

2009

# Thou Good and Faithful Servant

Carl E. Schneider

*University of Michigan Law School, carlschn@umich.edu*

Available at: <https://repository.law.umich.edu/articles/1953>

Follow this and additional works at: <https://repository.law.umich.edu/articles>



Part of the [Family Law Commons](#), [Health Law and Policy Commons](#), and the [Legislation Commons](#)

---

## Recommended Citation

Schneider, Carl E. "Thou Good and Faithful Servant." *Hastings Center Rep.* 39, no. 1 (2009): 10-1.

This Response or Comment is brought to you for free and open access by the Faculty Scholarship at University of Michigan Law School Scholarship Repository. It has been accepted for inclusion in Articles by an authorized administrator of University of Michigan Law School Scholarship Repository. For more information, please contact [mlaw.repository@umich.edu](mailto:mlaw.repository@umich.edu).

## Thou Good and Faithful Servant

by Carl E. Schneider

Lawmakers are stewards of social resources. A current debate—over screening newborns for genetic disorders—illuminates dilemmas of that stewardship that have particularly plagued bioethics. Recently in the *Report*, Mary Ann Baily and Thomas Murray told the story of little Ben Haygood. He died from MCADD, a genetic disorder that can make long fasting fatal.<sup>1</sup> Screening at birth would have let doctors alert Ben's parents. "After Ben died," Baily and Murray wrote, "his father became a passionate advocate for expanding Mississippi's newborn screening program to add MCADD and other disorders." Soon, the Ben Haygood Comprehensive Newborn Screening Act increased the number of genetic disorders covered by the state's program from five to forty and provided teams to follow up positive tests.

Is this a prudent and productive way to make public policy? Certainly it is understandable. Mr. Haygood knew that parents suffered and children died in ways newborn screening could prevent. He acted on his knowledge. The legislature knew that suffering and death could be prevented. It acted on its knowledge. Was it supposed to let Tiny Tim die?

Who could say yes? But was the legislature a good steward? In its first year, as Baily and Murray reported, Mississippi's expanded screening identified three cases of MCADD "along with twelve cases of other new disorders, out of a total of 116 newborn screening diagnoses." But "to help pay for the ex-

pansion, the state doubled the [screening] fee to seventy dollars. This meant that a substantial share of the resources for expansion came from Mississippi's Medicaid funds, since Medicaid covers more than half of Mississippi births." Around this time, Mississippi's infant mortality rate had been increasing, "Medicaid eligibility requirements were tightened, and some programs were cut."

One county's infant mortality rate, however, "fell sharply after a private charity began providing intensive in-home visits using local women as counselors and busing pregnant black women to pre- and postnatal classes." If resources spent screening had instead been spent on such a program, would more lives have been saved and more suffering averted? When legislators are confronted with the tragedy and passion of a parent like Mr. Haygood, such questions are painful and seem pointless. But if they are not asked, several anonymous Tiny Tims may die to save one whose story lawmakers hear.

The American College of Medical Genetics proffers a somewhat more systematic way to make screening policy.<sup>2</sup> Its "expert panel identified 29 conditions for which screening should be mandated. An additional 25 conditions were identified because they are part of the differential diagnosis of a condition in the core panel or are clinically significant and revealed by the screening technology but lack an efficacious treatment . . . or because there are incidental

findings for which there is potential clinical significance."

The ACMG report is a stride toward more orderly stewardship, and most states have implemented a version of the report's proposals. But like Mr. Haygood, the ACMG has purposes and passions that lead it to see a world in which screening is indispensable. Its report does address the issue of cost and benefit, but in such a cautiously qualified way that it's hard to embrace its conclusions. Furthermore, the report enthusiastically says that "screening is more than testing. It is a coordinated and comprehensive system consisting of education, screening, follow-up, diagnosis, treatment and management, and program evaluation." How would a "comprehensive system" affect costs and benefits? Finally, the report does not ask whether there are yet more rewarding ends to which resources could be put.

In a recent white paper, the President's Council on Bioethics sees screening from yet another perspective.<sup>3</sup> It finds the cost question harder than the ACMG. Few infants actually benefit: Of about four million babies screened annually, "about 5,000 are identified as having serious heritable disorders, most of which are, in varying degrees, amenable to treatment." And the "benefits and harms involved in each component of genetic screening" are "complex and elusive."

The white paper, however, is primarily interested in "ethical analysis" of screening. The white paper "[r]eaffirms the essential validity" of the "classical principle"—screen only for treatable diseases. It believes the ACMG report strays from that principle. First, the report favors screening for untreatable disorders if screening might produce clinically useful information. Second, the white paper concludes that the report embraces "a broadened conception of benefit that includes . . . helping society by providing opportunities for biomedical research aimed at understanding the natural history of the disorder and finding an effective treatment for it."

The white paper thus recommends mandatory screening "only for those disorders that clearly meet" the "treat-

able” standard. Screening for other disorders “may be offered by the states to parents on a voluntary basis under a research paradigm.” The “research” screening would have to meet two requirements. First, “[p]articipation in these pilot studies should require the voluntary, informed consent of the infant’s parents.” Second, “IRB approval should be obtained in each state.”

The white paper’s perspective, then, is essentially that of traditional bioethics. It focuses on the interests of the patient, fears that research may injure those interests, and treats informed consent and IRB review as presumptively desirable. How does that perspective look to the good steward?

When the state makes screening policy, it not only allocates its funds; it also shapes the way parents employ their time, energy, money, and medical services. Parents asked to give informed consent must devote those resources to their education. Were screening all that new parents had to learn about, imposing that education on them could make sense. But new parents have more pressing assignments. When I asked a family practice physician where screening ranked in his educational priorities for new parents, he snorted. He is anxious to teach parents to bring newborns in for attention when they have a fever, not to give babies water, to put babies to sleep on their backs, and much else that is not obvious and saves lives.

Requiring parents to spend resources learning about screening looks even less sensible given the sobering but ever-mounting evidence that informed consent cannot achieve the goal announced for it—equipping people to reason their way capably to well-founded and well-considered medical decisions. And the white paper presents evidence that education about screening is, if anything, particularly ineffective. But of course: Teaching and learning are hard. Good stewards of educational resources choose their battles cautiously.

The good legislative steward asks another question: If screening is needed, how should it be instituted? The issue is not whether parents may exempt children from screening. It is whether the

rule should be that children are screened unless their parents opt out, or that children are not screened unless their parents opt in. A large literature tells us that even when people care about a decision (like contributing to retirement accounts), they frequently leave themselves wherever default rules put them.

So which default rule best suits screening? That depends on two things. First, which rule best reflects parents’ preferences? That is, which rule is likeliest to leave parents where they want to be? The white paper shows that given a choice, in surveys and in life, almost all parents choose screening. So an opt-out rule both conserves social and personal resources and promotes parents’ autonomy (by giving them what they want without making them ask).

The second question about defaults is which rule best promotes broader social interests. The arguments for screening are that it protects newborns and their families while promoting valuable research. If so, the opt-out rule is again preferable. Furthermore, an opt-out rule attributes to parents a willingness to assist medical research when the risk is vanishingly small. That rule assumes parents recognize that their families benefit from generations of participation in research and can repay their debt by participating in research to help later generations. An opt-out rule thus honors the American tradition Tocqueville admired:

The free institutions which the inhabitants of the United States possess, and the political rights of which they make so much use, remind every citizen, and in a thousand ways, that he lives in society. They every instant impress upon his mind the notion that it is the duty as well as the interest of men to make themselves useful to their fellow creatures; and as he sees no particular ground of animosity to them, since he is never either their master or their slave, his heart readily leans to the side of kindness.

Much law is made in the way the Haygood Act apparently exemplifies. A

story is told that seems to reveal a dreadful wrong. Sympathy is won. Indignation is provoked. An “obvious” solution presents itself. The legislature adopts the solution without systematic argument or adequate evidence. For example, a federal ban on “drive-through deliveries” was enacted in this way. Congress barely discussed the Patient Self Determination Act’s (otiose) requirement that information about advance directives be offered patients. When the Department of Health and Human Services promulgated HIPAA, it proffered more anecdotes than rationales for aggrandizing its authority. The IRB system continues to be justified primarily by a rhetoric of scandal that has less and less relevance.

Newborn screening illustrates Wilde’s *mot*: “The truth is rarely pure and never simple.” Facts are elusive and ambiguous, yet until they are understood, principles provide little guidance. We value good stewardship, but we do not know what the real costs and benefits of screening are. The people and groups that are interested in policy have perspectives of their own. Legitimately. Mr. Haygood *should* think about families like his; the ACMG *should* look to genetics to improve health; the President’s Council *should* analyze issues in ethical terms. But *all* these perspectives are necessary, and who is to assemble, evaluate, and reconcile them? So bad money drives out good, and argument by anecdote, by scandal, and by outrage perpetually threatens to displace the burdensome and perplexing business of good stewardship.

1. M.A. Baily and T.H. Murray, “Ethics, Evidence, and Cost in Newborn Screening,” *Hastings Center Report* 38, no. 3 (2008): 23-31.

2. American College of Medical Genetics, *Newborn Screening: Toward a Uniform Screening Panel and System* (Washington, D.C.: American College of Medical Genetics, 2005).

3. President’s Council on Bioethics, *The Changing Moral Focus of Newborn Screening: An Ethical Analysis by the President’s Council on Bioethics*, December 2008, [http://www.bioethics.gov/topics/newborn\\_screening\\_index.html](http://www.bioethics.gov/topics/newborn_screening_index.html). (I am a member of the council. Parts of this essay draw on a personal statement I wrote to accompany the white paper.)