conflict at the roots of health care. In: Kliever LD, ed. *Dax's Case: Essays in Medical Ethics and Human Meaning.* Dallas, TX: Southern Methodist University Press; 1989:79.

28. Consider, for example, the case of *In re E.G.*, which was decided by the Illinois Supreme Court in 1989. EG was a 17-year-old Jehovah's Witness with acute lymphocytic leukemia who went to court to be allowed to refuse blood transfusions. The Court concluded that EG had the right to refuse blood transfusions but that she required her parents' concurrence (*In re E.G.*, 549 N.E.2d (Ill. 1989) at 328).
29. Again, as defined in note 25, health is a primary good, and medical care is one way to fulfill this basic need. When a child has a life-threatening illness for which effective treatment exists, parents authorize medical care to promote their child's basic medical needs. Sometimes, however, as discussed in the section "Pediatric Decision-making for Life-Threatening Illnesses When Effective Therapy Does Not Exist," below, treatment may not achieve cure and may cause more harm than good. In those cases, promoting the child's basic medical needs may mean refusing low-efficacy or experimental treatment and authorizing palliative care instead.
30. Rawls uses the term "lexical order" to refer to the requirement to satisfy the first principle before one can move to the second principle (note 25, Rawls 1971:42–3). Rawls explains that the correct term is "lexicographical order" but that this term is too cumbersome (note 25, Rawls 1971:43). Likewise, I hold that basic needs must be satisfied before one considers other needs and interests, and therefore refer to the lexical priority of basic needs over other needs and interests.
31. See note 21, Ross 1998:50–2.
32. See note 21, Ross 1998:66–9.
33. See note 21, Ross 1998:61–2.
34. Gaylin W. Competence: No longer all or none. In: Gaylin W, Macklin R, eds. *Who Speaks for the Child: The Problems of Proxy Consent.* New York: Plenum Press; 1982:35.
35. Purdy LM. *In Their Best Interest? The Case Against Equal Rights for Children.* New York: Cornell University Press; 1992:76-84.
36. See note 21, Ross 1998:61.
37. See note 21, Ross 1998:62; see note 34, Gaylin 1982:31.
38. Diekema DS. Parental refusals of medical treatment: The harm principle as threshold for state intervention. *Theoretical Medicine & Bioethics* 2004;25:243–64; Burt RA. Resolving disputes between clinicians and family about "futility" of treatment. *Seminars in Perinatology* 2003;27:495–502; Clark PA. Medical futility in pediatrics: Is it time for a public policy? *Journal of Public Health Policy* 2002; 23:66–89; Antommaria AH, Bale JF Jr. Ethical issues in clinical practice: Cases and analyses. *Seminars in Pediatric Neurology* 2002; 9:67–76.
39. Mercurio MR. An adolescent's refusal of medical treatment: Implications of the Abraham Cheerix case. *Pediatrics* 2007;120:1357–8.

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# *Response*

JEFFREY BLUSTEIN

Lainie Ross's position can be summarized in the following two propositions:

1. For highly efficacious life-saving treatments: When a minor of any age has a life-threatening illness for which a "highly efficacious" treatment exists—where "minor" is any young person up to the age of emancipation—she should receive it, whatever she or her parents want.
2. For inefficacious or experimental life-saving treatments: When a mature minor has a life-threatening



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> illness for which there is no effective treatment (perhaps because treatment is still in an experimental stage), her preferences have greater moral weight than when a highly efficacious treatment exists, although even then the minor's decision is less authoritative than that of a capable adult.

Ross acknowledges that there is a continuum from highly efficacious to slightly efficacious to inefficacious to experimental and that there will be disagreements among pediatricians and adolescent medicine physicians about when a treatment is sufficiently efficacious to warrant overriding a minor's or a parent's refusal of it. But she does not think that this detracts from the appeal of her two propositions. She also suggests that some narrowing of the disagreements may be possible if various features of the proposed treatment and its administration are taken into account.

For each proposition, there are four possible combinations of attitudes to a proposed treatment for a life-threatening condition: (a) minor agrees to treatment, parents agree to it; (b) minor agrees to treatment, parents reject it; (c) minor rejects treatment, parents agree to it; (d) minor rejects treatment, parents reject it. Given Proposition 1, there should be the same response to all four situations, namely, treat. But given Proposition 2, the responses should not necessarily be the same. For example, under (a), arguably it would be appropriate to treat; whereas under (d), it would not be.

The category of "minor," of course, encompasses very young people—those who would perish without someone to care for and protect them—newborns, toddlers, and those of so-called tender years—as well as adolescents—those who may be able to survive on their own but whose welfare, if left to their own devices, is likely to be imperiled in other ways: young people ranging from about 10 or 11 years up to about 18 or 19. There is no answer to the question of when a young person becomes a young adult when asked in this abstract way. Or rather there are multiple answers, depending not only on the cognitive and emotional capacities of the individual, but on how the adult role is defined in a particular social, cultural, and familial context and the ages at which individuals are expected to take it up. But when a person has become an adult, however that is determined, she is assumed to be her own person and to have a significant degree of authority over what is done to and with her body and her life. The authority over body and life, in the case of very young people, is hedged about in so many ways and by so many restrictions that one can scarcely call it authority at all. However, if parents do a good job raising their child, she becomes increasingly independent and less dominated by them and so acquires greater authority to direct her own life. Or so I believe, and I think Ross would agree. Surprisingly, however, the fact that young people's capacities for autonomous decisionmaking typically develop over time is scarcely reflected in the ethical analysis Ross provides.

When Ross does discuss the decisionmaking capacity of adolescents, she claims that their lack of worldly experience "distorts [their] capacity for sound judgment" and that they have not yet developed certain habits of mind that are needed for long-term autonomy. Of course, there are many adults for whom this is also true, but Ross nevertheless thinks it is reasonable to draw a fairly sharp line between adolescents and adults, because "at some point . . . the advantages of self-determination outweigh the benefits of further guidance and its potential to



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improve long-term autonomy.'' A great deal is covered—or perhaps evaded—by the expression ''at some point.'' In particular, one wants to know how this point is arrived at, that is, what factors tip the balance in favor of self-determination over further guidance and paternalism.

As an empirical matter, more people over the age of emancipation have the skills, understanding, and experience required for autonomous decisionmaking than persons under that age. At bottom, the rationale for drawing a distinction between the decisionmaking capacities of adolescents and adults, as Jonathan Moreno and I have argued in an earlier essay, has to do with the development of what we called ''a moral self'':

> There is no doubt that the normal adolescent is capable of recognizing selfhood: a teenager has long since developed the ability to say ''I'' with meaning. However, it is not nearly so clear that or when the normal adolescent develops a moral self, so that he or she can say with meaning, ''I value this or that,'' so that a particular decision is authentic, an expression of who I am in a moral sense, of what kind of person I am, of what is really important to me.[1]

When an adolescent has not yet developed a moral self, his choices would not be his in the sense that demands respect as an expression of his autonomy. There might still be grounds for respecting his choices, but this would not be because his choices reflect values that are authentically his own. Adults, by contrast, typically have acquired a moral self. Indeed, it is one of the marks of adulthood—not the only one, to be sure—for a person to have acquired such a self.

These generalizations about the capacities of adults and adolescents are important and hold in the majority of cases, but generalizations also commonly have exceptions, and here the exceptions are morally significant. There may be good reasons for drawing a line between adults and adolescents ''at some point,'' but this does not entail that the line should be held in all circumstances or that there cannot be good reasons to question its applicability in a particular case. This is especially relevant when considering adolescents. For, unlike very young children, about whom we can confidently and safely say that none of them possesses capacities of autonomous decisionmaking, the developmental literature tells us that adolescents, especially late adolescents, are significantly variable in this respect.[2]

One reason for this is that the decisionmaking capacities of adolescents are much more malleable by experience than those of very young children. The familial environments to which adolescents are exposed vary along a continuum from overprotectiveness to overpermissiveness, resulting in experiences that may differ widely—even among young people at the same stage of adolescence—and different levels of cognitive and emotional maturity. In addition, the specific experience of illness and disease can affect decisional capacities, in some cases causing significant developmental delay, in others a degree of sophistication that is beyond that of healthy adolescents of a comparable age. It is virtually a truism that normal adolescence is a time of enormous, sometimes turbulent, change, biologically, psychologically, and cognitively, and that the social contexts that are important to adolescents, including family, school, and peer group, also change. The combination of individual and social contextual change provides adolescents opportunities for growth unavailable to younger children, but these opportunities are not grasped by all adolescents



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in the same way or at the same rate. It is to be expected, therefore, that generalizations about the decisional capacities of adolescents will be somewhat rough and admit of significant exceptions, particularly as adolescents approach the magic age of emancipation.

According to Ross's analysis of the rights of adolescents to refuse potentially life-saving medical treatment, if the treatment is efficacious, their desires and preferences, whether for or against and however fervently expressed, have no independent moral weight. This is the not the case with adults, of course. Capable "adults" may refuse even efficacious life-saving treatment if they are adequately informed of their options, of the implications and consequences of their choices, and have not been coerced or otherwise unduly pressured. However, if adolescents are not a monolithic group with respect to their capacities for autonomous decisionmaking, if some are as good as adults in this respect, then this is an empirical fact that the ethical analysis should take into account. It may be suggested that we can only tell whether an adolescent has the requisite adult capacities if we do an individualized assessment of him or her and that this is too difficult, unrealistic, or problematic in some other way. I do not think this is so, but at any rate, it is something that has to be argued for, not merely glossed over by vague talk about "some point" at which self-determination outweighs parental paternalism.

Ross gives a second argument for overriding a mature minor's refusal of efficacious life-saving treatment, but it is no more convincing than the previous one. "Parental interest in raising their child according to their own vision of the good life," she says, "does not abruptly terminate when the child has achieved some degree of decisional capacity." There are two things to be said about this. First, "some degree of decisional capacity" is clearly too weak, because it matters considerably how much decisional capacity the adolescent possesses. Second, the issue is not whether the parental interest ends abruptly or gradually. In fact, parents may continue to have an interest in raising their child according to their own vision of the good life even after their child has achieved a degree of decisional capacity sufficient to give their treatment decisions independent moral weight. But having such an *interest* does not necessarily confer on parents *the right* to control the treatments their child will or will not receive and to override their child's contrary decision.

A particularly interesting case from a moral standpoint—and one about which Ross could have said more—involves a mature minor's refusal of low efficacy or experimental life-saving treatments. Should parental concurrence with the minor's decision be morally required? How should the preferences of the minor be weighed against those of his or her parents in the emotionally wrenching situation in which there is disagreement between them? Should the parents be able to exercise a veto over the minor's decision? Ross's Table 7 suggests that sometimes the minor's decision should prevail, even if the parents dissent, in part at least because the minor has sufficient maturity to make this decision. I agree. Certainly parental concurrence is morally desirable. After all, the emotional devastation they will naturally feel at the loss of their child deserves the utmost compassion. But this is arguably a situation where parents should no longer be able to control the course of treatment and where the mature minor's decision should have the same moral authority as that of an adult in comparable circumstances. At the same time, this is likely to be a situation in which the minor is in



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greatest need of the understanding, support, and love of his or her parents.

As this suggests, the distinction between efficacious and nonefficacious or experimental treatments has considerable moral significance in Ross's analysis. It is in cases of the former sort where the basic medical needs of the minor take on special significance and have "lexical priority over others needs and interests" of the minor as well as his or her parents. This concept of lexical priority of basic needs is essential to her account of the limits of parental authority—the so-called constrained parental autonomy account[3]—and also does much to explain her views on the limited decisional authority of minors. Here is how she explains the concept:

> Basic needs refer to primary goods as described by John Rawls. Health is a primary good and medical care is one way to fulfill the child's basic medical needs. Parents have a duty to provide a threshold of health care services to ensure that the child's basic medical needs are met.

Rawls presents his account of primary goods as a response to standard problems with the measure of satisfaction or welfare that utilitarians employ in their theory of justice. He bases his own theory on what he takes to be a shared conception of rationality, as well as some relatively uncontroversial appeals to psychology and beliefs about human nature. Of particular relevance for a theory of social justice are the so-called social primary goods—rights and liberties, powers and opportunities, income and wealth, and the social bases of self-respect. Other primary goods are natural—health and vigor, intelligence, and imagination—and they are less directly under the control of the social structure.[4] The purpose for which Ross introduces primary goods is, of course, different from that of Rawls. She is concerned with those primary goods that are more or less directly under the control of parents, although the social primary goods are presumably presupposed as well. They are presupposed in the sense that a basic structure that guarantees the social primary goods provides the necessary framework within which parents can effectively carry out their childrearing responsibilities.

Suppose we use the concept of primary goods to construct an account, not of social justice, but of individual practical rationality. Presumably, among other things, such an account will maintain that individuals have considerable discretion as to how they will balance the various primary goods against one another in the conduct of their lives, what sorts of trade-offs among these goods they will engage in. Of course, not every individual will or should have this discretion: Young children will not, capable adults will. So, for example, if we consider leisure and freedom from physical pain as possible candidates for primary goods, then capable adults should be able to decide how they will balance these against, say, work and longevity. Things are quite otherwise with minors, according to Ross. Her thesis of the lexical priority of basic medical needs comes to something like this: When there is an effective life-saving treatment, neither the minor nor his or her parents should be able to consider other primary goods in deciding what is appropriate medical treatment for the minor. Neither freedom from physical pain nor any other interest or need of the minor or his or her parents can even be considered until the minor's basic medical needs have been met.

I think this is implausible for the following reason. The effectiveness of a proposed life-saving treatment is not



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the only morally relevant variable here. Some treatments may be effective, according to Ross's definition of the term, and yet extraordinarily burdensome for the child, not only because of their painful side effects or the complicated course of care, but also because of their negative impact on the minor's ability to lead something like a normal life. Should not parents be able to refuse such treatments under these circumstances? And more controversially, should not at least some mature adolescents have the right to do so, even if their parents disagree?

## Notes

1. Blustein J, Moreno J. Valid consent to treatment and the unsupervised adolescent. In: Blustein J, Levine C, Dubler N, eds. *The Adolescent Alone.* New York: Cambridge University Press; 1999:101.
2. See Leffert N, Petersen AC. Adolescent development: Implications for the adolescent alone. In: Blustein J, Levine C, Dubler N, eds. *The Adolescent Alone.* New York: Cambridge University Press; 1999:31–49.
3. See also her book *Children, Families, and Health Care Decision-Making*. Oxford: Clarendon Press; 1998.
4. Rawls J. *A Theory of Justice*. Cambridge, MA: Belknap Press of Harvard University Press; 1971:62.

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# *Response*

ELLEN WRIGHT CLAYTON

Professor Ross argues that it is immoral not to provide what she describes as highly effective life-saving medical treatment to adolescents, regardless of their wishes or those of their parents. The clarity of her explication is extremely helpful, making clear exactly what the issues are. Professor Blustein has critiqued her argument on two grounds, both of which I will expand upon briefly before raising additional concerns. My comments focus in part on the role of the legal system in compelling treatment because the law is ultimately what makes children get treatment they and their parents do not want, not moral arguments.

Ross argues that it is reasonable to defer to the decisions of young adults "at some point," which she then defines as age 18. Although Ross is to be commended for refusing to lower the line based on the myriad minor consent laws and the mature minor doctrine—these are designed to protect physicians and nurses who provide teenagers with healthcare they need, not as paeans to the wisdom of youth—Blustein has elegantly demonstrated through his practice and his scholarship the enormous variability of capacity that exists among adolescents. Some adolescents *can* make these choices, and some parents can reasonably believe that supporting their child's choice is the right thing to do, even at the cost of their own loss. Admittedly, the orderly conduct of society depends to a large degree on having clear rules, but when the stakes are high enough, as they are when teens wish to forgo life-sustaining medical treatment, individualized assessment is warranted. It *is* possible to ask teens whether they understand that they are very likely to die without treatment



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