On children and proxy consent

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The meaning of valid proxy consent for children has recently been the subject of an important debate between Richard McCormick and Paul Ramsey on the ethics of experimenting with children.¹ Ramsey is willing to agree with McCormick that parental consent for a child to undergo some medical procedure is valid only if parents consider what the child would consent to if he could. But beyond this, Ramsey has a fundamentally different conception of the child from McCormick, and therefore gives a very different interpretation to this standard for valid proxy consent. In Ramsey's view, McCormick's basic mistake is to think of the child as a small adult, thereby overlooking the child's peculiar vulnerabilities and needs. In particular, McCormick fails to attend to the child's needs for 'preservation in life and healthful growth'.² In this paper, the author pursues Ramsey's suggestion that a correct analysis of valid proxy consent for children would replace the 'language of consent' with the 'language of need'.³ He does this by sketching a theory of parenthood that rests on two central notions: that of primary goods, as found in the writing of John Rawls, and that of autonomy.

Children's needs and the grounds of parenthood

Suppose parents are asked to give proxy consent for their child to undergo either routine medical treatment or an experimental procedure. In what sense is it consent *on behalf* of their child? A natural, if somewhat perplexing, answer is that parents must first ascertain what their child would want if he were able to give consent, and then give their permission for that medical procedure to be performed. But the claim that such and such a procedure is what the child would want is not particularly perspicuous. Since the child is not in fact able to give meaningful consent to a medical procedure, his consent must be constructed, and we need to know the point of view from which to construct it. One suggestion might be that parents should try to ascertain what their child, considered as an adult, would want. The problem with this suggestion, however, should be obvious. The child is *not* an adult, and the needs of children are in many respects quite different from the needs of adults. Since adults, especially in medical situations, often make

decisions on the basis of their perceptions of their needs, where needs are quite different, the decisions that are made in light of those needs, or that it is presumed would be made in light of those needs, might also be quite different.

It is clear, I think, that if one is to try to construct consent for children, and at the same time try to be faithful to the child's reality, not the adult's reality superimposed on the child's, one must consult the needs of children. But what are the needs of children, as distinct from those of adults? The first, and obvious, point to remark on is that children, unlike most adults, are dependent on others for their survival and development. It is an indisputable fact about children that they are not completely competent to care for themselves or supervise their own upbringing. In our society, the care and supervision of particular children is entrusted to particular parents, whether natural, adoptive, or foster, within the context of the nuclear family. Parents are expected to minister to the needs of their children, to supply them with a decent amount of food, clothing, and shelter, and to see to it that they receive at least minimal linguistic, social and educational competences. But dependency on parents is, or should be, temporary, gradually diminishing as children mature. Food, clothes, shelter, linguistic, social and educational competences should be provided not simply because children, like any needy persons, deserve our help, but because children should be reared for full lives, independently led. The end of child-rearing is, or should be, its own dissolution.

So far I have only given a *list* of children's needs. I have not tried to articulate the *principle* behind this particular list. In order to do this, I think it would be useful to call upon John Rawls' concept of primary goods. According to Rawls, primary goods are defined as those goods that any rational person would want, whatever else he wants.⁴ People do, of course, differ enormously in the details of the particular plans and projects that they construct for themselves. Some want to become doctors, some carpenters, some want to become parents, some want to live relatively unattached. But no matter what lives people want to live, there are certain goods that most people must have in order to advance their particular plans or projects, and of these goods they will want more rather than less. Thus, health and intelligence are prerequisites for the advancement

of ends, whatever these might be. Some level of income or wealth is normally required. People also need to have the protection of certain fundamental rights and liberties, such as the right to hold personal property or the right to be free of arbitrary arrest and seizure. In addition, people need to have the opportunity to pursue plans and projects they have designed for themselves. Finally, people must have a sense of self-respect, for without this, they may not bother to form plans of life at all, or if they do, they will not think them worth pursuing.

Let us now see the relevance of the concept of primary goods to the parent-child relationship. I should like to suggest that one goal of parents ought to be to provide their children with, or enable them to provide themselves with, primary goods that they will need to pursue their individual plans and projects, whatever these turn out to be. Thus, parents should see to it that their children are healthy, that they have at least a minimal level of intelligence, that they are provided with certain basic social skills which equip them to be self-sufficient in an economic sense, that they have a genuine opportunity to realise their particular projects, and that they have a sure sense of their self-worth. As far as rights and liberties are concerned, parents cannot of course in any normal sense *give* their children these things. But parents can and ought to support forms of government which respect basic rights, and can and ought to refuse to support forms of government which either fail to recognise them or restrict them to a significant extent.

But parental responsibility to provide children with primary goods is only part of a theory of parenthood. It is equally essential that parents do not have the right to determine for their children how they shall use these goods. Rather, parents have the further responsibility to develop their children's capacities for autonomous choice, that is, their capacities to adopt plans and projects and to pursue them as separate selves. It is not a justifiable end of of parenting to use a child merely as a means to his parent's satisfaction, to so arrange his upbringing that he will not be able to step back and formulate an independent attitude towards the factors that have influenced his behaviour and values. A central commitment of parenting ought to be to develop a child's capacity to want to be different from his parents.

Proxy consent and parenthood

I began this paper talking about the needs of children, and then I was led into a discussion of the grounds of parenthood. The connection between needs and parenting is perhaps obvious, but it might not be obvious what the relevance of all this is to proxy consent. The relevance seems to me to be this: in order to employ the concept of proxy consent in a way that is true to children, one must have some

idea of children's needs. Children need, if I am correct, to develop autonomy and to acquire the primary goods. The satisfaction of these needs is entrusted, in our society at any rate, to particular parents. The question, therefore, of what children would want if . . . , turns into the following question: what may parents do *for* their children to realise their autonomy and to see to it that they acquire the primary goods, or what may parents do *to* their children which will not jeopardise their eventual attainment of autonomy and the primary goods? The issue of proxy consent is, in effect, replaced by that of the rightful exercise of parental authority.

The theory of parenthood that I have sketched out has important results when applied in the medical context. Consider the following remark by Henry K Beecher on the use of children as experimental subjects:

'Parents have the obligation to inculcate into their children attitudes of unselfish service. This can be extended to include participation in research for the public welfare if judged important and there is no discernible risk'.⁴

The virtue of this comment is that it squarely poses the issue of proxy consent in terms of a view of parental responsibility. Whether or not Beecher's view is acceptable, however, hinges on the meaning of 'unselfish service'. For if Beecher means not non-selfish, but selfless service, then I cannot agree that parents have an obligation to inculcate into their children attitudes of unselfish service. I would say rather that parents have an obligation to instill in their children a respect for justice, for among the primary goods are rights and liberties, and justice demands that the rights and liberties possessed by one person comport with the equal rights and liberties of others.⁵ Moreover, having an attitude of selfless service suggests a willingness to sacrifice one's own interests for the sake of others, at least under some circumstances. It would seem to follow, therefore, that if children are to develop attitudes of unselfish, i.e. selfless, service, parents should be allowed to volunteer them for experiments in which there is more than minimal risk. Beecher, of course, is unwilling to accept this conclusion, for he goes on to say that parents should not volunteer their children for experiments in which there is a 'discernible risk'. But since it is quite unclear in Beecher just when there is a 'discernible risk', this qualification is not very enlightening. Are we to consider only risks to the child's health? Or are we also to consider, what is very different, risks to the child's developing autonomy? It is the latter that I would advocate.

In the end, I would agree with what Beecher says elsewhere,⁶ viz., that if children are to derive no benefit from an experimental procedure, then parents may volunteer them for it only if it poses no discernible risk. My real concern has been to

argue that whatever guidelines for proxy consent are proposed, they must be shown to be compatible with an acceptable theory of parental obligation. Moreover, if we are to prohibit discernible risks, it is necessary to specify *what* may not be risked to a discernible degree. In order to do this, we require some account of children's needs.

References

- ¹McCormick, R (1974). Proxy Consent in the Experimental Situation. *Perspectives in Biology and Medicine*, 18, 2–20.
- Ramsey, P (1976). The Enforcement of Morals: Non-therapeutic Research on Children. *Hastings Center Report*, 6, 21–30, August.
- McCormick R (1976). Experimentation in Children: Sharing in Sociality. *Hastings Center Report*, 6, 41–46, December.
- ²Ramsey, P. The Enforcement of Morals, pp. 23–26.
- ³Rawls, J (1971). *A Theory of Justice*. Cambridge, Belknap Press, p. 92, 60.
- ⁴Beecher, H K (1970). *Scarce Resources and Medical Advancement. Experimentation with Human Subjects*. Ed. Paul Freund, New York, George Braziller, p. 73, 76.