Regarding the Rise in Autism: Vaccine Safety Doubt, Conditions of Inquiry, and the Shape of Freedom

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Abstract Beginning in the 1980s in the United States, a growing number of parents of children diagnosed with autism and other problems related to neurodevelopment began to suspect that their children’s conditions were caused by, or somehow related to, vaccinations. By the early 21st century, the idea that something about childhood vaccinations are the cause, may be the cause, or may be one contributing factor in the apparently rising numbers of children with neurodevelopmental problems had spread widely. This article traces parent anxiety about a connection between autism and vaccines. It illustrates the ways in which a large number of parents think about potential risks of vaccines and make decisions about immunizing their children. It focuses on their doubt and responsibilities, and shows how they negotiate their relationship to medical expertise and the ethics of citizenship. Overall, this article explores the rise of autism into public awareness— as a mutable object of knowledge, a protean disease category, and an exemplar of the condition of uncertainty today—to show the limits of risk assessment as a way of managing life. [risk assessment, subjectivity, ethic of care, technologies of doubt]

Who knows what autism is? Probably a vulnerability that gets expressed in utero. Probably a genetic component. Probably an environmental cause. Something about a vaccine has an impact—but only for children with a pre-disposition. Whatever makes kids vulnerable to autism also makes them susceptible to adverse reactions to vaccines. Then, you can’t tease out what’s causal . . .

—Parent of a three-year-old child who has not received all vaccinations recommended for her age

The vaccine conversation is just hot and flying and it’s intense.

—Parent of unvaccinated three-month-old child

Connecting Vaccines, Autism, and Risk

What happens when a well-established health care technology comes up against citizen doubt and mistrust? How does a cohort of parents come to regard and manage everyday life when ethics, disease prevention, and medical fact finding are linked by the impossibility of assessing risk and the decoupling of medical expertise from decision making? Beginning in the 1980s in the United States, a growing number of parents of young children diagnosed with Autism Spectrum Disorder, Asperger’s Syndrome, Pervasive Developmental Disorder, and other language, sensory, and behavioral problems related to neurodevelopment
 began to suspect that their children’s conditions were caused by, or somehow related to, vaccinations they had received. By the early 21st century, the idea that something about childhood vaccinations are the cause, may be the cause, or may be one contributing factor in the apparently rising numbers of children with neurodevelopmental problems had spread widely among U.S. (and other) parents (Casiday 2007; Freed et al. 2004; Offit and Jew 2003). It was quickly augmented by a diffuse doubt about vaccine safety in general.

Connections drawn between vaccines and autism provide an emergent example of the contours of “risk society” today. Beck (1992, 2006), Giddens (1990, 1991) and others have described ways in which risk as a way of knowing and risk assessment as a technique for living constitute structural conditions of life in postindustrial society. Health and health care, particularly, are largely understood as risk reduction through individual risk assessment (Armstrong 1995; Dumit 2005; Rose 2006). The cultural penetration of the idea of a vaccine–autism link points to limits of risk assessment because risks, in this case, are not confirmed or denied for every child. Scientific evidence is not definitive and no amount of evidence is enough for some individuals. Self-reliance becomes mandatory. Anxiety and uncertainty remain and grow despite risk calculation (Beck 2000, 2006). These developments, in turn, feed doubt and underscore the inability of truth to settle once and for all.

Public health, popular culture, and science have been arenas in which the vaccine–autism connection has “lived” since the late 1980s. That some citizens now ask the law to determine risks as medical experts have long done shows that the risk assessment models of science (and thus of modernity) are no longer sufficient to determine truth.1 Perhaps we have reached the end of the era in which “risk assessment” is seen as a technique for managing life—for knowing how to live.2

This ethnographic article explores ways in which parents respond to the idea of a connection, the ways they lead their daily lives in a world of competing information without the possibility of certainty, and the ways they negotiate relationships with experts and with ethics of citizenship. In light of extensive medical literature documenting concern among parents about vaccine safety (Diekema 2005; Gust et al 2004, 2005; Salmon et al. 2005), and in the context of internet, media, and other widespread discourse about vaccine safety and risk, I interviewed a small opportunistic sample of 22 parents of young children. I spoke with 11 parents who have children unaffected by developmental problems and 11 parents who have one child or more with autism or a related developmental diagnosis. I elicited their various relationships to the circulating discourses about vaccine safety and risk, their awareness of connections being drawn between mercury and autism, and their own decision making, including quandaries about vaccinating their children.

The rise of autism into public awareness—as a protean disease category, an idea about vaccine risk, and an exemplar of the condition of uncertainty today—in invites further
consideration both of the organization of risk assessment in the face of doubt and of how vulnerability is constituted in risk society itself.

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By the late 1980s, some doctors, teachers, speech therapists, parents, and others perceived an increase in the numbers of young children affected with speech and language delays or the inability to communicate and learn at age level. The apparent rise in numbers of children affected by these disorders continued through the 1990s and into the early 21st century (California Department of Developmental Services 1999, 2003). By then, many viewed environmental toxins as the cause of these maladies or as a contributing factor, especially the ethylmercury contained in thimerosal, the preservative used in vaccines since the 1930s. Mercury is a neurotoxin.

The dominant feature about the new demographic face of these neurodevelopmental problems was that the rise in numbers of children broadly affected appeared coincidentally with an increase in the number of childhood vaccinations given routinely in the United States. This temporal correspondence was compelling (and still is for some parents) because a causal connection between thimerosal in vaccines and neurodevelopmental problems in young children was not conclusively disproved and was reported by the scientific community to be theoretically possible (Institute of Medicine 2004), even though the vast majority of scientific studies and reviews in the last decade find no scientific evidence for a causal relationship (Bonhoeffer and Heininger 2007; see also Colgrove 2006:234–236). This temporal correspondence, visible to many parents in their own experiences and audible to others through stories, opened and then sustained a cultural space for controversy about disease causation. It also led to a widespread wariness of vaccine safety that has not abated (Gust et al. 2008; Offit and Moser 2009).

**The Fluid Fact of Autism**

Today, 1 in 150 individuals is diagnosed with autism, making it more common than pediatric cancer, diabetes, and AIDS combined.

—Autism Speaks 2007

One effect of the temporal correspondence of more childhood disorder and more vaccinations is that autism stands out as yet another site in which disease classification and the understandings that flow from it are unstable and changeable. Like Alzheimer’s disease and attention deficit disorder before it, autism is an “object of knowledge” (Hacking 1995:5), a mutable category and symbolically loaded domain that captures and contains the fears of mostly middle-class U.S. parents. Autism refers to a broad range of behavioral, language, and communication deficits and problems associated with neurodevelopmental dysfunction. In terms of disease nosology, autism encompasses the range of symptoms currently labeled
Autism Spectrum Disorders. This includes Autistic Disorder, Asperger’s Disorder or Syndrome and Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS). These three classifications within the term, Autism Spectrum Disorders (ASD), are used by the Centers for Disease Control and Prevention (CDC) and are characterized in the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association 2000; see CDC 2007). A child may be given different diagnoses by different practitioners, and, parents I interviewed indicate that a diagnosis given by one expert is sometimes contested by another. Diagnoses may change over time. Autism reflects and represents a labeling process and a category of knowledge in which the boundaries of symptom inclusion and exclusion are fluid (Grinker 2007). In addition, autism-related diagnoses are not the only means for categorizing developmental delay. Children of parents I spoke with were given diagnoses of Sensory Integration Disorder, Global Developmental Delay, and Developmental Dyspraxia, for example.

What is now called Autism (or Classic or Core Autism) was considered a rare (incidence of 1–4 in 10,000) and epidemiologically stable disease from the time the diagnosis was introduced in 1943 by child psychiatrist Leo Kanner until the late 1980s to early 1990s. Beginning in those years the diagnostic criteria began to expand considerably. For example, Asperger’s Disorder emerged as a new diagnostic category in the 1990s (Fombonne 2003). A broad spectrum of behavioral symptoms gained acceptance. Greater recognition among parents and practitioners and better screening of children led to more autism-related diagnoses and fewer of other kinds of categorization (such as mental retardation). Specialist services increased, and, because services are accessed via diagnoses, more autism spectrum diagnoses were sought by parents. Since 1990, when Autism became a federal category for special education classification, “the number of children classified with autism by state education departments across the country has since increased approximately 25% per year” (Newschaffer and Curran 2003).

It has been difficult, if not impossible, for scientists to systematically unravel these interrelated variables to determine specific impacts of each on prevalence trends. Research indicates that the prevalence of children with autism spectrum disorder has risen dramatically in a little over a decade (California Department of Developmental Services 1999; Croen et al. 2002; Fombonne 2003, 2006), with a CDC study indicating an average prevalence rate in 14 states of about one in 150 as of 2002 (CDC 2007). Mutable disease classification and disease recognition are both central to the observed increase in prevalence rates. Most epidemiologists and clinicians agree that expanded diagnostic categorization, greater parental awareness, more refined testing of children, more health professionals trained in diagnosis and referring for diagnosis, and a growing demand for services that can be accessed only through an ASD diagnosis contribute to an increased rate of diagnosis, and thus, to the rising numbers of children with autism (Rutter 2005; Wing and Potter 2002). Yet some studies and reviews also leave open the question of whether there is a true rise in incidence (Croen et al. 2002; Wing and Potter 2002), and whether that rise could be because of environmental risk factors (Grandjean and Landrigan 2006; Newschaffer and Curran 2003; Rutter 2005).
A second effect of the temporal correspondence is that autism has come to take center stage in a not-yet-concluded story about why neurodevelopmental problems among children are—or appear to be—on the rise. Although assumed now to have a strong genetic component, specific etiology for symptoms that fall along the autism spectrum remains unknown. That open question lays bare a new master narrative for parents of young children: Something unnatural, not “normal” has happened that science is not explaining (Kennedy 2005b; Kirby 2005).

Because it is a mutable object of knowledge, with unknown specific etiology, and because the well-being of children and families is at stake, autism has become a pivotal figure in conversations about the truth claims of biomedical science and about what constitutes evidence and credible knowledge. Similar to AIDS, autism is a complex disease of signification (Treichler 1999). That is, it carries many meanings in a cultural milieu in which conflicts of interest in clinical medicine abound, trust in the public health apparatus and government has eroded and big pharma is held suspect.

**Subjects of Freedom**

Autism as object of knowledge is also a lens through which to view the work of subjectivity—because, as I show below, risk is an embodied “moral technology” (Ewald 1991). In an era in which ethical choice is privatized (Bauman 1995; Higgs 1998) so that the individual is morally responsible for health, parents reflexively practice and ponder an ethic of care and choice in relation to how they think about the risk of vaccines. Expertise must be incorporated into the self and considered in relation to risk. Vaccine safety doubt starkly exposes the problem of freedom (Rose 1999:84), that is, the capacity to determine the course of one’s own (and children’s) lives and the imperative to seek out the means to do so. The problem of freedom, in this case, is the problem of the enactment of an ethic of self-conduct, of personal responsibility, in the realm of vaccine safety.

This article focuses on parents, their doubt, and the ways in which they feel forced to rely on themselves. It highlights risk as the “peculiar synthesis of knowledge and unawareness” (Beck 2000:216) such that more knowledge leads to new risks and greater indeterminacy. The inability to know becomes pressing. And, although expertise is wanted, it is not trusted completely and can always be questioned. Living with the potential risk of vaccines and the anxiety of ever-partial knowledge is one form freedom takes for many parents in an era of unfulfilled risk calculation and management.

**Vaccine Subjects: Cautious Parents and the Evaluative Enterprise**

... the precautionary principle requires an active use of doubt, in the sense Descartes made canonical in his meditations. Before any action, I must not only ask myself what I need to know and what I need to master, but also what I do not know, what I dread or suspect. I must, out of precaution, imagine the worst possible ...

—Ewald 2002
Knowing that there could be any risk whatsoever of autism, of mercury toxicity, anything, I think, immediately propels you into this domain of reactivity. So here, in our lives with our baby, in this very intimate sphere of our lives, questioning is, for me, imperative ...

—New parents of unvaccinated three-month-old child

An awareness that vaccines are something to think about is already present and pervasive among a sizable segment of the cohort of middle-class parents whose children were born after about 1990 in the United States (Offit and Hackett 2003; Offit and Jew 2003). Vaccine safety talk is simply a part of their early childrearing experience. It is a common topic of mothers’ group discussions; it occupies a great deal of space on parenting websites. Learning about vaccines, deciding whether and when to vaccinate one’s children, and figuring out which vaccines to accept or decline, and when, are all part of new parent awareness today (Offit and Moser 2009).

I spoke with white, middle-class parents in different parts of the United States (although mostly in California) who hold a range of perspectives about childhood vaccination. Education levels range from high school to advanced professional degrees, and they work in business, the computer industry, health professions and the arts. They hold diverse political and religious views. Some parents had two or three children at the time of the interview (incl. two or three with diagnosed problems); others were new parents with their first baby. Fourteen of the 22 parents were wary of vaccines or the preservatives in them, did not feel absolutely certain that there was no relationship whatsoever between vaccines and autism, and had not (yet) administered all recommended vaccinations to their children. Five other parents had administered all required vaccines to their children, did not think there was a relationship between vaccines and autism, yet noted that they made sure there was no thimerosal in any vaccines their children received; four of those five parents has one or more children with an autism diagnosis. Several had chosen not to vaccinate a second or third child.

These parents share common discursive understandings about doubt, risk, and expertise that characterize the contemporary moment. Most importantly, they all actively sought or passively came across information about vaccine safety, risk, and connections with autism, and they reflected on those connections, had opinions about the health status of their children in relation to vaccines, and had made and were still in the process of making highly conscious evaluations about the safety of childhood vaccines for their own children. It was easy to locate parents who fit these criteria—they are everywhere. I deliberately did not speak with parents who consider themselves to be antivaccination, to be vaccine safety or “mercury” activists, or to be members of organized vaccine resistance groups. No parent I interviewed disagreed with the state of contemporary science about autism etiology today. That is, all are aware that autism has a strong genetic component, but that environmental factors might contribute to expression of genetic susceptibility (Institute of Medicine 2004:8).
Sources of Knowledge I: Pondering Risk and Protection

I asked parents to speak about sources of their knowledge about vaccines and, if possible, to articulate the criteria they use to evaluate information they receive. Some articulated the bases for their rationales about vaccinating their own children; some did not. I found that parents go about the task of self-education methodically or haphazardly, proactively or passively, but regardless, with a sense of openness to information from different sources.

I get information online, from medical research articles, anecdotally, and from Mothering Magazine essays. Also from print media and friends, including those who are in the medical community... You’re not just asking your neighbor, or your mom or your aunt anymore. [Mother who has given two of nine recommended vaccines to her three-year-old child, no developmental diagnosis]

My son was born in 2002. I decided to do a home birth. In the mother’s class I went to, the midwives gave us reading material... I knew about thimerosal already, probably from the midwife. When my son was born, we decided to wait before giving any vaccinations. There was lots of talk about vaccines in the mothers group I belonged to. That group has an annual conference on vaccines, a panel of parents and health care providers. I went to the panel for information. There was a great doctor there—she gave information on which vaccines are more important. Parents want to space out the vaccines. There were questions on how to separate the combination vaccines, how far to space them apart. Some people on the panel were absolutely against giving vaccines—I wasn’t interested in this... Attending that panel reinforced my feeling that I should wait, ... but it didn’t create that feeling. I was worried about subjecting an infant to all the stuff in vaccines so young. I learned about all the preservatives in that panel discussion. My intent was to do a delayed schedule of some of the vaccines. [Mother of two children, ages three and one, the oldest with a developmental diagnosis]

A few years ago, ... I had a mentor, a nurse, who had a baby and who was a few years older than me. She was postponing live vaccines until her child was about two. This stuck with me. So I decided that’s what I would do. [Mother of three-year-old child with no developmental diagnosis]

Vaccines came into my world during pregnancy—I was deciding what kind of birth to have. I was reading about midwifery, home births, alternative medicine. I read Mothering Magazine—got a lot of information there. But another source was the [community] parents’ network website... When I was six months pregnant a couple of chiropractors gave a seminar on vaccinations. They had an antivaccination stance. I didn’t expect this. What influenced me is that they said that true immunity comes from disease, not from the vaccine itself. They gave the example of chicken pox, measles, mumps and rubella. To be immune you need to get the disease. They said that the immune system is not developed until a child is five or six. It’s not like they didn’t have any information to back up their claims. With MMR I was aware of the controversies about developmental delay and autism. With that and the immune system, I decided the later the better, or not at all. Those were the themes I took away and that influenced me about when to give vaccines. [Mother of three-year-old child, no developmental diagnosis, who has received some vaccines but on a delayed schedule]

The internet, print media, health professionals, and peers offer an unending wealth of information about vaccines, autism, and risk to which parents of young children are exposed.
Parents have to find their own way through this overabundance and decide what is fact, what is not. Awareness of vaccine safety and harm is never static. It changes when new vaccines are added to the routine schedule, when dramatic reports of “adverse events” hit the media, when one hears about the child of a friend, or when one’s own child is given a diagnosis of a developmental disorder.

Sources of Knowledge II: Technologies of Doubt
Of the 11 parents interviewed whose children had received a diagnosis of autism or other developmental problem, six told tales of awakening to vaccine safety doubt. None of the 11 thought something in vaccines directly caused their child’s problems. Yet only one felt completely certain she could rule out the possibility that a nongenetic entity contributed to her child’s condition. A few thought mercury is possibly or certainly related to a child’s condition, especially the mercury in fish they ate while pregnant. Some truly don’t know. A few think vaccines did not play a role in their children’s problems, but they are apprehensive about potential vaccine harm nevertheless, both for diagnosed and subsequent children. One is convinced that vaccines played no part in her child’s problems, yet she also expressed a glimmer of doubt about that during our conversation.

Doubt sustains and enables its own persistence. The many means for knowledge production about vaccines and autism become, also, technologies for the maintenance of doubt. Parents described these now-pervasive technologies as they talked about caring for their children and thinking about their children’s problems in relation to vaccines. Websites that connect autism with vaccines simply by expressing concern; websites that offer techniques for recognition of a connection; community forums in which the safety of vaccines is discussed or opinions about safety are shared; class-action lawsuits; physicians who are sympathetic to parental worry and create personalized immunization schedules; parents who are convinced autism is mercury poisoning that can be cured; the many books and articles about vaccines and developmental norms; the broadening categorization of developmental disorder; genetic testing; nutritional therapies—all of these cultural phenomena that parents described enable doubt. These phenomena are interventions “into ideas” (Strathern 1992)—about cause and effect, surveillance and responsibility, diagnosis and treatments, forms of caring and the moral weight of knowledge, ignorance, and action.

The following two narratives are emblematic of how some parents come to be awakened to the possibility of a connection. They illustrate how doubt takes shape and sustains itself in types of information and modes of communication that enable suspicion and recognition. They show, too, how methods for seeking truth become linked to personal responsibility. These tales of risk and possible connection emerged within stories recounting the search for diagnosis and treatment. The shared dimensions of the storyline are this: An observed difference in a child prompts parents to seek advice and diagnostic information from multiple sources. At some point on this revelatory journey, sooner or later, the question of the role of thimerosal in vaccines arises—it is unavoidable. Parents
then must weigh whether or not to “merge” the knowledge they are acquiring from experts about their child’s condition with the wide variety of information they receive about vaccines. The extent to which they bring these two realms together affects the care of their children. An astounding array of means for knowledge production about the possible relationships between vaccines and autism has emerged in recent years and is taken for granted by parents today. Their stories, as they overlap and depart, serve as cultural documents of those means, of their “naturalness,” and of the ways the encounter with uncertainty is variously practiced.

#1. The mother of a boy born in 2000 (age six at the time of the interview) began to notice sometime in his first year that he was not inquisitive like other babies and that he did not move around. She began taking her child to experts—a developmental pediatrician and physical therapist—when he was a little over the age of one. He was diagnosed with PDD-NOS at 18 months. “We began to hear the autism word and thought, ‘This is a possibility.’” Other parents told her she needed a diagnosis, especially if she wanted services to help her child. At two years, nine months, her son was diagnosed with classic autism.

When he was three, he started making progress. Up until he was four, I gave him all the vaccines. I didn’t think about it. Everyone said, “get your kids vaccinated for the flu.” It was hard to get flu shots that winter; our doctor was out of vaccines. We went to the county clinic. Six months after that flu vaccine, with thimerosal, he was regressing. He’d hit a wall. I started trying to figure it out. I had dismissed vaccine arguments which I kept hearing about. I felt these were desperate parents. But I started reading about a big class action lawsuit. Our speech therapist told us about it . . . Then I started getting onto the websites—FEAT, SafeMinds. The “evidence of harm” yahoo groups were there. There’s a book, What Your Doctor Doesn’t Tell You about Vaccines [Cave and Mitchell 2001]. So, I was getting all the theories. And you compare your own experience to all this . . . Initially, I didn’t make a relationship between his regression and vaccines. I kept asking, “what am I doing wrong?” But about nine months later, after lots of reading about thimerosal, I did. So now my goal is never to put a mercury substance in him . . .

He got existing lots of vaccines with thimerosal after 1999. I decided to talk to the woman who initiated the lawsuit. I was interested but not convinced about the connection between autism and vaccines . . . I learned from an attorney that, in order to be part of the class action lawsuit, you need to file an adverse event report. That led me onto the VAERS website [Vaccine Adverse Event Reporting System]. You can look up the lots your child received . . . You send a letter to your pediatrician, requesting the lot numbers. Then you can look it all up on the VAERS website, where adverse effects are described. I compared my son’s symptoms to what’s on the website—they matched up. Oh my god. No one did the math about how much mercury kids were getting . . . This anger and agony dawned on me when I looked at the adverse event reports. It led me to add up how many vaccines with thimerosal he got . . . I could have added up the amount of mercury. I had access to those numbers. But I can’t. It turns my stomach . . . It made me firmly distrust the medical establishment.

He’s six. He should be getting other vaccinations. I need to go to the pediatrician and say I’m not giving any more . . . When I was pregnant I ate lots of fish—not raw but big amounts. I was a vegan before, but I wanted the protein for my baby. Then, afterwards, I find out fish is chock full of mercury . . . My personal belief? There is a genetic predisposition with some kind of environmental trigger. I just don’t know.\textsuperscript{6}
#2. The mother of two boys, born in 1999 and 2005, (ages 6.5 and 18 months at the time of
the interview), opened our conversation with the following comment:

I’m not by nature the kind of person who bucks authority. When my first child was born I
had heard rumblings about vaccines, but I didn’t pay attention. I thought there are always
parents who don’t want to treat their kids, who complain about medicine. My pediatrician,
at my very first visit, said, “Do you have any concerns about vaccines?” I’ll never forget that.
I replied, “No, I’m going to trust you.” I’ve thought a lot about that over the years. I often
wonder what I’d have done differently if I had had more information. But my answer is that
I would not have made different decisions. So, I gave my son all vaccines, including the
optional ones. For the first year he seemed normal. He never had classic regression; he just
slowed down, and was wild and uncontrollable. He had no language and very little receptive
language. In my mothers’ group, the other kids had an invisible bungee cord connecting
them to their moms; they would respond. I could see how different my son was.

His first diagnosis was PDD-NOS. Then later, high-functioning autism. Now, I’m very
grateful. He’s going to be in the normal first grade, with a one-on-one aide. Now he’d probably be given an Asperger’s diagnosis. He’s very smart; his language is very de
developed. Around age two we thought it was only a speech and language delay. Then tests
showed more delay, though never a classic case of autism. We started seeing more wor
ter signs. We started speech therapy, then occupational therapy, then a full
evaluation. All of this was after I did lots of reading and searches on the Internet and
talking with parents, including reading about vaccines.

It’s hard to read about autism without coming across stuff on vaccines. My faith in
mainstream medicine began to be significantly eroded when I started reading, and
through the parent networks. Ninety percent of the information that is useful to me has
come from parents . . . Again, I’m a very establishment person. Not on the left. So for
me to be converted says something. At first I didn’t take the vaccine link seriously. By the
time I had read about vaccines, [son] had had all the first vaccines . . . The IOM 1999
report was issued in June–July. My son was born in October. He didn’t get his first shot
until January 2000. At first, not knowing anything, I thought, well [son] didn’t get
thimerosal because it was after 1999. But then I learned it wasn’t recalled. It was still
manufactured. And lots were still on the shelves. Not until recently was it taken off of
shelves in doctors’ offices. So later, I did research on the Web, on 909shot. They have a
thimerosal calculator—a list of vaccines and manufacturers. It’s not 100 percent scientif
cal because it’s not by lot number, and I didn’t have the manufacturer’s dates. I did my
own research though. And I found that all his shots had thimerosal. My pediatrician said
one vaccine was “full thimerosal,” others had trace amounts. I even contacted the manu
facturers, and they said to contact your doctor. So, I’m mad at the pediatrician. I feel
she didn’t give me accurate information, based on my own research.

My view is that mercury absolutely contributes to autism, though it isn’t the only source.
After all, autism is present in kids who have never been vaccinated. It’s a combination of
genetic susceptibility—lots of genes—along with one or more environmental triggers.
. . . Thimerosal is an important piece of the puzzle, but not the only part. Parents want
to know how big a part.

Parents are divided about vaccines. One view is that only thimerosal is bad. Once it’s out
of vaccines, they are okay. A second view is that nothing in vaccines is good for suscep
sible kids. Then there are the people in the middle, the confused people. I’m in this
category. That’s why I won’t vaccinate my second child. We took a more conservative, or, you could say paranoid, view. Right now I feel he’s more at risk for vaccine adverse events than for the diseases.

Parents, such as these two mothers, respond to the idea of a connection—there is no way not to respond—and then “live in” a relationship to risk. That is, the uncertainty of “unknowable unknowns” (Casiday 2007:1061) and the necessity of protecting one’s child become parents’ language of risk and their lived experience of potential or actual harm.

**A Rise in Vaccine Safety Doubt?**

Although all 22 parents I interviewed described features of vaccine awareness, it is hard to know how many parents of young children are even cognizant of the circulating discourse of doubt and connection and how many are specifically troubled about vaccine safety. After all, childhood immunization rates in the United States have never been higher overall. That fact alone would lead one to think that most parents do not give vaccine safety a thought; that they maintain a predoubt consciousness about it. Perhaps most parents do not “see” the media stories, ads, and internet attention devoted to these topics or participate in discussions about vaccine safety, prominent as these have become. One analysis of data collected in 2001 from the National Immunization Survey estimates that slightly more than one percent of the U.S. birth cohort did not receive two or more childhood vaccines because of vaccine safety concerns (Gust et al. 2004:21). The Morbidity and Mortality Weekly Report of the CDC reported in 2006 that more than half of the states in the U.S. report fully vaccinating at least 95 percent of children entering school for the first time in 2005–06 (CDC 2006b). The excellent level of coverage is because of, in great part, state laws requiring vaccination for school entry. Yet another study of survey variables concluded that 13.2 percent of parents, although generally supportive of immunization, were also concerned about vaccine safety (Gust et al. 2005).

There are at least two indicators of a sea change in how parents have come to think about childhood vaccination in the last 15–20 years. The first is that the proportion of parents wanting and claiming exemptions from state-mandated vaccination requirements has been increasing (Salmon et al. 2005). State-mandated requirements about immunization have loosened in recent years. All states now permit medical exemptions; 48 states allow religious exemptions and, by 2006, 19 states had a provision for personal belief exemptions (Omer et al. 2006:1757). That newest exemption category followed the vaccine anxiety and, in fact, created a bureaucratic slot for it. Some states make exemptions widely available and easy to obtain. In California, for example, the personal belief exemption is available to anyone. It is easier to fill out the required form for it than to complete the school immunization form (Omer et al. 2006:1758). A case-control study showed that vaccine safety concerns were the main reason parents were claiming nonmedical exemptions (Salmon et al. 2005). The public health community is concerned about any drop in childhood immunization rates and has
devoted considerable energy to studies that reveal the extent of this development and that explore why (Gellin et al. 2000; Kennedy et al. 2005; Salmon et al. 2005).

The second indicator of a sea change is that most pediatricians and family physicians have at least some parents in their practices who refuse at least one vaccine (Freed et al. 2004). Immunization policy experts have noted, “The societal consensus that has supported the United States’ universal childhood immunization programs for the past 50 years shows signs of eroding” (Feudtner and Marcuse 2001:1158). A veritable flood of articles and editorials in the major peer-reviewed journals read by pediatricians has responded to the parent doubts, fears about vaccine safety and refusal to vaccinate with recommendations for how doctors can reassure parents about the overall safety of vaccines as well as how to communicate with parents who do not want to vaccinate their children at all or who want to delay or separate certain shots (American Academy of Pediatrics [AAP] 2005; Diekema 2005; Freed et al. 2004; Gust et al. 2008; Offit and Moser 2009).

Genealogies of Doubt: From Trust to Suspicion

*Key institutions of modernity such as science, business and politics, which are supposed to guarantee rationality and security, find themselves confronted by situations in which their apparatus no longer has a purchase and the fundamental principles of modernity no longer automatically hold good. Indeed, the perception of their rating changes—from trustee to suspect. They are no longer seen as only instruments of risk management, but also as a source of risk.*

—Beck 2006

Vaccination against lethal and devastating diseases is widely acknowledged as one of the major accomplishments (arguably the major accomplishment) of 20th century medicine, and childhood immunization is one demonstration of citizenship in a democratic society. One vaccinates one’s children for their own health and for the public good. Vaccination reflects a (civic) morality that balances, or weighs, personal rights (via the state exemption system) in a postindustrial, affluent society against principles of public health. Vaccination is a moral act because one’s personal decision about whether to vaccinate one’s child has a potentially serious impact on others. If a certain percentage of children in a community are not vaccinated, those children and others are vulnerable if there is a disease outbreak. The act of vaccination indicates confidence in the safety and efficacy of that particular technology and trust in the public health system to deliver the technology safely to the most vulnerable of citizens, newborn babies and very young children.

Vaccine Success: The Changing U.S. Childhood Immunization Schedule

In 1967, U.S. infants and toddlers routinely received five different vaccines for a total of seven diseases: smallpox, DPT (diptheria, pertussis, tetanus), polio, measles, and rubella (Marcuse 2006). Most of these vaccines required more than one dose, administered over a period of months or years, to convey full immunity. In 1971, with the growing success of
smallpox eradication programs around the globe, the smallpox vaccine was officially dropped from the U.S. recommended list (Colgrove 2006:165).

Throughout the 1990s, because of the success of vaccine research and development, new vaccines were added to the routine schedule. In 2006, nine vaccines for a total of 13 diseases were recommended for infants and babies by the AAP, the American Academy of Family Physicians, and the CDC's Advisory Committee on Immunization Practices. These include: Hepatitis B, (the first dose to be ideally administered between birth and two months of age), DTaP (diptheria, tetanus, and acellular pertussis), Hib (Haemophilus influenzae B), IPV (inactivated polio), MMR (measles, mumps, rubella), chicken pox (also called varicella), pneumococcal (PVC), hepatitis A, and influenza. Except for the influenza vaccine, which is recommended annually beginning as early as six months of age, each of these vaccines requires two to five doses for maximum protection, administered over a period of months in infancy and early childhood. It is recommended that children have all initial doses of these vaccines prior to age two (CDC 2006a).

The Uncalculability of Risk: “An Event in the History of Thought”
In 1997, the U.S. Food and Drug Administration (FDA) began a review and assessment of the risk of all mercury containing food and drugs. In June 1999, the FDA determined and then made known that infants who received the recommended number of childhood vaccines might be exposed to cumulative amounts of ethylmercury that exceeded Environmental Protection Agency (EPA) and other federal agency guidelines established for the ingestion of methylmercury, the form of mercury found in fish (Ball et al. 2001; Institute of Medicine 2004:5). This was an extraordinary revelation—both to vaccine experts (Halsey 1999) and to parents.

The idea that mercury preservative in vaccines caused or contributed to their children’s problems had already gained considerable traction among parent advocacy groups in the United States by the mid-1990s. Yet apparently, no one had considered that babies’ overall mercury exposure would increase as new vaccines, some with thimerosal, were added. And apparently, neither physicians, vaccine scientists, public health officials nor ordinary citizens were cognizant of the fact that infant mercury exposure had increased substantially between the mid-1980s and 1999 because of the rise in numbers of new childhood vaccinations and even bigger rise in the numbers of childhood injections overall, because most vaccines require multiple doses to be effective (Colgrove 2006:xiv; Freed et al. 2002).

Until 1999, thimerosal was used in three childhood vaccines—DTaP (the newest version of DPT that had been given for decades), Haemophilus influenzae b, and hepatitis B (Allen 2007:376; Institute of Medicine 2004:5). Most, but not all, manufactured forms of these vaccines contained thimerosal. In the first six months of life, a fully vaccinated child could have received as many as 187.5 micrograms of ethylmercury, depending on whether all vaccines contained thimerosal. The EPA had calculated that methylmercury levels for a child in the 95th percentile for body weight should not exceed 106 micrograms in the first
six months of life (Ball et al. 2001:1150). Yet no one knew if vaccine exposure to ethylmercury that exceeded that number was significant. This fact was a source of “confusion and contention” for vaccine experts in interpreting the safety of thimerosal in vaccines, as was the additional fact that two other U.S. governmental agencies had developed different guidelines for the safe exposure to methylmercury (Freed et al. 2002:1154).

In the interest of preserving public trust, in July 1999, the AAP and the U.S. Public Health Service (USPHS) issued a joint statement calling for the voluntary removal of thimerosal from vaccines “because any potential risk is of concern” (1999). European regulatory agencies made a similar public statement (AAP–USPHS 1999). Shortly after the joint statement was issued, vaccine manufacturers started to remove thimerosal from most childhood vaccines sold in the United States and Europe, and physicians began to remove thimerosal-containing vaccines from their office shelves. That process took time however and was no doubt uneven across the United States. The details of the removal of thimerosal-containing vaccines were not proactively tracked by government agencies. Investigative journalists note that, apparently, Merck distributed the Hepatitis B vaccine with thimerosal into 2002 (Levin 2004) and distributed other infant vaccines with thimerosal until the fall 2001 (Schulman 2005). State responses to the removal of thimerosal were uneven as well. California became the second state, after Iowa, to ban mercury-containing vaccines for pregnant women and children under the age of three, beginning in 2006. Thus, it took several years for thimerosal to be removed as a preservative from most U.S. childhood vaccines. It is still present in some flu shots, recommended now for all ages.

More Doubt; More Concern about Risk

In another development, the *Lancet* published an article suggesting a relationship between the MMR combination vaccine (measles, mumps, rubella) and gastrointestinal and regressive developmental disorders (Wakefield et al. 1998). That article, along with the press conference that accompanied its publication, sparked a media storm, a public wave of worry about the vaccine (incl. concern among British physicians and nurses), demands from parents to separate the components of that vaccine into separate injections, and finally, in 2004, a public retraction of support for lead author Wakefield’s hypothesis by the collaborators on the article (Colgrove and Bayer 2005; Murch et al. 2004). But generalized fears about the MMR vaccine grew and still remain on both sides of the Atlantic (Hobson-West 2007).

Together, the *Lancet* publication and the AAP–USPHS statement in 1999 engendered a tenacious link between vaccines and childhood developmental disorder. Formal retraction in the Murch and colleagues’ 2004 *Lancet* article did not sever the widely circulating connection it had created. After 1999, and possibly before, when one looked for or simply came across information in print or online about childhood vaccines, one also saw reference to autism and other childhood developmental problems. Conversely, when one sought information, or came across material on autism or developmental disorders, one invariably noticed reference to vaccines. The CDC website, specialized websites sponsored by concerned parent-initiated organizations and thousands of email groups that offered
information and resources about childrearing all brought these two topics together, whether to claim a connection between them, disavow any connection, or to air doubt and concern. The “fact” of the bringing together of these two topics became part of the cultural landscape. Everything parents absorb about vaccines and autism contributes to their understanding and, today, doubt and the “need” for information figure substantially in that understanding. The pediatric and public health and vaccine communities are well aware of this.

By 1999, a generation of well-educated, middle-class adults with infants and young children was already risk aware and skeptical. Not agitators, activists, or antivaccinationists, most parents of young children are, in the early 21st century, simply the most visible citizen subjects of our modern predicament. These citizens know full well that “facts” are never settled (Dumit 2000), regardless of what public figures claim. New information constantly changes the nature of truth. So parents doubt.

The FDA discovered the risk. Scientists struggled with its calculability and, indeed, with whether the risk could be proven at all. Parents responded with the following precautionary rationale: If our scientific and monitoring institutions and the experts who represent them do not know whether thimerosal is a risk to our small children, although it could be, and we cannot calculate how risky vaccines or their ingredients are, then we must live as though this risk were a fact, as though vaccines could cause harm. We must anticipate and try to prevent risk ourselves because we are not being fully protected by other means. Our expert institutions, no longer capable of the kind of surveillance that we deem essential and thus, no longer worthy of our trust, are now suspect (Beck 2006:8). Although thimerosal is no longer a specific worry, a generalized doubt about vaccine safety and risk persists (Offit and Moser 2009).

**Ethics, Indeterminacy, and the Shape of Freedom**

The range of responses to more vaccines and apparently more developmental disorder provide examples of the cultural work of subject formation—perhaps most importantly, the ways in which matters of health—and responsibilities surrounding health and risk—have become so central to “how to live” (Collier and Lakoff 2005:23). I explore the effects of the vaccine–autism connection on the consequences of the shape of freedom for parents of young children in the United States. Subjects of freedom (Rose 1999) are obliged to understand, determine, and enact life (to the extent possible) in terms of personal choice. Freedom is explicitly enacted through ethics (Foucault 1994), and, in the case of vaccine safety doubt, through the commitment to notions of health and risk, and through the right to and problem of choice in the face of risk and indeterminacy.

**The Burdens of Trust and Consumption**

... an individual who does not consider alternatives is in a situation of confidence, whereas someone who does recognize those alternatives and tries to counter the risks thus acknowledged, engages in trust. In a situation of confidence, a person reacts to disappointment by blaming others;
in circumstances of trust she or he must partly shoulder the blame and may regret having placed trust in someone or something.

—Anthony Giddens, The Consequences of Modernity, 1990

New parents today are inundated with information about the care of their offspring and techniques for good parenting—there are more advice books, magazines and websites than anyone can possibly read and absorb. For at least half of the 20th century, pediatrician Benjamin Spock’s book, Baby and Child Care (1998, published first in 1945 and updated in numerous editions), was the primary “bible” of child-rearing advice in the United States. By the late 20th century, the flood of media and information outlets had changed the constitution of authority and expertise about child rearing. Five times as many parenting books were published in 1997 as in 1975 (Hulbert 2004:13). The Web dramatically increased the flow of information and, importantly, public discussion and critique of information became more easily available to greater numbers of people. Today, in health and in life, one already knows that one must pick and choose among sources of “authoritative” knowledge to act responsibly. The site of child rearing provides one window onto the changing relationship between knowledge—as found, held, and evaluated by individuals—and the nature of expertise.

The plethora of information is accompanied by a surfeit of consumer products. Like so much of life in (affluent) neoliberal contexts, much of “good” parenting in the U.S. middle class is infused with consumerism (Taylor et al. 2004). One “needs” the safest car seat, stroller and crib, the most educational and stimulating (but not overstimulating) toys, the least toxic food, to keep one’s baby as healthy and developmentally on track as possible. Federal regulations about car seats, flame retardant sleepwear, cribs, toy safety, reinforce, guide, and naturalize “facts” about dangerous products and the need for careful scrutiny. Consumption is closely tied to risk awareness (Rajan 2005:21) and to an understanding of what one needs to be a good parent. Middle-class parent–citizen identity is constituted today, perhaps in large part, by this two-part understanding—consumption and risk—that frames how to live.9

The challenge for parents, faced with a sea of competing information about safety, harm, and best child rearing practices, is to discern which part of the deluge is reliable. What does one need to know? How much does one need to know? And then, how does one use that knowledge to make wise choices—about food, medicines, and everything else? The burden of responsible consumption infuses the ethics of parental care.

The burden of trust underlies and accompanies consumption choice. Giddens (1990) and Shapin (1994) both consider the “role of trust and authority in the constitution and maintenance of systems of valued knowledge” (Shapin 1994:16) to reflect on the ways in which trust is assumed and lived in modernity. Both note that familiarity with individual people and a system of “everyday recognitions” (Shapin 1994:410), which formed the basis of trust in the past, have given way to the necessity to trust in impersonal institutions and systems. Giddens (1990:21) describes this condition of modernity in terms of a set of “disembedding
mechanisms” in which social relations are “lifted out” from local contexts of interaction and are restructured across time and space in “abstract capacities” and “expert systems.” We must trust in expert systems to navigate our lives; there is simply no alternative. Air travel is perhaps the quintessential example of this fact:

We board a plane trusting it to get us safely to our destination not because we have familiarity with the design engineer or the pilot but because we trust that reliable systems of expertise were brought to bear in constructing the plane and will be devoted to flying it. [Shapin 1994:15]

Similarly, parents vaccinate children (and themselves) because they trust in an array of systems of expertise. Trust, in these circumstances, is inextricably bound up with modern institutions and thus is, for the most part, background to the task of living (Giddens 1990:83; Shapin 1994:16), like the air we breathe. Skepticism about those systems makes life troublesome for us (Shapin 1994:412). And skepticism imposes its own demands and anxieties.

Shapin asserts that the role of trust in systems of knowledge has been “practically invisible” because, paradoxically, “Trust and authority stand against the very idea of science” and legitimate knowledge, in modernity, “is defined precisely by its rejection of trust” (1994:16). Direct experience, empirical observation, the evidence of individual reason—these are the bases of factual knowledge.

Yet, citizens of the United States must rely on others for knowledge; and the only way to secure knowledge is through trust in people who are the “access points” (Giddens 1990:85), the representatives of expert systems. For they are the credible sources and authorities. Thus, trust is fundamental to grounding in the empirical world, and it remains background to everyday judgment and action most of the time.

It is largely through public catastrophes—a series of airplane crashes, the contamination of food and medicines, the appearance of a problem with vaccine safety—that our reliance on trust in abstract capacities and expert systems is brought into plain view. The vaccine-autism connection, although it has not been proven by medical science and is incalculable (and also because of these characteristics), has provoked a broad crisis over the trustworthiness of every aspect of expert systems related to vaccine production, dissemination, and reassurance. The matter of trust vis-à-vis mercury or other (potentially) toxic agents in early childhood vaccines has spread to questions about trust in vaccines in general. For example, on the NewsHour with Jim Lehrer, reporter Judy Woodruff (2007) asks the doctor guest, “How safe is the new HPV vaccine? Can the public trust the experts?” This is our late modern question.

When skepticism about expert systems becomes widely pervasive—when it crosses some threshold or “tipping point” in popular understanding—trust faces an uphill battle, especially for those who begin from the following widely held position: “Why introduce unnecessary, potentially toxic, potentially contaminating material into a child’s body?”
Although this new mother's claim about the substance of vaccines is an old one, shared by antivaccinationists for a very long time, the cultural work this sentence does today is supported first, by knowledge of increasing exposures to all kinds of environmental toxins and knowledge of their deleterious effects (Grandjean and Landrigan 2006); second, by increased public attention paid to bad reactions following individual vaccine injections; and third, by fear and suspicion generated by the 1999 AAP–FDA report suggesting that thimerosal should be removed from childhood vaccines as a precautionary measure. In the realm of vaccine awareness today, trust is not assumed and not invisible.

The Practice of Expertise

Active subjects of governance must decide how to act for the benefit of their babies, themselves, and for the public health. Decisions among the parents I interviewed about immunization, although mostly tacit and not necessarily well formulated, are based on at least four kinds of knowledge: assumptions about the protective role of the state and of expert systems in both disease prevention and the monitoring of medication safety (i.e., assumptions about the credibility of expert systems); childrearing practices and trends; “facts” about the infant body, immunity, and disease that derive from a combination of “scientific” and “folk” knowledges that are easily naturalized; and all kinds of specific information about medical safety, efficacy, and harm that informed citizens of late modernity must proactively access from a variety of sources, discuss with others, and interpret. The vaccine–autism connection highlights, perhaps above all, the powerfully felt need among some parents of young children to broaden their knowledge base about vaccines and vaccine safety, to bring “expert knowledge” (Giddens 1990) into the domain of personal responsibility. This is a huge task and, according to Beck (2006), necessary although impossible to achieve.

I was an expert after doing research on pregnancy, childbirth and breastfeeding. I’m still thinking about giving him the MMR vaccine, but I need to do more research. [Mother of a three-year-old child without developmental diagnosis]

My frustration is that there is so much propaganda on both sides. In the debate, it’s easier not to give any vaccines to your child, or to do them all on the recommended schedule, because doing your own research on which ones you really should give or want to give, when, and whether you should separate the ones that are given in combinations is very time consuming and agonizing. [Parent of two children, ages three and one, oldest with developmental diagnosis]

For active subjects of governance, self-regulating strategies (conscious or not) based on risk awareness, emergent biomedical knowledge, and other (disciplinary) discourses organize action and anxieties. Failure to care for the self and, by extension, infants and young children is, without question, understood in the United States today as a moral transgression. Risk avoidance and health promotion are moral activities, inextricably tied to notions of self-making and well-being (Rose 2006). Thus, the widely circulating open-ended meanings about the relationship of thimerosal in vaccines to autism and, more recently (since thimerosal has been removed from most vaccines), the diffuse concern about the combination
vaccines that never contained thimerosal or about all childhood vaccines has pushed child-
hood immunization into the realm of personal responsibility, and ethical choice, in a 
particularly powerful way because the need for personally acquired expertise has become so 
etwined with the enactment of responsibility at this and other sites of health identity.

The mother of a two-year-old child without developmental problems spoke for many when 
she explained:

I feel guilty that I didn’t do more research on vaccines. You can’t get away from the guilt, 
because you always need to do more reading, research. It goes on and on; it doesn’t end. 
The pressure to interview the doctor, to ask the doctor questions and more questions is 
avways there. Because you have the responsibility, not just of minimizing risk, but also of 
optimizing the physical, social and cognitive development of your child.

Parents can only partially appropriate the biomedical expertise related to vaccines. Their 
desire to do so is often only partial and sometimes ambivalent as well. Together, the burden 
of responsible consumption and the need to be better informed are productive of a specific 
sort of anxiety about the moral weight of ignorance and knowledge. For large numbers of 
parents, partial knowledge about vaccines cannot erase, and sometimes accentuates, an ever-
present vulnerability. Alienated from expert systems that have lost their relevance and 
thrown back onto themselves, parents cannot, yet must, trust experts.

For many parents, the need for advice from known, trusted experts oscillates with the need 
to develop and claim one’s own expertise. Some parents lean toward trusting the experts 
they know personally while some choose to do a great deal of research and interpretation of 
information on their own before making any decision at all. Moreover, parents have different 
thresholds for how much information seeking is enough, how much research one needs to do 
to have enough expertise to make a decision about immunization, to feel confident that vac-
cines are safe.

Conclusion

The obligation to extend one’s own expertise and a plethora of experts. The crisis in trust. 
The moral burden of consumption. The importance of maximizing a child’s potential in the 
era of mind and brain science (DiChristina 2007). Easily available means for the discovery 
and recognition of a vaccine–autism connection. The awareness of an ever-more toxic en-
vironment. Together these features of the U.S. cultural landscape give shape to ideas and 
ideals about how to be a good parent and what is good enough. Am I a bad parent if I do not: 
have genetic or mercury testing done; learn whether my child received thimerosal in vac-
cines, and how much thimerosal; give my child more vaccines; give my child therapies based 
on the idea that mercury toxicity contributes to his problems; do the work required to partic-
ipate in a class-action lawsuit; read the books, articles, and websites? Would I be a good parent 
if I do these things? The freedom to pursue information, therapies, and theories hangs over 
parents as it hangs over all health consumers. Having options is part of “the good” of auton-
omy, responsibility, and well-being in health matters today, even though those options
inevitably contribute to greater uncertainty, and even though former reliance on professional expertise is being challenged and sometimes undermined.

These features of contemporary life enable vulnerability, doubt, and the sense that self-responsibility is critical. In all of this, it is perhaps ironic that there seems to be only one stable fact: mercury is a known neurotoxin. Although no scientific studies have shown a clear causal relationship between thimerosal in vaccines and developmental disorder, the theoretical possibility named in the Institute of Medicine report (2004) together with emerging scientific knowledge about genetic susceptibility deepen the sense of risk and sustain the life of the connection.

The example of vaccine safety doubt illustrates how our social and ethical practices change as clinical medicine and bioscience advances. In the case explored here, those advances have taken the form of more vaccines, more diagnosis of developmental disorder, changing notions of autism and more demand for technologies that can lead to the discernment of truth. Middle-class parents facing the immunization of infants and young children navigate this landscape. They do so (and can only do so) as bricoleurs, incorporating the “fragments” of information, trust, rumor, therapeutic possibility, advice, and consumer know-how at their disposal—fragments that comprise the partial knowledge, partial expertise they must rely on to be good parents. And then, they use those fragments first, to explain to themselves the medicocultural phenomenon in which they find themselves embedded, and second, to act responsibly on behalf of their children.

Important in this example is how parents fall back on themselves with both a responsibility to their ignorance (Luhmann 1998; Rabinow 2007) and a hyperawareness of their partial, hesitant, and haphazardly acquired expertise. The moral compass that guides them in this open-ended, dual endeavor is their obligation to the well-being of their children, now seemingly unhinged from medical expertise. It is in this sense that we can speak about the end of risk assessment as a way of managing life and as an ethic for how to live.

The case of vaccine safety doubt provides one stark example of the late modern transformation in subjectivity, in which ever-emergent truth claims and truth seeking strategies are accompanied by risk and a normalized, ever-present uncertainty. Doubt becomes central to individual responsibility surrounding health and, for many, it pervades the ethical task of deciding how to live amid the “ecology of (partial and permanent) ignorance” (Rabinow 2007:102) that characterizes the contemporary world. Parents of vaccine-age children who live within a relationship to risk, doubt, and competing and contingent forms of knowledge forge a reflexive, flexible ethics. Their experience exemplifies the shifting knowledge–power–ethical terrain that characterizes subject making today. The case of vaccine safety doubt invites ethnographers and analysts to consider subjectivity in several ways at once: as a site for the anxieties and sensibilities of risk calculation amid uncertainty; as an illustration of the consequences of the embodied, troubled relationship between knowledge and ignorance; as
emergent identity shaped through cultural forms; and as a mode of linking self-awareness, ethics and social participation.

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Notes

Acknowledgments. Thanks to Sarah Hendlish, Joe Kushner, and Ann Russ who helped me begin this research. I am indebted to the parents who made time to participate in this project and who spoke thoughtfully about vaccines and the responsibilities of parenthood. Lori Freedman steered me in the right direction. Janet Berreman provided information and insights from pediatrics. Tom Newman offered an important perspective from epidemiology. Joel Adelson, Vincanne Adams, Deborah Gordon, Gelya Frank, Sarah Horton, Tom Laqueur, Dorothy Porter, China Scherz, and the April 17, 2007, Med Heads working group offered cogent comments on earlier drafts. Ann Oldervoll provided meticulous bibliographic support. Nancy Bagatell, Janet Dixon, Richard Grinker, Olga Solomon, Janelle Taylor, and two anonymous reviewers gave useful advice in refining the final version of this article.

1. In June 2007, the “Vaccine Court” of the U.S. Court of Federal Claims began examining whether childhood vaccinations are responsible for autism, in the largest group of cases the court has ever heard. In February 2009, the court found no causal link between vaccines and autism in three test cases. Many other cases are pending as of April 2009.

2. I am indebted to Vincanne Adams for emphasizing this point.

3. I emphasize the protean nature of autism—a mutable diagnostic label and category of knowledge.

4. The numbers, “1 in 150” are compelling and provoke fear in their own right—because it seems as though autism is spreading. When I started research for this article in 2005, the number deployed in the media, on websites, and in the medical literature was “1 in 166.”

5. I began with three parents of babies and young children whom I knew, who did not know one another. I asked them for referrals, and asked specifically for geographic and parenting style diversity. The study was approved by the UCSF IRB.

6. VAERS is an acronym for the Vaccine Adverse Event Reporting System, administered by the CDC and FDA. It came into existence in 1990, enabling parents to report observed reactions to vaccines.

7. For an explanation of “an event in the history of thought,” see Fleck 1979.

8. That idea “stands on the shoulders” of four events in late 20th century vaccine history in the United States: the specific lots of Salk polio vaccine that killed or crippled hundreds in 1955; the exposé revealed in the early 1970s regarding hepatitis vaccine trials using retarded children at the Willowbrook State School as experimental subjects; the swine flu debacle of 1976–77; and the controversy, beginning in the late 1970s, over pertussis vaccine safety. Each of these events led to a new mode of consumer participation vis-à-vis immunization and fostered a new dimension of state involvement in citizens’ lives. The Salk vaccine as cause of fewer than 100 cases of polio instigated the first successful litigation against a vaccine manufacturer (Colgrove 2006:187–188; Offit 2005). Exposé of the Willowbrook experiments led to the establishment of federal guidelines for the ethical conduct of informed consent both in medical research and clinical practice. The association of swine flu vaccine with Guillain-Barre Syndrome put informed consent and liability for vaccine-related injuries at the top of the vaccine policy agenda (Colgrove 2006:195). Finally, the controversy in Britain and the United States over the DPT shot as cause of brain damage to young children gave rise to widespread citizen activism about vaccine safety and harm and led directly to
the establishment of a national system to monitor vaccine adverse events and provide compensation for injury.

9. The overabundance of consumable items for babies and young children, together with consumer culture in general, has prompted a number of parents I spoke with to choose a “frugal” approach to childrearing, that is, to reject, as much as possible, the “need” to purchase so much stuff for babies and for living.

10. Robert Kennedy, Jr., an environmental hero and icon of responsible citizenship for a generation of Americans, lays out the details of this crisis in trust over the safety of childhood vaccines in an article published both in Rolling Stone Magazine (Kennedy 2005b) and Salon.com (Kennedy 2005a).

11. Rabinow, reflecting on an essay by Niklas Luhmann titled, “The Ecology of Ignorance” (see Luhmann 1998), notes that “we live amid systemic ignorance” (2007:102–104) while, at the same time, we must take responsibility for the future consequences of our actions. Ethics “has not been able to provide any criteria for this situation” (Rabinow 2007:102–103).

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