

CHOOSING FOR AND WITH CHILDREN

Consent, assent and working with children in the primary care setting.

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ABSTRACT

The complex ethical and legal concepts of consent, assent, capacity and best interests merit a fine-grained scrutiny in the context of providing healthcare for children. Empirical evidence points to children being much more competent than we are often prepared to admit and their views and concerns are not always given sufficient attention. Various models and guidelines help practitioners to redress this deficit and to assist in shared decision making with children and their parents. In addition, there is a case for adopting a more family centred perspective rather than an adversarial legalistic approach.

INTRODUCTION

General practitioners in the UK care for children on a regular basis; consultations involving children form over a quarter of their normal practice and 90% of children see their GP every year. But how much do GPs pay attention to how they engage with and seek assent or consent from their younger patients? How do they seek to ascertain whether children understand what they are proposing for them, and if they are content with these proposals? How much of this conversation is controlled by their caregivers?

In this article we shall be critically examining the ethical and legal frameworks, as well as the relevant empirical data regarding the concept of capacity, and the processes for seeking consent for and from children. We shall consider the distinction between assent and consent. We shall not be considering the law in relation to minors, and sexual and reproductive activity, albeit an important topic, as it merits a detailed review and is extensively covered elsewhere. Nor shall we be covering child protection issues, again a topic that deserves an article in its own right.

CHILDREN'S RIGHTS TO PARTICIPATE IN DECISIONS REGARDING THEIR WELFARE

From the late 1960's to the early 1990's the rights of children have been made more explicit and more robust in the UK and internationally. The 1989 United Nations Convention on the Rights of the Child, ratified by the UK in 1991, creates positive obligations on states to ensure that resources and services are made available to serve children's needs and interests. It mandates the right for every child to dignity, respect, and the opportunity to participate in decision-making.

With regard to consent, Article 12 states that the views of the child are given due weight in accordance with the age and maturity of the child. The

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European Association for Children in Hospital (EACH)'s charter, adopted by the European Union in 1986, states in Articles 4 and 5:

“Children and parents shall have the right to be informed in a manner appropriate to age and understanding. Steps should be made to mitigate physical and emotional stress. Children and parents have the right to informed participation in all decisions involving their health care. Every child shall be protected from unnecessary medical treatment and investigation”.

The UK Children's Act 1989 also states that children's wishes and views should be taken into account in decisions concerning them. Rights, however, do not confer *per se* automatic protection, for they require an environment in which they are valued and where the relevant resources are available. For example, some countries, despite legal prohibitions, tolerate the custom of child marriages even though this is damaging to the physical, emotional and reproductive health of the young females involved.

In the UK, the repeated failure of society to protect children from sexual and physical abuse is evident from the many reports of children who have suffered from sustained cruelty or neglect, some dying as a result. Furthermore, unlike the majority of European countries, children are accorded less protection from assault and battery than adults. The Children's Act 2004 allows the legal defence of 'reasonable chastisement' when hitting or smacking children, despite evidence that this is ineffective and may be harmful to emotional and cognitive development. This contravenes the recommendations of the UN Committee on the Rights of the Child and of the European Committee of Social Rights, the latter prohibiting corporal punishment, however specified.

The situation regarding children's well-being in the UK is not so good either. In a UNICEF report of well-being in childhood, the UK was ranked 18th out of 21 resource-rich OECD countries. In another study, the UK was ranked 24th out of 29 European countries for children's overall well-being. A report commissioned by the Children's Society found that the second most important factor associated with overall well-being was the amount of choice the child experienced in life (the first being happiness with family). This underlines how important this issue is for children.

LEGAL CAPACITY AND CONSENT IN THE UK

In law, assessment of capacity is, on the face of it, relatively straightforward. But in real life the

situation is considerably more nuanced and complex, particularly when dealing with an individual who will sooner or later acquire full capacity (or has capacity in some domains but not others) and who may already hold a set of values and beliefs that are set to withstand the course of time.

Capacity is defined as being able to:

- Understand and retain the information relevant to the decision
- Use or weigh up the information
- Communicate the decision by any means.

In UK law chronological age is not determinative of capacity, and competency is determined by *Gillick*, whereby the minor is deemed to have capacity:

...“if and when the child achieves a sufficient understanding and intelligence to understand fully what is proposed”.

The vagueness of the above language allows for considerable scope in interpretation and ultimately relies on professional judgment. A Gillick-competent minor is entitled to the same rights as adults in terms of consent and confidentiality. There may be occasions, however, when a minor refuses disclosure. This refusal may be overridden, according to professional guidance, if disclosure is:

- Against the public interest.
- Necessary to protect the child or young person from risk of death or serious harm, for example, neglect, sexual, physical or emotional abuse.
- The minor may be involved in behaviour that could put them or others at risk such as serious addiction or self-harm or joy-riding.

In relation to refusal of treatment, the picture becomes more complicated in that UK law has evolved in such a way that can be only described as a retreat from *Gillick*.

In two key cases (*re R* and *Re W*) the court decided that even a *competent* minor's refusal could be overridden. Furthermore, commentators have remarked that the stringency required for demonstrating competence appears to be greater for minors than for adults. In *re W*,¹³ Lord Donaldson described consent as fulfilling two purposes: firstly, providing a legal justification for doctors (using a flak jacket analogy) that protects them from the tort or crime of battery, and secondly, securing trust and cooperation. In other words, legal consent provides the 'bottom line'. Those with parental responsibility can provide proxy consent for the child or young

person. Parental responsibility includes the right of parents to consent to treatment on behalf of a child provided the treatment is in the child's best interests and the child cannot provide valid consent. The Children's Act 1989 outlines who has parental responsibility.

THE PROBLEMS WITH THE LEGAL MODEL

In essence, the law in relation to minors can be viewed as too simplistic by focussing only on one individual or body competent to make the decision (using a key holder analogy as in *Re R¹²*), and yet too diffuse in that there is the lack of a clear definition of competence. It can also be viewed as contradictory (a competent child can give consent but have refusal overridden).²⁹ Alderson criticises the law for failing to be child-centred, for focussing on the decision-maker and the protection of doctors, rather than promoting children's rights, and for providing an all or none understanding of decision making rather than offering a shared decision-making model. In fact, children who are not Gillick competent are not given any legal right to participate in decision-making at all.¹⁹ Furthermore, children may not be living in a stable home environment and may have a more stable and balanced viewpoint than their parents.

ALTERNATIVE MODELS FOR CONSENT

Alderson and Montgomery argue convincingly that children should play a greater role in decisions about their own health care. They point out that 'ignorance' is often based on lack of information or opportunity, and that experience may be far more significant than age in determining understanding. They argue, with examples drawn from empirical research, that children should be presumed competent for some procedures, even from the age of five, and set out a list of recommendations for a code of practice. These include advice as to how to give information to children with a variety of methods (e.g. drawings, books, toys), and how to determine understanding and preferences. Most of these recommendations are applicable to the general practice setting.

Other authors, having found that children even aged five to six years had a good grasp of the fundamentals of death support this radical view of children's capacity. The Royal College of Paediatrics and Child Health also considers it the duty of professionals to go beyond observing minimal legal standards and to demonstrate higher ethical standards of respect for children's views and concern for their welfare.

Alderson and Montgomery propose that the onus should be for the adult to demonstrate that the child is not capable of making the decision in question rather than the child having to prove competence. This aims to prevent professionals from 'following their instincts' without evidence. The value of parental support and guidance is not discounted. However their suggestion is that parents can still provide valid consent for their children providing that they do not exercise this power against the wishes of the child. In the latter situation, they propose that the health professional would have to ascertain that this represented a competent refusal. And if so, to respect the child's decision, subject to the supervisory role of the court and legal safeguards being in place for extreme cases, where refusal would lead to death or serious irrevocable harm. This position, however, does not chime with the existing common law .

SEEKING CONSENT FROM CHILDREN AND PROXY CONSENT

Priscilla Alderson, in her groundbreaking book, *Choosing for Children, Parents' consent to Surgery* based on empirical research, describes three broad strands running through proxy consent: firstly, 'moral feelings' (such as compassion and trust); secondly, medical and parental power; and thirdly the practical aspects in the design and running of wards and clinics that encouraged or excluded families.

Consent is a process and not a one-off event, and may sometimes require multiple discussions and conversations. Trust can be crucial for parents and for their children in responding to medical advice. As Alderson and Montgomery point out, the ideal of partnership in making decisions with health care professionals can be more challenging with children and young people; often involving a tripartite relationship where the child's role can be overlooked or eclipsed, particularly with younger children.

Children can be helped to develop competence by involving them from an early age in decisions regarding their health care. Even though this may involve more time and effort, including overcoming an initial reticence (but not willingness) to take decisions, it should be seen as an ethical imperative. This is particularly relevant in general practice where there is the opportunity for relationships to develop over time. Gaining children's participation in decisions is more likely to foster trust and improve long-term outcomes. If children are ignored, their hidden beliefs and concerns may never be uncovered, and they may infer that their views are of no relevance, causing disempowerment, disengagement, alienation and even hostility.

ASSENT

Including assent of young persons in the process acknowledges the importance of children's participation and empowers them to the extent of their capacity.

Assent should include the following elements:

- Helping the child to achieve a developmentally appropriate awareness of the nature of his or her condition.
- Explaining what s/he can expect from tests and treatment.
- Evaluating understanding and the factors that may be influencing the child.
- Gaining the willingness of the child to accept the proposed care without deception or coercion.

LEVELS OF PARTICIPATION

Several useful models of participation exist in the literature to guide those who work with children. For example, Hart's 'ladder of participation' (adapted from Arnstein) involves 8 levels. The first three ('manipulation', 'decoration' and 'tokenism') represent non-participation and the last five represent ascending levels of participation, starting from 'assigned but not informed' to 'youth-initiated, shared decisions with adults'.

Other models emphasise the importance of empowerment or opportunities and obligations. The Royal College of Paediatrics and Child Health also favours a stepwise approach starting with the provision of information in a child-friendly manner, to allowing the child to be the main decider.²¹

Lansdown advocates a more holistic approach, encouraging health professionals to explore:

- How decisions are made in the family.
- What decisions does the child already make at home and at school.
- What experience does the child have of this and other illnesses.
- The child's understanding of the disorder, the reasons for and the nature of the treatment, the risks and benefits, consequences and time frame.

Clearly one would not expect a practitioner to undertake this process at every consultation for a minor illness, but for a child with a chronic disease, these approaches may be of real value. Professionals should also consider how much time and space has been given to the child and whether he/she (the child) had the opportunity to talk to the professional alone and on more than a one-off occasion.

Recent neuroscientific and psychological research has shown that babies and children are considerably more intelligent than we had imagined – their brains work differently but are remarkably flexible and efficient.

BEST INTERESTS

What exactly do we mean by 'best interests' when considering infants, children and adolescents? 'Best interests' is a term that is widely used as a basis for policy and decision-making in clinical, social and legal contexts. It runs the risk of being presented as a checklist of considerations (see below), which can be ticked off in a routine formulaic manner without real understanding or reflection.

Kopelman gives a thoughtful and clear analysis of the concept, describing its historical development, and unpacking its different applications. She identifies three broad strands of usage, and provides robust rebuttals to the criticisms levelled against the best interests standard.

Firstly, the standard can be used as a threshold for intervention and judgment in child abuse and neglect cases when parental choices are considered to endanger a child. The next step is to decide what is best for the child in those circumstances, by using a standard of reasonableness and determining an acceptable standard of parenting.

Secondly, one can use best interests as a kind of gold standard - an ideal to promote children's welfare and/or to establish *prima facie*, rather than absolute, duties towards them. Ideals and aspirations can act, the author suggests, as lighthouses in the sea, giving us perspective and steering our course when making decisions. Considering what one can provide in an ideal world helps us to decide on the next best alternative, taking into account the limitations of real life.

Thirdly, the 'best interests' standard is used as a standard of reasonableness, guiding us to select wisely amongst available alternatives and to choose what most informed, rational people of good will would regard as maximising net benefit and minimising net harm, but allowing for the legitimate rights and interests of others.

The 'best interests' standard is criticised as being too wide in its scope, but, as Kopelman points out, judicial decisions include pragmatic considerations and the balancing of competing interests. For example, in *Re C*, the judge ruled that an infant should be tested for HIV, contrary to the wishes of both parents, but he allowed the HIV-positive mother to continue to breast feed. Another criticism

is that the best interests standard, enshrined in the phrase ‘The welfare of the child is paramount’¹⁶ is too individualistic and does not take into account the needs of others, is again not borne out by judicial decisions. For example, in *Re B*, resource limitations were acknowledged as a legitimate consideration. Some parents, however, manage to champion their children’s cause to obtain charitable contributions towards obtaining very expensive (and sometimes experimental) treatments.

Additionally, the ‘best interests’ standard is criticised for being vague in that one cannot be certain of the consequences – a problem that is inherent in all kinds of consequential reasoning. For example, nearly all clinical decisions are probabilistic – in fact, uncertainty and lack of data bedevil nearly all domains of life. One criticism that is difficult to rebut, however, is that decision makers often do not articulate or justify their norms, such as their views on the legitimate scope for professional responsibility or what constitutes adequate parenting. This was considered to be the case regarding the court of appeal’s decision to allow the separation of the conjoint twins, Jodie and Mary, and was eloquently criticised by Gillon.

A FAMILY CENTRED APPROACH

Children do not live in isolation and their wellbeing is strongly dependent on the nature of their attachments within the family. In fact, there is a case to be made to consider the family *per se* as a moral unit without allowing this to completely eclipse the needs and interests of the more vulnerable members of the family. The moral relevance of families does not often enter bioethical discourse - a deficit that Nelson and Nelson seek to remedy by introducing an ethics for families – “a theory of the special moral values of intimacy, in particular, of familial relationships”.

Because family members are bound together in a complex web of love and obligation, life-projects and traditions – a web valued for itself as something that makes life good – a family member will often find it rational not to appropriate the best for himself, but to take turns with the others.

Cultural differences also need to be taken into account for those to whom an atomised individualistic view may be viewed as alien and unacceptable. Furthermore, the welfare of other members of the family needs to be considered and put in the balance.

DUTIES OF PROFESSIONALS

If a minor is judged to be incompetent and requires medical care, then a professional has to act in the young person’s best interests and try to locate an individual who has parental responsibility and can

consent on the behalf of the young person. In an emergency, health professionals acting according to the legal doctrines of Necessity and Best Interests may take this responsibility.

The Mental Capacity Act (MCA) 2005 REF provides a statutory framework that empowers and protects vulnerable adults who are unable to make their own decisions, and provides guidance and a legal framework for those involved in their care. The MCA does not apply to those under 16 years except for the offence of ill treatment or wilful neglect of a person who lacks capacity within section 2(1). Most of the Act applies to young people aged 16-17 years, except that they cannot make a lasting power of attorney, or an advance decision to refuse medical treatment, or a statutory will.

In summary, the BMA sets out points to consider when deciding on best interests:

- Patient’s wishes, feelings and values.
- Ability to participate in decision making
- Physical and psychological needs
- Risks of harm
- Views of parents and family
- Implications for family of (no) treatment.
- Patient’s religious or cultural background
- Evidence of effectiveness of treatments
- Maximising patient’s future opportunities
- Risks from delayed treatment or non-treatment.

BEST INTERESTS – SHOULD PARENTS DECIDE?

Are parents the best placed to decide on the best interests of their children? This is a contested issue and has been raised in a number of legal cases where parents have either refused treatment for religious or other reasons, or else have demanded treatment against the recommendations of doctors.

Downie and Randall argue that the parental right to decide can best be justified by the importance of preserving intimate family relationships, rather than in terms of preserving best interests. They point out that parents will be taking into account the total good of the whole family, including the good of the siblings of the minor in question. They may not always be motivated by altruism or may take the view that certain moral absolutes are more important than the child’s wellbeing or his/her continued existence. In general, if there is disagreement between doctors and parents, a conversational non- adversarial approach is favoured, rather than settling the dispute in court. But sometimes the latter is the only way forward. These disputes can sometimes end in considerable acrimony.

CONCLUSION - THE WAY FORWARD

Children are smarter than we think. The consensus is that we should make efforts to engage with them and include them in decisions regarding their health care from an early age as possible. A model of shared decision-making and a stepwise approach for capacity and consent – absent from the legal framework, but present in all the professional guidelines – should form part of standard practice. General practitioners are particularly well placed to adopt this approach given their multiple sequential consultations with children and their role as family doctors.

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Submitted: 22 February 2010

Accepted for publication: 10 March 2010