
Children's Participation in Healthcare in the UK — Gesture, Rhetoric, or Real Involvement?

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In the United Kingdom (England, Wales, Scotland, and Northern Ireland) children and their best interests are protected through a range of best practice initiatives, and legislation and guidance at country, national, European, and global levels. Some of the recent commitment by the government may be the result of enlightened thinking, but some of it has resulted from the aftermath of at least two major healthcare incidents. This article reviews the UK's recent national and international efforts to protect its thirteen million children and ensure that their voices are heard.

In the United Kingdom (England, Wales, Scotland, and Northern Ireland) children and their best interests are protected through a range of legislation and guidance at country, national, European, and global levels. The United Nations Convention on the Rights of the Child (1989) established benchmarks that Britain could only ignore at its peril, and much of the legislation within the UK has been derived to a greater or lesser extent from the Convention. For example, in England, the Children Act (Department of Health 1989, hereafter, DoH) focuses on the welfare, safety and well-being of all children; particularly those in vulnerable circumstances. The Children Act is premised on the belief that whenever possible children should be brought up and cared for within their own families. The law aims to

... strike a balance between the rights of children to express their views on decisions made about their lives, the rights of their parents to exercise responsibilities towards the child and the duty of the state to intervene where the child requires it (DoH 1989, paragraph 1.1).

Needless to say, this balance is delicate and fragile. Other legislation has followed, the most major instance being the Human Rights Act (1998), which became law in October 2000. This law sets forth the rights of individual citizens with implications for consent and involvement in decision making.

Other guidance specific to children is in place. For example, the Patient's Charter (DoH 1996), which is effectively a children's healthcare charter, identifies children and young people's right

"Participation is a little like eating spinach: no-one is against it in principle because it is good for you."

—S. Arnstein (1969)

to be involved in their healthcare. Its provisions guide the work of the Children's Task Force in the Department of Health. Additionally, the government has a strategy and action plan to involve chil-

dren and vulnerable young people through listening, hearing and responding to their perspectives (DoH 2002). In the UK the boundaries between health and social care are breaking down and the issue of participation affects children in both settings. Interestingly, Murray and Hallett (2000) note that an anomalous situation may be developing in the UK in which (vulnerable) young people in welfare systems may be more active participants in major decisions affecting them than other young people in the UK.

Standard setting and comparison of practice has become central to health-care in the UK.

Focusing specifically on healthcare, the Child Friendly Hospital Initiative (CFHI, a collaboration between UNICEF and a number of other partners) is being piloted in the United Kingdom and in Kosovo, Pakistan, and Uganda. This program is proving influential well beyond the pilot sites (Southall et al. 2000). The CFHI is concerned with the physical, psychological, and emotional needs of children and their families. The CFHI promotes twelve standards, based on the mandate of the U.N. Convention on the Rights of the Child. These standards are globally applicable and apply regardless of where the healthcare contact takes place (e.g., home, hospital, community, or out-patient health facility). Standard 5 states: that "[t]hey [children] and their parents/carers are kept consistently and fully informed and involved in all decisions affecting their care" (www.child-friendlyhealthcare.org).

Standard setting and comparison of practice has become central to healthcare practice in the UK. Pediatric benchmarking, developed within the author's own institution, has led the way within the UK for sharing and developing best practice within children's nursing (Ellis 2000, Bland 2001). Basically, benchmarking is a continuous quality improvement approach that "supports the development of quality care" (Ellis 2000, p. 217).

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Benchmarking itself has seminally influenced the development of the Essence of Care initiative (DoH 2001a) that is being implemented across the National Health Service in England. Other frame-

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works of care, such as the one pioneered by Brook (2000), have been developed to help empower children (and their parents) to make choices about their care and treatment. There is, at national level, a commitment to involve users, caregivers, and user-groups in policy development, and Action for Sick Children has long fulfilled this role as a very influential parent-led pressure group. It has lobbied extensively for the rights of children and their parents in relation to healthcare services in the UK.

Children's nurses, through their professional organizations, have also emphasized the need to include children within decision-making processes. Many children's nurses in the UK espouse partnership nursing (Casey 1988) as *the* way to nurse children (although this is highly debatable), and research shows that nurses believe that involving children is essential (Miller 2001). As consumers of health services, children (and their families) are essential contributors to the planning and

development of children's nursing curricula and actively contribute their expertise to the delivery of classroom-based sessions. Parents and children, as key members of consumer groups in healthcare settings, advise on areas where nursing practice can be celebrated or improved and where developments in children's nursing education would benefit future practice (Sawley 2002).

So all's O.K. in the good old UK?

With abundant legislation, governance, and guidance, on-message ideology and philosophy, and the rise of consumerism and citizenship, UK must be serving its thirteen million children well. But, and it is a big but, much of the research that has been undertaken in the UK suggests that we (healthcare professionals) are either getting it wrong or falling some way short of addressing best practice. It would be easy to paint a gloomy picture of British children's involvement in decision making in general in healthcare (and healthcare research specifically). However, this picture would not reflect the totality of the situation or do justice to the perceived tensions.

Britain, like many other countries, has a somewhat paradoxical attitude and approach to children, and these attitudes and approaches are reflected to a greater or lesser degree in its healthcare services. There are still many children's voices falling on deaf ears (and minds). Within European law children are largely invisible (McGlynn 2002). A recent report on children's policy in the European Union (Euronet and Ruxton 1999) highlights the fact that it is "very difficult to identify children's wider needs and the issues that require priority political action" because of limited data.

Without adequate data, there are problems in achieving objectives such as enabling the "planning of EU legislation, policy and services to take a children's perspective into account." However, the EU Charter of Fundamental Rights which is soon to be adopted includes a specific provision on children and McGlynn (2002) states that it represents a "significant new phase in the EU's relations with children," and will "provide sup-

port for those demanding a more integrated and thoughtful approach to children in the Union."

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Qvortrup (1994) suggests, children are increasingly being seen as "human beings" rather than "human becomings." Certainly, within the UK, the current political and ideological zeitgeist embraces inclusion, involvement, and responsiveness to children (DoH 2002). However, the discourses on children and participation are complex, and, as Kjørholt (2002) proposes, many of these discourses are deeply embedded within other discursive fields.

Some of the recent commitment by the government can be considered a result of enlightened thinking, but some of it has resulted from the aftermath of at least two major healthcare incidents in the UK. These incidents are more fully described later in the paper but are often referred to as the Bristol Heart Scandal and the Alder Hey Organ Scandal.

While the impact of these incidents has been felt across all age-groups it has resonated particularly strongly within children's services. These reports provide a context to the contemporary drive to deliver effective, appropriate services and more fully involve children. Though they are not directly related to children's involvement (or lack of it), both reports highlight the fact that, despite some legislation, children as a group in the UK have too easily been seen as "Other." As such, their voices and needs have not been prioritized.

The Impact of Recent Public Inquiries

In July 2001, "Learning from Bristol: The Report of the Public Inquiry into Children's Heart Surgery at the Bristol Royal Infirmary 1984–1995" (DoH 2001b) was presented to parliament. It found that "a substantial and statistically significant number of excess deaths, between 30 and 35, occurred in children under 1 undergoing PCS [paediatric cardiac surgery] in Bristol between 1991 and 1995." The report shook the foundations of healthcare practice in the UK and found, among many other equally important issues:

a wider systemic weakness in the formation of policy in government, in that the particular needs and the voice of children and young people are generally given a low priority. This is despite the recognition in the UK of the UN Convention on the Rights of the Child, such that this recognition may appear to some to be a triumph of gesture over action (DoH 2001b).

This report demanded and received attention from professionals and the government. The ramifications of the report continue to be felt today. It is more difficult now for children to be put at the bottom of anyone's list of priorities in healthcare. A new National Children's Task Force has been appointed, along with a "children's czar" to lead the Children's National Service Framework (NSF). This NSF, which is currently being developed, is one of the most important outcomes of the report and includes such themes as partnership working, empowerment, and inclusiveness (DoH 2002).

Early in 2001, the report of the Royal Liverpool Children's Inquiry (DoH 2001c) was published. The press had a field day. This inquiry "set out to enquire into the removal, retention and disposal of human tissue and organs [from children] following Coroner and hospital post mortem examinations and the extent to which the Human Tissue Act 1961 (HTA) had been complied with." The report makes bizarre and gruesome reading in relation to the "large" collections of organs and tissues and the extreme distress experienced by the parents whose children had been "systematically stripped of his

or her organs" at post mortem without parental consent.

Because parents had not consented to the removal and retention of their children's organs and tissues at post mortem, consent or rather lack of consent became a key issue within this report. Although the focus was primarily on consent for post-mortem, the report has had a major impact on the way in which consent is now considered in all health and social care situations in the UK. This report has had, and continues to have, major repercussions for all healthcare practitioners and researchers and ultimately on the bodies governing and funding healthcare and research.

Participation or Protection?

Needless to say subsequent to the reports from Bristol and Liverpool there was a sense of heightened concern within society about all issues related to the ethics of research on or with children and children's involvement in decision making in general. Children had become (for a time at least) a political priority. They were important to the government who needed to be seen as responding to the pervasive concern (or embedded discourse) in society that children should be protected. The tensions are obvious – the need to involve children (and thus perhaps expose them to risks) is still perceived by some, to be at odds with the need to protect them (and thus reduce risk exposure). However, I would argue that involvement does not necessarily increase exposure to risks – the risks are different and need to be balanced.

Children in the UK are still perceived as vulnerable. Indeed, this vulnerability is identified within the Bristol Inquiry Report and perhaps therein lies a problem. The report states:

Children are a vulnerable group. They lack the means to speak up for themselves in the complex world of healthcare. It falls to adults, therefore, to protect their interests. If adults fail to do so, they fail the children to whom they owe a duty of care and who have rights which demand protection. (DoH 2001b, Section 2, Chapter 29, para 3, p. 425).

On first reading there would seem to be little wrong with this statement: basically children have rights, and adults have obligations. However, seeing children as different from us (adults) means that they can be seen as "Other." The above paragraph talks of children lacking the means to "speak up for themselves" and that adults must "protect children's interests." The problem that I have with this is that if children lack the means to speak, then healthcare professionals should be providing them with opportunities to speak and ensuring that we listen and respond.

Protecting children's interests might not seem to be contentious, but if we value children as credible reporters of their own experiences then they can protect (to a greater or lesser degree) their own interests. Adults should not necessarily or always mediate children's worlds. As Davie (1996) states: "The child after all can provide — given the chance — unique, often vital information about the matters under consideration.

Taking a stance in which adults are the sole protectors of children's interests implies that adults know what the interests of children actually are. Children do not necessarily agree with this notion. Children have their own social frames of reference in which they can be competent social actors. The overwhelming evidence from studies with children highlights that they value being involved and that they are competent participants. Research shows that children benefit from involvement and recognise when their views are overlooked or ignored (Carter 2002a, Carter in press). As one eleven-year-old boy stated:

They don't listen. . . . They just go on talking to each other. It's like they think I won't understand 'cos I've just beamed down from Planet Stupid — but I'm 11 years old and I do understand. You know, if anyone's from Planet Stupid it's them!"

The need for healthcare professionals to get it right is obvious. Despite our very best intentions we can very easily assert an adult orientation on children's voices, perspectives and desires. A story from a recent study (Carter, 2002b) clearly illustrates this.

Children had assented to generating data for me by completing scrapbooks about their perceptions of a new nursing service. In turn I had reassured them that I would help and support them. Jessica aged six, asked me to help her with the glue and glitter stage of a picture in her scrapbook. In my infinite (and adult) wisdom I decided that glitter and glue would be too messy (but not unsafe) to deal with in the back of a minibus that was going at 60 miles per hour down the motorway.

Jessica said that I'd promised to help her and now I was letting her down. I immediately started

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an explanation about why it would be inappropriate to get the glitter and glue out until I suddenly realised that Jessica's request was perfectly reasonable. We spent the next 10 miles or so coloring, glittering, and glueing in a delightfully messy but productive way. Jessica was happy with her picture and I was delighted with the data. This example is not one that reflects a dramatic, life and death situation but it does very clearly indicate how adults can listen but not hear or respect children's views and make adult-oriented decisions based on their own assessment of the situation. Our decisions are not necessarily the best. Children can teach us a lot about what is important.

Conclusion

There are many examples of excellent practice in the UK that demonstrate healthcare professionals "getting it right" for children. Many studies illustrate practice areas in which the transition from gesture to action has actually taken place (e.g., Brook 2000, Woodfield 2001, and Moules 2002).

Yet despite instances of excellent practice, other studies create more depressing reading. Work on the needs and aspirations of young ventilator dependent children (Noyes 2000) shows, for example, that children often feel marginalized and not involved in everyday decisions about their lives and care.

The journey to full participation is far from complete but significant moves forward have been made. In this respect I do not imagine that the UK is so very different from the USA. Mohr and Kennedy (2001) wrote eloquently of the complexity of reasons why children's voices are not routinely heard in the USA. In the UK, at Government level, rhetoric is gradually changing into real action and we are optimistic that it is not simply a case of gesture politics. The Department of Health's (2002) action plan for a NSF for children and child health services, identifies core principles for the involvement of children and young people. A key commitment within this document states:

Making change happen for children in the health service is much more than just the medical care of sick children – very important though that is. Children with illness, . . . must be cared for not only in terms of their medical, social and educational needs but also in the light of their own views and decision-making (p.4).

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It now becomes the responsibility of each and every healthcare professional to ensure that sick children receive the best of care and that they can actively participate in that care. It is, as Arnstein (1969) proposes, no good knowing that spinach (or participation) is good for children and health-

care professionals, we actually have to come to grips with participation and make sure that it happens.

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