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Affective Economies and the Politics of Saving Babies' Lives

Mara Buchbinder and Stefan Timmermans

In the fall of 2002, just hours after the birth of their daughter Lucia, Elaine and Nathan Schubert were recruited to participate in a pilot newborn screening (NBS) study conducted by the Genetic Disease Branch of the California Department of Health Services.¹ At first, the Schuberts were reluctant to participate. Lucia had been born several weeks premature and had already been through a lot; they did not want her “poked and prodded,” as Nathan later explained. But due to a persistent neonatal intensive care unit (NICU) nurse who approached Nathan several times to explain the study’s significance—“this is a life-saving test, potentially”—the Schuberts eventually consented. Five days later, they received a phone call from their pediatrician. Lucia had screened positive for 3-methylcrotonyl-coenzyme A carboxylase (3-MCC) deficiency, a rare metabolic disorder.² “If Lucia hadn’t been born at that *particular* hospital during that *particular* time frame of that pilot program window,” Nathan told us in an interview more than seven years later, “she would very likely be dead. And if not dead, perhaps severely mentally or physically retarded.”

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1. The Schuberts’ names are pseudonyms.

2. People with 3-MCC deficiency have a shortage of the enzyme that helps break down the amino acid leucine, leading to difficulties with metabolizing certain proteins.

Soon after Lucia's diagnosis, Nathan joined forces with the March of Dimes, a well-known US advocacy organization dedicated to improving the health of babies, and traveled to the state capitol several times with a team of clinician-scientists, advocacy organization representatives, and other parents like him to testify in congressional hearings about the importance of NBS. Parental testimony was carefully orchestrated to highlight the vastly different outcomes for two different children: one who underwent screening, and one who did not. Nathan recounted:

And I would get up and tell our story and then end it by saying, "I don't know where we'd be without newborn screening," and sort of finish on that note, very emotional. And then the mic would get passed to a mom I'd never met before, and she would say, "Actually, I would know. I know what that's like." She would tell [what happened] when you didn't get the newborn screening, sort of the flipside, the negative, so that was just horrible. I can't tell on this tape—too many tears.

Nathan's story and his family's experience served as our initial point of entry into the world of NBS advocacy. When we met the Schuberts in a genetics clinic, where Lucia was being treated for 3-MCC, we were in the midst of a three-year study of the consequences of expanded NBS in California.³ Nathan's story, however, prompted a shift in our temporal focus by raising a new set of questions about the cultural and historical conditions that had enabled the rapid expansion of state-mandated NBS across the United States.

In a country where health care is not a citizenship right, the decision of state governments to screen every baby for more than fifty rare genetic disorders is striking. Few other state-sponsored public health services in the United States provide universal access to citizens, regardless of insurance status or ability to pay. On the one hand, screening an entire population for rare genetic disorders constitutes a welcome shift toward democratized health care in an era in which many genomic technologies have been privatized and commercialized. On the other hand, expanding screening programs without concurrent attention to prioritizing health care needs or funding long-term treatment risks further entrenching inequalities and undermining the public health success of population screening.

For many screening targets on the universal screening panel introduced in 2006, the epidemiological evidence in favor of screening was equivocal—due to

3. Between 2007 and 2010, we followed seventy-five patients receiving follow-up care for positive NBS results in a metabolic-genetics clinic. For an overview of our methods and findings, see Timmermans and Buchbinder 2013.

the poor understanding of disease conditions and limited availability of effective treatments—and cost-effectiveness data were lacking (Botkin et al. 2006; Moyer et al. 2008). Moreover, in a climate of finite health care resources, funds spent on NBS may be diverted from other programs, which may be public health programs aimed at servicing the poor (Baily and Murray 2008). The low incidence of target disorders (Watson et al. 2006), barriers to accessing treatment following NBS detection, spiraling health care costs, and persistent health care inequities all constrain the long-term benefits of NBS in the United States (Timmermans and Buchbinder 2013), raising questions about whether modest outcomes are worth the investment of limited public health resources.

How was the expansion of NBS in the United States made possible, despite a significant departure from health policy trends and limited support for its benefits? Although multiple factors contributed, including technological advances (Levy 1998) and shifting ethical frameworks for population screening (e.g., Bailey et al. 2006), pressure from parent advocacy groups played an important role (Grob 2011; Paul 2008). Nathan Schubert's account of testifying to the California state legislature points to the specific function of affect to draw on widespread anxieties about "saving babies" from sudden death and accomplish advocacy goals. In this article, we analyze public records from NBS policy hearings to examine how NBS advocates deployed affect toward political ends.

Recent scholarship on humanitarianism provides a critical backdrop for our exploration of the affective entanglements that underlie some forms of political and economic engagement. Although advocacy surrounding global disaster relief and human rights violations may seem to bear little relevance to the efforts of comparatively privileged American parents to bring attention to rare genetic disorders, we draw on this work for two specific reasons. First, critical perspectives on humanitarianism have elucidated the tight interweaving of affect and politics by highlighting the role of moral sentiments in shaping political responses to crises (Bornstein and Redfield 2011; Ticktin 2011), particularly in cases where children's lives are at stake (Bornstein 2001; Burman 1994; Nichter and Cartwright 1991). Humanitarian projects may assert a normative claim about the ability for emotional responses to trump political divides, such as in the slogan for US aid to Ethiopia during the 1984 famine: "A hungry child has no politics" (Burman 1994: 243). However, this implied separation between affects and politics is merely rhetorical, since its logic depends on a politics of suffering that is, as Lori Allen (2009: 167) has put it, "presented as apolitical and relies on this framing for its power." Thus what affects seem to offer is not so much depoliticization as

a careful recasting of activist politics into a “sublimated form” (ibid.).⁴ Second, Didier Fassin’s discussion of the difficulties of critiquing “persons and institutions believed to be *above suspicion* because they are acting for the good of individuals and groups understood to be vulnerable” (2011: 37; our emphasis) offers a helpful frame for this article by reminding us of the perils of criticizing morally valued activities, such as screening babies for life-threatening disorders.⁵

Along with these works, this article interrogates how real or imagined human suffering is mobilized as part of political projects. We focus specifically on affective enactments within public discourses of NBS advocacy to analyze how, as in the testimony recounted above, parent advocacy narratives were carefully crafted in an attempt to produce an emotional response in policy makers. We argue that lifesaving interventions gather momentum within affective economies that cater to naturalized orientations to children such as sympathy and compassion while obscuring the fiscal and opportunity costs of public health programs. In what follows, we outline our theoretical framework for the concept of affective economies, which we define as *systems of exchange in which people enact and elicit emotional responses for social and political ends, such that affect comes to serve as its own currency and yield its own profits and costs*. We then apply this framework to the case of parent advocacy in the expansion of NBS. By describing how emotionally invested parent advocates have marshaled affect within NBS policy arenas, we demonstrate the capacity of affective economies to displace traditional economic constraints on universal health care coverage, such as concerns for spiraling costs. In doing so, we illustrate affective economies as a powerful catalyst for forms of political action that may inadvertently sustain public health inequities even as they seek to redress them.

Affective Economies and Emotive Institutions

NBS policy hearings of the sort Nathan Schubert described are exemplary of what Geoffrey White (2005) has called “emotive institutions.” The concept draws attention to the social forces that elicit and shape collective emotional experi-

4. We draw here on Allen’s (2009: 167) analytic distinction between two political domains of human rights projects: “politics occurring in a register wherein demands such as respect for democracy, representative government, and constitutional procedures are reference points and, on the other hand, politics that occurs in a sublimated form through nebulous efforts to evoke empathy for suffering.”

5. We have encountered similar resistance from NBS insiders after describing some of the troubling consequences of expanded NBS. S. Lochlann Jain’s (2010: 92) discussion of the difficulties of critiquing cancer clinical trials is also relevant here.

ence. Rather than merely the settings in which preexisting emotions are aired, “emotive institutions . . . consist of socially situated discursive practices that variously evoke, represent, and transform emotional experience” (White 2005: 248). White defines *institution* broadly, as a type of public forum. Therefore, although emotive institutions may include ritual activities, such as village meetings in the Pacific Islands designed to work out social conflicts, they need not be temporally bound, such as in the case of national war memorials. In such settings, emotions “find much of their power in situated activities that support public representations and enactments that variously reimagine and re-emotionalize the histories they work to represent” (White 2005: 248–49). What is most important for our purposes here is White’s suggestion that emotions acquire meaning and social force from their location within fields of public discourse (cf. Abu-Lughod and Lutz 1990). The underlying points are that, in public arenas, emotional experience is socially orchestrated and that social institutions help facilitate culturally meaningful forms of emotion.

To push this idea even further, we would like to suggest that emotive institutions have the power to produce more than just emotions: they may also channel emotions to generate political currency transferrable to a wide range of contexts and situations. Building on work by feminist theorist Sara Ahmed (2004), we use the term “affective economies” to reference the circulating networks in which emotion, feeling, and sentiment are exchanged for social and political ends. As Ahmed (2004: 119) observes, “In such affective economies, emotions *do things*, and they align individuals with communities—or bodily space with social space—through the very intensity of their attachments.” We find the concept of affective economies helpful for understanding the political forces that animate health activist projects, for reasons we work out below.

The concept of affective economy is closely related to the notion of moral economy, which is often traced to E. P. Thompson’s (1971) work on eighteenth-century English peasant bread riots. The concept of moral economy has been used to highlight how norms of reciprocity and deservingness are invoked in economic systems, in contrast to capitalist notions of market-based exchange (e.g., Griffith 2009; Rivkin-Fish 2011). Here, however, we focus specifically on the role of affect in constituting the reciprocal obligations that undergird moral economies. We use the term *affect*, as opposed to *emotion*, to emphasize the expressive dimensions of feelings and sentiment.

We also build on recent scholarship that highlights the role of affective transactions in neoliberal economic transformations. Vincanne Adams (2012) draws on fieldwork in post-Hurricane Katrina New Orleans to illustrate how neoliber-

eralism cultivates an “affect economy” when state institutions fail to respond to large-scale disasters. In the wake of the privatization of recovery, Adams (2012: 211) argues, affect has become not only a register of suffering but also “a fiscal potential” that quite literally capitalizes on its ability to generate labor and profits in a depressed economy. Like Analiese Richard and Daromir Rudnyckj (2009), who proposed the concept of “economies of affect,” we recognize the emergent, productive power of affective exchange and understand economy more broadly than its strictest Marxist sense. However, we offer a more fine-grained exploration of the discursive enactment of affective economies than has been presented elsewhere.

Dimensions of Affective Economies

A critical feature of affective economies (and emotive institutions, too) is that affect operates socially by resonating with and reinforcing broadly felt public sentiments. The collective dimensions of affect are absolutely essential to activist projects, which draw on widely accessible emotions such as fear, anxiety, and compassion in order to garner political will and accomplish advocacy goals. Ahmed’s (2004: 120) use of “economies” suggests this social function: “I am using ‘the economic’ to suggest that emotions circulate and are distributed across a social as well as psychic field.”⁶ We propose that emotions are displayed instrumentally within public forums to tap into similar emotions in others to produce political effects. What is at stake, then, in affective economies is a type of social exchange: the ability of an individual’s experience to provoke an affective response in another. In other words, affect has exchange value within public forums. From this perspective, emotions entail complex social relations and power negotiations as much as internal, “natural” processes.⁷

A second key feature of affective economies, which builds on the first, is that affective displays are designed for a specific audience. Political discourse theorist William Gamson (1992: 19) argues that “the essence of public discourse is the sense of speaking to a gallery.” The notion of a gallery suggests not only that affec-

6. While Ahmed’s view of the circulation of emotion in affective economies risks reifying emotion as a material object, she is not suggesting that affective economies are the net effect of discrete emotions that travel from one person to another. Instead, Ahmed argues that affective economies contain a constitutive force that acts on the social body, such that the final product is more than the sum of its parts.

7. This is not to say that emotions can ever be reduced to their public display (cf. Wikan 1989). For the purposes of this article, however, we are chiefly concerned with how affective life permeates the public sphere.

tive economies are, in the first instance, crafted—that is, manufactured to have particular social and political effects—but also that they are crafted with *particular* recipients in mind. In turn, the gallery shapes affective economies by influencing expectations and attributing intentions with respect to affective displays and by actively defining their meaning and political purchase. In this sense, the gallery is an agentive audience. Drawing on Judith Butler's (1997) theory of performativity, we argue that affective economies endow their publics with a particular capacity to act. Sensitivity to the productivity of affective discourses and their public reception—what Charles L. Briggs (2005) has called their communicability—thus plays an important role in generating and sustaining affective economies.⁸

A third and final dimension of affective economies relevant to our purposes here is that activist narratives and affective displays are invested with a particular kind of cultural authority that counters the more traditional forms of rational authority that are often thought to guide political action. Susan Leigh Star (1991) has drawn attention to the important issue of spokespersonship, noting that science gives authority to some and silences others and that disease advocates may appropriate, counter, and dilute the language of science. For example, Steven Epstein (1996) demonstrated that part of the success of the first wave of AIDS activism in the 1980s was due to the status of many activists as educated professionals combined with their moral credibility as individuals suffering from a terrible disease. By highlighting the “credibility struggles” that characterized early AIDS research and treatment activism, Epstein illustrated how moral credibility could overcome scientific credibility.

We next examine the testimonies of NBS parent advocates to the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children to describe how affective economies are constituted within policy arenas. We highlight, in particular, how parent advocates attempted to generate political currency through (1) establishing resonance with broadly felt public sentiments, (2) producing particular audiences, and (3) creatively deploying cultural authority. Here our focus is on the production of affective displays, rather than their reception.⁹ Before turning to the parents' narratives, we first historically situate the expansion of NBS in the United States.

8. Although we do not have space to address this issue in detail here, it is important to note that affective economies need not revolve around a copresent audience. As Donald Brenneis (1986) has observed, an audience may include several different groups of intended addressees, layered over time.

9. We acknowledge that these dimensions overlap, but we separate them here for heuristic purposes. The question of efficacy—how and why specific testimonies were successfully enrolled by political supporters to catalyze policy change—lies outside the scope of this analysis.

The Expansion of Newborn Screening

State-mandated NBS has been in place in the United States since the 1960s, when Robert Guthrie developed a bacterial assay that enabled early detection of phenylketonuria (PKU), a rare metabolic disorder characterized by the inability to break down the amino acid phenylalanine. PKU appeared to be an exemplary case for NBS: it can be treated easily with a low-phenylalanine diet, but when left untreated, the accumulation of phenylalanine levels in the blood can lead to mental retardation. By the time a clinical diagnosis can be made, irreversible damage has already occurred. In the decades that followed, other screening targets were gradually added to NBS panels. Still, because screening programs were regulated at the state level, there were significant disparities between states in the number and types of screening targets.

It was not until the development in the 1990s of multiplex technologies, which enable screening for multiple disorders using a single blood specimen, that the conditions were in place for the large-scale expansion of NBS panels. In 2006 the American College of Medical Geneticists (ACMG) issued a report recommending that states screen for a standardized panel of twenty-nine primary conditions as well as twenty-five conditions that constituted their differential diagnoses and would be detected incidentally while screening for the core set (Watson et al. 2006). The ACMG report was controversial within medical circles for several reasons. First, bioethicists objected to the departure from a decades-long consensus on World Health Organization criteria for population screening, which stipulated that the individual patient must stand to benefit from screening (Wilson and Jungner 1968). The report's authors argued instead that screening could be justified by family and societal benefits, such as increasing scientific knowledge of rare disorders. Experts in preventive and evidence-based medicine also criticized the criteria used to evaluate potential screening targets, which favored disorders that could be detected using multiplex technologies; the limited data about the effectiveness of NBS as a preventive measure; and the overreliance on expert opinion rather than scientific review (Moyer et al. 2008).

In light of such concerns, some physicians and ethicists questioned whether investing in screening for rare disorders was the best use of limited public resources and advocated a more cautious approach to the expansion of screening panels (Baily and Murray 2008; Botkin et al. 2006). However, discussions about cost-effectiveness have historically been limited in US health policy (Ubel 2001), where disease advocacy organizations have shaped legislation and funding priorities for medical research considerably over the past twenty years (Best

2012; Dresser 2001; Epstein 2008). Thus, in contrast to countries like the United Kingdom, where NBS policies have taken shape around explicit conversations about public health priorities (Wieser 2010), there were no such discussions in the United States.¹⁰ Enthusiastic advocacy groups and professional organizations lobbied to turn the ACMG recommendations into state policy, prompting a nationwide expansion and standardization of NBS. Within a few years, every state began screening for the core set, and additional disorders have since been added to the recommended panel.

At this point, it bears repeating the truly remarkable nature of universal NBS. The US health care system, which is composed of a patchwork of public and private insurers, might have heralded a market strategy for NBS in which only families who could afford to pay would be encouraged to screen. Yet this did not happen. State-mandated NBS stands out precisely because it flies in the face of an increasingly neoliberal health care system. Parent advocates explicitly framed their efforts to secure universal screening for all babies born in the United States in contrast to the rational economic calculus by which money is invested in screening only if it passes some threshold of cost-effectiveness. We contend that this surprising result depended, in part, on the ability of parent advocates to marshal babies as icons of innocence and demonstrate the insufficiency of market-driven health care. In this way, affective economies aimed to disrupt the existing health care economy.

Rachel Grob (2011) makes a compelling case that NBS expanded “like a house on fire,” with the efforts of parent advocates as a prime source of the combustion. Parents served as policy drivers to jump-start the legislative process through fund-raising, political organization, and direct lobbying of legislators. The March of Dimes Foundation had endorsed a preliminary version of the ACMG report even before it was officially published, organized publicity campaigns in local newspapers, and fielded expert and lay testimonies at hearings—such as that of Nathan Schubert, the parent in our study. In many states, March of Dimes representatives were members of state NBS advisory committees (Howse, Weiss, and Green 2006). These efforts helped establish broad-based support for the expansion of NBS (Paul 2008: 11–12).

To be clear, we do not want to imply that parent advocacy on its own was

10. Mary Ann Baily and Thomas H. Murray (2008: 27) attribute the lack of a national conversation about health care priorities to the patchwork nature of the American health care system: “The American health care system is not really a *system*. It has no institutional structure to take responsibility for stewardship of collective resources and force consideration of opportunity costs of decisions about public health programs or additions to standard clinical care.”

sufficient to determine the course of screening history. Other factors, like technological innovation and regulatory support, also played an important role. It is also important to note that parents do not have equal opportunities to advocate for their children. Such advocacy work requires specific forms of political and cultural capital that is unequally distributed in the United States and elsewhere (cf. Fullwiley 2011; Rouse 2009). But when filtered into the political arena through advocacy organizations such as the March of Dimes, the narratives of parent advocates formed an important discursive counterweight to the pitch for more measured expansion.

The Secretary's Advisory Committee

A key event in the history of NBS in the United States was the establishment, in February 2003, of the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children. The US Health Resources and Services Administration commissioned the committee to advise the secretary of the Department of Health and Human Services on how to reduce genetic disease-related morbidity and mortality in newborns and children. Committee members, who are appointed by the secretary, include medical, technical, and scientific professionals with expertise in children's genetic disorders, as well as members of the public with a special interest in heritable disorders. The committee meets three times per year to develop recommendations regarding NBS policies and priorities, review evidence for proposed additions to the standard screening panel, and evaluate new screening technologies.

From the beginning, parent advocates played a key role in the committee proceedings. Prominent parent advocates, such as the president and CEO of the Genetic Alliance, Sharon Terry, served on the committee, and parent advocates were invited to speak at each meeting during a scheduled public comment period.¹¹ Parents offered dramatic testimonies of how their lives had been irrevocably altered by children's rare genetic disorders, suggesting that things might have been otherwise had NBS been available at the time of their children's births. The meetings have also been open to the public and frequently attended by journalists and advocates. At the same time, the public perspectives elicited by policy makers have typically been limited to a narrow constituency: parents whose children suffered due to disorders that might have been detected by NBS or those who, like Nathan Schubert, had children who were diagnosed through screening. This

11. Terry became a well-known advocate following the diagnosis of her two children with pseudoxanthoma elasticum. See Novas 2006.

approach has overlooked the perspectives of many other parents whose children will be subjected to mandatory screening, including families whose children have received false positives or experienced other negative consequences. Following Briggs (2004: 167), we draw attention to “the political-economic parameters that shape how particular accounts get placed within—or excluded from—the circulation of public discourse.” Below we use parental testimony collected from the recorded minutes of the Secretary’s Advisory Committee meetings from 2004 to 2010 to illustrate the dimensions of affective economies we outlined above.

Public Sentiments

One of the key objectives of the parent advocates who made comments to the Secretary’s Advisory Committee was to establish that the public welfare was at stake in NBS policy. This required advocates to persuade committee members that although the disorders targeted by NBS were in general quite rare, the fate that had befallen their children could potentially happen to any child. In short, to elicit a shared sense of urgency, parents had to first *perform* their emotional distress and then *evoke* similar emotions in their audience, all while emphasizing the temporal exigencies of screening. They accomplished this, in part, by using affective language and terror imagery to amplify a sense of collective fear about the hidden dangers facing the nation’s children that could erupt and attack with little warning. As we will show, advocates drew on some of the same language that has been used to describe disasters, epidemics, and human rights atrocities to victimize babies, thereby altering the landscape of suffering as well as the stakes of political inertia.

Micki Gartzke, a woman whose daughter died of Krabbe disease, a rare metabolic disorder, testified repeatedly to the Secretary’s Advisory Committee.¹² Since 2001, Gartzke has been the education and awareness director of the Hunter’s Hope Foundation, an organization founded by the former professional football player Jim Kelly and his wife, Jill, after their son Hunter was diagnosed with Krabbe disease. In June 2004, Gartzke (2004) offered the following comments to the committee:

We found ourselves standing right on a fault line at the epicenter of an earthquake. Our foundations were rocked. Uncontrollable, around-the-

12. Krabbe is a type of leukodystrophy, a group of rare genetic disorders that affect the central nervous system, leading to motor difficulties. Early-onset Krabbe disease usually results in death by age two. Because we draw on publicly available data, we use real names here and in the rest of this article.

clock, unsoothable crying started. In one day, just like that (a snap of the fingers) we went from having a virtual lovefest with our daughter, to being cast as the three central characters in a dark and grim nightmare—so unimaginable by those who have not stood in similar shoes, that any description I could give would not bear the full weight of the darkness.¹³

Gartzke's impassioned account exemplifies how health activists draw on emotions to garner political support. Employing metaphorical language, she first compared the emotional blow of her daughter's suffering to standing amid an earthquake and then to starring in her own personal nightmare. By drawing on popular knowledge of terrifying events, she made an otherwise unfathomable emotional experience relatable to her audience. Gartzke contended that this experience was so incomprehensible that even these evocative images could not plumb the depths of her sorrow. Yet the purpose of this affective imagery was precisely the opposite: to repackage her unimaginable experience into a familiar form and evoke in her audience a sense of her suffering and loss. Gartzke (2004) concluded her narrative with a dramatic exhortation about the benefits of screening: "I have a crystal clear picture of the importance of newborn screening. I know a little boy born with the same disease ten days before my daughter; he was identified at birth, my daughter at ten months. Today he is in the first grade and my daughter has been buried in her grave for five and 1/2 years."

While Gartzke used the metaphor of a natural disaster to represent the terror of living through her daughter's diagnosis and eventual death, many parent advocates employed a different sort of disaster imagery. One of the most frequently recurring images throughout the public comments was a reference to children as "ticking time bombs." In June 2004, Jana Monaco (2004), the mother of two children with isovaleric acidemia, reported: "While we were trying to come to terms with Stephen's condition and prognosis, we discovered that he was a walking time bomb waiting to ignite and that this whole situation could have been avoided had he benefited from Comprehensive Newborn Screening at birth." Likewise, in January 2005, Jill Levy-Fisch (2005a), the president of the Save Babies Through Screening Foundation, stated: "Since the last meeting, approximately 530 unscreened babies with disorders have been born. I now view these babies as ticking time bombs. Time is of the essence." And later, in 2010, when the committee was considering a proposal to add critical congenital cyanotic heart disease to the universal panel, Olivia Easley (2010), a Maryland parent, shared the following about her daughter: "Veronica's heart was a ticking time bomb. The symptoms of heart failure in

13. All cited minutes are available from the first author upon request.

babies are too nonspecific; heart disease is, therefore, ripe for a delay in diagnosis. Veronica's disease escaped detection by me, my husband, my extended family, my perinatologist, the newborn nursery nurses, and by her own pediatrician."

In cases of infant loss, where the brute force of suffering is irreducible to language, stock phrases like "ticking time bomb" come to stand in for the unutterable. The metaphor is rhetorically effective because children's genetic disorders, like bombs, can be life threatening yet evade ready public detection, while the imprecise nature of bomb threats distributes danger widely across public space. The idea of a "ticking" time bomb further underscores the sense of temporal urgency: it is not sufficient that screening take place sometime in early childhood—it must occur *immediately* after birth because the bomb might go off at any moment.¹⁴ Moreover, while an earthquake is unavoidable, a bomb may be thwarted with the right preventive action.

In a variation on the theme, Jim Kelly (2004), in his June 2004 comments, compared the situation of children born with undetected genetic disorders to that of a nation facing a terrorist threat: "I can't help but think that if we received a terrorist threat that thousands of our infants were going to be killed by the end of 2004, our Nation would use all the money and power we had to stop it and we would stop it! We have a worse threat right here, today, in our midst that is 'silently' killing our children." In 2004, with the September 11 attacks still fresh in the national consciousness, it is likely that Kelly's reference to terrorism conjured a particular sense of collective fear and urgency. His metaphoric language cast NBS as a means to fortify the nation against unforeseen threats and depicted that fortification—or preparedness (Lakoff 2008)—as critical to ensuring the health and productivity of future citizens. The political force of this affective economy was thus to recast these rare genetic disorders from isolated struggles facing individual families to silent circulating killers, threatening national security. Moreover, by figuratively locating the committee members on the receiving end of national terrorist threats, Kelly's testimony also portrayed the committee members as powerful to respond to them. We discuss this dimension of affective economies next.

Crafting Audiences

Parent advocates used specific tactics to propel audience members into action by crafting them as particular kinds of responding subjects. This involved a two-step strategy: first, inciting a sympathetic emotional response toward the plight

14. For some children in our study, even NBS did not come quickly enough: several children had already endured irreversible neurological damage by the time their screening results were delivered.

of parents with regard to children's hidden genetic disorders and, second, persuading policy makers that they alone held the power to defuse the palpable threats.

Fred Modell (2010), cofounder with his wife, Vicky, of the Jeffrey Modell Foundation for Primary Immunodeficiency, exemplified this strategy in the following remarks made at the January 2010 meeting of the Secretary's Advisory Committee: "Tomorrow, another 11,000 babies will be born in this country. Your decision today can give great comfort and hope to those new mothers and fathers who will not have to risk a tragedy and a loss of their child to severe combined immunodeficiency [SCID] or lymphopenia."¹⁵ Modell's careful mixture of shame and flattery imputed tremendous agency to the committee. Momentarily leaving aside the fact that a "decision today" could not possibly affect the babies born tomorrow—the committee was only authorized to offer recommendations to the secretary of health and human services, who took weeks or months to review its reports and set the national policy—Modell deftly cast the committee as gatekeepers of parental emotional well-being. Moreover, here, as elsewhere, the specific use of the word *baby* helped marshal an affective response, insofar as babies occupy a special moral status as the ultimate icons of innocence, helplessness, and vulnerability. Just as breast cancer screening campaigns have effectively drawn on women's status as the "weaker" sex (Aronowitz 2007), babies motivate care, safeguarding, and protection.¹⁶

Following Butler (1997), we suggest that it is through such affective accounts that parent advocates worked to constitute committee members as saviors in the moment of their address and hold them accountable for children's health. Butler has argued that political discourse not only acts upon listeners but also contributes to their interpellation as particular kinds of acting subjects (cf. Althusser 1971). From this perspective, "the address animates the subject into existence" (Butler 1997: 25). By casting the committee members as uniquely qualified to offer comfort and hope to the parents of tomorrow, parent advocates constructed their audience as decisive agents of lifesaving efforts and, in doing so, drew them into powerful affective economies.

Some parents used techniques similar to those of Fred Modell but with a less threatening spin. Rather than put the livelihood of future generations of children

15. The Modells established the foundation in memory of their son Jeffrey, who died from complications of primary immunodeficiency.

16. Yet as Nancy Scheper-Hughes (1993) reminds us, the protection of vulnerable babies is critically shaped by cultural conditions and material constraints.

on the committee's shoulders, Missy Bornheimer (2010) thanked the committee for the role it had played in saving her child's life.

Mr. Chairman, I would personally like to thank you and each of the members of the Advisory Committee for giving Dawson and our family . . . a chance at life. You have played a huge role in saving my baby's life. My days are filled with smiles, laughter, and happiness because of you. . . . Because of you, I get to be a mom to one of the most wonderful babies in the world. And how do you express thanks for something like that.

Here Bornheimer attributes the positive emotions associated with parenting to the committee's diligence. Similarly, Gartzke (2005a) addressed the committee personally to thank them for their efforts: "Your focus on the children and on the families, your commitment to excellence, and your dedication to creating universal access to comprehensive newborn screening is not only life saving, but it is also helping to create an even better America. Thank you." Such comments interpellate committee members as ethical subjects and reinforce their critical obligations to children and families.

Nathan Schubert, the parent in our study, reported that some parent advocates brought their children to NBS policy hearings in California to help elicit sympathy:

It helped to have a family up there, I think, that was—I guess I could say a victim, if you will, of no policy in place. Because their experience was tremendously negative. These are severely debilitated [*sic*] children that were there, very heart wrenching. It's hard to go up there and say, "By the way, this doesn't have to happen." And then get someone saying, "Well, I think we shouldn't do that." So I think it was an easy argument to make.

Similarly, Deborah Heath, Rayna Rapp, and Karen-Sue Taussig (2004) describe how a group of parent advocates brought their children on lobbying campaigns to garner political support for research into a rare, life-threatening dermatological disorder. As one of their interlocutors provocatively put it, "Parents use their bloody, blistering babies like a battering ram' to capture Congressional attention" (Heath, Rapp, and Taussig 2004: 155). In both cases, the children's presence personified the high stakes of political inaction, revealing a calculated effort to elicit a compassionate response. The parents correctly inferred that their children's visibly impaired bodies would strengthen their audience's emotional reaction, making the lobbying efforts more difficult to refuse. In this way, the children served to divert attention from the fiscal concerns that pervade the US health care economy and encouraged legislators to do "the right thing."

These examples demonstrate how affective enactments are mobilized toward political action by crafting audience members as policy actors capable of delivering social justice and holding them accountable to their constituents. Affective economies turn on the assumption that affect has exchange value in the policy arena: parent advocates routinely rely on the potential to convert affect into political currency. The potential for such economic conversion enables parents to overcome their more limited access to other relevant forms of capital, such as scientific knowledge, which we discuss next.

Deploying Authority

The final dimension of affective economies relevant to NBS advocacy is that activists are invested with a particular kind of cultural authority that emanates from firsthand experience rather than traditional forms of rational authority. During the public comment period of the Secretary's Advisory Committee meetings, parent advocates portrayed themselves not only as spokespeople for NBS but also as the possessors of an alternative form of expertise that would be uniquely valuable to policy makers. In July 2005, Levy-Fisch (2005c) suggested, "We provide insights in the lives of affected families like nobody else can." At the same meeting, Gartzke (2005b) emphasized the specialized knowledge of parents like herself: "Parents whose children were not identified, even though there is currently a newborn screening available for that disease, have specific valuable knowledge and experience that is of great importance."

Parent advocates framed their expertise against other, less accessible sorts of political capital by suggesting that scientific knowledge (of both the target disorders and the benefits of screening) was incomplete and society could not afford to wait to set policy until the research gaps were filled in (see also Epstein 1996; Silverman 2012). From the perspective of affected families, the affect of urgency trumped the ability to make statistical claims about the efficacy of screening. As parent advocate Stacy Barrett (2010) put it: "With immune deficiency, we cannot afford to wait for this Board to decide whether it can be statistically proven that screening for SCID is cost effective and meets other rigid rules that focus on [the] population of newborns, instead of each newborn as an individual. Action needs to be taken now. While we wait for numbers and testimonies, countless children have lost their lives to this condition."

Barrett's argument offered a counterweight to epidemiological evidence, suggesting that rather than put a face on statistics, the narratives of parent advocates might trump statistical claims altogether. This conceptual move invoked a new

civic epistemology (Jasanoff 2005) for shaping health care policy that reframed predominant discourses of cost-benefit analysis and created new forms of authoritative knowledge. The attempt to disrupt professional evidentiary standards calls to mind Lorraine Daston and Peter Galison's (2007) notion of epistemic virtue, a concept that highlights the moral values attached to ways of knowing. Moreover, it can be seen, following Epstein (1996: 8), as not only "more than just a 'disease constituency' pressuring the government for more funding, but . . . in fact an alternative basis of expertise."

A critical point of distinction for this alternative form of expertise is that, while epidemiological practices track the impact of screening at the population level, advocates define success in terms of the individual (Cody 2009). As Monaco (2005) argued, "Evidence that NBS saves lives and prevents mental retardation and death [does] exist. The fact that it might not be tremendously high numbers is irrelevant, and every child's life should count. Waiting for more [or] better evidence translates into more lost lives and brain damaged children because these disorders are very unforgiving when . . . missed." Monaco's emphasis on "lost lives" and disabled children underscored the affect of urgency and suggested that policy makers could not afford to wait for the science to catch up. Few would argue with Levy-Fisch's (2005b) point, at the April 2005 Secretary's Advisory Committee meeting: "Newborn screening saves lives. I do not think that is a fact that can be disputed." The disputed issues from a policy perspective, however, were not only how *many* lives were saved and at what cost—including the opportunity costs of screening and the harms that might be incurred as a downstream consequence of screening—but also whether cost was even a relevant factor when individual lives were at stake (McKie and Richardson 2003). According to advocates, what mattered most was not such population outcomes but the preservation of each individual life.

Conclusion

Within the broader context of the US health care system, the decision to screen every baby for more than fifty rare genetic disorders is a remarkable public health achievement. Parents have played an important role in the dramatic expansion and standardization of NBS in the United States over the past decade. This article has considered how parents faced with children's life-threatening genetic disorders have mobilized affect as a political resource to accomplish advocacy goals. The use of affective pleas in NBS policy stands out against more dispassionate economic or epidemiological arguments, such as that of cost-effectiveness or the

burden of disease. Not only were the cost-efficacy data lacking and epidemiological evidence equivocal, but parents also relied on the political tool that was most available to them to strengthen the case for expanded NBS: they reenacted the emotional toll of dealing with a child's severe disability or sudden death to individualize suffering.

Affective economies have a long history within fields of public discourse. Children, in particular, carry a strong moral weight in these affects of urgency because they so easily elicit compassion and sympathy. For example, US health advocates have used "poster children" strategically since the 1940s to garner public attention and resources for conditions from polio to cancer (Krueger 2007). Yet, although the pragmatic play of emotions in advocacy movements is not a new phenomenon, our framework for affective economies emphasizes the *orchestrated, discursive enactment* of affect toward political aims.

We have traced the discursive processes by which affect is channeled into political action to illustrate how health advocates deploy affect creatively to render the most intimate family matters an issue of public concern. We proposed the concept of affective economies to describe the processes of circulation, exchange, and conversion by which health activists mobilize affect through political channels and incite policy makers to act, and we identified three key dimensions. First, activists draw upon publicly accessible emotional experiences to evoke a compassionate, urgent response. Second, advocacy narratives constitute policy makers as uniquely capable of taking political action. Third, health advocates imbue their narratives with an epistemic virtue (Daston and Galison 2007) stemming from intimate experience, which they juxtapose against traditional forms of scientific authority.

We have argued that within the contours of such affective economies, affect comes to serve as its own currency and yield its own profits and costs. On the one hand, the political capital garnered through affective appeals can translate into concrete fiscal resources, such as funding for government-sponsored public health programs. NBS was implemented through state public health agencies, and the Secretary's Advisory Committee helped ensure that some federal dollars were earmarked for these efforts. Furthermore, the work of parent advocates contributed to the passing of the Newborn Screening Saves Lives Act of 2007, which provided federal funding for NBS education and outreach (see GovTrack.us). That affective accounts are often more lucrative than epidemiological arguments can help explain why a disproportionate share of monetary resources is funneled into research for breast cancer, for example, than into research for other, more prevalent diseases (Klawiter 2008). Likewise, an implicit understanding

that children's suffering can be economically profitable underpinned the formation of several advocacy organizations that raise funds to promote expanded NBS by publicizing the tragedies that families have endured when their children were not subjected to screening.¹⁷

At the same time, however, affective economies can result in several troubling consequences. The most obvious political drawback of making policy on emotional grounds is an opportunity cost. As Mark Nichter and Elizabeth Cartwright (1991) point out, affective incitements to "save the children" perpetuate a politics of exclusion insofar as they deflect attention from other critical issues. Rachel Kahn Best (2012) terms this the distributive effect of advocacy, suggesting that advocacy efforts shift the distribution of political and economic benefits toward groups that are more likely to organize. The distributive effect of advocacy has real fiscal and social consequences. For example, infant mortality rates in Mississippi *increased* rather than decreased following the expansion of NBS, which *may* have resulted from the diversion of state Medicaid funds to pay for the screening (Baily and Murray 2008).¹⁸ Thus affective economies may inadvertently reinforce the inequalities that they seek to correct. Erica Bornstein (2001: 614) makes a similar point with respect to international child sponsorship programs, which, she argues, "have the potential to create localized experiences of lack that stand in the face of benevolent attempts to bridge distance and that may inadvertently be enhanced by humanitarianism itself."

Impassioned parent narratives also mask critical differences between conditions as different as 3-MCC, which has a straightforward, noninvasive treatment, and Krabbe disease, for which the only cure, a bone marrow transplant, is associated with considerable risk and has demonstrated only modest efficacy (Kemper et al. 2010). Moreover, a screen enables early diagnosis but no guarantee of outcomes: advance knowledge cannot always save a baby's life. In our study, three

17. For example, Levy-Fisch founded the Save Babies Through Screening Foundation following her son Matthew's diagnosis with short-chain acyl-CoA dehydrogenase (SCAD) deficiency. Actor Scott Baio and his wife, Renee, founded the Bailey Baio Angels Foundation after their daughter Bailey received a false positive diagnosis of glutaric acidemia.

18. Baily and Murray (2008) are appropriately cautious about interpreting such findings because causality cannot be determined. Nevertheless, they point out that a portion of the funding for Mississippi's NBS program came from the state's Medicaid program, which had undergone substantial cutbacks around the same time that the new screening program was introduced, due to the election of a new governor who promised to reduce taxes. Baily and Murray (2008: 24) ask, "Were the changes in Medicaid a factor in the increase in infant deaths? Could infant lives have been saved if the state had increased the availability of Medicaid services and provided state funds to subsidize transportation for low-income rural black women so they could access prenatal care more easily? It is hard to know."

children out of seventy-five died despite early diagnosis. Parents dealing with the tragic consequences of genetic disorders despite NBS are rendered invisible by an affective script that valorizes prevention as a lifesaving key.

A final limitation resides in the emotional foundation of the political strategy: affective economies risk association with irrationality and emotional excess. To cash in on emotions politically requires careful crafting of affective scripts. Not every baby, not every death, not every advocate, not every emotion begets political action. In the case of fetal alcohol syndrome, for example, mothers are pitched against infants and lose spokespersonship over their offspring (Armstrong 2008). Affective economies must convey a sense of moral worth: these babies deserve to be saved, and their parents' emotions deserve to be acknowledged. This may help explain why many health advocates who successfully channel affective economies closely resemble their political counterparts in race and class terms—though, of course, they must also have the time and social capital necessary to invest in advocacy work.

The affective economies framework illuminates how affects such as fear and love travel and gain currency when advocates mobilize audience sympathies and cast policy makers as uniquely qualified to intervene on behalf of a vulnerable other. The ubiquity of affective economies in the US health policy arena may help explain the patchwork of disease-based legislation that does not always seem to make sense economically or scientifically but can be rendered emotionally powerful. The result of health policy steeped in affective economies is continued tinkering with a stratification of the deserving sick.

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