

## Debate

# The family rule: a framework for obtaining ethical consent for medical interventions from children

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### Abstract

*Children's consent to treatment remains a contentious topic, with confusing legal precepts and advice. This paper proposes that informed consent in children should be regarded as shared between children and their families, the balance being determined by implicit, developmentally based negotiations between child and parent—a "family rule" for consent.*

*Consistent, operationalised procedures for ethically obtaining consent can be derived from its application to both routine and contentious situations. Therefore, use of the "family Rule" concept can consistently define negligent procedure in obtaining consent from children, and could be used as a unifying framework in the development of new professional guidelines. A "guideline"-based approach to children's consent to treatment may offer greater individuality than a "rights"-based approach, though careful training and oversight will be needed for it to be effective.*

*(Journal of Medical Ethics 1999;25:491–496)*

**Keywords:** Child; adolescent; consent; guidelines

### A contemporary confusion

We do not know how to obtain valid consent to treat children. Laws, guidelines and advice all exist, but at present they contradict each other, or lead to consequences that may be unsatisfactory.

### Legal frameworks

In England and Wales, children's legal ability to agree to treatment is largely defined by case law, though the Children Act<sup>1</sup> does permit refusal of medical or psychiatric examinations by children deemed competent. The case of Gillick v W Norfolk & Wisbech AHA<sup>2</sup> established that the age at which a child is competent to give consent is based on professionals' judgment of whether the child has capacity to understand the significance and implications of the offered procedure. Other cases<sup>3,4</sup> since have separated refusal of treatment

from consent for treatment.<sup>5</sup> Now, children have no final right to refuse treatments—even if supported by their parents—before the age of eighteen. These decisions apply both to mentally ill youngsters and to mentally well youngsters who have refused treatment through religious conviction. However, judges are reluctant to intervene in such cases, and prefer the matter of consent to be dealt with whenever possible by professional agencies.<sup>6</sup>

In the United States, the position is quite different. Contrary to their English counterparts, American judges have decided that the ability to consent to a treatment implies the ability to refuse it.<sup>7</sup> This has led to the development of the concept of "assent". Children are considered to "assent" (or its alternate, "dissent") when they have sufficient competence to have some appreciation of a procedure, but not enough competence to give fully informed consent.<sup>8,9</sup> The age of assent is currently estimated as being about twelve.

Both of these frameworks raise problems for the practitioner. The English approach seems muddled. For example, children may not refuse treatments, but can refuse examinations. The child's consent is related to agreement with the practitioner, as well as to the child's developing autonomy. In general, English law provides children with fewer safeguards against coerced treatments than mentally ill adults.<sup>10</sup> Therefore, it has been subjected to blistering academic criticism.<sup>11,12</sup> However, it can be philosophically justified, using the concept of coherence.<sup>13</sup> In the Gillick case, evidence for the child's capacity came from the child agreeing with a decision the doctor already considered rational ie, the child's rationality was coherent with the doctor's, and so could be considered equivalent. This additional qualification did not apply in either *re R* or *re W*. Therefore, despite evidence for the intellectual comprehension by *R* and *W* of the proposed

interventions, it is not possible to claim that R or W were able to follow a freely and *rationally* adopted (moral) policy, and so it was adjudged that they lacked autonomy.<sup>11</sup>

Assent does not address the point. The practitioner controls the delivery of the intervention. Agreement with the intervention is one factor the practitioner has to take into account before proceeding. Therefore, the practitioner needs to know how to *respond* to agreement or disagreement from the child, the parents or both. Calling the child's agreement "consent" or "assent", and the parents' "proxy consent" or "parental permission" does not tell the practitioner how to respond to them, or how they differ. In fact, guidelines for obtaining assent are equivalent to those for obtaining consent.<sup>9, 15</sup> Therefore, assent disguises, rather than resolves the difficulties apparent in English law.

### Guidelines for good practice

In the United Kingdom, professional guidelines for obtaining consent in children have been developed for clinical practice,<sup>15, 16</sup> and for research.<sup>17</sup> However, their effectiveness has been challenged. Many newly qualified doctors are unaware of them, and have had no training in obtaining consent from children, even though practitioners find this difficult.<sup>18, 19</sup> At present, perhaps as many as one in five children are receiving mental health treatments against their wishes.<sup>20</sup> Children should not be exposed to significant risk solely for research purposes.<sup>21</sup> However, there is no generally applicable categorisation of "risk".<sup>18, 22</sup> Furthermore, the justification of "proxy consent" (where a caretaker consents for the child) is much weaker in research.<sup>23</sup>

### Ethical recommendations

Two broad trends have developed here. One emphasises the importance of autonomy, usually within a rights-based perspective.<sup>12, 23</sup> There is a stringent approach to proxy consent, with emphasis on external oversight and legal remedies. The risk is rigidity, and a failure to accommodate children's developmental limitations. In research, such emphases may materially impede children's ability to make beneficial contributions to society as a whole.<sup>24</sup> The alternative approach considers the child's consent within the child's social network, respect for the child's autonomy being a benefit provided for the child.<sup>25, 26</sup> However, the combination of caretaker and practitioner is not in itself sufficient to guarantee the child's welfare—some external oversight is also needed.<sup>27</sup> There is

no compelling reason to give primacy to the principles of either respect for autonomy, beneficence,<sup>13</sup> and so this conflict remains unresolved.

Empirical research is not consistent with a generally applicable "age of consent". Concepts of personal cause and effect are well established by 24 months.<sup>28</sup> Behaviour showing understanding, acquiescence to everyday requests, and behaviour showing concern for the benefit of others is apparent by 18 months.<sup>29, 30</sup> Thus, children have the basic abilities required for consent by their second birthday. By the age of seven, emotional factors are *more* important than developmental factors in predicting comprehension of medical procedures,<sup>31</sup> and the use of appropriate techniques could significantly improve younger children's comprehension of medical procedures.<sup>32</sup> But, children's comprehension of medical procedures is limited compared with adolescents,<sup>33</sup> and children between six and twelve understand psychiatric hospitalisation in general, rather than individualised terms.<sup>34</sup> This fits the modal age which United Kingdom patients, parents and practitioners think children can make decisions about surgery,<sup>12</sup> and the age of assent. However, adolescents lack the social independence needed to make fully autonomous decisions, being vulnerable to external pressures, and benefiting from firm guidance.<sup>35, 37</sup> We have seen that the standards applied to children's autonomy shift in a conservative direction when refusing treatment is dangerous. Thus, both situational and developmental considerations should affect our approach to consent in children.

This paper contributes to the current debate on consent in children by proposing the concept of "family rule". It tries to show that this concept—defined below—is a useful organising principle which clarifies many of the difficulties currently besetting this debate.

### Consent and the family rule

There are two broad classes of consent. When practitioners seek consent, they usually want to perform some action. The subject therefore consents to experiencing an event. *Consenting to an event* can be contrasted with *consenting to a rule*. In this latter case, one agrees to follow a set of prescriptions and prohibitions that regulate one's general conduct. Examples might include joining a monastic order, or the army. Consent to a rule takes primacy over consent to an event. Consider a soldier in the army who goes absent without leave. At this point, the soldier has withdrawn consent to follow the instructions that kept the soldier in barracks. However, both the army and

the soldier accept the need for punishment in these circumstances. Indeed, one punishment the army can inflict is to refuse to accept the soldier's continuing commitment to the rule—"dishonourable discharge". Thus, consenting to a rule can legitimately circumscribe exercising one's right to consent in ways that break the rule.

For children, the most important rule they consent to is that of their family. Acceptance of the family rule implies that parents may inhibit their children's right to consent. However, the family rule, and children's consent to it, differs from that of the examples above. Consent by children to their family rule is implicit. This is obvious in biological families, but even in adoptive or foster-families, the fit between the child and the family is evaluated *before* the child-caretaker relationship is formalised. Secondly, the family rule must promote the welfare of the child. It is this goal that legitimises the parents' power over their children, as the inequality benefits both.<sup>38 39</sup> Thirdly, consent to the family rule is not an all-or-nothing affair. The child's development requires repeated renegotiation of the rule's application from infancy to adulthood. Thus, consent to events in a child's life may fall within or outside the family rule, depending on the child's and the family's situation.

### Involving the child in treatment decisions

To consent rationally the child needs information about what will be experienced, and how the intervention might help the child. These requirements determine the minimum information the child needs to give informed consent. Therefore, the practitioner needs to:

- a) Inform the child what will happen if nothing is done.
- b) Describe the intervention.
- c) Describe how the proposed intervention will improve things.

Following this order allows obtaining consent to be a natural next step. The child can be asked:

- d) Whether the child agrees with the practitioner that the proposed intervention does indeed produce a better outcome than doing nothing.
- e) Only then, should the child's consent to proceed be sought.

We have seen that consent to the family rule diffuses the child's right to consent, in a manner negotiated between the child and its caretakers. Respect for the autonomy of the child must include respect for that diffusion. The practitioner must consider five conditions:

- I. The child can give informed consent within the family rule. This is a "full family decision", with child and parents cooperating on the basis of the same information, to arrive at informed consent. Thus, a full explanation is given to both the child and parents.
- II. The child cannot give fully informed consent, but the area of consent lies within the family rule. In these circumstances, the child has delegated some of its right of consent to its parents. Giving information to the parents alone in these circumstances is *not* sufficient, as parents may not convey sufficient information to children.<sup>40</sup> However, giving reduced information to the child is ethical, provided the basic requirement of informing the child of future experiences is met.
- III. The child can give informed consent, but does not consent to the family rule in this area. This is the situation covered by the Gillick judgment, and so the child's wishes must be respected.
- IV. The child cannot give informed consent, and also does not consent to the family rule. Children may make such a decision for four reasons. First, the child may have delegated the need for rational consent to the parents under the family rule. He or she can afford to protest or acquiesce irrationally, knowing that the parents will override this, and that they know that he or she does not wish to be treated as capable of consent. Secondly, children may misjudge their capabilities. Third, expressing individuality may be more important than rational acquiescence. Finally, the child's ability to consent rationally may be impeded by a mental illness or handicap. In these cases, decisions should be made on a case-by-case basis as to whether the residual benefit compensates for a coercive approach.
- V. Irrational decisions made for the child by a parent are unethical. When a parent offers proxy consent, that consent is legitimised by the family rule, which implies that the consent is given for the child's benefit. If the parent takes such a decision irrationally (which includes not considering the child), then the parent has been reckless about ensuring that the child benefits from the parent's decision.

Both this approach and its associated assessments are consistent with currently accepted guidelines.<sup>41 42</sup>

### When caretakers disagree

The family rule is not supporting the child if the parents disagree with each other. However, the family rule is essential in the consent process. Therefore, the professional has two duties: first, to do everything to bring the parents to agreement; and secondly, to recognise whether agreement is impossible in the timescale required for the proposed treatment. In the latter case, the practitioner has to support the child *against* the disagreement between the parents.<sup>43</sup> The practitioner therefore has a duty to accept the view of the parent judged to be acting in the child's best interest. This is consistent with the current legal position, where consent by one person with parental responsibility is sufficient.

### When caretakers and practitioners are in conflict

Conflict between caretakers and practitioners can arise when families are reckless in making decisions about their children, and when families hold views that are incompatible with the treatment offered. For example, one family might refuse a psychiatric appointment because it might result in the child disclosing abuse, while another might refuse blood transfusion for religious reasons. The first case is non-contentious: the family rule is not benefiting the child, and may be overridden by the professional.

Difficulty arises in the second case, where the family and extrafamilial agencies are not in agreement over the beneficial calculus to be used in assessing benefit to the child. Here, Foot's<sup>44</sup> distinction between mandatory and elective principles is helpful. Mandatory ethical principles are those that admit no rational disagreement, for example, opposing murder, or torture for pleasure. Elective principles are those where convincing ethical arguments may be set up either to support or oppose them. Foot considers the right to abortion to be such an elective principle. To fulfil principles of autonomy and beneficence in relation to the child, the professional may override the family rule only for mandatory principles, when the professional's argument has greater moral force than the family's. This position does not support professional ethical intuition; people on either side of an elective principle will feel that they are "right". Therefore, these cases should be referred to the courts. However, in the most difficult cases the courts would need to take expert advice from ethicists, as well as other professionals in child health and care.

### Consent in research

In medical research, the intervention is to obtain information about a disorder, rather than improve any individual child's condition. So, all work together to obtain the information, but differ in the roles each takes, and the benefits each receives. The researcher has a duty to ensure that all the participants should benefit, and obtaining consent for research should be based round the relationship, which continues for the duration of the study. Research subjects stand to learn more about their condition. Others perceive their contribution as valuable. They increase the probability of an improvement in the prognosis of their disorder. These goals are broadly in line with those of the researcher, and so the relationship is as between colleagues. However, the researcher cannot claim the practitioner's duty to persuade the child (or family). The practitioner should make the benefits of participation clear, because when decisions about participation are made benefits need to be balanced against inconvenience. The family rule determines the balance between child and family, as discussed above. Thus, the ethics of acceptance of "proxy consent" research is determined by the family rule. Despite this, the imbalance of knowledge between researcher and subject makes the risk of unfair persuasion greater than between professional colleagues—hence the need for an ethical committee. The information gained is one of the benefits to the participants. Therefore, it should be made available to them, when the study is completed, in a form they can understand.

Children participating in comparison groups "normal controls" are unlikely to benefit from the main research results, even indirectly. They are therefore in a similar position to donors to charity, donating time and effort instead of money. Benefit deriving from a charity is unlikely to outweigh the adverse consequences of a child being a control against the wishes of the parents, whatever the family rule. Therefore, while there may be circumstances (abused children for example) where it may be appropriate to accept the research subject child's consent without parental agreement, this cannot be so for controls or comparison groups.

### Consent and the mentally ill child

Fulford<sup>45</sup> has shown that mental and physical illnesses are not conceptually distinct. Therefore, issues of consent applicable to one will be applicable to both. The Mental Health Act 1983 may be invoked in any situation where mental illness has impaired the ability to consent, and one of its roles

is to protect the rights of individuals so incapacitated. Therefore, in principle the Mental Health Act is as relevant to children as adults, and could be applied where appropriate, to ensure their rights and to protect others. Professionals need to be reflective about the processes they have used to obtain consent, and to take care to design and implement minimally coercive treatments. However, children differ from adults both in the mental impairments or illnesses they express, and the interactions between those and their (more limited) capacity for consent. We have already seen that great care is needed in assessing children's ability to consent, their honesty in consent, and the role of the family in helping consent, and current training in the use of the Mental Health Act makes little reference to children. Therefore doctors and social workers should have separate guidelines and training in the application of the Mental Health Act to mentally ill children.

### Conclusions: can professional practice protect children's rights?

The concept of the family rule can coherently structure professional practice in obtaining consent from children, in both routine and exceptional situations. This therefore allows both training and standard-setting in obtaining consent to treatment from children, and so can set a reliable boundary between good and negligent practice in obtaining consent from children. Such a boundary could be given supervisory weight by explicit guidelines from government, or the governing bodies of relevant professional agencies. This poses an alternative to current recommendations for explicit legal definition of children's rights of consent.<sup>12</sup> For example, it may be possible that the method of obtaining consent, as well as the presence of consent, might be made a matter for negligence proceedings. If this were so, it would allow greater individual flexibility than the imposition of statutory "rights", whose legal interpretation might be inappropriate for unusual or difficult cases. However, experience with the Mental Health Act<sup>16</sup> suggests that new procedures or standards resulting from this model, especially those relating to giving children information, will need careful oversight if they are to be properly observed in practice. Identification and training of staff able to evaluate consent from children, using this approach, will therefore be essential if it is to be adopted.

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