FROM THE EDITOR

Evidence and Ethics

Everyone agrees that access to health care is an ethical issue, particularly for children. The promise of newborn screening, of course, is that it promotes access: it identifies children with serious but treatable disorders and (if the program is complete) connects them to effective care. If access is an ethical issue, however, then so is cost-containment: one obstacle to providing access is that costs are out of control, and therefore (as David DeGrazia argued in these pages a couple of issues ago) it is imperative that we think about cost-containment. One *problem* with newborn screening according to two articles in this issue is that some of the tests now in use in some states—and recommended for use across the nation by a federally funded panel of experts—raise costs more than they promote access. In fact, these articles assert, these tests may actually impede overall access by spending limited resources.

To Bruce Lin and Alan Fleischman, physicians with the March of Dimes and authors of Another Voice (on the facing page), this position is wrong both about the constraints imposed by the cost problem and about the procedure for evaluating newborn screening. When it comes to the treatment of children with severe health problems, access is restrained by cost, they assert, only if state policy-makers have decided that it will be. Funds should be allocated to meet these very special health needs—full stop. And it's hard to allocate funds on the basis of evidence of effectiveness, they maintain, for the simple reason that the extreme rarity of many of these disorders means that effectiveness must be evaluated on the basis of a small sampling of case reports rather than population-based studies.

For me, as editor, one of the lessons of this exchange is bioethicists should become more engaged in questions of access, benefit, and cost, and how to appropriately balance them against each other. Perhaps because bioethics emerged mainly out of philosophy and theology, bioethicists have a lot to say about the nuances of autonomy and the moral weight of "human nature." (Nothing against this topic; it's where my own work is.) When it comes to evaluating a technology or an intervention, we may only gesture at beneficence or, as a colleague of mine likes to say, "sprinkle a little justice around."

The exchange in this issue makes clear that there are unresolved problems in balancing costs, benefits, and access. What is the role of evidence in making health care allocation decisions? Certainly we want it when we can get it; when is it necessary? Does it figure differently in clinical decisions, best practice guidelines, and public health decisions? What if we are forced to make allocation decisions not between groups of children, but between children and adults: should we put a markedly higher priority on children's health needs? Or is focusing on children's health needs just a political strategy? What are the best ways of comparing different benefits—must one invoke QALYs and DALYs?

Papers on these and similar questions are welcome in the editorial suite here.
—**GEK** ■

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