

28TH ANNIVERSARY SERIES



INSTITUTE FOR BIOETHICS AND HEALTH POLICY & DEPARTMENT OF PEDIATRICS

DIALOGUES IN RESEARCH ETHICS

DIALOGUE 192

Newborn Screening: Challenges For Consent in Population Studies

Don Bailey, PhD
RTI International

12 noon, Friday, October 25, 2019
Mailman Center for Child Development, Room 5003
Lunch provided; first come, first served.

Newborn screening is generally conducted without consent, on the premise that having one of the disorders screened constitutes a medical emergency for which there are proven benefits of very early treatment. Screening for disorders with insufficient data on benefit must be conducted with consent. Our Early Check research project offers free, voluntary screening to every birthing parent in North Carolina, but getting valid consent at a population level remains a formidable barrier. Efforts to ensure voluntary enrollment and to improve parental understanding could inform future decisions about the role of consent in NBS and the viability of a “second-tier” consented platform of conditions that do not meet rigorous standards for NBS but are of great interest to families and still offer potential benefits.

Dr. Bailey is a Distinguished Fellow at RTI International, where he directs the Center for Newborn Screening, Ethics, and Disability Studies. For 27 years he was on the faculty of the UNC Chapel Hill as a W.R. Kenan, Jr. Distinguished Professor and, for 14 years, director of the Frank Porter Graham Child Development Institute. His research addresses early identification and intervention for children with disabilities, as well as family adaptation to disability. His publications address newborn screening, early intervention, disability and family support. He directs several NIH-funded projects on newborn screening and the ethical, legal, and social consequences of genetic discoveries and the disclosure of genetic information to families.

Dialogues in Research Ethics is a series of monthly seminars. For more information, phone UM Ethics Programs at 305-243-5723 or E-mail ethics@miami.edu.

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