

## Book Reviews

*Saving Babies? The Consequences of Newborn Genetic Screening.* By Stefan Timmermans and Mara Buchbinder. Chicago: University of Chicago Press, 2013. Pp xii + 307. \$30.00.

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*Saving Babies* begins with a detailed account of a compelling case study: the case of U.S. celebrity couple Renee and Scott Baio and their daughter Bailey. Screened at birth for, among other conditions, organic acidemia oxidation disorders, Bailey tested positive. However, Bailey's test result was right on the threshold of what was considered a positive result. There followed 10 weeks of further testing and investigations, before the result was deemed a "false positive" and Bailey was discharged. From a medical perspective, false positives are a routine occurrence that attract little attention, but the examination of the Baio's case here draws out the social perspective: the impact on the Baio's relationship, on their ability to bond with their daughter, and on the way in which everyday decisions (how to feed her, whether to take her on outings) became shaped through the lens of her test results. As an introduction to the hidden consequences of newborn screening, the case works beautifully, but it also highlights the fact that the response to these consequences is less than straightforward. Scarred by their own experiences, Bailey Baio's parents might understandably have adopted an antiscreeing position; instead they launched a foundation to promote the expansion of newborn screening in the United States. As Stefan Timmermans and Mara Buchbinder note, the channeling of these parents' difficult experience into proscreening activism is a revealing indication of the appeal of newborn screening—an appeal that is both inherent and difficult to counter. The authors also tell us that, regardless of the final outcomes for their children, all parents in their study were steadfast in their support for the principle of a newborn screening program.

Though the scene is set with a single case study, this book is based on an extensive program of rigorous academic research. Between them, Timmermans and Buchbinder carried out ethnographic work spanning almost three years, including observations, recordings of consultations, attendance at clinical team meetings, and interviews with families. Data were analyzed following the principles of abductive analysis. This breadth of

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data enables the authors to go beyond the official discourse—that newborn screening saves both lives and money—to examine instead the impact not only on families, but also on the medical profession itself. Following a review of newborn screening policy in the United States and the way in which it has developed since its historical origins in screening for phenylketonuria (PKU), the authors focus on some of the underlying assumptions. Foremost among these is that more information is always better, or that families will welcome such information even when its meaning is ambiguous or no effective treatment can be offered. Perhaps less obviously, the notion of screening for a condition implies that there is some certainty regarding what constitutes the condition in the first place. In fact, Timmermans and Buchbinder show how the newborn screening program has blurred boundaries between health and disease; does a raised enzyme level or a single genetic marker in the absence of any other pathology, signs, or symptoms mean that an infant should become a patient? While parents and families have to deal with the fact that the apparent promise of a quick diagnosis at birth may not be fulfilled, and that their child has become a “patient in waiting,” clinicians have to deal with the practical problems of implementation, doing “bridging work” to fill the gap between the vision for the program and the way in which it is actually experienced by users. Managing diagnostic uncertainty is a key feature of this bridging work, and as the authors show, “patients in waiting” are created in interactions with clinical staff.

Through their careful analysis, Timmermans and Buchbinder show how competing tensions are managed in practice and the active work that this requires from clinicians. Newborn screening programs have epistemological and ontological consequences, because they change both how we know about disease and what we understand as a specific disease. This production of information that no longer fits the existing knowledge base has to be translated into new operating procedures, and treatment protocols must be reconsidered. However, the authors demonstrate how erring on the side of caution by sticking to existing treatment protocols is favored by clinicians as well as parents, not simply to minimize risk but also because it maintains a singular identity for those “with” a particular disease; it protects the disease as well as the patient.

In the latter part of the book, the authors turn their attention to the extent to which expanded newborn screening lives up to its promises. They highlight how early detection and clinical attention is not always sufficient to prevent serious morbidity, and that where asymptomatic patients commonly face diagnostic uncertainty, so symptomatic patients with rare disorders face prognostic uncertainty. As a result, they argue that it is less than straightforward to claim these patients have been “saved” by early intervention. In addition, the spotlight is turned on the way in which a parent’s ability to keep a child alive is affected by inequities in the U.S.

health-care system. Such inequities include the presence or absence of health-care insurance and the geographical distance to specialist facilities, but these can be mitigated or exacerbated by the parent's cultural capital and their ability to enlist help with support and transport and to get others to take their child's condition seriously. Timmermans and Buchbinder end with a call for greater responsibility from policy makers in addressing what families *experience* as a result of these policies—the unintended consequences of newborn screening.

This work is a scholarly book that is also beautifully written and eminently readable. It will undoubtedly find an audience among medical sociologists, but it deserves a wider readership among public health scholars and students and makers of public policy as a case study of how public health programs are experienced, and how they can potentially create disease as well as detecting it.

*In the Public Interest: Medical Licensing and the Disciplinary Process.* By Ruth Horowitz. New Brunswick, N.J.: Rutgers University Press, 2013. Pp. xii+261. \$75.00 (cloth); \$29.95 (paper).

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The extent to which members of the medical profession have managed to maintain their considerable professional discretion and self-regulation in spite of threats from a range of external pressures has been the focus of sociological debate. One area where traditionally medical professionals have maintained tight control is in the disciplining of their own colleagues, although even in this context there has been pressure for increasing transparency and accountability to the public. *In the Public Interest* sheds light on this and a range of other issues through a study of the work of medical boards in the United States, which are legislated to control who can practice medicine; more specifically, Ruth Horowitz's primary focus is on "the ways medical boards frame their discussions and the conditions under which public members can participate effectively in decision-making processes" (p. 4). The evidence on which this analysis is based derives primarily from the author's long-term experience (from the late 1980s onward) and observations acting as a public member of two distinctly different medical boards in the same state and further complemented by observation of two other boards. Thus, this study could be described as an ethnography using both participant and nonparticipant observational methods, with the author taking a number of different positions such as board member, public sociologist aimed at improving the work of the board in the interests of the public, and more inde-