

Ethics and Newborn Genetic Screening: New Technologies, New Challenges



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The United States has the first and the farthest-reaching newborn genetic screening program in the world. In recent years, individual states have expanded their newborn screening programs to include many more genetic conditions, as new medical knowledge and new testing technologies have become available. The contributors to this provocative collection study the complex ethical and policy challenges present in the changing newborn screening environment and offer guidance to professionals, policymakers, and the general public.

Experts from the fields of bioethics, genetics, pediatrics, public health, health policy, law, and political science identify and analyze four social and ethical issues critical to newborn screening policy: the distribution of costs and benefits; information, consent, and privacy; consultation and decision making; and race, ethnicity, and socioeconomic status. In the process, the contributors capture the difficulties of trying to forge ethical public policy at the intersection of parental concerns, new technologies, and economic interests.

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