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## Testing Testing

by Carl E. Schneider

Last year, Congress passed the Ryan White Care Act Amendments of 1996. The amendments authorize ten million dollars for each fiscal year from 1996 through 2000 for counseling pregnant women on HIV disease, for "outreach efforts to pregnant women at high risk of HIV who are not currently receiving prenatal care," and for voluntary testing for pregnant women.

The amendments compromise a central question: whether prenatal and neonatal AIDS testing should be compelled. The compromise is complex. The director of the Centers for Disease Control and Prevention is instructed to establish a system for states to use to discover and report the number of cases in which infants have acquired AIDS *in utero*. The secretary of the Department of Health and Human Services (DHHS) is to use those reports to decide whether the following practices have become routine: to provide HIV testing for infants whose mothers have not been prenatally tested; to disclose the results of such tests to the mother and to others who have or are likely to have legal responsibility for the child; to disclose the results of prenatal tests for HIV disease promptly to the pregnant woman; to provide counseling along with test results; and finally for states to prohibit health insurers from canceling insurance because someone has HIV disease or has been tested for it.

If the DHHS secretary decides these five practices have become routine, states wanting full funding under the Ryan White Care Act must legally require each one. However, states need not do so if their rate of new cases of perinatally acquired AIDS has declined by at least 50 percent since 1993 or if "[a]t least 95 percent of women in the

State who have received at least two prenatal visits (consultations) prior to thirty-four weeks of gestation with a health care provider or provider group have been tested." Finally, the DHHS secretary must have the Institute of Medicine prepare a report for Congress on the amendments' effectiveness in reducing the perinatal transmission of HIV.

The question whether prenatal and neonatal HIV testing should be the uncoerced or even uninfluenced choice of pregnant women and mothers has been debated for some time. There has been a good deal of feeling that testing should not just be more widely available, but that it should be vigorously encouraged and even compelled. However, that sentiment has often been met (especially in the academy) with skepticism and even hostility. One eminently moderate example of such skepticism is the report of the National Research Council's Panel on Monitoring the Social Impact of the AIDS Epidemic.<sup>1</sup>

The panel's report explains that children who are infected with HIV

need extra attention from the point of birth . . . [R]oughly 20 percent of newborns with HIV become ill with AIDS-related infections within a year of their infection. Once ill, they tend to spend more days in the hospital than adults with AIDS. They typically have chronic growth problems, as well as developmental problems in both motor and language skills . . . And all the required care will be delivered by someone who knows that it is highly probable that the child will die.

The report adds that "most clinicians now believe that it is important to identify in infancy children who may be in-

fectured in order to begin prophylactic treatment and to monitor them for signs of treatable infections."

These data, of course, suggest one motivation for testing: to identify children who may need special care. This identification, however, is not straightforward. All pregnant women infected with HIV pass on antibodies to their newborn children. But only about a quarter of those children are actually infected.

Having described a rationale for aggressive testing, the panel's report expounds the opposing view. The report says that if pregnant women are tested to identify children who might benefit from medical attention, "the state is, in the view of many, using the woman simply as a vehicle for reaching her child." If the state tests children after birth without their mothers' consent, the state "imposes two forms of intrusion on the mother. First, it compels her to learn her own status [since the test reveals the mother's antibodies] . . . Second, . . . imposing the test overrides the mother's control over her child in a society that leaves nearly all decisions about children to parents."

In short, the report approaches testing primarily in terms of the mother's rights, although less emphatically so than many other comments. This is surely a basic element of the way a court would approach the question. And the report's cautious conclusion—that "the great reluctance to override parental choice is probably defensible"—might well be the result courts would reach were the issue fully litigated. But a thorough judicial treatment of the rights question would encounter a number of revealing complexities.

The report says, "When the Supreme Court speaks of a constitutional presumption of biological parents' control over a child's life, it is speaking of rights that belong to the parent, not rights that belong to the child." Parents' constitutional claims to the *companionship* of their children surely does partly rest on our social respect for the fact that "most parents regard begetting and raising children as one of life's most fulfilling activities." Perhaps that also ex-

plains parents' constitutional claims to make *decisions* for their children. That basis for parental rights is unproblematic where the parents' interests seem to coincide with their children's, so that the contest is between the state on one hand and the parent and the child together on the other. But should parental fulfillment be a basis for parental rights where that fulfillment may injure the child?

Even if one's answer to that question were no, parental rights might still be justified on the theory that freeing parents to make decisions for their children protects the children. The rationale would be that generally parents know and love their children better than the state and that parents will therefore, again, generally, make wiser decisions for their children than the state. But then what do we do when the question in a case is whether the general rule applies? The panel's report does propose "some child-centered reasons why a mother . . . might refuse testing for her child." These include the stigma the child might suffer and the possibility that the mother's learning she was HIV-positive might "interfere with her capacity to parent." But the report also acknowledges, and with reason, that "empowering parents to refuse HIV testing for their newborn appears to pit the interests of parents against the interests of children since a child cannot be treated if her or his illness is not known."

But suppose the report is correct in saying that the relevant right is the parent's and not the child's. Is this appropriate? Parents' rights are justified, the report says, by our social respect for the fulfillment they find in parenthood. Do we not socially respect the fulfillment, the health, and the lives of children? Should we not promote those interests by attributing rights to children? These questions have increasingly been asked in recent years. They are inspired partly by concern about the prevalence of child abuse and by the fear that strong parental rights have inhibited attempts to keep parents from harming their children. For example, some years ago ideas about parental rights helped intensify reluctance to remove abused and ne-

glected children from their parents. Today, that reluctance is receding. Similarly, cases in which parents who had become separated from their children for a number of years have sought to retrieve them from the people who had raised them since birth have provoked uneasiness about ambitious versions of parents' rights.

Whatever the basis for parental rights, legal doctrine does not hold that the state may never infringe them. Of course the state needs good reasons. But here its reason looks impressive, since protecting the health of infants is such a worthy enterprise. The state must also show that its means—here mandatory testing—are necessary to reach its goal—protecting infected children. But if the state could make such a showing, the individual's right would yield to the state's interest. *Roe v. Wade* itself illustrates that principle, for there the Court permitted states to regulate abortions ever more fully as pregnancy progressed and the state's interest grew.

In 1994, the year after the panel's report, the debate over prenatal testing was complicated by news that perinatal transmission of HIV can be reduced from about 25 percent to about 8 percent by administering zidovudine to HIV-infected women. This development, welcome as it is, seems to intensify the claims of both sides. Now prenatal testing does not just identify children who might need treatment. It also identifies women who could be treated to protect the children they would soon bear. This development enhances claims for prenatal testing, since it offers the prospect of actually saving some children from becoming infected.

On the other hand, this same development sharpens the mothers' rights argument by bringing it closer to the kinds of claims about reproductive freedom that animated *Roe*. Once again, however, judicial rights thinking is not unambiguous. *Roe* held that government may not prohibit abortions in many circumstances. But the cases that followed *Roe* suggest that *Roe* instituted something less than full-fledged reproductive freedom. In those cases, for example, the Court has countenanced

regulations that influence but do not dictate women's choice whether to have abortions. And the abortion-funding cases say that government may seek to sway reproductive choice through its budgetary powers.

It is morally and legally necessary to discuss testing in terms of rights. Not only does the controversy about it raise questions of human rights, but—as I have sought to show—even the legal language of rights offers some resources for recognizing and probing the complexities those questions raise.

But the law's resources can take us only so far. Much of the rights literature on testing disappoints because it seems so much absorbed by the arguments for one side. Too little of it attempts to explore how the conflicting rights claims can be compared and reconciled. The panel's report is markedly more concerned with children's interests than much of the literature. But even it seems to detail the parental rights with thoroughness and force, discussing the other possible claims hardly more than implicitly. This failure of the literature may be understandable. Ultimately, the law is baffled by conflicts between the interests of two rights holders. It is baffled because, as I suggested, the law has failed to articulate satisfactorily the basis for the rights it has announced. And it is baffled because reconciling rights requires a subtlety and a sensitivity to particulars that law, as a system of rules, cannot easily attain.

In addition, of course, the wisdom of any testing policy turns on more than rights. We need to ask whether even mandatory testing will significantly reduce the rate of perinatal transmission of HIV, whether similar improvements could be obtained in other ways, and even whether spending scarce funds on the perinatal transmission of HIV is the best expenditure of public health dollars.

#### Reference

1. National Research Council, Panel on Monitoring the Social Impact of the AIDS Epidemic, *The Social Impact of AIDS in the United States* (Washington, D.C.: National Academy Press, 1993).