# Respecting the Health Care Decision-Making Capacity of Minors

*by Carson Strong*

*The* Decision-Making Guidelines *document raises some unanswered questions and lacks arguments to support assertions made. This paper identifies and initiates discussion of these issues surrounding the decision-making capacity of minors.*

The Midwest Bioethics Center has developed an important, thought-provoking document on the role of minors in health care decisions, entitled *Health Care Treatment Decision-Making Guidelines for Minors*.[1] A central issue addressed in the document is the extent to which minors should be involved in decisions about their health care treatment. The following clinical case illustrates this difficult and controversial topic:

> Jim, twelve years old, was diagnosed with acute lymphocytic leukemia at age seven. During the past year and a half, he has had multiple relapses, but is now in remission. His current chemotherapy regimen involves treatment every two weeks, and he is experiencing a significant amount of nausea and vomiting. During the two-week period of each course, he feels well for five to seven days. Jim is "fed-up" with chemotherapy. He states that he is "tired of being miserable most of the time" and wants to stop the treatment. He is aware that without chemotherapy he will soon die, and he has a realistic understanding of what death means. However, Jim's parents do not want to stop treatment. They believe that the chemotherapy might maintain his remission for a significant period of time. Jim is their only child, and they believe that the side-effects are a worthwhile price for Jim to pay to prolong his life.[2]

If Jim understands the implications of his decision, and if his considered view is that stopping treatment is the preferable course of action in light of his own values and goals, then respect for his autonomy supports the halting of chemotherapy. On the other hand, if Jim's wishes are not firm or sufficiently thought through, and if treatment has a reasonable chance of extending his life with a quality that he would find acceptable, then respect for his well-being supports continuing chemotherapy, at least temporarily. Careful consideration of Jim's refusal would require, therefore, further exploration of several factors: the likelihood that treatment would extend his life; whether additional interventions are possible to deal with the side effects of chemotherapy; the extent to which Jim has a realistic understanding of the alternatives; and whether his refusal is indeed the best choice for promoting his values and goals.

In fact, the extent to which Jim's wishes would be given due consideration would probably vary, depending on the particular hospital and health professionals providing his care. Practices vary concerning the extent to which children who are capable of participating in decision making are actually allowed and encouraged to do so. One impetus for the development of the Midwest Bioethics Center's document was the realization that minors often are not allowed to participate in decision making to the extent to which they are capable.

## A New Conceptual Model

*Decision-Making Guidelines* presents a "new conceptual model" for health care decision making for minors. As I interpret the document, the main aspects of this new model can be stated as follows:[3]

1. Health care decision making should honor

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minors and involve them to their fullest capacity in treatment decisions;

2. There is a morally relevant distinction among three categories of minors: those lacking any decision-making capacity, those with developing capacity, and those having decision-making capacity;

3. Minors with decisional capacity should be allowed to make treatment decisions;

4. Minors with decisional capacity should have the right to make advance directives. This includes the right to name a surrogate decision maker other than their parents;

5. For minors with decisional capacity, communications and records related to their health care should be kept as confidential as possible;

6. For children with developing capacity, assent is required for treatment in nonresearch as well as research contexts. In some cases, this requirement can be overridden by other ethical considerations;

7. The concept of parental consent should be replaced by parental permission. Parents, then, do not have the final say concerning provision of treatment; assent of the child with developing capacity is also a requirement;

8. Children with developing capacity have a limited right of confidentiality against parents and guardians; and

9. Disagreements between parents and children with decisional capacity or developing capacity should be handled by conflict resolution.[4]

This new conceptual model is important because it presents views concerning a number of central ethical issues in the treatment of minors, and it thereby provides a useful focal point for further discussion.

## Unanswered Questions

Despite its importance, the document has a weakness that is often found in position statements and guidelines prepared by committees; namely, it lacks arguments to support its assertions. Also, the document gives rise to a number of questions that it does not directly address. These weaknesses are forgivable, perhaps, because the document, nevertheless, prompts needed discussion of such issues and questions. The important questions left unanswered by the document include the following:

- When there is disagreement between minors with decisional capacity and their parents which cannot be settled by conflict resolution, what principles should be used in deciding whose wishes should prevail? Should the minor's wishes always take precedence, or should the parents' wishes sometimes prevail?

- What reasons can be given to support respecting the limited decision-making capacity of minors with developing capacity? Respect for their decision-making capacity is a central thesis of the *Guidelines*, yet it is not defended.

- When disagreements between minors with developing capacity and their parents cannot be settled by conflict resolution, what principles should be used in deciding whose wishes should prevail? Should the parents' wishes always have priority, or should the minor's wishes sometimes take precedence?

- When there is a conflict of confidentiality between a child with decisional or developing capacity and the parents' desire or need for information, what principles should be used in deciding whether confidentiality should be protected?

There is a need for discussion and debate of all these questions. In this paper I will address those issues involving the decision-making capacity of minors.

## Conflicts between Parents and Minors With Decisional Capacity

A strength of the *Decision-Making Guidelines* is that it recommends conflict resolution when there is disagreement between minors with decisional capacity and their parents. This process includes informing, counseling, and efforts to mediate disputes. Hopefully most disagreements between

minors and parents are resolved in this manner. However, occasionally conflicts cannot be resolved in this way. In such cases, health care providers are faced with the question of whose wishes should prevail. Although these cases might be infrequent, it is important to examine them because doing so helps us to understand the role of the minor in decision making.

When minors possess decisional capacity, respect for them requires respect for that capacity, just as the autonomy of any person with decision-making capacity, regardless of age, deserves respect. Decisional capacity, not age, is the morally relevant consideration. This supports the view that the minor's wishes should prevail over the wishes of the parents.

***The decision about whether a minor has decisional capacity depends on the specific situation; the greater the potential harm to the minor, the greater the burden of proof.***

However, conflicts between parents and minors who supposedly have decisional capacity sometimes revolve around the question of whether the minor really has the capacity autonomously to make the decision in question. The judgment that individuals, whether minor or adult, have decisional capacity is more open to question when their decision is likely to be seriously harmful to themselves. Such questioning is appropriate and reflects the responsibility of caregivers to prevent persons who lack autonomy from harming themselves. When significant harm seems likely, we should require strong evidence in support of that person's decisional capacity. In general, the greater the harm, the greater the burden of proof that the individual has decisional capacity. To fulfill the burden of proof, individuals would have to give an account that explains why their choices are reasonable given their values and goals and that demonstrate an adequate understanding of the facts.[5]

Therefore, the decision about whether a minor has decisional capacity depends on the specific situation; the greater the potential harm to the minor, the greater the burden of proof. The parents' wishes, then, should prevail when the following conditions are satisfied: the minor's decision is reasonably expected to cause harm to himself; the parents' decision is reasonably expected to benefit the minor; and evidence for the minor's decisional capacity is not sufficient to meet the burden of proof posed by the level of harm involved.

A variation of the well-known Dax Cowart case (White 1975) provides an example of this situation. In this version, Dax is only sixteen years old when an explosion causes severe burns on his face and most of his body. Aggressive treatment, including painful dressing changes, is necessary to save his life. His mother wants him to be treated, but Dax states that he does not want to be treated. He does not want a life in which he no longer can play football and have the active lifestyle he once enjoyed. Discussion reveals that young Dax does not have a realistic understanding of what his life might be like with rehabilitation and the passage of time. Moreover, the traumatic injury has occurred recently, and it is possible that Dax has not yet overcome his state of psychological shock. These facts support the view that he lacks decisional capacity to make such a momentous decision as refusal of life-saving treatment. His mother's wishes should be respected, at least until such time as Dax gains the capacity to make his own decisions.

## Why Should Limited Decision-Making Capacity Be Respected?

Clearly, respect for children as persons requires respect for their well-being. In fact, this is such a strong requirement that paternalism toward children is morally justifiable. By paternalism here I mean actions that interfere with the liberty of children and which are carried out because they are reasonably intended to prevent significant harm

to the child. However, if we accept paternalism toward children, it might be argued that even when we act in a manner that respects their autonomy, what we really are doing is following a model of decision making based essentially on respect for their well-being. After all, decisions about whether to respect autonomy would be based on whether doing so would result in harm. Given these considerations, asking the following questions will facilitate a better understanding of the moral basis of our behavior toward children: Why should we respect the limited autonomy of children? Is it simply because such action is sometimes consistent with promoting their well-being? Or are there other reasons for doing so?

There are several types of arguments surrounding these questions. One is to argue that respect for the limited autonomy of children can be justified by the consequences of doing so. Such arguments might be based on consequences for either the child or others. A different approach would argue that failure to respect the limited autonomy of children is inherently wrong, based on nonconsequentialist considerations. Let us consider how these various types of arguments might be stated.

Arguments based on consequences for children might take several forms, depending on the particular moral interest in question. One version focuses on children's interest in the promotion of their well-being: Respecting the limited autonomy of children is sometimes justifiable because doing so not only is consistent with, but actually promotes, well-being. For example, it might be pointed out that the happiness of children is a component of well-being, and that their happiness is promoted by respecting their wishes. According to this argument, however, respecting children's wishes would not be justifiable when their decision is reasonably expected to result in harm to themselves. Thus, this argument is consistent with paternalism toward children, and it provides a plausible reason to respect the wishes of children concerning medical treatment whenever doing so is not reasonably expected to result in harm to the child.

Another version focuses on children's interest in the development of autonomy: Respecting the limited autonomy of children is justifiable because it promotes further development of their autonomy. When they are allowed to make decisions, children learn through this experience to do a better job of making future decisions. They learn the importance of being informed, of considering the consequences, of thinking through the decision. Thus, their decisional capacity increases more rapidly than it otherwise would. Whether this cause and effect relationship exists is an empirical question that would have to be addressed. Although this might be a promising line of argument, evidence supporting the causal relationship in question would be needed before we could regard this argument as acceptable.

Arguments that address consequences for persons other than children might focus on persons who are fully competent to make their own decisions. It could be claimed, for example, that failure to respect the autonomy of children would weaken respect for autonomy in general and that this would weaken respect for the autonomy of fully competent persons. As before, this argument rests on a supposed cause and effect relationship, the existence of which is an empirical question. Although this argument also seems worth considering, evidence would have to be presented supporting it before we could regard it as acceptable.

The view that failure to respect the limited decision-making capacity of minors is inherently wrong is based on the idea that respect for persons with developing capacity involves, among other things, respect for those actions that *are* autonomous. According to this view, one need not be fully competent to make decisions in order to deserve to have one's autonomous actions respected. One might think of this as an extension of the Kantian view of respect for persons.The Kantian view can be described as holding that autonomous individuals have a moral standing that requires others to respect their autonomy. This extension of that view holds that individuals with partial autonomy — those who have the

capacity to make some, but not all, of their decisions autonomously — have a moral standing that requires others to respect those autonomous actions. This view concerning those with developing capacity seems reasonable. After all, why shouldn't we regard respect for persons as including this extension of the Kantian view?

The above considerations, especially the argument based on promoting the well-being of the child and the extension of the Kantian view, support the position that there is at least a prima facie moral requirement to obtain the assent of children with developing capacity prior to treatment. They also support the contention that, for minors with developing capacity as well as those with decisional capacity, parental permission may be a more appropriate concept than parental consent. The reasons for favoring "permission" rather than "consent" apparently are based on the following considerations:

The concept of *informed consent* by a fully competent patient implies that the decision is entirely the patient's, except perhaps in extraordinary circumstances.[6] Similarly, the concept of parental proxy *consent* might be taken to imply that the decision is entirely the parents, except in extraordinary circumstances.[7] Such an understanding of parental proxy consent would be inconsistent with the notion that assent of the child is required. The concept of parental *permission,* by contrast, does not convey that the decision is entirely that of the parents.

These considerations support the concept of parental permission only when either assent or consent of the minor is a moral requirement. In particular, they do not support the replacement of parental consent by parental permission for minors who lack decisional capacity. In this context, parental consent is a reasonable concept. Although collaboration between parents and health care providers is an appropriate model for decision making, parents have the moral authority to be the final decision makers for children without capacity, except in extraordinary circumstances. This understanding of the parental role is consistent with the concept of consent. Thus, the *Guidelines* seem to err when they use the term "permission" rather than "consent" in discussing decisions for minors without decisional capacity.[8]

## Conflicts between Parents and Minors With Developing Capacity

When there are disagreements between minors with developing capacity and their parents that cannot be settled by conflict resolution, whose wishes should have priority? I believe that there are situations in which the wishes of the minor with developing capacity should have precedence over the wishes of the parents. The following case example illustrates this view:

> A mother brings her nine-year-old girl to a gynecologist who has experience in performing examinations of children who are suspected to be victims of sexual abuse. The mother is seeking custody of the child. The child has returned from a visit with her father, whom the mother suspects of abusive behavior. The matter was investigated by the local child protective services agency, which concluded that there are no grounds for the allegation. The examination for signs of sexual abuse would involve a visual examination of the child's body, including a genital examination. The mother signs a consent for the examination but the daughter is reluctant. She cries when asked to undress and tells the physician that this is the third examination in a week. She states that she does not want to be examined, but the mother insists that the physician proceed.[9]

A refusal by the physician to perform this examination is justifiable, based on several considerations. First, it is unlikely that the exam will benefit the patient, given that the previous investigations have uncovered no evidence of sexual abuse. Second, it appears that the exam will cause emotional distress to the patient. Third, this minor with developing capacity is unwilling to give her assent.

On the other hand, there are situations in which a parent's request for treatment should be honored, despite a child's unwillingness to assent. The clearest examples involve cases in which treatment is highly likely to be effective in preventing serious harm to the child. Prevention of harm to

the child, together with the child's lack of full decisional capacity justify overriding the child's wishes in such situations.

These considerations support the view that decisions about whether to respect the minor's wishes should be made by weighing the competing values on a case-by-case basis. The greater the harm that would occur to the child as a result of following his wishes, the stronger the argument for overriding those wishes. The less the benefit derived from overriding the child's wishes and the greater the child's decision-making capacity, the stronger the argument for respecting the child's wishes. (This casuistic approach to decision making has been argued elsewhere. See Strong 1988.)

## Conclusion

The *Decision-Making Guidelines* contribute to the discussion of the role of minors in decision making. Distinguishing three categories of minor patients — those lacking any decisional capacity, those with developing capacity, and those with decisional capacity — is a helpful way to approach what is admittedly a very complicated topic. The concept of parental permission also is reasonable, although the extent to which it is applicable is overstated in the guidelines. Further discussion of arguments for respecting the limited autonomy of minors with developing capacity is needed. Critical assessment of the strengths and weaknesses of these arguments will contribute to a better understanding of the belief that we ought to respect the developing autonomy of children.

## Endnotes

1. For brevity, I shall refer to this document as *Decision-Making Guidelines*.

2.This case is discussed by Foley, Stanfill, and Strong (1985).

3. Section 1.0 of *Decision-Making Guidelines* identifies items 3, 6, and 7 in this list as the fundamental aspects of the model being proposed. However, it is clear that the other entries in this list also state main features of the model.

4.The concept of "conflict resolution" is explained in Section 2.4 of *Decision-Making Guidelines.* It involves a variety of mechanisms for resolving conflicts including additional medical consultation, case management conferences, mediation, and use of ethics committees.

5. In this discussion I have used the term "harm" in its ordinary sense, meaning an injury to one's interests. To harm oneself is to cause oneself to be worse off than one otherwise would have been. In the case presented at the beginning of this essay, for example, a main concern was whether Jim would be harming himself by refusing life-prolonging therapy. If one holds that the benefits for Jim associated with a longer life outweigh the side-effects of treatment, then one might conclude that Jim's refusal of treatment is harmful to himself. In that event, stronge evidence would be needed to support the judgment that Jim had decisional capacity. It would be necessary for Jim to give an account, based on an adequate understanding of the facts, that explains why his choice is reasonable given his values and goals.

6. An example of extraordinary circumstances might arise when a patient's refusal of treatment is likely to cause serious harm to third parties. In some cases, for example, courts have ordered life-saving treatment of parents over their refusal, in order to prevent harm to dependent children. However, such court-ordered treatment is controversial.

7. In this context, extraordinary circumstances might involve parental refusal of treatment for a child when that treatment is necessary to promote the child's well-being.

8. See Section 7.1.b of *Decision-Making Guidelines*.

9.This is a composite case based on actual cases.

## References


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