
Minors and Health Care Decisions: Broadening the Scope

by Joel Frader

MBC's Document on the health care decision making of minors provides health care professionals with guidelines for helping minors participate in their own decision making. What is needed now is to bring these considerations as presented in the Document into health care centers outside the hospital walls where children most often encounter the health care system.

Midwest Bioethics Center's (MBC) Document, *Health Care Treatment Decision-Making Guidelines for Minors*, presents the opportunity to evaluate the way our society deals with decisions regarding the health care of minors. Having worked on a related document for the Committee on Bioethics of the American Academy of Pediatrics (which also benefited from the efforts and wisdom of Bill Bartholome), I am aware of the value and difficulties of crafting such a document. My examinations of the issues in this paper stem from an interest in the topic, from a careful reading of the *Guidelines*, and also from work on the Academy's statement (Committee on Bioethics 1995).

Policy guides have to accomplish two somewhat incommensurate tasks. First, and perhaps most important, policies must clearly and succinctly provide guides for action. As a result, policies nearly always emphasize procedure. The need for brevity and the priority placed on process mean that the second task, to provide an understandable rationale for the policy's existence, often leave the substantive basis for the policy unclear. This difficulty poses the greatest challenge. In my view, several substantive matters in MBC's *Guidelines* require further work.

Conceptual Quandary

The largest intellectual hurdle in examining decision making for minors involves the grounds on which decisions should be made when 1) there is

a dispute about the preferences of a minor with decisional capacity who does not have a legal entitlement to choose for him or herself, or 2) there is a dispute over how to treat a minor who clearly lacks decision-making capacity. The *Guidelines* rely on the well-worn notion of "best interests." Unfortunately, the phrase gives us little guidance about what constitutes either the medically or morally right thing to do.

The "best interests" problem includes two aspects. To begin with, one needs to decide *who* should determine "best interests." At one point in the *Guidelines* (4.10) we read that parents (of children without decisional capacity) are the "appropriate" decision makers unless "the course of action chosen by the parents is clearly contrary to provider's judgments...." Elsewhere (4.4) the document acknowledges that families have a "wide range of goals, beliefs and values" which may vary among cultures and which presumably deserve our respect. The second problem then involves drawing, perhaps arbitrarily, a line between the diverse and potentially conflicting views of family members and those of health care professionals. Again, it isn't clear what should serve as the substantive basis for such line

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drawing. How can we know who should make a decision if we can't clearly define the acceptable limits on decisions?

Examples will help explicate the difficulty. Recently, several adolescents received publicity when they refused various recommended medical treatments. A boy in Florida declined to have another liver transplant when he and his family learned his previous graft was failing. Another boy, from New England, ran away from home to avoid continuing cancer chemotherapy. Media reports indicated that he had a lymphoma with a high rate of long-term (decades), disease-free survival or cure. In both cases the patients cited the burdens of treatment as more than they wished to bear. The transplant patient had the support of his family; the cancer patient's family apparently wanted him to continue treatment. The controversial practice of female genital alteration or mutilation raises different issues. This procedure involves manipulations of the genitals of girls and young women, ranging from removal of the clitoris to radical surgery removing the labia and closing the vagina opening. The surgeries are intended to preserve sexual purity and enhance male sexual pleasure. They have strong supporters in a variety of African and Middle Eastern social groups.

My point here is to demonstrate that in many cases *MBC Guidelines*, as well as those from the American Academy of Pediatrics, fail to help us know either who should make treatment decisions or inform us which decision deserves support. "Best interests" may depend on where one sits or how one has been socialized. Policy statements that fail to analyze key concepts like best interests will never achieve their intent of providing clarity in ethically confusing situations. The conceptual confusion also leads to linguistic hedging, like the promise not to reveal confidential information "unless it is important to your care" (6.1.o) or to have one's "values" and "beliefs considered" (6.2.b).

The *MBC Guidelines* also contain instances where one might wonder about the conceptual grounding. For example in the prologue we read

of the importance of recognizing "the developing capacity of minors for rationality..." This is both interesting and problematic. Most of us believe that intellectual development and maturity enhance the ability of humans to engage in rational process. But it isn't clear whether or not we want to insist that minors demonstrate rationality in order to convince us they may make their own decisions. Using this criterion (rational thought) for minors employs a different standard from the one used for adults. Rationality is not a criteria for determining legal or clinical decision-making capacity. Adults need to demonstrate that they understand what is at stake in a decision, can manipulate information concerning the consequences of decisions, and express a preference for one decision over another, but they don't have to show that their decisions are logical or rational. Decisions to follow inherently nonrational, faith-based precepts, for example, defy such a standard. I am not sure we want to require minors to demonstrate rationality in order to make their own health care decisions.

Though only a minor one, another conceptual model involves DNR orders (2.6). The definition of DNR includes the notion that such orders prevent cardiopulmonary resuscitation (CPR) when that action is deemed futile or "inconsistent with the patient's values, wishes, and goals." But futility introduces problems of process (who decides when something is futile) and substance (that is, something may be called futile if it can't, even in theory, work, if it never actually works, if it only rarely works, or if it doesn't work enough to satisfy someone's prejudice). I doubt the drafters of the *MBC Guidelines* would endorse the unilateral professional declarations of futility that some use to assert physician authority.

Beyond Institutions

The focus on hospitalization in the *MBC Guidelines* also poses a challenge. Arguably, institutional settings pose the greatest threat to the personal integrity of children; certainly for high stake issues like forgoing life support or privacy/confidentiality issues, in-patient facilities are key sites.

For these the *Guidelines* can help.

But minors most frequently interact with the health care system in offices or clinics. We need guidance about how (theoretically and practically) to respect growing personalities and minds in the mundane but pattern-setting encounters happening countless times a day. What about the fifteen-year-old's preference, contrary to the views of her father or nurse practitioner, to have strep throat treated with oral penicillin rather than an injection? What about the six-year-old child with fever and ear pain who won't permit the clinician to insert the otoscope? After how many minutes of professional or parental effort to soothe and explain would one be justified in restraining a kicking, screaming, protesting child to complete the exam?

Surely some among the drafters of the *Guidelines* would say that exercise of power sends the wrong message to children, and we should not permit such action except in emergencies and when all other reasonable alternatives have been attempted. But others, probably most health care practitioners, would protest and claim impracticality and inefficiency. Children, many of these professionals will say, will not be seriously or permanently harmed by having their fears and misunderstandings ignored in the interests of getting on with providing health care. Neither parents nor practitioners, we will hear, have the time or the energy to address and overcome each child's anxieties and irrationalities.

I am not sure how to address this tension between the importance of conveying care and concern for the feelings of children and the demands of busy practices. Every time I encounter a child overcome by fright, perhaps based on his or her previous health care experience, my heart goes out to the patient and I want to do whatever it takes to make this encounter a good one. Then, while I try what I know will help the child and the line-up of new patients, students, and residents needing my attention grows, my anxiety also grows. I don't think that child development or moral theory can help with these situations. I suspect some old-fashioned empiricism could

help. How much do children at different ages remember unpleasant, even coercive interactions with health care professionals? How do these encounters influence feelings and attitudes toward

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medical experiences as the child grows? Some facts might provide a more solid basis for policy on these matters.

Generalities

The *MBC Guidelines* remind us that the children's rights movement has a long way to go. Hospitals have made substantial progress in the second half of this century in recognizing the needs of institutionalized children for emotional support. Similarly, the law and the health care professions have come to appreciate the potential for serious conflicts of interest between children and adults; we understand now that child abuse and neglect are frighteningly prevalent. But we don't have routines for incorporating the thoughts and beliefs of children into their own health care. Adult priorities don't readily accommodate the additional time and skills needed to effectively communicate with children in ways that will bring them into the medical decision-making process. We have much work to do.

I am particularly concerned with children outside of hospitals who suffer from chronic and/or life-threatening disorders. Decades of study have shown that these patients typically have knowledge and insight for their situation that extends

beyond ordinary expectations. I'll conclude that they need to protect the adults around them (Vernick 1973; Alby and Alby 1973; Bluebond-Langner 1978; Spinetta and Maloney 1978). Though we now do better with providing these children opportunities for discussions of impending death and what it might mean, we still have not done much to allow the patients to help plan their last days.

For example, some school systems have permitted minors with lethal conditions (muscular dystrophy, progressive lung conditions, and so on) to continue their education. However, these systems often deny the same students the decency of forgoing unwanted CPR should they stop breathing at school (Scofield 1992; Youngner 1992; Strike 1992; Herlan 1994; Rushton et al 1994). Some emergency medical response systems will honor advance directives by adults that decline intubation or CPR, but refuse to heed documents drafted by minors or by minors and their parents (who in hospitals could readily agree with staff to limit interventions). In these situations, fears of legal liability or confusion about what state or local laws authorize stand in the way of humane death. Where necessary, we need to fight for statutory change, but more importantly, we need to convince organizations to put aside their apprehensions and do the right thing.

The thrust of my concerns is this: in tertiary care pediatrics we have made progress for children regarding the right to forgo excessive medical treatment that adult patients won some time ago. The *Guidelines* underscores and formalizes those achievements. What we need to do now is broaden our efforts in two important ways: 1) help children receive the recognition they deserve regarding ordinary health care decisions (that is, with respect to routine diagnosis and treatment) and 2) move the gains achieved in specialized centers regarding end-of-life care to settings outside the hospital walls.

We should not underestimate the difficulty of these tasks. The conservative mood of the United States in the mid 1990s indicates that efforts to establish what are seen as new rights (for children

or anyone else) will meet substantial opposition. And, as noted above, the problems are not only philosophical. The current emphasis on "efficiency" in health care means that there will be greater emphasis on technical efficacy and "productivity" in health care encounters. This trend does not augur well for the additional time and "soft" (psychosocial) skills needed to take children seriously. Our work is cut out for us.

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