

Arsht Research on Ethics and Community Grant

The Ethics of Newborn Screening in a Society with Low Health Literacy

2007-2008

Faculty: Lee M. Sanders, M.D., M.P.H.

Student: Julia Sein

School of Medicine

Abstract

New technology allows newborns to be screened for an increasing number of medical conditions at birth. Unfortunately, one in 5 US adults has low health literacy. This impairs the capacity of individual patients, clinicians, medical systems, and public-health systems to absorb this sudden wave of new health information. It also raises important ethical issues for the medical system and for policymakers. **Questions:** Ethical issues include equal access to health services, communicating future risk of medical maladies, providing adequate information for informed consent, parental rights to child health information, child rights to health information, and public responsibility for health screening programs. **Methods:** Under guidance from a Scholarly Advisory Committee, we propose to explore these issues in three ways. (1) We will conduct a comprehensive literature review to include not only peer-reviewed articles, but also health-information materials for parents and clinicians. (2) We will conduct a series of interviews with key stakeholders affected by newborn screening, including parents (with low and adequate health literacy), clinicians, and policymakers. Standard methods of qualitative and quantitative analysis will be used to analyze the results of these interviews. (3) We will make publicly available the results of both the literature review and the interview protocol through at least one peer-reviewed publication, as well as through link on the University of Miami Ethics Program website.

Please do not copy or quote without permission. For more information, please contact the University of Miami Ethics Programs at ethics@miami.edu.