# Ethics and Newborn Genetic Screening: New Technologies, New Challenges

Editors: Mary Ann Baily and Thomas H. Murray
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The product of a Hastings Center project on ethical decision making for newborn screening, *Ethics and Newborn Genetic Screening: New Technologies, New Challenges* should be required reading for all those concerned with the evolution of infant screening and, more broadly, children's health policy. Although not all contributions to the edited volume are equally compelling, the book brings together some of the best minds and clearest thinking on the issues at stake. A reasonable conclusion is that the recent expansion of newborn screening in the US—and in all jurisdictions (including my own province of Ontario, Canada) that have followed the lead of the deeply flawed American College of Medical Genetics report, "Toward a Uniform Screening Panel and System"—is without moral justification.

Noting the distressing concurrence in one US state of an expansion in the mandatory newborn screening panel (with corollary demands on Medicaid funds) and an appalling rise in infant mortality rates (alongside restrictions in Medicaid funds), the editors argue that newborn screening policy is only ethically acceptable when it (1) is evidence based; (2) considers the opportunity costs of its investments; (3) seeks to fairly distribute costs and benefits; and (4) respects human rights. An important conclusion of this moral framework is that newborn screening policy should be removed from its silo and made to defend itself alongside all other investments that might support the imperative of improved infant and child health. One might quibble that such moral ends are more typically advanced by health economists, clinical epidemiologists, and political philosophers than bioethicists, but there is no doubt in this reviewer's mind that these are the correct metrics.

American developments are the focus and overarching concern of all contributors. Newborn screening in the US is typically mandatory, and several authors dwell on this distinctive legal approach. In Canada newborn screening is pursued under the auspices of implied consent. Other jurisdictions (The Netherlands) have moved to more explicit consent processes even while infant screening remains highly recommended. In *all* of these jurisdictions, newborn screening initiatives seek to minimize parental discretion. The moral justification for this is that infant screening is effective and necessary, indeed essential. Yet in the absence of evidence on the effectiveness of screening for many newly added conditions, expanded panels abrogate the social contract wherein minimal parental discretion is justified by the demonstrated effectiveness of screening—whatever the jurisdiction or enrollment mechanism. However, the editors do highlight a distinctive moral challenge in the US: unlike other jurisdictions, the US lacks coherent mechanisms to fairly allocate the costs of screening or ensure that families receiving positive screening results (including affected infants, false-positive cases, and the growing cohort of infants with uncertain diagnoses) are guaranteed appropriate care. Under these circumstances, the burden of proof for those who would seek to expand screening panels should be very high indeed. The books' editors have ceded some space to the proponents of expansion, but the weight of commentary is decisive in its dissent. Those in the US, and those profoundly influenced by US developments, can only hope that advocates, health professionals, and policy makers will agree.

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