purported to be at the centre of their work with children and what they did. Drawing on Smith's (1992) work on emotional labour, Gray (2009) and Gray and Smith (2009) noted that there is still no common language to describe and communicate the emotional labour involved in work with children in hospital. Gray (2009) also noted that emotional care is not only subsumed into the sphere of women's work and as such taken for granted as a natural way of working; he concurred with Anderson (2008) that caring work remains undervalued. It appeared that letting the children down or being involved in interventions that did not work well was a form of emotional labour that left both Mandy and Steph feeling guilty. That said, this is an adult's view. Bluebond-Langner (1978) established that children in hospital become experts in translating that which adults find difficult to talk to them about, I felt sure that Lauren would have gleaned, and would therefore know, that the catheter had snapped. She later told me she had "*...it snapped...*"

My analysis points out that it was not only the adults who were engaged in emotional labour. However, the children's emotional labour was not simply undervalued, it remained hidden.

Knowing the Children

It is also important to note that Mandy and Emily had cited Kelvin's lack of co-operation rather than his needs to conclude that the time that they had to devote to him was inadequate. In other words, it was Kelvin's behaviour rather than the extent or type of care that he required that was used to construct him as being difficult. Interestingly, when Mandy had time to reflect on this she commented on the structural limitations (too many demands at one time) and then used these to explain the shortcomings and inadequacy in his care. Kelvin's needs had added to her burden of work that she was struggling to manage.

These revelations were significant in the development of my analysis for a number of reasons. During my field work, I noted that the student nurses and health care assistants had spent a lot of time in the process of admitting children to the ward. The purpose of the admission was different to the medical assessment undertaken by medical staff. It consisted of a nursing assessment using a model for nursing children that was developed in England during the 1980s (MacDonald 1988 and Clarke 1988). The development of this model followed the publication of the Report of the Nursing Process Evaluation Working Group (1986). The model was developed by linking the developmental stages of the child (Sheridan 1973), with the activities of living (Roper, Logan and Tierney 1983), to provide a nursing framework that would useful for practice rather than an administrative task (McDonald 1988). As such, it reflected the dominant thinking of the time and constructed children as important but passive recipients of nursing. It was intended that this new guide to nursing practice would help nursing staff to get to know the children, ensure that the knowledge gained from the assessment was used to minimise any disruption to their usual routines at home, enable an easier induction into the ward, and minimise adverse effects of hospitalisation following discharge.

It appeared to me that the time accorded to the process of assessing the children on their arrival to the ward reproduced the illusion that the staff were working to get things right for individual children. In turn, this suggested that the structural and material factors that framed the practices within Study ward were malleable, flexible and changeable. However, my work with the children, and Mandy and Steph's reflections, brought this into sharp contention. It was not that the intention to work in a child-centred way was missing; it was that other factors made this impossible (Birch, Curtis and James 2007). Gray and Smith (2009) noted that that needing to simultaneously care and control people gives rise to unresolved conflicts, *'especially where discrepancies arise between daily practices and therapeutic ideals'* (pg 257-258). James, Curtis and Birch (2008) have referred to this as the 'thin red line' that is too easily crossed when attempts are made to manage the border between control and participation. While the staff on the ward seemed oblivious to this, the children were not.

It was not that the nursing assessment had lost its meaning; rather that it had been developed at a time when different values gave precedence to objective checklists. It was never intended as a tool for eliciting the voices of children or understanding their meanings; it was meant to assess children as objects against latent-age developmental norms. It was no longer fit for purpose but used relentlessly. The consequences of this were especially evident for Kelvin. The admission processes had failed to elicit the importance of this third operation. Kelvin was on a quest to be normal and being normal, or more like other children, mattered to him a great deal. More than that, the ward staff knew nothing of his previous admissions or of his aspirations. His real interests were subjugated.

It was perhaps too easy to explain the shortcomings in Kelvin's care through recourse to the dominance of organisational imperatives. I now contend that the assessment tools used by the nurses were out of date. They belonged to a different era when children's agency and competence was denied. Coupled with the dominant discourse of family-centred care and partnership working with parents (Shields and Pratt et al. 2007, Coyne and Cowley 2006, Franck and Callery 2004, Savage and Callery 2000, Callery 1995, Darbyshire 1994, Casey 1988), the

assessment processes further subjugated the needs of children and shattered the illusion of Study ward as place that had space for children's competence and voice.

Drawing on Foucault's (1991) concept of the 'gaze' Milligan (2003) argued that any dominant discourse can disable understanding by presenting a landscape that is both superficial and limiting. The underlying influence of children as dependent and in need of protection and the dominant discourse of family-centred care meant that relying on adult proxies had become 'right thing to do'. This meant that adult understandings masqueraded as children's wants and wishes. It is of course speculative to assume that, had the nursing assessment enabled a more complete understanding of Kelvin's previous experience, his care could have been prioritised differently. Perhaps even more importantly, the assessment had failed to elicit the effective strategies that Kelvin had developed to act in his own best interests. It was these aspects of the nursing procedures and processes and the subsequent contribution to his care that were lacking. This led to a misunderstanding of what mattered to Kelvin and revealed shortcomings related to knowing the children as individuals; for me a fundamental factor in child-centred practice.

Consistent with the preference given to the organisational imperatives of getting the job done, the staff seemed to work on the basis of knowing the children as surgical patients rather than knowing the children as individuals. In keeping with Liaschenko (1997) May (1992) had argued that the power of talk was fundamental to knowing patients as individuals. Yet, the practice of delegating the admission processes to the most junior members of staff not only left them as those who were least skilled as the outward facing conduit between the organisation and the children, it meant that the children were exposed to the most junior members of staff when they were possibly feeling most anxious and vulnerable.

As already noted, the admission procedures and processes took up a great deal of time, but this provided the ward staff with a rare opportunity to spend time with the children. In many ways it was a missed opportunity that not only rendered the children as little more than patients with medical diagnoses in need of hospital treatment; it created a significant barrier in terms of the ward staff getting to know the children. It seemed that the qualified nursing staff had created a system that

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worked against their best interests and in turn this worked against the best interests of the children. The staff then resorted to blaming the children for the shortcomings in their care.

Difficult Children

Mandy's account is important with regard to this as it enabled me to establish that her representation of Kelvin and her construction of him as *difficult, unco-operative and stroppy* were based on partial knowledge. In turn, this negative construction had permeated into the constructions that others had of Kelvin, and these were confirmed by other staff and his father. It seemed that knowing the children as individuals was a fundamental aspect of child-centred work and an important element in my developing theory.

Family Feuds

However, it was not only the children's relationships with staff that were strained. Kelvin's father had approached me during a field work visit to explain how difficult he was finding it to be with Kelvin on the ward. He explained that he sometimes left the ward to avoid losing his temper. He told me how he looked forward to my visits as it meant he could use the time for respite away from the Kelvin. It seemed that Kelvin's father was also experiencing emotional labour. He also expressed his disquiet at being the go-between for Kelvin and the nursing staff. As Kelvin was not always able to get what he wanted from the nurses, and given that he was at times unable to get things for himself (due to his limited mobility), he relied on his father to act as the mediator between him and the nurses.

Kelvin did not rely on his father to predict or know for him; rather he did what he could from the confines of his bed to have his father mediate with the ward staff on his behalf. As if to underline this, Kelvin asked to speak to me. He had been listening to a conversation between his father and me regarding the management of his pain. It was clear he had something to say about getting his father to mediate:

JL   *"Now, you've just asked me a question about what was it your dad   was saying to me. Did you want to talk about that?"*
K   *"Yeah."*

JL "Is it when Dad said to me about when you had pain and he had to ask the nurse as it would take a long time?"
K   "Yeah."
JL "And that you might get cross with him, is that it? Yeah."

K   "Well, I wasn't going to get cross with him. I would just, like, get annoyed."
JL "So you'd get annoyed..."
K   "Uh-hum."
JL "And then what would you say?"
K   "I would just like... I don't know what I would say... "
JL "If you can't tell me what you would you say, can you tell me what you would do?"
K   "Well, I would just, like, tell Dad to go and get the nurse and keep telling him to get the nurse until I got it. I would say 'get them, get them, get them, get them."
JL "Right. OK. So you'd just keep repeating yourself?"
K   "Yeah, because it was really sore."
JL "Because it was really sore?"
K   "It would get sorer and sorer and sorer."

For Kelvin, it was not simply a matter of getting pain relief. He explained that having to do this left him feeling upset.

JL "Yeah. And how does that make you feel?"
K   "Upset, because I'm not getting really treated properly."
JL "Because you're not getting treated properly? So you'd get upset? And what do you think your dad feels about that?"
K   "Unhappy."
JL "Unhappy. Is that a problem, Kelvin, this getting sorer and sorer for you, why you've been in hospital this time?"
K   "Yeah."
JL "It was? Do you want to tell me a little bit more about, then?"
K   "No."
JL "No. We'll talk about it again at another time."
K   "Yeah."

While the subjective experience of adult-adult relations between nurses and parents and the impact of hospitalisation on attachment relations has been extensively researched and reported (see chapter 2); the impact of hospitalisation on resident adult-child relations and the subjective experiences of child-hospital staff relations remain unexplored. However, it seems that the negative impact on the relationship between Kelvin and his father was clear. Both were left feeling upset and unhappy and the cause of the upset appeared to be directly related to Kelvin's pain and his inability to get what he needed from the hospital staff.

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In a paradoxical turn, it seemed that when the children encountered difficulties with getting what they needed they then used strategies that led to them being labelled as *'difficult and stroppy'*. This resulted in double jeopardy. In a remarkable twist, the shortcomings in care that they encountered not only led to negative constructions of them as individuals, it sometimes resulted in them experiencing further shortcomings in care.

Having analysed this aspect of my work with Kelvin I sought to establish if there were similar encounters to support or refute my developing theory that child-adult relations were strained. Peter's mother had left the ward to go to work. His grandmother had arrived to sit with Peter but was met with an instant rebuke. Peter knew that I brought my black bag and that he could choose a present. He asked straight away.

P   *"Can I have a present?"*

He chose the pen with a flashing light and recording facility. While he was fiddling with the pen and trying to find out how it worked he turns to his grandmother and said...
P   *"You're fat, you're stupid!"*
GM *"Oh dear,..."*
Both I and his grandmother were embarrassed and somewhat confused by Peter's outburst. This seemed to be out of character. I asked him if something was wrong. He became increasingly agitated and hid behind his sheets. He was leaking a lot of urine from around his urethral catheter and said he wanted to *'wee through his willie'*. I offered to get Mandy. She came straight away and noticed that his boxers were very wet. Peter went very red in the face and started to cry. He said he was going to be sick. Another nurse, Gill, came to the bed with a syringe filled with medicine. Peter asked what it was.
M   *"It's your pain killer."*
P   *"Which one is it?"*
M   *"Which one? Paracetamol."*
Peter revealed his knowledge that some medicines made him sick.
P   *"Is it the one that makes me sick, is it the one that made me sick yesterday?"*
M   *"No."*
Peter took the medicine. Mandy went to release the clamps on Peter's catheters (of which he had two).
P   *"No, don't [he hesitates]... Yes, do."*
One of Peter's bags drained but the other did not. Peter complained about back pain. Mandy appears to ignore this and leaves. Peter turned to his grandmother:
P   *"Look, I've weed."*

There was a large amount of urine on his boxer shorts and he told his grandmother to take them off. As she did this his urinary catheter moved slightly and he squeezed the gauze fastened with tape to the end of his penis. Peter started to panic.

P   "Get Mandy. Get Mandy."

His grandmother called Mandy who came with fresh tape and gauze to secure the catheter. Peter tried to pull the damp tape off and was encouraged to do so by Mandy. She then replaced the gauze and tape and helped him into clean boxer shorts. Peter's bottom sheet is also a little wet and Mandy asks Peter if she should change it.

P   "No, no [hesitates]… Yes, I'll get out."

Mandy went to re-clamp Peter's catheters but he refused to let her and tried to wriggle out of the way. Mandy accidentally caught his skin with the plastic clamp, and Peter became upset.

M   "I'm sorry Peter. I'm so sorry."

Peter turned to Mandy and hit her. She laughed. He laughed and he continued to smack her. He then turned to me and smacked me.

Disrupting the Work of Staff

The similarity between the observed episodes with Kelvin and Peter is stark. Peter knew that he was being rude to his grandmother, though I remain unsure if this was due to his pain, his urine leak, that his mother had left or just his being mischievous. Regardless, I came to interpret this as a form of pestering. It had the desired effect of drawing her full attention. I am also unsure whether it was his pain or embarrassment at being wet that led to him hiding behind the sheets. In a similar account, Beuf (1978) noted that a six year old child tried to hide behind sheets when a doctor tried to examine his genitalia. However, in Beuf's account, the child's resistance was met with a rebuke from his parents in order that the doctor could continue; moreover, there was no attempt to seek the child's assent or co-operation with the procedure. In contrast, Mandy had been eager to let Peter take the lead and had regretted that she had needed to rush Kelvin. His requests for Mandy to attend to him mirrored Kelvin's strategy of insisting that the nurse attended to him. Steph had also revealed her shock when Lauren's JP drain had snapped.

Another similarity between Peter and Kelvin's' behaviour lay in how their immediate reaction was to tell Mandy to stop what it was that she wanted to do. Both reconsidered this. Peter gave outright permission for her to continue, and Kelvin stated that he was glad that she had done so. It appeared that during the nursing

episode with Peter, Mandy used considerable skill to develop a rapport; assess his willingness to allow her to intervene and create the right conditions for him to consent to what it was she wanted to do. She also demonstrated considerable skill in getting Peter to work in his own best interest and did not react to Peter smacking her. In response, Peter seemed to trust Mandy, and, in keeping with other children on the ward, often asked for her by name. The only discernible difference that I could identify between the two encounters was the external pressure that Mandy had faced during the nursing episode with Kelvin caused by the competing demands of the child coming from the high dependency unit. However, the children knew and they had developed insight regarding the need for a protective adult. Fathers and mothers (and other adult visitors) were important instruments that the children used to access precious resources.

Protective Child-Adult Relations

As noted in chapter 5, many of the children had relied on their parents and other adults to ensure that they gained access to the hospital services that they required. During the analysis I became aware that many of the children spontaneously placed importance on their adult visitor's presence, Stephen not only explained why it was important for his mother to be there, but he also told me why he needed other adults if she could not stay with him. He understood that the ward staff could not be expected to meet all his needs:

S   *"This is very important; well I think it's important. But this is for mums, dads and the children. You need your mum with you. Your mum would want to take care of you, and you need your mum to help you and look after you because when your mum's there you know nothing is going to go wrong. Do you know what I mean?"*

J   *"Yeah, why is that?"*

S   *"You know, you're just left there sometimes, and there's like a little room where everyone has to stay. Once this is a bit weird but, it was about 7 o' clock, I don't know why I got up that early but, mum went for... went to get a coffee, and I wondered where she had gone. I got a bit frightened, so that's why you need your mum there, she looks after you and helps you."*

J   *"Why do you get really frightened when Mum's not there?"*

S   *"Because I get really worried. You don't know where's she gone or when will she be back."*

Other children had struggled to articulate why it was important for their mothers to be there, however they agreed that it was important.

A   *"[Mum being there] makes you feel safer. I know why but I can't explain it."*

S   *"Because your mum is your mum, isn't she? I can't explain."*

J   *"My mum being there and my dad - I feel better when they're with me."*

Celeste explained that she would feel scared should her parents not be present

C   *"If you've just woken up from an operation, it's easier if your mum or your dad were there, because you love them and if they weren't there you'd be OK with the nurses, but you'd be a bit scared. When you wake up, obviously you're going to be frightened and obviously you'll have nurses there, but if you have your mum and dad then you feel safe, and know you're OK."*

Sarah went to great lengths, using concepts with which she thought that I would be familiar, to help me to understand that she knew that there was an association between feeling safe and being loved.

J   *"Do you ever feel not safe?"*

S   *"When my mum's not there."*

JL   *"So to feel safe your mum's got to be with you?"*

S   *"Or someone."*

JL   *"Or someone."*

S   *"I don't like being on my own."*

JL   *"Why?"*

S   *"It's boring. I'm a chatterbox and I've got no-one to chat with. But I don't mind if I've got something to do."*

JL   *"Can you think why you need your mum there to feel safe?"*

S   *"It's my mummy."*

JL   *"What does your mum do or why does that make a difference?"*

S   *"Are you married?"* [I nod]

S   *"Do you know when you first dated...when you're with him you must feel a bit safe, you feel dead cosy and....like that, that's what I feel with my mum."*

JL   *"Can you give me another word besides safe for that?"*

S   *"Love."*

JL   *"Love, and if mum's not there and you're on that hospital ward... do you feel unloved?"*

S   *"No, I feel like on my own. Mum will kind of stay, [but] sometimes she has to go home for a night to get stuff and that. It's so boring. I've got no-one to talk to."*

Seb had agreed with this.

J   *"Why, what will happen if Mum's not there?"*

S   *"Well, I always like having someone with you because you feel warm, you've always got something to do because... There's always someone there, because my mum went home and my granddad was there and when my granddad went home, someone else was there. It just it helped me to manage, I should say. It just helped me to manage, because I had an adult looking after me 24 hours a day."*

However, for Seb it was a reciprocal process.

S   *"Think of the mums: the mums want to see their children, don't they?"*

He also gave consideration to why the nurses could not be relied on.

J   *"And what about the nurses, Seb, the ones that are there to look after the children, because they're adults aren't they?"*

S   *"Yeah, but sometimes they have to go to the other people as well, but your mum, your mum's there non-stop. Well, your mum can be there non-stop."*

Seb's comments reinforced Roberts (2010), Coyne and Hayes et al. (2006), Coyne (2006) and Hawthorn's (1974) conclusions regarding the importance of having parents on the ward with children. However, in my study, using the children's words amplifies not only the emphasis they place on the importance of supportive adults but they reveal the depth of their knowledge regarding being an in-patient. For the children, having their mother or other adults there served multiple purposes. For Seb it was having his own personal nurse; he and other children spoke about it reducing fear and increasing their perception of feeling safe. The adults who came into hospital to be with them also helped them to get the things that they needed. Sometimes this help was of a practical nature, like bringing food or toys from home. It included getting drinks and having someone with whom to spend time. More importantly it helped the children to navigate a world that was alien. Study ward was a social world that was reproduced by the staff to help them get the job done. The children used their adult visitors as instruments in their quest to reproduce Study ward as place with space for children.

Sometimes the children's parents were needed to negotiate on their behalf or even to intervene to prevent them from being harmed (Sarah's father had to intervene to prevent hospital doctors from causing damage to her hip). This was further evidence that adults were often important mediators between hospital staff and the children.

Still, my analysis revealed that the relationship between the children and their adult visitors was sometimes difficult and sometimes broke down. This could leave individual children marooned. Celeste had stressed that she had not always been able to rely on her parents and then had relied on other adult visitors who were close by:

C   *"I'd ask the person next to me, if her parents are there, to get a nurse.... or wait till my mum came back."*
JL   *"Is that alright?"*
C   *"If you really need something, I don't think it is, but if you don't need it desperately then it's OK."*
JL   *"Can you think of something when it wouldn't be OK if you really wanted something?"*
C   *"If I needed a drink."*

Sometimes she had needed to rely on other adults to get her parents to respond to what it was that she wanted.

JL   *"Can you tell me about that?"*
C   *"My dad was there and he was asleep. I couldn't move and I needed a drink. I tried to reach out for his leg, but his leg was pulled in. Then that man had to come and tell him..."*
JL   *"To wake him up?"*
C   *"Yes."*
C   *"That was the first time, but the second time I was throwing teddies at him."*

I Am, I Have, I Can

Key in these explanations was that for the children to realise their practical agency it was necessary for the adults involved to be able and willing to intervene. John (2003) related the notion of practical agency to the emerging concept of resilience. Grotberg (1995) defined resilience as

'...a universal capacity which allows a person group or community to prevent, minimise or overcome the damaging effects of adversity..."

Three sources of resilience for children were identified from an international study of 600 children across 30 countries (Grotberg 1995). Combined, these three factors (*'I am' 'I have'* and *'I can'*) are thought to help children to overcome adversity. For Grotberg (1995) *'I have'* related to trusting relationships, structure and routine, access to role models, encouragement to be autonomous and access to health

education welfare and security. '*I am*' incorporated the notion of individual worth, self respect, a willingness to be responsible and a certainty that things would work out well. '*I can*' incorporated the ability to communicate, solve problems, manage feelings and impulses, and seek trusting relationships. The notion of '*I can*' was directly related to children being able to draw on their social capital which in turn, enabled them to call on supportive adults (and in some cases other children) to help them through a crisis. This was evidenced in my study by the children calling on supportive adults and using them as instruments to get what they needed.

Work on resiliency has since been further developed by Daniel and Wassell (2002a, 2002b, 2002c), and their resiliency framework has been incorporated into the Scottish national strategic framework guiding the care of children and young people (Scottish Executive 2007). Of particular note here is that Daniel and Wassell's framework advances Grotberg's ecological model of resiliency by incorporating eight areas for assessment; safe; achieving; active; responsible; healthy; nurtured; respected and included[26]. In keeping with Glover (2009) I contend that such a resiliency framework may offer an alternative conceptual base for guiding the care of children in hospital as such a framework would accommodate the notion of children's lives being punctuated by strengths, difficulties, disadvantage and advantage at different times in different contexts (Killan 2004). It is also possible that using a resiliency framework would enable hospital staff to develop their capacity to enter the social world of children. Some staff appeared to have little capacity to take account of the children's agendas, and to the children this was sometimes overt. A resiliency framework could be used to shift the work inherent in inclusion and participation from that done by children to that done by nurses.

Freaky nurses

I found the children to be remarkably tolerant of the way in which the staff worked. They seem to internalise the tacit and informal rules that governed the work on the ward. That said, some of the children expressed their intolerance when staff hurt

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[26] Daniel and Wassell's framework has been incorporated into the Getting it Right for Children and Young Person's Plan (Scottish Executive 2007)

them through carelessness or incompetence. Seb had communicated his intolerance of incompetence when a nurse had, on more than one occasion, hurt him with a tympanic thermometer.

S   *"There was this really, I'm being a bit nasty here but there was this freaky nurse."*

JL   *"Freaky nurse?"*

S   *"Yeah she was. In the middle of the night, when I'm half asleep, she takes my temperature. She sticks it in my ear and, like, yanking it in my ear, and I'm, like, it hurts. It doesn't need to go so far in."*

JL   *"Right."*

S   *"It doesn't need to push it to the extent. I could actually feel it here."*

JL   *"Could you?"*

S   *"Banging here [points to the side of his head]."*

JL   *"Was that all of the nurses or just one?"*

S   *"Just one of them."*

JL   *"And you called her a freaky nurse…why does that make her freaky?"*

S   *"Because it hurts, it really, really hurts, you're supposed to look after your patients not wreck their ears."*

Seb's mother attempted to temper his intolerance by suggesting that he was groggy after the anaesthetic and not really capable of making judgements such as he had. She had suggested that anything anyone did would have hurt. Seb rejected this, correcting his mother by stating that this nurse had done the same thing on two separate occasions. He had compared what this nurse had done with how other nurses had used the same piece of equipment. Sarah was also intolerant of nurses whom she considered to be incompetent:

S   *"When I went in last time, they pulled a big tube out of me. They pulled a big tube out. I've got a big scar from it. My doctor and everyone said that I should have had, you know, an anaesthetic to have it taken out; or gas for the pain; but this one nurse she decided that I didn't need it. And it wasn't just a little tube. It was, like, that big, [indicates about 18 inches], and I'm not going over the top there, am I [asks her mother to confirm]? It was that big and it came out, and I've still got a scar from where it came out. They pinned me down. About five nurses pinned me down to get it out from me. They all had to grab hold of me, you know, to get it out."*

For Sarah, there was a ring leader who was responsible for this incident.

S   *"It was just that one nurse, because I remember her, because you remember someone like that don't you?"*

JL   *"Right."*

S   *"All the rest said that I could have some gas you know for the pain but she decided that I didn't need it."*

I was alarmed by this incident but not as alarmed as Sarah had been. It had clearly left a lasting impression on her. In fact, wanting to tell someone about this incident was the main reason that Sarah had been so keen to talk to me. She described it as the most *'rememberable thing'* that had ever happened to her. In my opinion, this was a very fitting word to use. She also advised me that if I told the nurses on the ward one thing, it had to be *'don't pin them down.'*

I found the details of the event that Sarah had described shocking. I knew that the physical restraint of children had been considered commonplace and an uncontested practice prior to the publication of guidelines on holding children for clinical procedures. I was also aware that more recent publications had pointed out the potential for enduring emotional impact following inappropriate restraint (Pearch 2005, Hardy 2004). Since, the RCN (2010) has published new guidance and opted for the term 'restrictive physical intervention'[27] in preference to the term restraint. Central to this guidance is the notion of involving children, seeking their consent and co-operation, and using pharmaceutical agents and distraction as appropriate. This underlines the importance of involving children in decisions that affect their care. Yet, Sarah's views had been dismissed. This provided further evidence of the fluidity and unstable construction of the children as competent actors. It also pointed to the experience of children being related to the behaviour and decisions made by individual members of staff. There was no collective ethos.

I was unable to pursue this incident further as the member of staff involved (described by Sarah as wearing a navy-blue dress) was no longer employed by the Trust. However, the uniform described by Sarah suggested that this person was in a lead position and therefore, in a better position than most to advocate on behalf of the children, and situate their best interests at the centre of the ward work. Sarah's experience represented a missed opportunity to make the life of one young person, who had endured much and had much more to endure, a little more tolerable. Brady (2009) Randall, Stammers and Brooke (2008) and Ślusarska, Krajewska-Kułlak, and Zarzycka (2004) have noted children's preferences for 'good nurses'. In

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[27] available at http://www.rcn.org.uk/__data/assets/pdf_file/0016/312613/003573.pdf

particular, Brady (2009) noted that young children have the capacity to make moral judgments on the nurses with whom they work. In keeping with Joe's notion that nurses help to keep children safe, the children who participated with Brady (2009) expressed their preference for nurses who did things properly and on time. Despite the best efforts of themselves and their parents, the children were, on occasion, subject to indefensible practice

The findings from a study of children in hospital in Ireland (Lambert, Glacken and McCarron 2008) concluded that hospitalised children were positioned along a continuum conceptualised as visible-ness (sic). According to the authors, this concept incorporated both vision and voice. The continuum was portrayed as having opposing ends – being overshadowed and being at the forefront. Although presented as a conceptually complex finding, Lambert, Glacken and McCarron's (2008) work highlighted that the children had a preference to be in the foreground and background at different points in their experience. They reported that sometimes they were in the background when they would rather be in the foreground. My findings add to this understanding as they demonstrate that the children knew their needs were often subordinated by organisational imperatives and the competing demands of other children, that some nurses were simply not good enough, and that they worked hard to disrupt the work of the staff to get what they needed.

In contrast to the findings reported by Lambert, Glacken and McCarron (2008) Sarah's recollection of having her Jackson Pratt drain removed revealed that she was neither in the background or foreground when her Jackson Pratt drain was removed, her competence was denied, her right to refuse treatment was denied, and her efforts to make known her dissent were ignored. This analysis concurs with the findings reported by Noyes (2000) regarding ventilator dependent children's views of their hospital care and Place (2000) regarding the dehumanising of children in hospital. Having mascot status offered no protection and, as noted by Lambert, Glacken and McCarron (2008), it was often the children who regularly attended that were sometimes marginalised.

However I contend that the term marginalised fails to convey the sense in which the children's voices were subjugated and subordinated. While their bodies were always present, their status as humans appeared at diminished and sometimes invisible. Place (2000) drew similar conclusions from an ethnographic study of nurses working in a children's intensive care unit:

"...(Intensive care) nurses are skilled in both combining elements and separating them into human and non-human elements. Failure in either undermines their claims to expertise....In this sense they it is easy to see how the practical problem for the nurses of 'losing the children in between' [is]...lost in the confusion of the boundaries of what is human and what is not..." (Place 2000 p 193).

However the children with whom I worked were not complicit in this. They did what they could to disrupt the work of the staff in order to re-establish their competence and voice. The disruptions acted as a reminder to the staff that the children were individuals and competent actors. This aspect of my analysis enabled further conceptualisation of the children's competence and how this was acknowledged, denied and re-asserted by the children.

Sometimes, using supportive adults as instruments helped them to do this. However, the cultural context of the ward spilled over and sometimes the children's relationships with their supportive adults became dominated by conflict.

SUMMARY

The findings presented in this chapter suggest that Study ward was two worlds; one inhabited by the staff and the other inhabited by the children. When the two worlds are considered side by side they not only point to the children and staff working to different goals, but they suggest very different realities. Study ward was a place for children in which there was little space for their voices. The children's goals were future-oriented and related to their desire to minimise their difference from other children (in a physical sense), and reduce stigma. Their interests in getting better or being more like other children were strong driving factors in their acceptance of hospital treatment. In contrast the hospital staff seemed to be oriented in the present, concerned with getting their job done.

The children in this study were neither passive recipients of care nor necessarily passive in relation to the decisions made regarding medical interventions. Their sense of self, manifest through self-determination and their social agency, manifest through disruption to the staff's work, suggested that they resisted being dehumanised and objects of the hospital staff's work.

The result was that some children were constructed as being difficult and stroppy, children's requests for information were ignored, and children's actions were misunderstood and interpreted in ways that conflicted with the children's intentions. This was most evident when the children told staff to stop what it was they were doing while knowing that it had to be done. In turn the children judged the performance of staff. Failing to know them as individuals, causing harm, hurting them when it was unnecessary and 'pinning them down' were considered unacceptable by the children. Sometimes this spilled over and the children experienced strained relations with the staff and their supportive adults.

There was evidence that the staff struggled to deliver the care that they determined the children to need. Constructing children as being difficult was in part a defence against unrealistic demands created by organisational imperatives. Through reflection and reconsideration, both Steph and Mandy were alarmed and shocked

by what had happened to the children with whom they had worked. Emotional labour was implicated in this. It seemed that both the staff and the children on Study ward were the victims of too many demands, too little time and too many children. In addition, the assessment process was out-of-date, time consuming and failed to elicit the children's views and sometimes failed to elicit their previous experience. Despite this, the staff seemed caught up in ineffective administrative procedures, most often delegated to the most junior members of the team. For me this represented a missed opportunity to work towards a more inclusive and participatory model of practice. While some of these findings are consistent with those from studies of children in hospital in Ireland (Lambert and Glacken et al., 2008 and Coyne and Hayes et al., 2006) and to some extent the findings reported by Waters (2008) from her ethnography in a children's renal unit, none offered a detailed description of the cultural context of their field in which their work was undertaken and all had excluded children considered to be too ill to participate.

My work with the children during the acute phase of their illness helped me to see beyond the more usual constructions of ineffective communication and consider the opportunities that may be realised from a conceptual shift from family-centred care to one of creating the right conditions in hospital wards to support children's resiliency. All of the children (apart from Ged and Kamran) alluded to, and some demonstrated, the importance of using the adults on the ward to help them to get what they needed. The children seemed to be using their agency constantly in one of two ways; to act on in their own best interests or to draw on their social capital to achieve their ends. Having supportive adults on hand appeared to create the right structural conditions for the children to be heard, and it appeared to make a significant difference. Still, this was not always the case. The significant contribution made by adults (both workers and visitors) to the experiences of the children became more apparent in my analysis of the children who found themselves alone on the hospital ward.

CHAPTER 7

FINDINGS (3)

THE CHALLENGE
CHILDREN'S VOICE AND COMPETENCE

Many of the children who had participated in this study had endured complex and difficult lives. While it would be little more than speculative to conclude that the children's physical and intellectual difficulties contributed in any way to their being accommodated or members of reconstituted families, it was a distinct possibility (see chapter 3). It would also be speculative to conclude that some of the children had been subject to neglect, yet lengthy delays to surgery for some children suggested this was likely. Regardless, most of the children had endured difficult lives, repeated hospital admissions and invasive corrective surgery. Yet, this chapter illustrates how it was those children who were most vulnerable that were most likely to have their needs diminished and contained, and that it was these children who were most often confined to their beds. As they were less able to call on their social capital and practical agency this meant that they became further diminished and subject to routinised care and were often confined to their beds.

Children who were not represented by adults on the ward spoke of being bored, being ignored, being confined to bed, being sad and being angry. Paradoxically, it was those children who were most vulnerable who were the least likely to use verbal communication, least able to articulate their needs but the most likely to be subject to unintended harm. This led me to conclude that there were significant professional development needs for staff regarding the additional and heightened needs of vulnerable children admitted to hospital. Some children developed effective resisting and rebellious strategies such as *'calling out'* *'shouting'*, *'crying'* and *'pestering'* to alert staff to their needs. Usually, these were effective in making themselves visible and signalling their care needs. However, they were not always successful and they required a certain amount of strength to pursue. Children who

were sick or those who were in the initial post-operative days had depleted strength. For others, asserting themselves was simply not an option. In such circumstances they would rely on helpful adults (their visitors and the visitors with other children) to signal their need for care. However, as discussed throughout the findings chapters, there were many occasions when children were on their own and when there were simply too few staff to meet the children's needs. Sometimes, the individual needs of some children became obfuscated by the busyness that was reproduced by the staff on Study ward on a daily basis. On other occasions the individual needs of children were ignored. My work with the children and subsequent analysis revealed evidence that it was often those children most in need of attention who were at most risk from unintended consequences as they struggled to meet their own demands.

Finding Solace in bed

During a fieldwork visit to the ward I had spent time observing Jodie, a four year old girl who had been admitted to the bed opposite the nurses' station on the main ward during the previous evening. She was in a full-sized bed and looked very small. She was unaccompanied.

> Jodie has been alone since I arrived, about 90 minutes now. She has nothing on her bed with her; she is lying on her side. She is very quiet but watchful. I go over and start to read her a story. She is very responsive and asks for more stories. Elspeth, the play-worker notices my intervention and provides Jodie with some colouring pencils and some pictures. Then a staff nurse who has been assigned to look after her goes across and asks if she would like to go to the toilet. Jodie nods in agreement. The staff nurse dresses her in a pink fluffy dressing gown and pink fluffy slippers. Jodie still has her pyjamas on; this is unusual. The staff nurse opens her arms to Jodie and Jodie climbs inside. The staff nurse carries her to the toilet then carries her back to her bed. She puts her back to bed and takes her slippers off. The young girl assumes her watchful position... She has been admitted with a suspected repeat urinary tract infection for observation. There is no reason why she can not walk or get out of bed. I asked why no-one was with her. The ward staff are not sure but tell me that she is fostered. It is now dinnertime. The health care assistant approaches Jodie with sandwiches and crisps that are in a plastic box covered with cling-film. The plastic box is left on the bedside table. Jodie just looks at the food and makes no attempt to open it. I point this out to Elspeth the play-worker; she goes across to Jodie's bed and rips the cling film, she cuts the sandwiches up. Jodie nibbles a corner of a sandwich and begins to eat the crisps... Nobody else goes to play with, feed, or talk to Jodie.

I wondered what Jodie was making of her experience. Later that afternoon, her foster mother arrived with her sister. Jodie's countenance was immediately transformed. From sitting quietly, she jumped off the bed, ran around to the other side and put on her slippers. It appeared that her competence was once again acknowledged and her confidence had returned. So too had her ability to walk. She was no longer marooned. I explored my observations with Lucy, and Elspeth. Lucy the health care assistant had previously raised some concerns she had about the children's mealtimes.

L   *"When the children have a dinner time; if they have it on the bed they don't eat, if you are with them or they are sat on a table with other kids then they will..."*

Despite this, Lucy had simply placed the box containing sandwiches and crisps on Lucy's bed table. She told me that it was the nurses' job to check what it was that the children had eaten. Being intrigued by this I asked Lucy about Jodie.

J   *"I was watching Jodie yesterday. She spent most of the day by herself. The play-worker spent a lot time with her but apart from that she was by herself. I noticed that when she got her dinner, you know, when I asked what would happen, I think Elspeth went over and she cut it up for her and things. She ate a sliver, a little tiny corner of her sandwich. She ate most of the crisps. That was it really. I thought nobody checked ..."*

L   *"Checked what?"*

J   *"Well, I noticed that when her foster mother came she actually fed her... That's why I was asking you yesterday what happens around the feeding of children..."*

L   *"I think this is what it is all about. I think at mealtimes you are getting involved with the kids, we could get involved with them more..."*

No-one had spent time with Jodie during her dinner time and she had eaten very little. Interestingly, later that same day, Jodie was fed by her foster mother. Her foster mother explained that Jodie had difficulty with food and always needed help to begin eating. Her foster mother also disclosed that both Jodie and her sister had been through some difficult times with their own mother and that they were unsure whether or not they were allowed to eat. It appeared that Jodie's previous experiences meant that she was unlikely to act in her own best interest, and in the absence of her foster mother, she was unable to draw on her social capital or able to use her practical agency to get what it was that she needed.

My conversations with Lucy served to underline the importance of a thorough nursing assessment in order to create the right conditions for the children to thrive in hospital, but it also underlined the need for hospital staff to be aware that children who were on their own may have particular difficulty in attracting attention or having their care signals acknowledged and understood. The following day Jodie received lots of attention from the ward staff, especially from one of the health care assistants and the play workers. Over the course of the day the pictures that she drew and coloured were placed behind her bed and on the bed rails. She seemed to be continually occupied. Her bed space was transformed from a clinical space to a space that reflected not only that the bed was occupied but that it was occupied by a child who was actively engaged in the work of children, play. It is possible that Jodie's experience was transformed through the process of my work with the staff to examine what was going on. I discussed my observations of Jodie with Elspeth.

She explained what she thought had been going on.

E   "To be honest, and it's not an excuse, but I just think people get so wrapped up in doing the big things that the little things get missed. You know even down to basic care on the wards, things like getting the child bathed or washed and teeth done, that doesn't seem to happen on here and I find it sad. Sometimes I'll do it, 'come on we'll go and have a bath' especially with the children that I know who are, like, our long-termers. And you know that when they're in hospital it's the only bath they're going to get for the next year or whatever, you know. The girls are a bit different because with the girls you can make it into a pampering session. They like that, and we'll go and do that. But I think, like, going to brush your teeth, that routine of get up, get dressed or change your pyjamas, have your breakfast, that doesn't happen, and I think it's a real shame...Jodie has not had a wash this morning. I'm sure she's not had a wash this morning..."

Inherent in this insight is the acknowledgement of the priority given to 'doing big things'. This suggests that there was a tacit if not explicit hierarchy of work activity that the staff prioritised in preference to meeting the individual and social needs of some children. Elspeth acknowledged that she thought that different children, particularly those who were quiet, needed special attention, but that they would be the children least likely to receive what it was that they needed. It was not that the children's needs and demands were totally unrecognised; it seemed to me that the staff had developed particular strategies to contain and confine the children's needs.

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These insights further supported my contention that Study ward was a place for children in which the staff struggled to find a space for children's competence and agency.

This was especially noticeable when the children were quiet or silent and lacked the support from a supportive adult who could intervene on their behalf. Containing the children's needs by confining them to their beds meant that Study ward staff were able to contain the additional burdens inherent in work with unaccompanied children (Roberts 2010). While Callery's (1995) work was fundamental in identifying the additional burden to staff posed by resident parents, understanding the needs of children who are alone in the context of hospital wards has remained elusive (Roberts 2010, Zengale-Levy 2006, Livesley 2005, Cleary 1992, National Association for the Welfare of Children in Hospital 1987). Yet children have reported being alone as a cause of concern and distress during their hospital experience (Zebrack, Chesler and Kaplan 2010, Wilson and Megel et al 2010).

My analysis adds additional insight into the experience of children who are alone in hospital. They present with an additional set of needs, but these were often contained rather than met. Not only could the children's needs be contained if they stayed on their beds, but their actions could be controlled to such an extent that the burdens on the staff could be reduced. In this way, the needs of quiet, silent and unaccompanied children could be defined within and managed as part of the routine work of the ward. To underline the extent to which she understood this, offered a comparison between Jodie and another girl of the same age who had been on the ward the previous day.

E   "It's so little to be on your own at four. If you compare Jodie to Georgie,
      Georgie's got a more mobile mind, she's articulate and she's bounding around
      on the bed, she's able to advocate on behalf of herself. You've got Jodie, who
      isn't like that ...but it's 'what can we do to raise the needs of those children?"

The comparison between Georgie and Jodie was particularly poignant. Georgie had been admitted to the ward the previous day in order for the staff to try to pass a urinary catheter. Georgie had come to the ward with her grandmother and they had

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both agreed that I could observe her interactions with Elspeth. Despite several patient attempts to persuade Georgie to have the catheter passed she resolutely refused; but her refusal was accepted. Elspeth explained what was happening with Georgie:

E   "The reason for that is we've worked with Georgie now for a number of weeks at home and in hospital... We don't want x appointments pinning her down and trying to put a catheter in because ...if she does go down for a surgical intervention we don't want to absolutely petrify her with being in hospital, or me, or the nurses that she's going to be involved with in the future. Push her to the point where we think 'OK, we are going to do this' but, because of her age as well, we find that between the ages of three and six... From seven they're starting to understand more, and because she really didn't understand... She doesn't feel poorly..."

Georgie had attended the hospital as a day case on a number of occasions, and a range of different strategies had been used to persuade her to comply with the need to insert a urinary catheter. The staff had used dolls, drawings, playing and even Georgie's sister, who had been diagnosed with the same condition, to demonstrate what it was that they wanted Georgie to do. In contrast to what Sarah had endured during the removal of her Jackson Pratt drain, Elspeth was able to justify taking a tolerant approach to persuading Georgie to have a urinary catheter inserted and was certain of the potential harm that strategies such as pinning her down might engender. She also justified the approach by appealing to the notion of Georgie's understanding being directly related to her chronological age. In addition to this, a deeper justification and judgement on Georgie was being made when Elspeth described her having "a *more mobile mind*", being *"articulate"* and *"able to advocate on behalf of herself"*. She was judged to have exhibited self-determining capabilities.

When compared to the experiences of Ged, Kamran and Jodie, Elspeth insights and explanations suggested that those children, who had a supportive adult present, were articulate, and those able to act in their own interests were more likely to their views taken into account. heard and acted on. Letting Georgie lead on whether or not she acquiesced to having a urinary catheter passed was accepted as best practice with children in hospital. This provided further evidence of my contention that children's competence was constructed by staff and that the judgement of this

often rested on social skills. This then meant the children who were seen as competent commanded greater respect from some staff and were more able to participate in decisions affecting their care. In turn they were more able to call on their social capital.

In contrast, Jodie was a new patient. Her foster mother was unclear about the nature of her medical condition and she was unable to stay in hospital with Jodie as she had other caring responsibilities at home. In addition to their different personal attributes, it seemed that considerable differences between Jodie and Georgie were how well they were each known to staff, the level of engagement of their families, the staff's judgement of their competence and the difference in their patient status. This analysis presents a different explanation to that offered by researchers concerned with the notion of unpopular patients (Stockwell 1972), as these children were not unpopular. Nor did my analysis resonate with that of Johnson (1997) who reported evidence of nurses making social judgments about adult hospital patients. It was the children's competence that was in question.

It seemed to me hat it was necessary to understand that children would behave differently in unfamiliar contexts with different adults present (Mayall 2008). In addition, it seemed reasonable to me that the children needed adults not only to be sensitive to their signals for care, but to know that their experience of child-adult relations would impact on their ability to signal a need for care (Howe 2005). For me, key among this, was the need to recognise and acknowledge that being quiet was not necessarily a sign of contentment and ignoring the children's calls for attention was a risky strategy, but it was not only the children's calls for attention that were ignored. Sometimes the strategies they developed to help them cope were also ignored.

Alone

In this study, the children who were on their own and those who had experienced difficult family lives seemed to be particularly at risk of being constructed as being dependent and easy to control. Kamran's foster parents had described him as

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being *'quieter than usual'* during his stay in hospital as though he was disarmed by the strange environment and the restrictions placed on his movement. I also came to understand how his interpretations were similar to those of many of the other children. He explained:

K   *"I had to stay on my bed..."*

His foster father concurred:

G   *"He was told not to move because of the catheter so he couldn't go and get any toys. I didn't even know there was a play room..."*

His foster father explained that he had been given little time to settle in on arrival at the ward (an observation made by Curtis, James and Birch 2007 in a study of children's perceptions of hospitals). For Kamran this had compounded the strangeness of the environment and added to his boredom as he did not know where any toys were kept. The consultants, nurses and social workers had all *'come at random'* when he arrived on the ward, and he was never shown around. Watching the television was the only activity that was offered to him during his stay. Rather than finding comfort by being in bed, Kamran was marooned, especially in the evening and overnight. Confining children to their bed rested on claims to this being a necessary part of their treatment plan, but the children did what they could to escape.

The Escapees

Not all of the children accepted the constraints imposed by being told to stay on their bed. Some found cunning ways to escape their bed and the ward while others simply climbed over the bed rails to get what they wanted. Fion had been told to stay on her bed. She described to me how she had found this to be very boring but had managed to escape from the confines of her bed on a number of occasions. Fion explained how she had managed to be *'taken out'*.

J   *"What else did you do then, when you had to stay on your bed?"*
F   *"My dad would go and get me some videos from home and from the video case which was in the corner, and I was watching videos and TV."*
J   *"It was OK. Is there anything else you would have liked to have done?"*
F   *"Erm, gone outside for a walk."*
J   *"Tell me about that, tell me why you would have liked to have gone outside."*
F   *"Erm, because it was boring inside."*

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J   "Was it boring?"
F   "After a while."
J   "What could the nurses on Study ward do to make it less boring, for somebody like you?"
F   "Erm, I don't know. Just take you out."

Fortunately for Fion, her parents took it in turns to stay with her. If neither of them could stay, one of her grandparents would. My use of the term fortunate here, reveals my developing theoretical position that children who were accompanied were usually more fortunate than those who were not. She told me that they had intervened and taken her out of the hospital in a wheelchair to look at the collection of birds in the car park. She had relished these outings.

Joe had also explained how keen he had been to leave the ward with his mother when she went to the canteen to get something to eat. Even though he felt dizzy and sick and had needed to stop and rest on the way back, he had been determined to get off his bed. Many of the children took what opportunities they could to get off their beds or leave the ward.

Lauren had realised that she could use her work with me to escape from the ward. We had been looking for somewhere to go and play together and she had told me about a secret room

L   "I know where there's a secret room."
JL   "A secret room, shall we go there?"
L   "Yes, I'll show you."

I had helped Lauren into her wheelchair, done what I could to prevent her catheter and catheter bag from becoming snagged in the chair's wheels, and asked her to show me the way. She explained that we needed to leave the ward. Being intrigued, and in keeping with the tacit rules of the staff being in charge, I sought and was granted permission to take her off the ward to find her secret room. Lauren led me on a full tour of the hospital telling me to go left and right and asking me to turn around when she said that we had gone the wrong way. She especially wanted to go into the canteen to have a look around, and I willingly acceded to her request. By the time we had completed a circuitous route and arrived back at the ward door Lauren declared with a laugh that there was no secret room and told me that we

would have to go into the playroom. Nonetheless, she seemed quite pleased with her impromptu hospital tour. Although Lauren had no known adult with her, she had recognised and used my power as an adult to execute her escape. This contrasted sharply with the children's experience of being denied access to the playroom.

For other children, simply executing an escape from their bed was cause for celebration. I had noted in my field journal that Sam had yelped with delight when the student nurse agreed that he could sit out of bed while she changed his sheets that were covered with toast crumbs.

> *He persuades her to let him sit on the chair. He rejoices when she agrees and sings 'aye aye yippee, yippee, aye' very loudly by way of celebration.*

Some children were less fortunate, and, on occasions, I observed children who were marooned on their beds and left to their own devices to get what they needed. This meant that the children were not only marooned but that their bed became an island of distress.

Islands of Distress

At times the bed seemed to symbolise the children's experience of being captive; Caron had told me that she had had to wait for over an over for a nurse to get her out of bed during which time she endured considerable pain. She had pointed at the bed rails and explained that she was unable to climb over them. Nor was she able to manipulate herself into the space between the end of the bed rails and the bottom of the bed escape; though she had given considerable thought to trying.

Signalling Distress

Confining children to their bed rested on claims to this being a necessary part of their treatment plan, but the children contested this by doing what they could to escape. When the failed or when they could not escape the children were left feeling bored, ignored and distressed. In contrast to the quiet children like Jodie, other children communicated their distress in ways that were hard for the staff (and me) to

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ignore. I had noted in my field work journal how one young child of 18 months was playing happily with his foster mother in a cot. She had been with him throughout the night, it was getting towards mid-afternoon and she wanted to go for a shower and to have something to eat. She signalled to the staff nurse who agreed that she could leave the ward. The staff nurse promised to stay with the boy if he became upset.

As his foster mother left the ward the boy became extremely distressed. He was in his cot with the cot sides raised and started to call out and when his foster mother failed to return his cry turned into a scream. It was loud and piercing and the other visitors on the ward turned to watch. The staff nurse went to him but was unable to console him. She tried to distract him, played with toys, wrapped him in a blanket and walked with him but he resisted all her attempts to comfort him. He was consoled only by the return of his foster mother. She expressed surprise at his behaviour but also said that she was unsure about the home life that he had already experienced. She determined that she would have to stay by his side no matter what happened. Of particular note during this observation was how one child could behave in a way that would ensure that the staff took note of their distress. This episode also brought into sharp focus the experience of other children who also showed signs of distress when they were left on their own and on their beds, but were less able to communicate their distress so effectively.

Unable to Signal Distress

It was late, 8pm. Sam was lying on his back crying quietly. He had been to theatre that day for his operation and had been back on the ward for about 3 hours. He has a continuous peripheral morphine infusion, a separate intravenous infusion, 2 stents, a suprapubic and urinary catheter. A pulse oximeter is attached to him via a probe fastened to his thumb. His mother and father left about 5 minutes ago. He is lying on his back and crying quietly. I go over to him and ask if I can help.
S   *Will you hold my hand?*
J   *"OK" I say, and hold his left hand. He winces a little and says*
S   *My mum always hold this one [gesturing to his right hand].*
J   *OK, shall I come around there?*
S   *Nods and keeps looking anxiously over his right shoulder.*
J   *Is something wrong, Sam?*
S   *I'm scared at night. It's the window.*

> J   *You're scared – what are you scared of?*
> S   *He looks over his right shoulder again.*
> S   *The monster.*
> J   *Where's the monster?*
> *He gestures over his right shoulder towards the window. The window opens out onto a narrow alley way. There is a yellow brick wall on the other side of the alleyway with a window. It is very dark and all that can be seen is the reflection from the inside of the ward. I realise that Sam is worried about something peering through the window:*
> J   *Shall I close the blind?*
> S   *Yes.*
> *I try to close the blind but it is broken and won't pull down. I ask the student who is close by if she will help me to drape the bed curtain across the window. We use his bedside locker to keep the curtain in place. I also re-arrange Sam's pillows, placing one high up on the bed so that it blocks his view of the window. He seems less anxious and appears to settle. I go back to the nurses' station but he calls out again. The student nurse asks me if she should sit with him, and I agree she should. As soon as she is sitting down the staff nurse call down the ward asking her to admit 'the new child'. She leaves Sam on his own. He starts to whimper and then starts to moan a little more loudly. I go back to him*
> J   *Can I help Sam?*
> S   *Will you rub my tummy?*
> J   *Of course.*
> *I had watched his mother rub his tummy before she left for home. It is becoming clear to me that Sam is not going to settle. He is still scared and anxious and wants someone to stay with him. It is getting late I know that I have to leave for home*
> J   *Sam, I have to go.*
> S   *Will you tell that lady?*
> *He points at another visitor. He wants her to come and sit with him. I know this is not possible but he persists.*
> S   *Is she coming?*

Marooned on his bed, Sam was incapable of moving very far and was completely reliant on the ward staff to meet his physical and emotional needs. It was not that the ward staff were ignoring Sam and doing nothing; they were busy. They were always very busy. Their busyness seemed to shroud the fact that for children hospital can be a scary place (Coyne and Conlon 2007). The night staff had just arrived and the ward handover had started. Several children had been to theatre. During this episode of field work I became aware that I shared something of the ward staff's dilemma when working with children who were unaccompanied but in need of adult attention. I had written:

> *I know that Sam needs to have someone with him but there is no-one who can be. I have left him knowing that he is distressed and I am complicit in his suffering.*

I had told the ward staff what he had said about being scared and the next day he was moved to a bed that was still by a window, but one with a blind that worked. This indicated that the staff acted upon information gleaned from the children in an attempt to improve the children's experiences. What was missing was effective insight into how children signalled a need for care, especially when they were alone. According to the findings reported from a participatory research study with 4 – 6 year old Finnish children regarding their hospital related fears, (Salmela, Salanterä and Aronen 2010) security, confidence, understanding the meaning of the situation, participating, asking for help and protecting one-self, emerged as important coping strategies. Given his situation, Sam was unable to use any. A few days later when we discussed his being scared, he laughed and told me that he thought someone was knocking at the window. What he had feared now made him laugh. This provides further evidence of the need to work with children during episodes of distress to understand their perception of what is going on and develop understanding of the changing nature of their experiences over-time, throughout their in-patient experience. On a second occasion, Sam's repeated calls for a nurse again went unanswered. He told me how the nurses' often *ignored* him. I was building a Lego car with Sam. He kept looking down the ward towards a baby in a cot.

JL   *"What are you looking at?"*
S   *"That baby."*
JL   *"Do you like babies?*
"S   *"I don't like it when they cry. Can you ring my mum?"*
He called out 'nurse' on at least 6 occasions.
JL   *"Do you shout to them a lot?"*
S   *"When I want them."*
JL   *"Do they always come?"*
S   *"Sometimes they ignore me."*
J   *"Why do they do that?"*
S   *"I don't know."*
JL   *"How does it make you feel?"*
S   *"Cross."*
JL   *"Cross, what do you do when you get cross?"*

He did not answer. I took his silence as a form of dissent and a signal of his displeasure. Sam was losing patience with me. He shouted out for a nurse over and over. I pointed out that his nurse was changing a baby's nappy. He repeated his shout for a nurse over and over again. He started to ask if I would ring his mum, over and over again.

Continuing to work with Sam, I found out why he wanted the ward staff to telephone his mother. He was due to go back to theatre the next day. He understood that he could not have anything to eat in the morning and wanted to fill his tummy that night. His mother had left some tuna sandwiches in his locker drawer. Sam always had square sandwiches. The ones that have been left are oblong. Sam did not think that these were for him; he seemed convinced that they were his mothers and he did not want to eat her sandwiches. He wanted to ask his mother if he could eat them.

His attempts to get a nurse to ring his mother went on for some time. Suzanne promised that she would do this, and he agreed to wait. Caron who had been admitted into the next space had already told me that Sam called for a nurse every 2 minutes and that they did not always go to him. I had been chatting to Caron for 2 minutes. When I turned back to look at Sam he had leant over his bed rail, and his intravenous line was stretched. He had opened the locker drawer, found the sandwiches and was eating them. I went to him and asked him to sit down on his bed. I did not know how long the sandwiches had been there. I gestured to the student who came across. I explained my concern and she offered Sam some toast for supper. He was delighted and offered his sandwiches up.

Suzanne was worried that his mother would be unnecessarily concerned, but Sam insisted, and at last Suzanne telephoned his mother. He learned that the sandwiches were his but he no longer needed them. He had toast. On reflection, I thought that it was good luck that he had not fallen out of bed, that his intravenous cannula had not been dislodged, and that he had not been injured. I asked if he was enjoying his toast. It emerged that he was no longer hungry, but he was then cold.

S   "I need toast to warm me up, I'm cold… Tell me the rest of the story."
Sam settled down.

Once again, as with Ged, the staff seemed concerned not to worry parents. Their concern for parents appeared to take precedence over the children's requests to contact their absent parents. Yet their parents often made it clear that wanted to be contacted in the event that their children were upset or unsettled.

Climbing Over Bed Rails

Left on his own, Sam was not content to have his needs ignored. His determined efforts to act in his best interests by having a nurse call his mother had failed. It seemed that while some of the children complied with the instruction to stay on their

bed, others interpreted this as a more fluid instruction. They did not get off their beds but were not willing to wait for what it was they needed. This meant that a number of children were at considerable risk from harm, and that the bed rails constituted an additional risk. The National Patient Safety Agency (2005) reported that there had been 10 fatal accidents and many serious injuries caused by the inadequate use and maintenance of bed rails in the previous 5 years. Yet I never witnessed anyone undertaking a risk assessment of the children's needs for bed rails. In addition, the bed rails in use were often poorly fitted and some children simply pushed them to the side when they wanted something from their locker. Benjie's mother, who worked for social services, expressed her concern at this. This concern was passed to ward staff. Knowing that they would be moving to a purpose built unit in the near future meant that they had given up asking for additional equipment. When they had they had simply been told that it would be different when they moved. While I never witnessed any children being harmed by the bed rails I witnessed many near misses.

Other children used different strategies to signal their distress. One was becoming vigilant when ward staff approached their bed. Regardless, their signals were sometimes ignored. This was most clearly evident when the children's knowledge of themselves and the strategies that they had developed to help themselves cope were disregarded by ward staff who assumed a privileged position in terms of adults' knowing best:

> *I had been sitting on the left hand side of Kelvin's bed chatting to him. I noticed that he suddenly became very alert when an agency nurse approached his bed from the right hand side. His urine drainage box was hanging from the right hand side of his bed. Kelvin winced, and I wondered what was wrong.*
> *K "It's my catheter," he said, pointing to the other side of the bed.*
> *The agency nurse approached.*
> *AN "Don't try to tell me that it hurts if I touch this, because I've had the same thing and I know it doesn't hurt."*
> *K "No, no, no!"*
> *Kelvin was visibly distressed and continued to insist that it hurt.*

The agency nurse emptied his drainage bag, cleaned the clamp and recorded the result on the fluid balance chart. Kelvin seemed satisfied that she was finished. I decided to explore with Kelvin what he thought about her approach. Kelvin had

developed more sophisticated methods to manage his fears, although his attempts to do so were sometimes thwarted by adults who thought they knew better. Kelvin had experienced more than 50 previous admissions to hospital. His father had explained that he tended to 'anticipate a lot.' This explained his vigilance as the agency nurse approached; a finding reported by Waters (2008) from her ethnographic study of a children's renal unit. I knew that the act of emptying a urine collection box could not hurt but Kelvin's fear that it would was tangible. When I next worked with him I asked him if he could tell me something about what had happened to explore if I could glean a better understanding of what this incident had meant for him and how he had interpreted this experience.

K   *"She said something like, 'It can't hurt. I've already had this done.'"*
JL   *"Mm. What did you think about that?"*
K   *"Well, I just thought, well, she's an adult. It might have been like, not as sore and she might have been able to take it better, if you know what I mean."*

A complete transcript of my conversation with Kelvin can be found in Appendix 7, as this illustrates the patience, skill and time that are needed to elicit children's insights and explanations. Kelvin's detailed explanation illustrated that he had thought about the problem, used trial and error to work it out, and had understood that the solution to his anxiety about people emptying his bag was in his own hands. He was demonstrating his resiliency in the face of adversity.

Being in hospital was an active rather than passive social event. This assumption may seem at odds with two generally established positions; that patients (at least adults) become socialised into a sick role in hospital and acquiesce to being passive in-patients (Parsons 1951, Goffman 1961), and that children are subordinate to the adults with whom they share places and spaces (Johns 2003). However, I contend that some of the children in this study demonstrated a strong sense of self and were engaged in the work of maintaining their status as active social agents throughout their stay in hospital; a notion that is fully consistent with the claim that children influence the worlds in which they live (James and James 2004). That said, this was hard work and not always rewarded with the desired outcome. In this way, my analysis of the children working hard was similar to the findings reported by Waters (2008). Unfortunately, were able to engage in the labour required. It became clear

that children not only rely on adults to act on their behalf, but they actively influence how this is done. In other words, other people, most often adults, are used as instruments by the children not only to manage the structural components of their experience but also to assist in their interpretation of this experience to derive subjective meaning.

Kelvin, like the other children on bed-rest was in a good position to act as his own 'look out' from his bed. The bed was no place of safety and certainly offered no guarantee of a pain-free existence. In effect Kelvin, like many of the other children, was his own guardsman; his own sentry; vigilant to incursions into his territory. Many of the children exhibited this vigilance, using particular cues to determine who had interventionist intentions. This was signalled by the carrying of tape and gauze or by wheeling a stainless steel trolley in their direction. In keeping with the findings reported by Waters (2008) I observed that many of the children became extra vigilant when the ward staff approached their bed. In this, their behaviour was not dissimilar from children who endure abuse or those who face adversity. They would stop what they were doing to assess the potential of the ensuing attack. Of note here is acknowledging that such insight can only be gained from entering the social world of children by working with them in the social contexts that frame their experience.

Sometimes the children sought solace in their bed. There were occasions when the nurses knew that the children wanted their attention but they continued to prioritise other work over the children's demands. I became aware of the plight of some of the children when I first arrived on the ward and was spending time organising my field-work at the nurses' station. It was often during my walk around the ward that I became aware of the children who needed or were trying to get the nurses' attention but had been unsuccessful. During an early visit, I was checking the in-patient board and looking at the beds to see which were occupied by children who met the entry criteria for the study.

Having to Wait

There was an older boy (about 15 years) who, given his size, looked strangely out of place lying on his bed positioned directly opposite the nurses' station. He was very still and his eyes were closed. Occasionally, he winced. He was not on his own. His parents were with him, sitting just off to the side of his bed, they both had their heads back and their eyes closed. I went to talk to him and asked if everything was OK. He explained that he was in a lot of pain. I offered to tell his nurse, but he said that she knew. He had been waiting for pain relief for at least 30 minutes. His mother explained that they just wanted to get him home so that they could get him 'sorted'. By describing it in this way they had used "sorted" in the opposite way to what Seb had meant. The staff on Study ward had failed to meet his needs.

The boy had retreated to his bed and was lying very still in order to manage his pain and derive some comfort. I had the impression that his parents were making a determined effort to contain their anger. I knew the staff nurse who was responsible for his care. I went to her and told her that the boy was in pain and asked if he could have some analgesia. Her reply was abrupt.

E   *"He'll have to wait, I'm busy doing everything else. He's going home and he can have something from his TTOs [to take out prescription] when I have got everything else ready..."*

While this staff nurse's decision to complete a series of tasks before administering analgesia made sense to her in terms of time management, and though it provided evidence what she had priorities to sort, it seemed anathema to the espoused ward philosophy. A difference with regard to staff priorities, what needed their attention and the priorities of the children was tangible.

Getting Attention

In particular, the children who were alone and confined to bed seemed to struggle to get the attention of nurses. One boy called out 'nurse' repeatedly. Although I could hear him, the other staff working at the nurses' station appeared not to. When I investigated, and consistent with Cleary's (1992) findings, I found him desperate for the toilet and very worried about wetting himself.

That the organisation of some of the work should come before the needs of the children appeared to be uncritically accepted by some of the ward staff. That children were expected to endure pain and wait for pain relief had become an accepted way of working. It was not only the ward staff who accepted this; some of the children and their families also appeared to accept this as irremediable. In such circumstances, some children used the bed as an environmental carapace to ward-off the threat to their autonomy and the threat to their control. This meant that some of the children used the bed in an attempt to manage perceived threats or unmet need. In other words, 'going to bed' was a strategy that the children and staff could use to gain control, regardless of this relating to physical or emotional needs. When, as was often the case, children were quiet, this quietness was not a passive act; it was a chosen strategy. As Lewis (2010) noted,

"...a preference by children for silence, despite elaborate ethical protocols and careful procedures to facilitate their voicing of view, warrants more notice".

Containing Emotional Needs

I had described Ged as 'all over quiet'. She was quietly spoken and appeared shy. When I first met her she was smiling, and we had spent some time playing, but over the following days she became unwell. She had diarrhoea and had been moved from her bed on the open ward to one of the large transplant cubicles at the far end of the ward. I had hoped to continue my work with her, but she was too ill. I interpreted her turning away from me as I entered the cubicle as an indication of her declining my invitation to work together that day. Her parents tried to persuade her to join in, but I explained that it was fine that she had chosen not to do so.

They went on to tell me that they had left her sitting in 'the big chair' on the previous Saturday morning at 11am when they left to go and visit their other children at home. They explained that they had chosen not to tell her that they were going home. Instead, they told her that they were going to get a cup of tea. When I asked why they did this they explained that if they had told her that they were going home she would have screamed and cried. Not telling her was preferable, for them at

least, because it 'avoided her getting upset'. Their decision had been supported by the staff.

On the journey home they telephoned the ward to enquire after Ged. The ward staff explained that she was 'fine, in fact she has asked to go back to bed'. It seemed that the ward staff had used Ged's request to get back into her bed as an indication that she did not need any attention. Passing this information to her parents seemed to suggest that they would also be content knowing that she was confined to her bed. As with Jodie, it was quite possible that they had misinterpreted her quietness. When her parents returned to the ward at 5pm on the Sunday, Ged had simply said:

G   'You've been gone a long time'.

This provided further evidence that children who were in need of care would sometimes seek solace in their bed. It also pointed to the potential that ward staff would fail to recognise being quiet and being still as behaviours worthy of their attention.

Having to Shout

That children had difficulty attracting the attention of staff was noticeable on many occasions. A number of the children in phase 1 had explained to me that they had experienced some difficulty in getting the attention of staff when they were confined to their bed. Seb had explained that he knew that he had a pull cord to attract the nurses' attention but failed to use the call cord because he was afraid that he would pull the wrong one.

S   "Yeah, because that cord thing, I didn't have one, actually... I didn't know where it was."
JL   "You didn't know where it was. How do you know you had one, then?"
S   "Because everyone else has one."
JL   "Right."
S   "There was this cord next to me, but I had no idea what it does. I was afraid of pulling it."
JL   "In case?"
S   "In case it might be, but erm, it might be security alarm or emergency thing."

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Sarah had also told me that she thought that nurse call buttons were available but that she was unable to use them because she was too sick.

JL "Did you have a bell or something?"
S   "Yes, but I couldn't reach it."
JL "You couldn't reach the bell."
S   "It was at the top of the bed."
JL "Did they give it to you? Did they say, your bell's here, here you are Sarah?"
S   "Yes, but if you can't move, you can't reach it."

In fact, the ward was not fitted with call buttons or nurse call cords. Jo had commented on this, and, comparing her experiences on Study ward with her stay in High Hill Hospital, she suggested that it would be a good idea to have them fitted. I had asked her what she did to get the attention of staff when her mother was not present:

JL "Would you tell somebody?"
JL "So you would wait for the nurse to come to you? What would you do if you wanted a nurse and they weren't with you at the time?"
J   "I don't know."
JL "But if Mum wasn't here now and it was like this and I wasn't here and you wanted a nurse what would you do? How do you tell them you need them if they are not with you?"
J   "I wait."
JL "You just wait. Is that a problem?"
J   "Sometimes."
JL "That is something the children have said. Other young people have told me that it is a problem for them, how to get attention of people if they want something."
J   "In High Hill Hospital you had the nurse button, and if you needed the nurse you press the button, but they don't have it here."
JL "What did you think about the nurse button?"
J   "I think it helped when you needed them."
JL "Is that something you think they should have here?"
J   "Yeah."
JL "If you want somebody and you can't get them, how does it make you feel?"
J   "I don't know."
JL "You are quite near to the nurses' station, do you know that is called the nurses' station? Is that a good thing to be near to that?"
J   "Yeah."
JL "Why?"
J   "'Cause they can see you better."

Many of the children had come to understand the need for an adult to be present to ensure that they could get what they needed. In the absence of this and the absence of call buttons their preferred strategy was to shout.

JL   *"So when you were there last time, if you wanted a nurse or something how did you get hold of one?"*

S   *"Shout someone."*

Seb and Caron agreed:

S   *"So you can say, 'Mum can you get a nurse for me and the nurse is there'. But you have to shout the nurse…If you mum's not there you'd have to shout her."*

       "Just like when Mum's here, she has to do everything…she has to go and get the nurses in to look after me. And when you're here, just little things like if my water falls on the floor, and I can't pick it up. They'll come if you shout for them. But they don't always hear."

JL   *"But how easy is it for you to shout for them?"*

C   *"I'd have to wait until they're nearby. In the night I just don't care. I just shout at them."*

JL   *"Really. What would you shout?"*

C   *"Their name… Mum would say before she went, 'Make sure if you need anything, you shout. Yeah'. She tells the nurse that I'm probably going to shout."*

Even when I watched as Ged was physically passive while having her catheter re-taped, she cried, shouted and screamed, albeit very quietly.

Ged's Mitrofanoff catheter had just slipped after being caught on the bed rail. Her father went to tell the ward staff immediately. Two nurses came to her bed. One of the staff nurses removed one piece of plaster off her abdomen. The other one said "We'll get that fixed."

Ged was playing with the finger puppet. The first staff nurse leaned over and removed her nappy.

SN   *"How much has drained?"*

Ged stopped playing with the puppet. She seemed confused. She was laughing and crying and shouting and screaming - all at once.

G   *"I want some tape on."*

SN   *" I've got some tape."*

The staff nurse leaned over Ged who was still screaming.

SN   *" I'm sorry."*

G   *"Some more, some more!"*

The staff nurse fixed more tape to the catheter.

SN   *"You're a good girl, aren't you?"*

G   *"Thank you."*

Her thank you was very poignant. The health care assistant approached and asked Ged what she would like for lunch. She asked for a ham sandwich with crisps, and started to eat this as soon as it arrived. Ged's ordeal was over and she quickly returned to her usual pattern of quiet playing.

A further insight gleaned from this episode of field work was the extent to which the ward staff assumed the right to command the bed and bed space as a place of work. Regardless of what the children were doing, how long visitors had been with them, or if the children dissented from working with the ward staff, the hospital staff assumed, at all times, that the bed and bed space were legitimate places for work. In this regard, the children became the objects to be worked on, or objects that were the subject of the work.

A Place of Work

I realised that I had internalised this tacit rule when the medical consultant arrived one Saturday morning to speak to Sam's parents. I had just taken the camera out of my bag and had shown Sam how to use it. As the medical consultant approached, and without any hesitation and certainly without a direct request, I moved from my position next to Sam at the side of the bed to stand at the bottom of the bed, some distance away. I simply moved 'out of the way'. That this had been the right thing to do was reinforced by the way in which the medical consultant and his team failed to acknowledge this gesture. They simply ignored me. For them my behaviour conformed to the tacit rules that governed the dominance over the bed space. I conformed without question, yet this rule was never explicitly communicated. This was important as it seemed to mirror the fluidity of the children's existence. Any acknowledgement of their competence was subject to this being of some benefit to the adults on the ward. At times, especially when their demands were considered to be unjustified or of little importance, they were forced into the background. I had unwittingly conformed in the same way. A key difference was that my compliance was easily won. I knew that Sam was becoming trigger happy with my camera and that there was limited memory space. He was using this up by taking pictures of everyone and everything in quick succession. While I had tacitly accepted my position as a subordinate whose existence could be ignored, Sam was active. I was passive and waited helplessly until the medical consultant had completed his conversation with Sam's parents. While I had internalised the rules of engagement on this hospital ward, Sam had not. I was not a usual or needed part of the team, and I felt surplus to requirements. In some ways, Sam was the disinterested object

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of the intense discussions taking place but he wasted no time in exploiting his newly acquired invisibility to try out the camera. This episode served to uncover the several layers of social complexity in operation in the day-to-day, ordinary work on a children's hospital ward. In part, it highlighted the rules of engagement; the rules of space and place ownership; the rules guiding the use of professional anger; and the rules relating to when it was legitimate to seek ever more invasive interventions to control and contain the children's activity.

The consultant comes to see Sam. He looks at Sam's abdomen. The F grade staff nurse joins him at the side of Sam's bed. She explains that one of Sam's catheters has fallen out. Everyone is focusing on Sam's abdomen. No-one is talking to Sam. 'I'm really not happy' the consultant says 'Why have they fallen out?'
Click
The staff nurse explains that Sam is a great wriggler and that he is very active. His mother agrees and says he never stays still at home, in fact during the night they often go into his bedroom to straighten him out in bed again. The consultant explains to his mother that while it is expected that the stents may fall out it is not the case for the suprapubic catheter, he explained that if his urethral catheter was to fall out then he would have take him back for open surgery.
Click.
He asks where she lives. Given that this [in his opinion] is not too far from the hospital, he concludes that Sam should stay on the ward. This is based on his conclusion that the ward staff would have a better chance of managing his catheter and preventing accidental removal, than his parents.
Click.
He reiterates that, 'They must not come out'. The consultant moves away from the bed, the staff nurse asks if he will prescribe a sedative to help the staff manage Sam. 'Perhaps' he replies.
I wonder if the staff nurse is as certain as the consultant about the possibility of keeping Sam's catheter in place. The interaction between Sam's parents, the F grade staff nurse and the medical consultant had unsettled Sam's mother, but my attention had turned to the camera. During the conversation with the consultant Sam was clicking the camera. I was feeling uncomfortable; out of control. I did not feel able to intervene given the serious nature of the discussion but I wanted to rescue my camera.He throws the bed covers back, opens his legs wide and takes a picture of his penis, urinary catheter in place.
Click.
He seems very proud. This was not in my plan.
J   'What do you want me to do with that Sam?' I ask.
S   'Show them, but not my face. It's beeping [my camera].'The picture card is full. Fortunately, Sam's face is not on the picture, nor when I check, his penis. I have a photograph of my blouse, the F grade, the consultant and the registrar. I also have lots of pictures of bed sheets. Sam's aim with the lens was not good but I have no camera to continue with that day. Sam wants to talk to me. I get out my recording device.

That the bed was a place of work was again highlighted when the registrar returned to the ward a few minutes later.

> I had been playing dominoes with Sam for some time. While he had seemed completely disinterested in the interaction between his parents and the consultant, he has been listening to his mother's concern that his catheter may well fall out. The staff nurse is with him, she is recording his blood pressure using a Dinamapp. Sam wriggles against his pillow. 'Is it finished?' He looks over his shoulder to the Dinamapp display. 'Yes,' he says. He takes the cuff off his arm. The registrar has returned. She has a pack of sterile gauze, an alcohol wipe, a packet of sterile latex gloves and a roll of Elastoplast.
> S "What is she going to do?"
> Dr "I'm going to tape it so it does not come out. OK, Sam?"
> The registrar goes to wash her hands.
> S "What is she going to do?" Sam appears a little agitated.
> SM "It's OK. It will stop you panicking about them coming out."
> S "Stop me panicking. Will it stop me panicking?"
> Sam repeats this over and over. The registrar comes back to the bed. This time I introduce myself. She tells me she is the consultant's registrar. The curtains are drawn around Sam's bed. This signals her intent and that no-one should interrupt. She bends over Sam and begins to remove the first piece of tape that is very poorly stuck to his skin. Sam screams. He screams and screams. She quickly removes the tape, cleans his skin with the wipe and applies the Elastoplast. There is little interaction between her and Sam, but Sam continues to scream. The staff nurse comes into the curtained area around his bed.
> SN "Are you alright, Sam?"
> I suggest that they switch his story tape on. Having secured the stent to his abdomen, the registrar turns her attention to the tape that is no longer fastening his urinary catheter to his leg.
> S "OK", he says.
> As the registrar goes to remove the slack tape he screams again. I try to distract him with a balloon but I am unsuccessful. As soon as the tape is off his leg, he stops screaming and reaches for the balloon. Now he is ready to play. Later, I asked Sam why he screamed.
> S "I don't know" he replied.
> He takes hold of his pyjama top and shows me, using this, how the tape pulls on his skin. It shows me how his skin is pulled up then pings back down when the tape is taken off.
> S "It's sore," he says.
> I help his mother to fix his bed.
> JL "Always check your tubes before you move, I say. Can you lift your bottom up?"
> This instruction is interpreted by Sam in his own unique way. He flips his hands behind his head and does a crab!! He has lifted his bottom, but not in the way I had expected or hoped that he would. I was aware that I was a little frustrated with Sam; but it was my request that lacked clarity. During the analysis I realised that I am culpable of blaming Sam when he does not interpret my inadequately communicated requests as I intend. The fault is mine but I slip easily into my professional status and become the latest ward recruit to place the onus for making sure his tubes do not come out on Sam. I would rather blame him than take the blame myself. I had recruited myself into the team with responsibility for surveillance control.

Within this lengthy interaction there was no discussion or negotiation between the nursing staff and the registrar. In fact, the registrar and consultant had seemed to

communicate with Sam's mother in preference to the nursing staff, even though the message being communicated was about nursing work.

Somewhere in the midst of this interaction was a nine year old boy. His body was the focus of the intense discussions. It seemed that the best Sam that could do was to communicate his distress while enduring the intervention in much the same way as Peter, Ged and Kelvin had done in similar circumstances. This meant that the children communicated their distress through resistance, most often demonstrated by them making a noise but on occasion by being silent. As the following excerpt from my field journal illustrates, the busyness of the ward defeated the many attempts that the children made to be heard.

Saturday afternoon. There are four members of staff, three staff nurses, (one agency nurse) one student and no health care assistant. This is noticeable as there seems to be no-one to see to the 'little things'. The ward is quiet, by this I mean there is little noise. The three trained members of staff are very busy. They have been working with the medical staff, accompanying them on rounds and then following through with the children on treatment prescriptions. A child was admitted in the night following a transplant. There is a constant stream of telephone calls about this child with the nurses conveying messages to the medical staff in the child's cubicle. Steph is responsible for the care of this child. They have asked for help but there is none. The managers have said that they will try to find extra help for tonight. Steph cannot 'special' this child as she is unable to stay in the cubicle. She arranges a table and chair just outside of the cubicle so that she can watch over the children on the ward and still watch over the child in the cubicle. She is cross:
SN   'It's always like this.'
The young boy in the cot nearest to the transplant cubicle at the bottom of the ward has been distraught since his foster mother left the ward for a shower and to get something to eat. His screaming meant that Kerry, the other staff nurse had to spend a great deal of time with him. I have spent some of the afternoon talking to Jo and the rest with Sam. Sam's dressings were a concern. His top sheet was covered in a blood-stained serous fluid, and the tapes securing his stent and his suprapubic catheter were lifting from his skin.
Later that afternoon I have to leave. Sam's dressings have still to be renewed. The staff have had no breaks or drinks since I arrived (4 hours). I make a tray of tea and coffee. They are grateful. They come to the nurses' station for a drink. I mention Sam's dressings again, and Steph promises that they will find the time to redress his catheters. Again I am complicit.

Position on the Ward

In my earlier conversation with Jo I had mistakenly made the assumption that the children in the beds nearest to the nurses' station were the most visible to staff and she had agreed. This was not surprising as I knew that sometimes children who were considered to be the most sick were often admitted into beds in locations that could be observed easily. This was illustrated by Steph's decision to place a table and chair in a position that enabled her to observe the children in the beds on the open ward while at the same time observing the child who had been admitted into the transplant cubicle. This also highlighted that some of the ward staff were more sensitive of the need to be visible to the children in order that they could signal their need for care or attention. This was particularly important in the context of inadequate nurse call systems. Other children had worked out that their position on the ward was important but they knew that being opposite the nurses' station was not necessarily the best place. As already noted, for Jo, being near the nurses' station was important, but for Caron, the beds next to the treatment room provided the best chance of being able to get the attention of the ward staff.

C   *"People go past the treatment room, and I'm here, I quite like it. They come past and I can shout them."*

For the most part, being visible to staff or being next to a busy part of the ward worked, but during one field visit I witnessed a serious event that involved Jo's mother who suffered from diabetes. To compound matters, this event took place during a Saturday afternoon visit when the ward was extremely busy:

There is a sudden commotion – A staff nurse calls the other staff nurse to Jo's bed. My first reaction is that she must have deteriorated. A renal registrar has just arrived on the ward; the staff nurse calls him over and asks for the emergency team to be bleeped. Jo's mother was sitting in a high-backed chair at the side of Jo's bed. The chair, with Jo's mother still in it, is dragged down the ward to the treatment room. One staff nurse turns to the other and tells her to go and get some chocolate. As the canteen is closed for refurbishment, a make-do shop selling chocolate had been set up just down the corridor from the ward entrance. The emergency team arrive and run into the treatment room. The staff nurse runs out and returns with the chocolate. There is a further commotion; the ward resuscitation trolley does not have the medication needed. The staff nurse runs out to another ward to get this. Jo is sitting by her bed looking very anxious. I went over to see if there was anything I could do. J "It's my mum, she's diabetic and she's had one of her turns, I noticed that she was looking at me but not seeing me. That's what she does. My brother looks after her at home."

In such extreme circumstances neither the strategy of shouting or being close to a busy area of the ward had worked in Jo's favour. In addition, the level of Jo's fatigue and her general feeling of being unwell meant that she was physically unable to shout. She did not have the strength. She was also involved in caring for her mother, just as her brother was. This seemed to be something of a family strategy, as Jo's brother, who was a few years older than her, often visited when her mother could not.

Being unable to attract attention by calling or shouting applied to a number of children around the time of their operations. It also applied to those children who seemed to be naturally quiet or reticent such as Kamran, Ged, and Jodie. These children in particular seemed diminished on the ward. That said, there was also evidence that those children with a loud voice, those children who repeatedly shouted, or those children who were thought not to have a legitimate or priority need for care could also be ignored. This was illustrated during some of my work with Sam. While I played with him he started to call for the nurse. This was not uncommon. Even when Sam had asked his mother for something and she was unable to meet his demand he would often shout out to a nurse.

In part, Suzanne's reaction seemed reasonable, Sam's catheter had been checked and it was thought to be secure. Sam did not agree with me, he continued to shout when he wanted something.

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> *Suzanne came over to him. She reassured Sam that the stent was alright and left him. Sam continued to wriggle in his bed. He wanted the stent to be refastened with tape. He repeated his assertion that it was coming out. He shouted for a nurse.*
>
> *S   "Nurse! Nurse! Nurse! Nurse! Nurse!"*
>
> *I continued to play with him and as we played he continued to talk to me but continually interjected with a loud call for a nurse. He clearly considered me to be an incompetent adult. While I am useful for playing and reading books I was no help in getting him what he wanted. Suzanne passed by his bed on her way to the treatment room. She kept her eyes averted from him. Sam spontaneously states:*
>
> *S   "See what I mean, Mum?"*
>
> *SM   "What?"*
>
> *S   "That: they always say 'wait a minute' then they never come."*
>
> *I was sure that Suzanne had heard him. I asked her about it She had. She explained that she did feel 'bad' about ignoring Sam but that most of the time when she had gone to him he did not really need anything and that she was busy with the other children.*

I discussed the lack of call buttons with several staff. One staff nurse revealed that the *Patient Line* facility could be used by children to call nurses but that it had never been commissioned. She also added that she thought it would make little difference as most often, alarms were ignored. An observation I made on many occasions. It seemed that the needs of individual children were prioritised through a tacit hierarchy that was discernible during very busy times. Acute and life-threatening needs always took priority; though this did not guarantee the children's safety, especially if their needs were poorly matched to the skills and competence of the staff. Of note was that the children with acute or life threatening needs also needed to have many quantitative measurements taken for interpretation by medical staff. Other needs were subordinated by these and became subsumed into the everyday, ordinary, busyness of the ward.

Working in partnership with children in Swedish pre-schools, Markström and Hallden (2009) drew out the *'immanent conflicts'* that existed in institutions for children that are both concrete (in the sense that they create both conformist and deviant behaviour) and structural imperatives (in that they reflect the structures that define and construct childhood in a particular way). This is important for my work as it highlighted the tensions inherent in institutions that seek to control children (such as hospitals) driven by dominant discourse such as safety. In addition, the espoused philosophy of child-centredness and the appeal to being child-friendly were often in

direct opposition to competing discourses that were driven by organisational and medical imperatives. This analysis then enabled me to identify and interpret other strategies as those intended to control the children.

Contested Resources

The group of people in control of the most important and to some extent necessary shared resources, such as the ward lighting, televisions, access to the playroom and food, was the ward staff. It was the responsibility of the nurse in charge at any time to determine when the televisions and main ward light would be switched off. Sarah had pointed this out to me when she expressed her frustration that the TVs were always turned off at 9 pm and that she was expected to go to sleep.

S   *"At City ward they had to turn the telly off at 9 pm. At 9 o'clock and I'm 15. I don't turn my TV off at 9 o'clock at home. I was sat in bed for like two to three hours - just sat there bored stiff."*

However, she was resolute in her determination not to sleep. Kelvin and his father had used a different strategy when they wanted to watch an important football match after the 9 o'clock curfew. They surreptitiously gained access to the play room and continued to watch the game in there. Just as Celeste and her mother understood that anything emitting a noise was a legitimate cause for breaking rules by interfering with ward equipment, important football games seemed to hold a special status and provide sufficient justification for breaking the rules.

The Light

It seemed to me that the main ward light was sometimes used as an instrument of control to manage the children's demands. One evening when the staff had been particularly busy, the staff nurse in charge of the ward simply walked towards the main light switch, stated, *'I've had enough,'* and turned the light off. It was 8 o'clock; a full hour before the official curfew. The serendipitous nature of this event amplified what the children had told me. I watched as the visitors to the ward scrambled to switch on small bed-side lights. I did not witness anyone complain. It was as though we shared an understanding that the staff nurse had signalled that she was at the

end of her tether and that we would be ill-advised to challenge her decision. During my conversations with the children, their parents often told me that the staff 'never stopped' and that the ward was a 'very busy ward'. Indeed, throughout this work I had often described the ward as being busy. For visitors to Study ward this seemed to signal that the staff had to do what they could to get their work done. Turning the light off was almost a symbolic gesture that represented turning the children's demands off. I was coming to understand that it was unlikely that the children would complain when adult visitors, including myself, were complicit in accepting this symbolism and dominance over the ward resources.

This event served to underline the importance of the resources that came as a package with the bed. The need for a functioning bed-light was clear. However, some of the bed-side lights had no bulbs. On one occasion when I asked if I could have a bulb to put into one of the bed lights I was told that the ward was not allowed to hold a stock of light bulbs. This was because a number of bulbs had been delivered some time ago and all had gone missing. The ward staff had to send in a work requisition to the engineering department for light bulbs even though this meant that some children would be without a bed-side light for some time.

Regular adult visitors to the ward understood this. In fact Caron's father was so accustomed to this that he had developed something of a ritual with regard to checking the bed space. One evening when Caron arrived to be admitted onto the ward, he checked to see if there was a bulb in the light fitting. Discovering that the bulb was missing he simply went to the next empty bed, removed the light bulb from the light fixing and fixed it into Caron's light. When I asked the staff about this they explained that the hospital was due to be closed in the next few years and that it was pointless asking for anything to be fixed. This was explained to me on a number of occasions, often accompanied by a shrug of the shoulders.

I had interpreted the shrug of shoulders to indicate that the staff had tried, failed and given up in the quest to secure maintenance of equipment. A contest for the light and light bulbs had become a situated and fixed ritual that illustrated the extent to

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which the children relied on their visitors to ensure they had access to basic ward resources. It also underlined the extent to which children admitted for the first time and those considered outliers could be disadvantaged.

The Playroom

One of the most contested was the play room. Again, depending on who was in charge, the playroom was out of bounds during the evenings and for part of some weekends. At times it doubled up as a waiting room. Incoming children would sit with their relatives waiting for another child to vacate a ward bed. Children who had called in to see a nurse specialist or doctor would be asked to wait in the playroom. The school teachers and play workers spent most of their time in the play room, but the mess in the playroom led to arguments between the different staff groups on the ward. The main contest took place between the play worker and the nursing staff.

During my field work I noticed that the playroom was just another place for the ward staff to use to get their job done. A notice on the door proclaimed the playroom to be out of bounds to all but patients, available only to those who had an accompanying adult and closed after 6pm. These rules were explicit, but not consistently applied. There were other factors at play. When I inquired why this was so I was told that it was sometimes too difficult to watch the children. On one occasion I had witnessed Lauren and another child walking towards the playroom door. A staff nurse who was sitting behind the nurses' station shouted over to them, "*you can't go in there, it's closed...*". The children accepted this and went to Lauren's bed. They clearly had nothing to do and were bored, but this was ignored. I had witnessed children's explicit communication about boredom being ignored on other occasions. One boy had made clear to the nurse who was clearing away his lunch that he was bored. She simply walked away, so it was not surprising that more subtle signals of boredom where either missed or ignored. Boredom had become part of the expected experience for children in hospital.

On a different occasion, I sought permission to go into the play room after 6pm to work with Lauren. We were granted special status and told we could use it as we would not '*trash it*'. Lauren was delighted and kept telling me that we must be doing

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special work. Having witnessed children being repeatedly denied access to the playroom, I discussed this with Elspeth.

E   *"I know this is an extremely busy ward, but my frustrations are that things just don't get looked after. Things get broken, things get left out, you know, and it's expensive things. And there are places to be put, you know, in the office there's a box for things to put in, even if the nurses haven't got time to pack it away, or can't put it away because the cupboard's locked, there is a box where they can put things."*

Locking things away was unremarkable for Elspeth. She explained that the nursing staff failed to take care of play equipment and that this resulted in equipment getting broken.

E   *"Especially when a child is discharged and they've maybe got a valuable piece of equipment like this DVD player, for instance. Instead, I spend most of my time looking for it. Where's it gone, has it gone home with that patient? Has it gone to another ward with that patient? Things like paints and stuff like that, I try to put them away before I go home because they'll just get dumped in the play room. Well, that's no good because I'll come in, and they'll be everywhere. It'll be they've painted the floor, and also it's not fair on the cleaner. We've got a great cleaner on here who tidies the playroom because she has to before she can clean it. Well, that's not part of her job, but I'm very fortunate that she actually will do that and then clean the playroom."*

JL   "Is this a big area of contention, do you think, between nursing staff and play staff?"

E   *"Yeah, I think it's kind of 'that's not our role', 'that's not our remit', you know. But my argument would be that I use the treatment room sometimes as well, but if I just left all my stuff around the treatment room and then walked out and expected somebody else to come in and clean it up... I came in last week and there was a plate of half-eaten sausage and chips left on the table. I come in to find the babies' feeding jars which are glass just left in the play room."*

The justification for denying children access to a precious place to play lay in keeping the children safe. That the real interest appeared to be who would win control over the playroom and its resources remained unacknowledged. There has been increasing interest in accessing children's views about hospital environments (Coad and Coad 2008) and the impact that the environment has on the experience of health and illness (for an example see Sherman, and McCuskey et al 2005). Wyness's (2009) work was helpful in helping me to think through potential solutions to this seemingly intractable position.

In his critique of the practice of participation with children, Wyness (2009 p 404) differentiated between the concepts of place and space. He concluded that children's places, designed and managed by adults, often excluded children as social agents or cast them as 'political actors in waiting'. He suggested that the concept of children's space incorporated the notion of a degree of autonomy and recognition, and conveyed a sense of children enjoying the 'status of participants'. While I witnessed few events that suggested the children were accorded the status of participants, the portrayal of space and place, with space providing a bridge to participation, held some promise with regard to restructuring child-adult relations in a hospital ward. When considered alongside Devine's (2002) argument regarding children's citizenship, using these concepts to create the chance of making a brighter future for children in hospital warrants further consideration. This also helped me to further interrogate other methods used by the ward staff to control and constrain the children.

The Food

Most often, at meal times the health care assistant on duty would write down on a green paper towel the choices of food available for the children. She then went from bed to bed asking the children what they wanted to eat. I thought that this particular ward ritual did little to entice the children to eat food. They could not see what was on offer but often guessed that sausages and mash would be on the menu. Another staple was fish fingers (*'rubbery'* fish fingers), and yet another sandwiches and crisps. There were two contests with regard to food: what the children would be offered and what they would eat.

The children were by no means silent with regard to their opinions on food. Seb had asked me to explain to the staff that they simply needed to check to see if the fish-fingers were cooked half way through the cooking time. If they were not they should return them to the oven being careful not to overcook them. This would avoid the rubbery texture. Sarah explained how one of the benefits of being on a bowel cleansing diet was that *'at least I didn't have to eat the food.'* In spite of this, Sarah explained that access to food was important, *'especially when you're in for two*

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weeks or more.' Her family would often go to the local fast-food restaurant to buy her food that she liked.

Caron's grandmother would cook food for Caron, her parents and her sister. Her parents would bring it to the ward and re-heat it in the microwave in the parent's accommodation at the end of the ward. They then ate the food together, balancing their plates on the small shelves that ran around the edge of the corridor to the parent's accommodation. Eating together was a shared family ritual that they kept to when they could in spite of Caron being in hospital. Caron much preferred her grandmother's food to that which she was offered by the staff. Kelvin was also looking forward to his grandmother's home-cooked soup and was very disappointed when she had forgotten to bring it with her when she came to visit.

On one occasion I had offered to help the health care assistant to give out the food. I had asked several children which of the available desserts they preferred. When I went to the kitchen to get these, one dessert had been set aside on the kitchen work-top. I explained to the health care assistant and ward domestic that this was what two of the children had requested. It transpired that this dessert had been plated up for the staff to eat. They were somewhat disgruntled that I had offered this to the children. I was somewhat alarmed that the children did not even get to choose from all of the available options. On this occasion the children got the food, and I never witnessed the withholding of food at any other time. It is also possible that this was a one-off occasion, but I did not think that it was. It served to highlight how dependent the children were in terms of knowing what had been prepared for them to eat and how much they relied on the ward staff to make what was on offer available to them. Interestingly, there was a strict rule that no staff should eat food taken from the food trolley. This incident also served another purpose. It highlighted just how tenuous my relationship with the ward staff was.

On another occasion during a field work visit, the staff nurse who was in charge of the ward took the food from the food wagon, arranged it onto a trolley and wheeled the trolley onto the ward so that the children could see what was on offer. This event

had taken place during a particularly busy period. The staff had taken no breaks nor had anything to eat or drink for some hours. I commented that I had not seen the food served in this way before and asked the staff nurse why that may be. She simply said that the other staff 'could *not be bothered.*'

The eating experience for children on the ward had come under scrutiny and it was planned to order a dining table that could be used by the children at mealtimes when they were not on bed rest. There seemed to be little attention being paid to the plight of children who had no choice but to eat their meals at bed tables. Even bed tables were a scarce resource. There were insufficient bed tables for each bed space to have one. Even when a bed table was available they were often cluttered with samples of urine or empty sample bottles. Sometimes, used gauze and tape would be left on the bed table, even when the children were using them as dinner tables. The bed table became part of the arsenal of furniture that could be commandeered by staff to help them to get their work done.

SUMMARY

The theoretical insights presented in this chapter illustrate the extent to which the children were constantly reinforcing or re-inventing strategies to maintain their authenticity. In essence, the children were constantly engaged in the work of acting in their best interests. The extent or difficulty of this work, the labour involved and the success of their strategies depended largely on the response from the adults and the staff with whom they engaged. This meant that the strategies that they developed and found successful in one instance did not necessarily work in the same situation with different adults. The children became entangled in a struggle to have their signals for care acknowledged.

This struggle was played out in public with the children using a number of instruments – adults, beds and bed rails; and a number of strategies that included making a noise (calling and screaming), or pestering. While the children never told me that they deliberately broke the rules; in the absence of supportive adults I witnessed them taking matters into their own hands.   Still, the extent of labour involved in this work was too much for some of the children. When this was the case, the children asserted themselves through quietness, silence and retreating to their bed.

The bed space was a contested place. Sometimes it was by the children as a space in which they tried to manage their pain and emotional distress. At other times it was used as an instrument of control and constraint. The children became extra-vigilant when ward staff approached their bed space but there was little they could do to prevent their bed space becoming a place used by staff to get the job done. Whilst I agree with Markström and Hallden's (2009) assertion that the need to control children provides sufficient evidence of their social agency; working to control children while at the same time making a claim to be child-friendly and child-centred are not easily reconciled.

In other words, this chapter has demonstrated that the children's voice and competence was a challenge for staff and that some of the children were more able

than adults to exploit this. The staff responded to the tension that inherently existed at the ideological border of adult control and children's participation by asserting control over the children and the shared ward resources.

CHAPTER 8

FINAL DISCUSSIONS AND CONCLUSIONS

In this chapter I set out my thesis, the study limitations and consider the implications for practice and future research. *Key points are highlighted in bold italic*.

The aims of this research were pursued through two research questions:

- How do children interpret and give meaning to their subjective experiences of being hospital in-patients on a children's ward in one tertiary referral centre?

- What methods would best enable the discovery of children's knowledge?

These questions gave rise to 3 specific research objectives:

1. To work in partnership with children.

2. To examine critically the extent to which the research methods used enabled children's participation.

3. To discover, explore and reveal something about the children's subjective interpretations of being hospital in-patients.

This final discussion confirms that the aims and objectives were met and reiterates the key messages from this work. In particular, the first section emphasises the conclusions derived from partnership work with children and a critical examination what of was unique about the methods used to engage a diverse group of children (objectives 1 and 2). I then present the meaning of voice in this work (objective 2) and set out the challenges that my conclusions present to other researchers working with children. The final section summarises the outcomes of the study and presents the key messages derived from the findings (objective 3). It emphasises that these not only challenge established assumptions but provide unique insights into that current knowledge regarding the care of children in hospital.

ACCESS TO CHILDREN FOR THE PURPOSE OF RESEARCH

The purpose of this research was to discover something of children's knowledge regarding their experiences and interpretations of being in-patients in order to further the debate concerned with children in hospital. Throughout the duration of the study there had been increasing disquiet about an over-reliance of proxy adult views and a growing acceptance that children are social agents who interpret and derive subjective conclusions from what they experience (Bluebond-Langner, Bello Bellasco and Wander 2010, Lewis 2010, Coyne, Hayes and Gallagher 2009, Christensen 2004, James and James 2004). Engaging children in research is not straightforward, especially in the context of the NHS where children are often positioned as subordinates to the adults who design and develop services (Coyne 2010). A great deal of patience and tenacity is needed when negotiating access to children through key gate-keepers. The key message is that *researchers need to maintain high ethical standards and be tenacious in promoting the voice of children to challenge the paternalistic and protectionist claims of stake-holders who resolutely refuse access to children for the purpose of research work.*

METHODS

This study has met objectives 1 and 2 by demonstrating the value of entering the social worlds of children to work with them at times in their lives when they face adversity. However, the way in which any adult positions children will affect how they listen to them (Punch 2002). Taking a critical standpoint meant that I could turn a critical lens on the knowledge that I held about children and the knowledge that I held about children in hospital in particular. Children's views may differ significantly from those of adults (Bluebond-Langner, Bello Bellasco and Wander 2010, Alderson 2008). When I started this work, research concerned with children in hospital had largely ignored the voice of children. Since then, some researchers have made important inroads into the inclusion of children regarding their experiences in hospital. In keeping with this, the methods used in this study were chosen as part of a deliberate strategy to position children as active social agents so that they could

comment on their individual experiences, and work with me to influence and shape the research study. The key message from this is that *researchers need to position children as active social agents and develop creative methods to ensure that research agendas are shaped by the views of children. This does not need to be limited to children's opinions on children: their views on other matters should be sought.*

Adopting a raft of engagement strategies meant that children were included who had been excluded in past research (for instance children with special needs and those enduring acute illness). However, as noted in chapter 3, making determined efforts to include children regardless of their abilities meant that I worked with a diverse range of children. Some of the children had been subject to significant disadvantage; while others had endured complex and difficult lives. Overall the children had characteristics associated with vulnerability (Lewis 2010, Liamputtong 2007, Davis, Watson, and Cunningham-Burley 2008). Of the children that participated in this study, three were accommodated by statutory service, all but one had life-long or life-limiting illness; all but two had some form of physical disability, and two of the children had been diagnosed with learning difficulty. In addition, few had the same surname as their mothers, suggesting that they were members of reconstituted families.

A determined and deliberate inclusive approach to the recruitment of children revealed the depth of individual children's knowledge and that knowledge was not related to their capability or capacity. This advances current knowledge regarding which children are able to participate effectively in research. The key message from this is that *researchers should reach out to all children rather than rely on those considered to be competent, articulate and capable.*

A particular strength of this work was the use of ethnographic methods that enabled the development of firm research questions over time. This method enhanced partnership working with children and meant that the participants were involved in the refinement of the research questions (James 2001, Bluebond-Langner 1978).

Research work with children is more about active listening (Lewis 2010), spending quality time with children in the social places that they inhabit (Davis, Watson and Cunningham Burley 2008), and being willing to challenge adult assumptions about children's knowledge (Bluebond-Langner, Bello Bellasco and Wander 2010) rather than about meetings, project planning, project management and consultations. The key message from this is that *researchers should use creative inclusive methods to ensure that children can shape the focus of the research when it is not possible for them to be involved in all aspects of the research process.*

Too often researchers have avoided work with children during times when they are considered to be 'too ill' to participate. This means that those children in most need of being heard are those most silenced (Lewis 2010, Bluebond-Langner) a classic case of double jeopardy (Bella Bellasco and Wander 2010). Children's views and opinions on what is most important during the moments in their lives when they face greatest adversity have remained hidden for too long. In keeping with objective 2, the methods used in this study challenged the assumption that some children are too ill to participate in research work. Field work methods are an effective means to work with and learn from children during these times. The key massage from this is that *researchers need to reach out and work with children during the times in their lives when they face adversity to develop a better understanding of what is going on and what matters most to the children during these times.*

CHILDREN'S VOICES

Children's voices have become increasingly important in the design, delivery and evaluation of services to children (Christensen and James 2008, James and James 2004, Mayall 2002). Yet, too often, children's voices are associated with the spoken word and conversations. This work has challenged this notion. Children's voices take many different forms. The spoken word and conversations represent just one form of voice (Lewis 2010). Many others exist. Turning away, shouting, crying, rebelling and resistance are some that were revealed in this work. Children's voices go beyond that which they say. The key message from this is that *children's*

voices are manifest in their actions and their words, but children voices are also represented in their silences.

Children's participation should be governed by children, with adults using their power to support and scaffold children's efforts when needed. Entering into the social world of children and spending time with them there is what makes a difference (Davis, Watson and Cunningham-Burley 2008). The children in this study had little interest in entering my world. For me, this was the essence of children's participation. The key message from this is that the **work of participation should rests with the researcher. It is for researchers to work hard and enter the many worlds of children rather than this becoming the work of children.** These findings provide further evidence of meeting objectives 1 and 2.

LIMITATIONS TO THE STUDY

The study was limited by my novice status as a field worker, my experience of ethnographic methods and the subjective nature of the data analysis. I was learning on the job. I have attempted to write an honest account, acknowledging the many mistakes that I made along the way. I also realise that there will be other mistakes of which I remain unaware. Regardless of these limitations drawing on constant comparative techniques, I have presented a rigorous and comprehensive account of the children's knowledge. I have also made determined efforts to let the children speak

Children expect little more than acknowledgement of their competence and their right to participate or decline in research activities when asked. They are remarkably tolerant of adults who know less about their world than they do. Letting the children decide when the time was right to step down from active participation (closure) is the right thing to do. The key message from this is that **children are often willing to help adults navigate and understand the social worlds of children. Respecting their right to participate or decline is a key attribute in this.**

The number of children who participated in the study was small, particularly when compared to the number of children admitted to hospital wards in the UK every year. Generalising the findings to other children admitted to other hospital wards in the UK is not possible, but this was never the purpose of this work. The children in this study told me something about their experiences and how they had interpreted these. By doing so they revealed their knowledge and have participated in the development of new understandings and contributed to the debate concerned with children in hospital. The findings presented here advance the insights provided by Bluebond-Langner, Bella Bellasco and Wander (2010), Lewis (2010), Coyne, Hayes and Gallagher (2009), Lambert, Glacken and McCarron (2006). The key message from this is that **research work with children is more about developing insight into children's worlds from the perspective of children and less about reaching generalisable findings.**

Despite determined efforts I was unable to work with children who did not speak English as their first language, or those who used augmentative communication. Additional cultural and practical factors introduced by non-English speaking children would add important insights. The key message from this is that **future research should include children from different cultural backgrounds and those who use alternative means for communication to explore their unique insights and knowledge.** These findings provide further evidence of meeting objective 2.

FINDINGS

Transition to Patients who are also Children

Entrées

The children had made sense of their need for hospital admission by talking about events that were sometimes harrowing and always disruptive to their lives. The children described their entrées to hospital in terms of planned, unplanned, unexpected and unexpected events. This offers new insight into the experiences of children admitted to hospital and advances the findings reported by (Coyne, Hayes and Gallagher 2009, and Lambert, Glacken and McCarron 2008). A key finding is that **the children's terms conveyed the disruption that admission to hospital**

brought. The children's terms also underlined that their experiences of being in hospital always began with them being in trouble at home.

Tug of War

Children's access to Study ward was embedded in a working culture that was manifested as a culture of conflict and deceit. It was not uncommon for the true nature of the medical diagnosis for some children to be withheld from the ward staff in an attempt to persuade them that the children required less care than was often the case. This was a new insight. While the rhetoric of child-friendly and child-centred approaches provided the illusion that individual children were central to the work of the hospital, structural mechanisms related very clearly to business functions. For the children, being in the right hospital and the right ward was key to having a better experience. This was also a new insight. Children who were out of place or 'outliers' were incongruent with the skills and competence of the staff, and, in turn, this left them subject to unintended harm. Yet, as noted in research undertaken in Holland by Beringer, Fletcher and Taket (2006), there were no systems in place to help the staff to manage the demands for beds. A key finding is that a lack of organisational systems to manage the admission of children to hospital beds, has a deleterious impact on the experience of children admitted to hospital. The **children's initial identities became reduced to that of their medical diagnoses. The ultimate reduction was 'It': a return, it seemed, to the days before individualised patient care.**

Induction to Study Ward

The children associated subtly nuanced admission practices with felt security and safety. Key amongst these was being expected and feeling welcome. Feeling welcome included having an allocated bed with 'puffed up' pillows. This was a unique finding and has not been reported elsewhere. In keeping with findings reported by Beuf (1978) regarding the experience of children in hospital in the USA, being uniquely identified symbolised that as in-patients the children were subject to different rules. The findings reported here add that being allocated a bed was part of this process. Rather than many of the rules being made explicit, the children

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discovered what they were by watching others, reading signs on doors, or getting them wrong. A key finding is that *the children's transition to being hospital in-patients who were also children was symbolised through the allocation of a bed and their being uniquely identified. Being a hospital in-patient meant being subject to different rules. These rules were not explicit, and often subject to change depending on which staff were present. This made it harder still for the children to navigate their way through Study ward.*

Child-Adult Relations

Reducing Difference and Stigma

In keeping with Goffman's (1963) theory on stigma, keeping their differences from other children secret suggested that the children worked hard to manage their social identity and reduce stigma. Their quest to be more like other children was a strong motivator. Even when previous attempts at similar surgery had failed they continued their pursuit to become more like other children. Contrary to the dominant concept of the hospital as a total institution with the staff informing the children who they had to be (Goffman 1961, Beuf 1978), the findings reported here point to new insights. These are consistent with those of Alderson (2008) in that being the same as other children was important in how the children felt regarding belonging to the social group of children. *The key finding is that the children with physical difference worked hard and were prepared to endure multiple interventions to become more like other children and they were actively involved in making things better for themselves.*

Knowing the children

A great deal of staff time was devoted to admitting children to the ward. This process involved an assessment of their needs. The tool used to undertake this was no longer fit for purpose as it failed to elicit the children's perspective on what they needed. A consequence was that the staff knew the children as patients rather than individuals. As reported by Place (2000), the staff worked to get their job done, and at times, the children's bodies became the object of their work. The underlying notion of children being dependent and in need of protection meant that

communicating with adults had become the 'right thing to do'. The findings from my study revealed that adult understandings masqueraded as children's wants and wishes. This led to new insights regarding the children being constructed as difficult, stroppy or needy. In turn, the children judged nurses as 'freaky' or inadequate especially when they hurt the children unnecessarily or 'pinned them down'. The children's emotional labour was evident when they reported that these experiences left them feeling sad or cross. This has not been reported elsewhere. Knowing children as patients is a limiting model of practice. Knowing children as individuals is essential in tailoring the care and interventions to their needs. This requires more than consideration of effective communication strategies. A key finding that advances Lambert, Glacken and McCarron's (2008) notion of 'visible-ness' and one that has not been reported elsewhere, is that the **hospital ward was a place for children in which children's voices were seen as a challenge rather than a fundamental aspect of the work.**

A radical shift in the theoretical assumptions that currently inform nursing practice with children is needed to ensure that the children's view of what is intended is elicited and their emotional labour acknowledged. The acknowledgment of children's emotional labour when hospital in-patients has not been reported elsewhere. **A key finding is that *emotional labour is not confined to the work of adults.*** As the children's experiences unfolded, their emotional labour became evident. A more inclusive and participatory model of practice that acknowledges this is urgently needed.

Strained child-adult relations

The children were not complicit in accepting the ward staff's model of working. In keeping with Harrè's (1988) theory on personal being but challenging Goffman's (1961) theory of hospitals as total institutions, the children had a strong sense of self, self-identity and self-determination. They resisted being dehumanised and depersonalised. They did what they could to re-assert their competence. At times this included disrupting the work of the staff. Overall, the children were resilient and drew on their social capital and practical agency (Glover 2009, Daniel and Wassell 2002a, 2002b, 2002c, John 2003, Grotberg 1995) to get what they needed. This is a

new finding and has not been reported elsewhere in relation to children's experience as hospital in-patients. The children used supportive adults as instruments. This sometimes led to strained and difficult relationships between the children and their visitors and between the children and the staff. This has not been reported elsewhere. This offers new insight into the nature of child-adult relations in the context of a hospital ward. A key finding was that *child-adult relations in a hospital ward go beyond the need to have a supportive adult with children. Sometimes protective, these relationships can deteriorate, become strained and difficult. This matters because children are heavily reliant on adults in a children's ward to get what it is that they need.*

Inhabiting Different Worlds

Being in hospital was an active rather than a passive social event. This may seem at odds with the well-established understanding that patients acquiesce to a passive patient or sick role (Parsons 1951). Study ward constituted two worlds, that inhabited by staff and that inhabited by children. This suggested that the children and the staff experienced different realities. This has not been reported elsewhere in relation to children in hospital. While the children were oriented to their futures, the staff were concerned with their present. Regardless of the adults acknowledging or denying the children's competence, it was most often the children who had to navigate their way into the world of the staff. The children developed strategies in order to act on their own behalf and to further their own interests in this world. This is a novel perspective on the experience of children in a hospital ward which promotes a more valid approach to child-centred care. A key finding is that *the concepts of being child-friendly and child-centred did little more than provide an illusionary façade for adult-centred patterns of knowing.* My analysis revealed that while Study ward was a place for children, there was insufficient space for children's voice and competence.

Children's Voice and Competence

In some ways, the fact that the staff denied the children's competence adds further to the theoretical insight into children's competence in this work. The need to control

and contain children is evidence of their ability to disrupt adult priorities (Markström and Hallden 2009). It seemed that the professional and adult ideologies at the centre of Study ward created a familiar landscape that helped hospital workers to navigate, control and understand the world of Study ward. This meant that the children's world, situated incongruously between their social agency and structural mechanisms, was hidden. Their voices and their work was, therefore, also invisible to staff at times. A key finding was that *much of the children's work was unrecognised, unacknowledged or subverted by the 'official' work of the staff. In turn, the busyness of the staff further mitigated against the children being heard.* Over-reliance on the proxy voice of the children's adult carers' as the authentic source of required information negated the need to involve children at all or at least to minimise their role and deny their competence. This has not been reported elsewhere.

Confined to Bed

Some children sought solace in their beds. They used their bed as a place to contain emotional and physical needs. Waters (2008) noted that hospitalised children often became vigilant during their time in hospital. However, the findings reported here advance this and offer new insights. Even when bed-rest was part of a treatment plan, the children worked hard to escape the confines of their bed. Escaping to the chair at the side of the bed or managing to escape from the ward was a cause for celebration. Those children who could not escape were bored, which then left them feeling sad. Most often, children used supportive adults to help them to escape from the confines of their bed. Some of the children who were alone were far from passive; they rebelled, resisted and called out to signal their need for care. When they remained unheard, some were exposed to risks of harm by standing on beds, manipulating the bed rails, or climbing over them. Children who had been in-patients previously had worked out that being near to the nurses' station or next to the treatment room offered some privilege in getting the attention of staff, but this was no guarantee of assured attention when needed. In the absence of supportive adults, it was the quiet, shy, reticent and sick children who became marooned. They were silenced. Their needs were diminished and

contained, they became subject to routinised care, and their beds were experienced as islands of distress. These key findings have not been reported elsewhere. *Children were most often successful in executing an escape from their bed when their resident parents were available, although, having a parent resident was no guarantee that the parent would or could intervene on behalf of the children. Quiet, sick and shy children who were alone were the most likely to have their needs diminished and become subject to routinised care. Children who were alone sometimes risked their safety by taking matters into their own hands.*

Many of the children became extra vigilant when the ward staff approached their bed. In this, their behaviour was remarkably similar to that of children who endure abuse or those who face adversity. They would stop what they were doing to assess the potential of the ensuing attack. A key finding was that *the bed was no place of safety, and the children became extra-vigilant, especially when members of staff approached. In this, their behaviour mirrored that of children who have endured other painful and diminishing experiences like mal-treatment.* This insight further advances the findings reported by Waters (2008). I contend that such insight can only be gained from entering the social world of children and working alongside them to gain greater insight into the social contexts that frame their experience.

Contested Resources

It was evident that the ward staff had most control over shared ward resources such as the light, food and access to the playroom. These resources were constantly contested. Sometimes the shared resources could be controlled such that they limited or contained the children's needs, for instance switching off the main ward light. Sometimes the contests related to physical space such as that around the bed. The children's access to space was controlled and often limited to their bed, but even this was transformed into a place of work when the staff had things to do. The play room was the most symbolic location in the ward as a place for children, but it was often out of bounds. These insights have not been reported elsewhere. A

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key finding is that *closing curtains or seeking permission to go into otherwise restricted areas was a form of protest that the children used to challenge their diminished status as patients.*

Theoretical Conclusion

The cultural, structural and material components in Study ward promulgated an ethos of it being child-friendly and child-centred, but this was an illusionary façade. Working with the children helped me to see into a different reality. Study ward was a place for children dominated by adults who reproduced a working culture of conflict and deceit to manage the admission of patients. The children who were admitted as hospital patients were 'sorted' through a number of structural processes. The allocation of a bed and their being uniquely identified (identity bracelet) signalled their transition from children to hospital in-patients who were also children. In turn, this signalled that they were subject to different rules. The tools used to assess the children's needs were no longer fit for purpose. The staff knew the children as surgical patients rather than people and the children's bodies became the objects of the staff's work. This meant that the children experienced their competence as a fluid and unstable concept. They resisted being de-humanised and often engaged in hard labour, drawing on their social capital and practical agency, and using adults as instruments to reassert themselves as competent human-beings. The staff used a number of strategies to contain and control the children's competence that often manifest in their demands. In response the children did what they could to disrupt the work of the staff in order to be heard. When they were unable to attract the attention of staff, the children acted in their own best interests to get what is was they needed, regardless of this exposing them to the risk of further harm. Those children who were less able to draw on their social capital and practical agency became marooned, and their beds became islands of distress. Although a place for children, it was a place in which there was little space for children's voices or competence.

CHAPTER 9
RECOMMENDATIONS

Practice

The findings of this study suggest that the work of participation rests with the children who are hospital inpatients. This needs to shift such that the work of participation is located in the sphere of the staff's work. Staff who work with children are morally obligated to know the children as individuals rather than as patients. A radical critique of the current models and frameworks used as tools to assess the needs of children is warranted. *A more inclusive and participatory model of practice is urgently needed.* This should incorporate key concepts derived from the sociology of childhood. These include the concept of voice as a multidimensional concept that manifests in children's words, actions, silences, resilience, competence and agency.

Children in the right place have a better experience. The development of *clear organisational structures* that support rather than supplant child-friendly initiatives regarding admission to hospital is indicated so that children get to the right place first time.

Children who are alone in hospital, especially those who are quiet, sick and shy, and those who have experienced difficult home lives are the most likely to have their needs diminished and to become subject to routinised care. *Special efforts should be made to ensure that children who are alone are visible to staff* and that their *care-signalling needs are recognised* and acted on.

Urgent attention should be paid to **the means by which children can signal their needs for** *care and the ways* **in which staff can become more sensitive to recognising these**.

The **professional development needs of staff** with regard to meeting the needs the needs of children who are 'looked after' and those who have endured difficult lives and disadvantage **require urgent identification**. It is paramount that the needs of those children who are the most vulnerable are not simply contained but fully met by staff that are sensitive and alert to the needs of children who are disadvantaged and those who have complex health and social care needs.

Research

Further research, using participatory methods with children is needed to:

- Understand the research priorities and questions that children have regarding their hospital care.

- Understand the unique needs of disadvantaged children and children with complex health and social care needs.

- Understand the subjective experience of children who are alone in hospital wards.

- Understand more regarding the nature of child-adult relations including those that children experience with supportive adults and those they experience with professional staff.

- Understand the experience of children during their most acute phase of illness and the most difficult times of their hospital experience to develop a better understanding of what is going on and what matters most to them during these times.

- Understand the experiences of children from different cultural backgrounds and those who use alternative means for communication.

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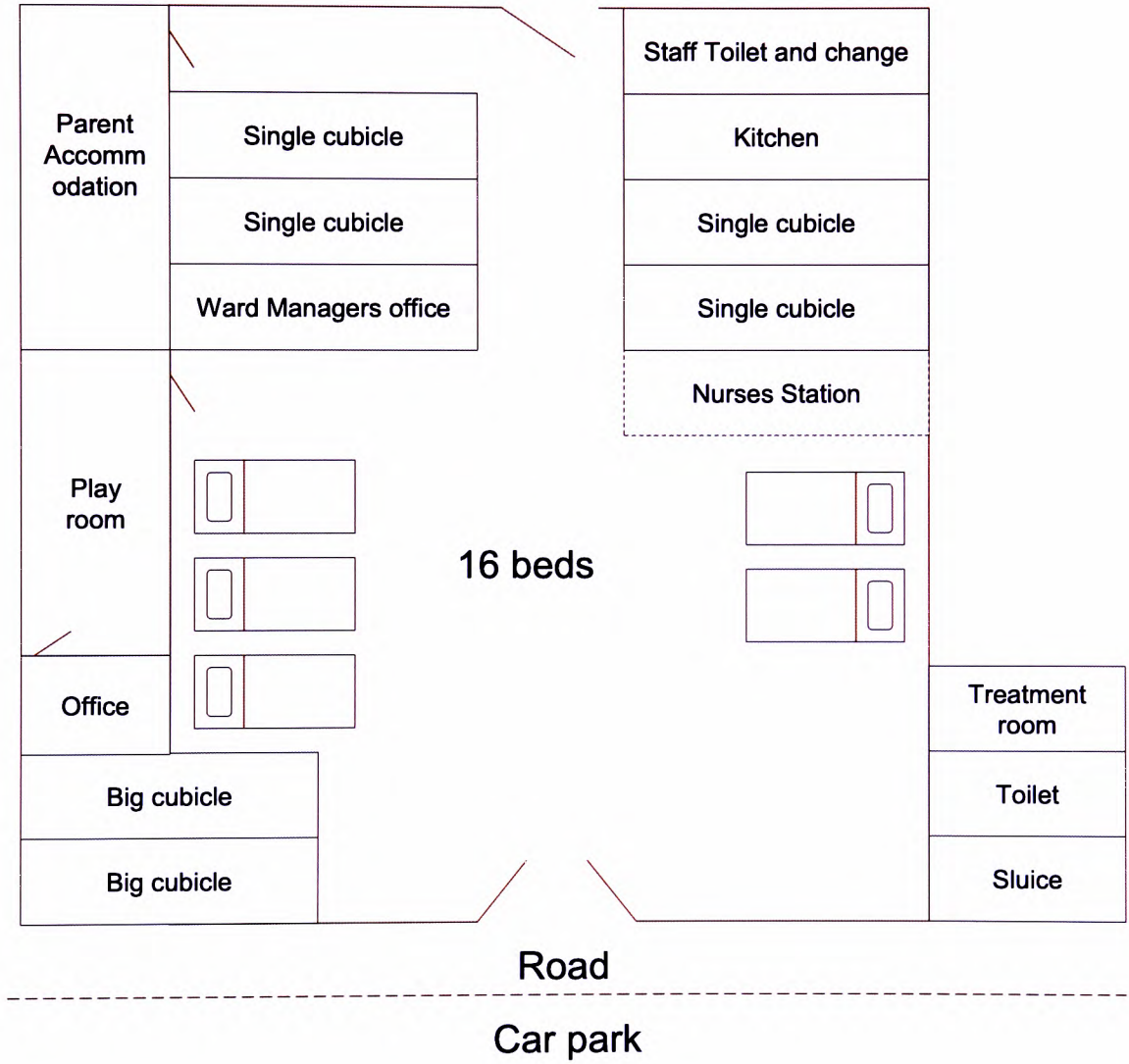
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APPENDIX 1

SCHEMATIC OF STUDY WARD

Schematic of Study Ward

Parent Accommodation	Single cubicle	Staff Toilet and change
	Single cubicle	Kitchen
	Ward Managers office	Single cubicle
Play room		Single cubicle
	16 beds	Nurses Station
Office		Treatment room
Big cubicle		Toilet
Big cubicle		Sluice

Road

Car park

APPENDIX 2

CHILDREN QUESTION AND ANSWER LEAFLETS

Hello, my name is **Joan Livesley**

I work for the University of Salford.

I teach students of children's nursing and do research.

Your parents or carers have agreed to ask you to read this leaflet.

The nurses and doctors in Manchester want to make sure they keep children safe and secure while they are in hospital.

I am inviting children to join me to do some research so that we can tell them what children think about this.

Would you like to help me?

If you would, I would like to talk to you about being in hospital.

What happens to you when you are there? Do you feel safe and secure? Is there anywhere you feel less safe? What would you change to make it better? What do you really like about being there?

I can speak to you on your own or with other children.

If you would like to talk to me please ring, text or email me to let me know.

My phone number is 0161 295 7018 if I'm not there please leave a message and I will return your call.

My text number is 07966934134 please leave a text message and I'll text you back.

My email is j.livesley@salford.ac.uk, if you email me I will email you back.

YOU MAY HAVE SOME QUESTIONS

What will I have to do?
I will arrange to meet you so that you can tell me what it is like being in hospital

How long will I have to talk to you?
For about half an hour but if you have a lot to say it could be longer
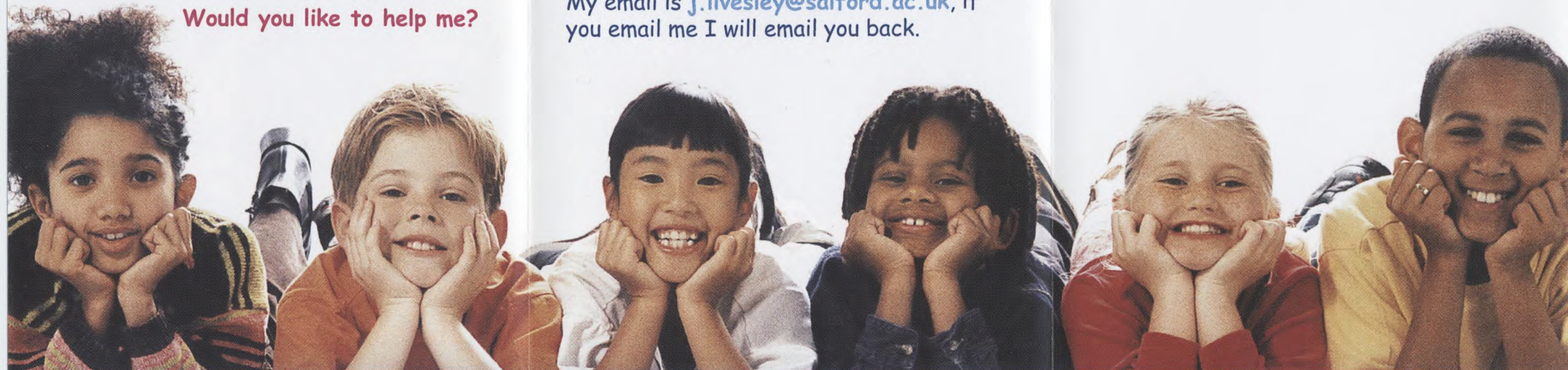
Where will we meet?
We will meet in a room in the hospital where you feel comfortable or at another place that we choose together.

Can someone come with me?
Yes, anyone you choose

Will it just be talking?
No, I will bring some games and pens and paper so that you can play or draw as well

---

Will you write down what I say?
Maybe, but I would like to tape what you say if that's okay with you

Do I have talk to you?
No, you don't. But if you would like to take part, please ring, text or email me so that I know.

Will anyone else find out what I have said?
Yes, I want to tell other people who work in hospital what you think so that they can make changes if they need to.

You can choose another name so that when I tell other people what you have said they will not know who you are.

I may need to speak to someone else if you tell me someone is hurting you, but I promise that I won't do anything without speaking to you first.

What happens next?
We will arrange a time and place to meet.

When I have finished talking to all the children who want to take part I will write about what you have all told me.

I will also have some meetings with other adults from the hospital in Manchester and other hospitals around the country.

I will make sure that they know what you think about being in hospital and what they can do to keep children safe and sound. You can join in with these meetings if you want to.

Can I change my mind?
Of course you can, at any time. If you want to talk to me now but change you mind in the future that is fine and you do not have to talk to me again

What if I am not sure?
That's okay, take your time. You can talk to someone else, my supervisor or me if you're not sure what to do

Safe and Sound

Thank you to Michael for the logo

An Invitation To Children Who Have Been in Hospital

Hello, my name is
Joan Livesley

I work for the University of Salford. I teach students of children's nursing and do research.

Your parents or carers have agreed to ask you to read this leaflet.

The nurses and doctors who work with you try hard to keep young people safe when they are in hospital, but there may be things you would like to tell them about being safe that they don't know. I am inviting young people to do some research with me so that we can tell them what you think about safety.

Would you like to help me?

If you would, I would like to talk to you about what happens when you are in hospital? Do you feel safe? Is there anywhere you feel less safe? What would you change to make it better? I can speak to you on your own or with other young people.

If you would like to be involved please ring, text or email me and let me know.

My phone number is **0161 295 7018** if I'm not there please leave a message and I will return your call.

My text number is **07966934134** please leave a text message and I'll text you back.

My email is **j.livesley@salford.ac.uk**, if you email me I will email you back.

You May Have Some Questions

What will I have to do?
I will arrange to meet you so that we can talk about being in hospital.

How long will I have to talk to you?
For about an hour but if you have a lot to say it could be longer.

Where will we meet?
We will meet in a room in the hospital where you feel comfortable or at another place that we choose together.

Can someone come with me?
Yes, anyone you choose.

Will it just be talking?
No, we may do some fun exercises as well and I will bring some refreshments.

An Invitation

To Young People Who Have Been in Hospital

Will you write down what I say?

Maybe, but I would like to tape what you say if that's okay with you.

Do I have talk to you?

No, you don't. But if you would like to take part, please ring, text or email me so that I know.

Will anyone else find out what I have said?

Yes, I want to tell other people who work in hospital what you think so that they can make changes if they need to. You can choose another name so that when I tell other people what you have said they will not know who you are.

I may need to speak to someone else if you tell me someone is hurting you, but I promise that I won't do anything without speaking to you first.

What happens next?

We will arrange a time and place to meet. When I have finished talking to all the young people who want to take part I will write about what you have all told me. I will also have some meetings with other adults from the hospital in Manchester and other hospitals around the country. I will make sure that they know what you have said about being in hospital and what they can do to make sure they keep you safe. You can join in with these meetings if you want to.
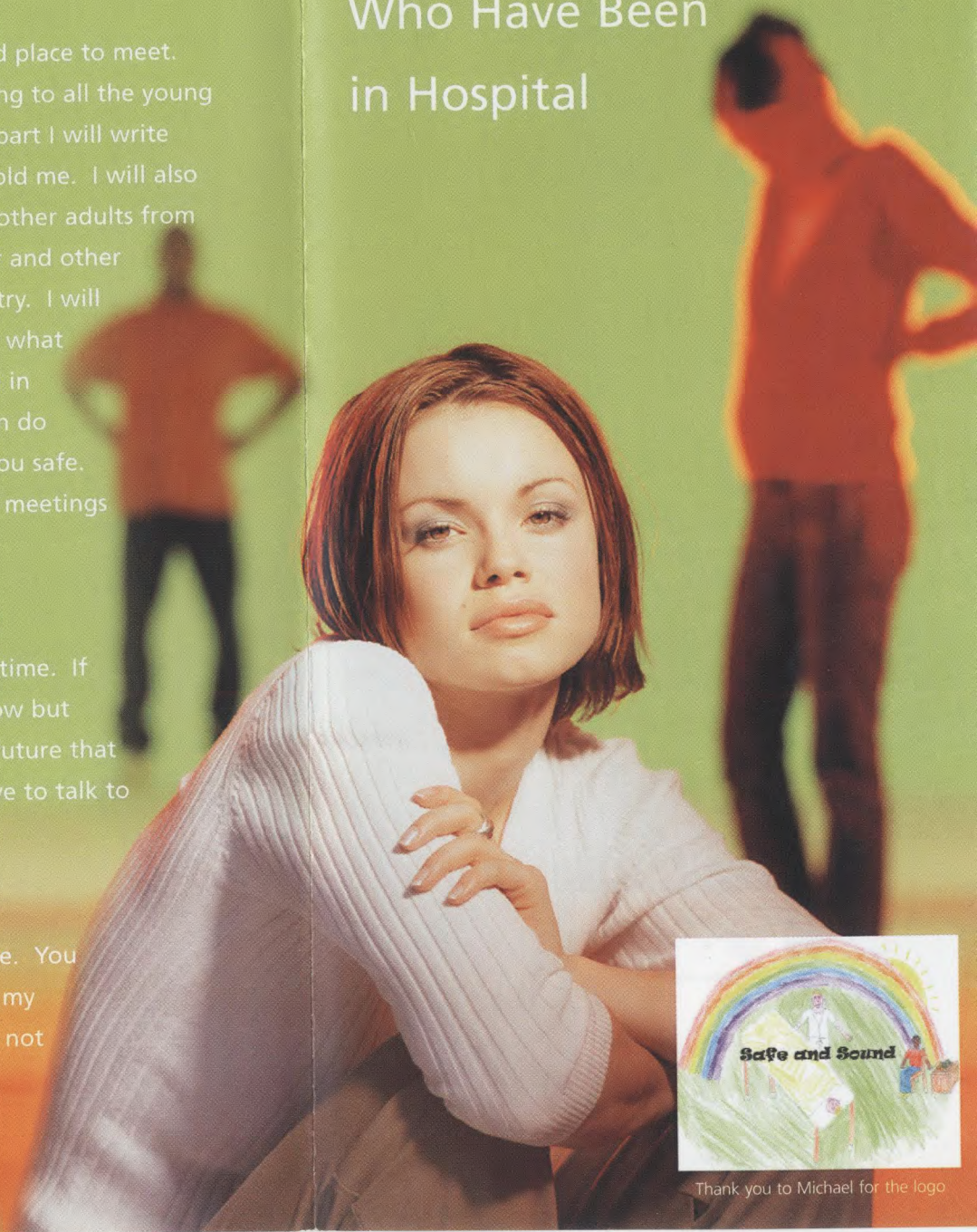
Can I change my mind?

Of course you can, at any time. If you want to talk to me now but change your mind in the future that is fine and you do not have to talk to me again.

What if I am not sure?

That's okay, take your time. You can talk to someone else, my supervisor or me if you're not sure what to do.

Safe and Sound

Thank you to Michael for the logo

APPENDIX 3

RESEARCH AGREEMENT FORM

(EXAMPLE)

Safe and Sound

Research Agreement Form

I confirm that I have read the information leaflet sheet about the Safe and Sound study dated [] and I am happy for Joan Livesley to contact me to talk about my child being involved

Name: Date:

_____

My Relationship to the child:

_____

My address:

_____

_____

_____

_____

My contact details:

Telephone Number:

Mobile:

Email:

APPENDIX 4

RESEARCH CONSENT FORM

PARENT AND CHILD

(Example)

Working with Children and Young People in Hospital
Research Consent Form

Part A (to be completed by the parent/carer)
I confirm that I have read the information leaflet sheet dated [] for the above study and have had an opportunity to ask questions

I understand that my child's participation is voluntary and that he/she is free to withdraw at any time without giving a reason without his/her treatment or legal rights being affected.

Name: Signature: Date:

_____
My Relationship to the child:

_____

Part B (to be completed by the child)
I agree that I have asked any questions I wanted to about this study and would like to take part in the research

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected

Name: Signature: Date:

_____
Part C To be completed by the researcher

Name: Signature: Date:

APPENDIX 5

IINFORMATION FOR PARENTS AND CARERS

(Phase 2)

(contact details removed)

Michael Aged 10

An Invitation
To Children and Young People on Wrigley Ward

Information for Parents and Carers
October 2006

RESEARCHER

Joan Livesley, RSCN, M.A., BSc
University of Salford
Centre for Nursing, Midwifery and Collaborative Research

RESEARCH SUPERVISOR

Professor Tony Long, RSCN, M.A. BSc. PhD.
University of Salford
Centre for Nursing, Midwifery and Collaborative Research

http://www.research.salford.ac.uk/scnmcr/SCNMCR.homepage.htm

Who am I?
My name is Joan Livesley. I work as a senior lecturer at the University of Salford. I am currently undertaking research with children to find out about their views on safety in hospital. I do have previous experience of doing research but this project is being supervised by Professor Tony Long. Tony is also employed by the University of Salford; he is also children's nurse.

Why do you want to speak to my child?
Your hospital consultant has given permission for me to ask you if I can approach your child to see if they would like to be involved in this research project. Before you decide whether or not to give your consent for them to do so, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information and discuss it with your family and friends if you wish. You may also wish to discuss it with your doctor or nurse. Please ask me if there is anything that is not clear, or if you would like more information. You can take time to decide whether or not you wish to take part.

Who has reviewed this study?
This study has been reviewed by the University of Salford Ethics Committee, the Central Manchester Local Research Ethics Committee and has been approved through the hospital research governance procedures.

Does my child have to take part?
No, even if you give permission for you child to take part but they do not wish to, no pressure will be put on them to do so. This will in no way affect their care, treatment or legal rights in the future. Even if you child decides to take part now, they can, without explanation, withdraw from the study at any time in the future.

What do you hope to find out?
I hope to find out how children view safety in hospital.

What will you do with the findings?
The findings will be used to produce a tool kit that can be used by people who work in hospital, and those who train people to work in hospital to create an environment that helps children feel safe

What would my child's involvement be?
Initially, this would involve me being with your child while they are in hospital, observing what they do, what happens to them and talking to them about their experiences. If your child would like to talk to me once they have gone home I that is fine as well. I can arrange for a 1 to 1 interview at a time and place convenient to you.

Will you write down what my child says?
I will, but with your child's permission I would like to tape record some conversations with them.

Will you do anything else besides talking to my child?
Yes, I will use games and other fun activities to help the children and young people tell me about their experiences of being in hospital. The activities will be age appropriate and children will only have to join in with those that appeal to them.

How long will the observations?
The observations will last between 2 and four hours over a period of 1 to 2 days, or longer if you child agrees to this. I promise that at all times, only to observe those things that you child wishes me to. They can, at any time, ask me not to observe what is happening.

Can I stay with my child?

Yes, of course, and any other person you or your child wish to be present is welcome.

Who will find out what you observe or what my child has said?

I will write about the observations and what your child has said and I will give presentations to hospital staff and at professional conferences. This is to make sure that their views and opinions are heard by as many people who work in hospital or train others to work in hospital with children as possible. Your child will be asked to choose a name different to their own, so that nobody can identify them as an individual. Any information which is collected about you or your child during the course of the research will be kept strictly confidential. However, should your child disclose that someone is harming or hurting them then I will have to tell somebody else. I would also like to inform your G.P. that your child is taking part in this study but will not do so without your consent.

What happens if something goes wrong or my child becomes upset?

Although extremely unlikely, should any child become upset during the observations the observation will stopped and you will be informed. I can explain how you can access the Patient Advisory Liaison Service and you and your child will have confidential access to a counsellor/psychologist who is on the review group for the study. The study is covered by the compensation arrangements for research by the University of Salford. If you are harmed due to someone else's fault, then you may have grounds for a legal action. If you wish to complain or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms will be available to you.

What if I am not sure?

Please take your time to decide, you may wish to discuss the project with your doctor or nurse. Please contact me or my supervisor if you wish to discuss any aspect of this invitation.

What happens next?

If you are willing for your child to take part, please pass on the children's invitation attached to this information sheet asking them if they would like to take part. If they would like to take part, just let me know, If I am on the ward you can tell me directly, if not, please ask one of the ward staff to put the consent form in the research box on the nurses stations or contact me directly. You will find the contact numbers on the front and back sheets of this information pack.

Will our information remain confidential?

Yes, all children and families who agree to take part will be given names different to their own in any written or verbal presentation. All research data will be kept in a secure locked archive and all personal information will be treated as confidential unless any child discloses that they are at risk of harm. The research tapes, notes and typed interviews will be kept for 10 years. At the end of this time your child may have their interview returned or I can arrange to have it destroyed.

What will happen when the research is complete?

I will write to you and let you know what I have found out, you will be invited to meetings of parents, children and hospital staff to discuss the findings. You will also be invited to join events where the findings will be disseminated to others.

Can I or my child become more involved in the research?

Yes, I am looking for adult and child volunteers to join the study review group. This group will meet at least once per year; review the research processes and the findings as they emerge. If you or your child would like to become involved with this work, please let me know

Who do I contact for more information?
Please contact me or my supervisor for more information or to discuss any aspect of this research further. Postal addresses, telephone, email and text contact numbers are listed on the front and back sheets, or, ask one of the ward staff to leave me a message and I will get back to you. You will be given a copy of this information sheet to keep along with a copy of your consent to approach your child to take part and a copy of your child's signed consent or witnessed assent.
Thank you for taking the time to read this information leaflet

SAFE AND SOUND
CONTACT DETAILS

RESEARCHER

Joan Livesley

By post

Joan Livesley
University of Salford,
Centre for Nursing, Midwifery and Collaborative Research,

RESEARCH SUPERVISOR

Professor Tony Long

By Post

Professor Tony Long,

NOTES
Please use this sheet to make any notes or questions that you wish to discuss about the research

APPENDIX 6

Ward Staff Information
(contact details removed)

Salford Centre for Nursing, Midwifery and Collaborative Research
Safe and Sound - Working With CHILDREN
Information to Ward Staff

Who am I and why do I want to do this research?
I am a qualified children's nurse, currently employed as a senior lecturer at the University of Salford. I am currently pursuing research studies into the safety of children in hospital.

What is the aim of the Research?
The aim of the research is to work in partnership with children, provide a detailed account of their experiences of being in hospital and use the findings to disseminate best practice and effect changes to education, policy, practice and research that impact on the safety of children in hospital.

Why does this research need to be done?
It will improve our understanding of how children experience hospital and help us to identify what aspects of hospital contribute towards or mitigate against safety.

How is the research being carried out?
The study is being conducted in 2 stages.

Stage 1 – Interviews with children
Children aged seven years and above, who had been in hospital in the last 18 months have told me what they think about being in hospital; what worked, what helped them to feel safe and what could and should be improved. I will use what the children have told me to focus my observations on what really matters to the children.

Stage 2
Observations
Observations and in depth discussion with up to 10 hospitalised children aged 4 years and over will be undertaken on Wrigley ward. I will write field notes and may tape record discussions with the children and their parents/carers. I will also be asking staff to take part in detailed tape recorded discussions. These interviews will explore staff views on children's safety in hospital.

Do I have to take part?
No you don't, but if you are willing to talk to me please contact me to let me know. My contact details are given at the end of this leaflet.

How will I know if the observations are taking place?
I will leave a timetable of when I will be undertaking observations on the ward. I expect the observations to take place from July 06 until October 06, 2 to 3 days per week for 2 to 4 hours at a time.

Who has given permission for this research to take place?
The research has been reviewed by the University of Salford Ethics Committee, the Local NHS Research Committee and has been approved through the hospital research governance procedures.

I have some questions, who can I talk to?
Please contact the researcher Joan Livesley or the research supervisor Dr Tony Long

APPENDIX 7

Transcript of conversation with Kelvin

JL "I wanted to ask you, I don't know if you'll be able to explain this, but if you can it would really be useful "

K "Uh-hum."

JL "You know, when I came in on Friday..."

K "Yeah."

JL "You were being looked after by the lady who had the stripy top on. Do you remember? Dark hair?"

K "Oh, right, yeah, yeah."

JL "And while I was sitting here, she came over to your bed and she went to the side to do something to your box."

K "Yeah."

JL "Do you remember? You said, 'No, no, no, no....'"

K "Yeah."

JL "And do you remember, she said, 'Why? It doesn't hurt.' Can you remember what she said to you?"

K "I can't remember exactly."

JL "What do you think she said?"

K "She said something like, 'It can't hurt. I've already had this done.'"

JL "Mm. What did you think about that?"

[interruption from nurse with medication for Kelvin]

K "Right, what were you asking me again?"

JL "Right, I was asking you about when she said to you, you remembered that she said something like, 'It doesn't hurt. I had something like that done.' "

K "Oh, yeah."

JL "Yeah."

K "Well, I just thought, well, she's an adult. It might have been like, not as sore and she might have been able to take it better, if you know what I mean."

JL   *"Yeah. And when you say she's an adult, are adults different from children?"*

K   *"Well, they're older and [would go] through a bit more pain than children would."*

JL   *"Right. Are you a child, Kelvin?"*

K   *"Kind of."*

JL   *"Kind of. What does that mean? Can you explain?"*

K   *"Well, you're not, you're kind of, not grown up. Well, you're grown up, but you're not a real grown up."*

JL   *"OK."*

K   *"You're not an adult. You're not a teenager, but you're not a baby, either."*

JL   *"No, no. That's right. What's an adult, then?"*

K   *"Someone over 21."*

JL   *"Someone over 21. And what can adults do that you can't do?"*

K   *"Drive, drink."*

JL   *"Drive and drink."*

K   *"They can look after you better."*

JL   *"Do you think when she said to you, 'I've had that done and it doesn't hurt', did it help?"*

K   *"I don't know."*

JL   *"Can you remember how you felt when she said it?"*

K   *"I really don't know."*

JL   *"Was it only then, when she went to touch your bag, you said it was really sore? ... I've come back today and you've found a solution. You can have it clamped."*

K   *"Uh-hum."*

JL   *"So how did you work that out?"*

K   *"Well, when they went to the right side [of the bed], it was sore. So when she was there, I clamped it and it worked."*

JL "You just did it by chance?"

K "No, I just went, 'What's that white thing?' and pressed it in, and it worked."

JL "And what did she say, the person who was here when you clamped it?"

K "She kind of knew."

JL "She kind of knew? Who was it?"

K "It was... I think it was that nurse [points to Mandy]."

JL "This one here?"

K "Yeah."

JL "And does everybody do that for you now?"

K "Yep. Well, they don't do it. I do it."

JL "Right, OK. Because you're only clamping it for a minute, that's okay with the consultant, is it?"

K "I don't know. It's just a minute or so."

JL "So not very long, is it? And it worked. Why do you think that worked so well?"

K "Because it kind of stops... well, it isn't touching your bladder. There's nothing near your bladder. And like, what's inside isn't even going near your bladder."

JL "Right."

K "When it's clamped."

JL "And you think that's why it works?"

K "Yeah."

JL "So you found the answer to the problem?"

K "Yeah."

JL "Is that the best way to do it?"

K "I wasn't sure."

JL "Mmm."

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K *"Or not have it at all."*

JL *"So the best thing would be not to have it at all?"*

K *"Yeah."*

JL *"But if you've got it, the best thing is ...?"*

K *"Clamp it when you're getting it, like, emptied."*

JL *"You clamp it when it's getting emptied? And you worked out that that works. Would you tell other children that that's what they have to do in the future?"*

K *"Yeah, I would suggest that, yeah."*

JL *"You would suggest it? That's interesting, isn't it?"*

K *"Yeah."*