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## **Cause for Question: Risk and Postmodern Panic in the Vaccine Safety Debate**

MaryGrace Trifilio  
*CUNY Hunter College*

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Cause for Question: Risk and Postmodern Panic in the Vaccine Safety Debate

by

MaryGrace Trifilio

Submitted in partial fulfillment  
of the requirements for the degree of  
Master or Arts in Anthropology, Hunter College  
The City University of New York

2016

Thesis Sponsor:

December 21, 2016  
Date

Marc Edelman  
Signature

December 21, 2016  
Date

Murphy Halliburton  
Signature of Second Reader

*For Josephine Trifilio Como,  
who championed compassion, reason, and pool days.*

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## **Introduction**

For as long as there have been vaccines, there have been vaccine refusers—those who fear and subsequently oppose vaccination—going back as far as the introduction of variolation and public distrust of the crude inoculation technique in the Middle Ages. Parents and activists have opposed vaccinations for differing reasons throughout history. The contemporary iteration of vaccine refusal is popularly attributed to a fear of developmental disorders in children, specifically Autism Spectrum Disorders. While this explanation for vaccine refusal is not entirely inaccurate, it is incomplete and oversimplified. Through a content analysis of non-vaccinating parent blogs and ethnographic field work, this study attempts to understand and explore the more complex reasons for modern vaccine refusal and the worldview through which modern vaccine refusal occurs.

## **Why I Chose to Study Vaccine Refusal**

I cannot remember exactly when the issue of vaccine safety came to my attention, but by the second half of 2012, I was thinking about it quite often.

In the winter of 2010, my beloved Aunt Maria gave birth to her first child, a very photogenic blue-eyed boy named Gianni. While she never really considered forgoing vaccinations altogether, my aunt would routinely express some apprehension before appointments with the family pediatrician. Gianni was set to get all of the vaccinations as per the Centers for Disease Control and Prevention vaccination schedule, which meant that in the first year of his life, he would receive 22 separate shots. The question regarding whether vaccinations and developmental delays, specifically Autism Spectrum Disorders, were truly linked was still unanswered for many parents, and the fear this uncertainty caused was palpable whenever my aunt returned from the doctor's office. She would sit vigil to monitor Gianni's behavior and attention, his temperature and complexion.

A year later, a new baby joined the family. Her parents named her Grace. She had a joyous temperament, slept through the night, never had a hard time feeding, and did not mind being passed from cousin to cousin—an exhausting exercise for most infants in my large family.

A week after she turned one in September of 2012, Grace had her first seizure while in the bathtub. She was sitting up in the water, playing with whatever bath toys her father had arranged in front of her when suddenly, the upper half of her body jerked forward and her head dipped into the water, fully submerging her face. It looked like a particularly animated sneeze. She popped back up and began screaming. She was alert but continued to twitch in her arms and hands. Her father called for an ambulance. He had seen something like this before, during his days as an EMT.

It took nearly six months for doctors at New York Presbyterian and the Children’s Hospital of Philadelphia to settle on a diagnosis, later confirmed via genetic testing. Grace has Dravet syndrome, which is described by the Dravet Foundation website as a “rare and catastrophic form” of epilepsy. The onset of Dravet usually occurs around a child’s first birthday and the condition causes delays in cognitive, behavioral, and motor development. Most children diagnosed with Dravet syndrome do not survive to adulthood.

Before the official diagnosis was confirmed, a seemingly well-meaning doctor pointed out that Grace’s first seizure occurred just days after she received the Measles, Mumps, and Rubella (MMR) vaccine. Despite their knowledge that Grace has the SCN1A genetic mutation and that her fate was decided well before her birth, her parents have not given up on their belief that the MMR vaccine had something to do with the onset of her condition. According to Grace’s mother Anna, “The shot is what triggered the Dravet. Who knows if it would have ever really come up without the vaccine?”

The seed of distrust had been planted in the minds of those near and dear to me. My subsequent frustration with what seemed like a rogue pediatrician partaking in non-scientific talk and simultaneous apprehension with labeling non-vaccinating parents as simply “crazy,” “stupid,” or “irresponsible,” led me to question what vaccine distrust was, culturally, all about.

## **Outbreak**

On December 28, 2014, an 11-year-old California boy developed a rash severe enough for his parents to bring him to the emergency room at a nearby hospital. The week before, the family had visited Disneyland in Orange County, California, where the boy contracted measles. He had not been vaccinated against the disease.

How did a virus, thought to have been eliminated, make a comeback?<sup>1</sup> What role did proponents of vaccine choice play in the 2014-2015 Disneyland measles outbreak? Who are non-vaccinating parents and why do they refuse to vaccinate their children? Finally, what are the sociocultural components that distinguish the current wave of vaccine refusal from earlier iterations?

Within weeks of the first confirmed case, the California Department of Public Health confirmed that at least ten people who had visited the theme park between December 17 and December 20 had been infected with the measles virus. By February 2015, 125 people contracted measles as a result of the Disneyland outbreak. While public health officials were unable to identify patient zero, genetic testing of the virus showed that the particular strain of measles infecting Disneyland visitors and those with whom they later came into contact was the same strain that caused an epidemic in the Philippines, suggesting that patient zero may have either been a foreign tourist or someone who recently traveled outside of the United States.

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<sup>1</sup> The Orange County Disneyland outbreak was not the only measles outbreak in 2014. There was also a large outbreak in an Ohio Amish community, similarly caused by the strain responsible for Philippines epidemic. This outbreak was, arguably, the result of a very different ideology compared to the California outbreak, as the Amish “practice group solidarity and rejection of modern conveniences” (Gastanaduv, Budd, Fisher, Redd, Fletcher, Miller, McFadden et al. 2016:1344).

Measles is spread via contact with the nasal or throat secretions of an infected person and can be contracted simply by being in the same room, or theme park, as someone who is carrying the virus. A single droplet resulting from a single sneeze can infect several people. It takes between ten and 12 days for signs of a measles infection to appear, so determining the contact point can be difficult. According to the World Health Organization (WHO), the first sign or symptom of measles infection is usually a high fever. The WHO online Fact Sheet on measles explains subsequent symptoms:

A runny nose, a cough, red and watery eyes, and small white spots inside the cheeks can develop in the initial stage. After several days, a rash erupts, usually on the face and upper neck. Over about 3 days, the rash spreads, eventually reaching the hands and feet. The rash lasts for 5 to 6 days, and then fades. On average, the rash occurs 14 days after exposure to the virus (within a range of 7 to 18 days).

Because measles is a virus, it cannot be treated with antibiotics, which only work on bacterial infections. Antibiotics *are* given to children with measles if they develop secondary bacterial eye and ear infections or pneumonia. In the absence of anti-viral treatment, the WHO Fact Sheet on measles recommends two doses of Vitamin A supplements, especially for children in developing countries, which help prevent damage to the eyes, and oral rehydration fluid to “replace essential elements that are lost through diarrhea or vomiting.” Those infected who go without such supplementation can become blind or die due to dehydration. (As of October 1, 2016, The World Health Organization displayed on its website that the measles virus claimed 114,900 lives in 2014. None of these deaths occurred in the United States.)

The Disneyland outbreak was such a shock to public health because, at the start of the new millennium, the Centers for Disease Control and Prevention (CDC) declared measles eliminated from the United States. There had been no transmission of the disease in 12 consecutive months. Public health officials had been working to eradicate the disease since

1967. The CDC credited the elimination of the virus to a successful national vaccination campaign—successful because of the rate at which the program achieved inoculation.

While the national average rate of vaccination among non-Hispanic whites did not change between the years 2000 and 2014, the rate of vaccination among all other race/ethnicity groups (non-Hispanic blacks, Hispanics, American Indians or Alaska Natives, and Asians or Pacific Islanders) was on the rise. For example, in 2000, 87.9% of non-Hispanic black children between 19- and 35-months-old were immunized against measles, mumps, and rubella. By 2014, the vaccination rate for black children made its way up to 90.3% (National Immunization Survey 2000 and 2014).

The national average rate of immunization among non-Hispanic whites did not change in the 14 years between the virus's elimination and the Disneyland outbreak. However, some parts of the country did see a significant downturn in the number of white children immunized. In New York City, for example, pediatric vaccination rates of measles, mumps, and rubella (MMR) among non-Hispanic whites dropped from 98.0% of children in 2000 to 95.4% in 2014 (National Immunization Survey 2000 and 2014).

According to the annual Kindergarten Assessment completed by the Immunization Branch of the California Department of Public Health, 99.5% of children enrolled in private and public kindergarten programs were up-to-date with their MMR shots in the autumn of 2000. The same assessment completed for the 2013-2014 school year shows that only 92.7% of public kindergarten students and 87.6% of private kindergarten students had received the MMR vaccinations on time, according to the CDC schedule. The MMR vaccination rate was lower in private schools than it was in public schools for every year the California Kindergarten Assessment was completed, between 2000 and 2015.



The "Protection" section of Vaccines.gov explains that when a "critical portion" of a population is vaccinated and thus immune to an infection, that population has achieved "community immunity" or "herd immunity." The rate of vaccination required to achieve herd immunity varies depending on the virus. Roy Anderson and Robert May estimate that between 92% and 96% of the population must be vaccinated to prevent an outbreak of measles (1985). However, "given the highly contagious nature of measles," Maimuna Majumder and colleagues argue, "vaccination rates of 96% to 99% are necessary to preserve herd immunity and prevent future outbreaks" (2015:494). These researchers estimate that as few as 50% and not more than 86% of the children in the communities affected by the Disneyland epidemic were vaccinated. "Substandard vaccination compliance is likely to blame for the [Disneyland] measles outbreak," as evidence by the low vaccination rate among the communities hit hardest in California (Majumder, Cohn, and Mekar 2015:494).

### **The (re)Introduction of Doubt and Distrust**

Development of the MMR vaccine as we know it today took some time. In the same year that he was awarded the Nobel Prize in Physiology or Medicine for the cultivation of the *poliomyelitis* virus, which allowed for the development of the polio vaccine, John Enders, together with Thomas Peebles, isolated the measles virus. Merck made the measles vaccine available in 1963. The formulation made available in 1968, with a weaker live virus, is the same formulation in use today. In 1971, the measles vaccine was combined with the vaccines for mumps and rubella. Until 2009, when Merck halted production of the univalent measles, mumps, and rubella vaccines, parents were able to request that their child receive the three inoculations separately. Today, only the combined MMR or MMRV (with varicella, also known as chicken pox) are available.

In lieu of vaccinating children according to the CDC's schedule and risking vaccine injury, some parents choose to adopt an alternative schedule, vaccinating their children more slowly and later in life, or file for exemptions from required immunizations altogether. In every state, education-related regulations grant immunization exemptions to children for medical reasons. For example, children with life-threatening allergies to neomycin, eggs, or other components of the vaccine and children who have other contraindicated conditions cannot receive the MMR shot. All states except for California, West Virginia, and Mississippi grant religious exemptions.

Before the Disneyland outbreak, parents were allowed to file for both religious and philosophical or personal belief exemptions in California. This is no longer an option. New York parents are also unable file philosophical objections. Instead, they must either obtain documentation from a doctor showing that there is a medical reason that their child cannot receive a vaccination or they must file a religious objection, arguing that they genuine and sincere beliefs contrary to vaccination. Personal belief exemptions are an option in 18 other states. A non-vaccinating parent can look to the National Vaccine Information Center, an organization of vaccine choice proponents, for advice with regards to filing exemptions.

Heidi Larson and Louis Cooper, researchers at the London School of Tropical Medicine and Hygiene and Columbia University, respectively, argue that vaccine distrust and rejection are influenced not by scientific thought but by sociocultural factors (2008, 2011). They call for more research that not only looks at the underlying beliefs and values influencing non-vaccinators but which also addresses public distrust of medical science.

The current iteration of the anti-vaccination movement, the history of which goes back to the development of the first vaccine against smallpox (Wolfe and Sharpe 2002; Durbauch 2000), is often attributed to an article published in *The Lancet* in February 1998—"Ileal-lymphoid-nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in

children,” by Wakefield et al. While the title may seem too clinical or obscure for the general public (it was written by and ostensibly meant for other pediatric gastroenterology investigators), the paper became one of the most widely referenced sources for non-vaccinating parents (Paul Offit 2015). The findings and discussion section of this now-retracted paper state,

Onset of behavioural symptoms [in the study sample] was associated, by the parents, with measles, mumps, and rubella vaccination in eight of the 12 children...We identified associated gastrointestinal disease and developmental regression in a group of previously normal children, which was generally associated in time with possible environmental triggers (Wakefield et al. 1998:637).

Research on the etiology of autism, including a paper published in *The Lancet* one year after Wakefield et al., has since pointed out the serious shortcomings of Wakefield’s study (Taylor, Miller, Farrington and Petropolulos 1999). One of the most compelling reports, a systematic review completed in 2014 analyzing 67 separate pieces of research, concluded, “There is strong evidence that MMR vaccine is not associated with autism” (Maglione, Das, Raaen, Smith, Chari, Newberry, Shanman, Perry, Goetz and Gidengil 2014:1).

The deficiencies of the Wakefield et al. paper go beyond the erroneous suggestion of a causal relationship between vaccinations and autism spectrum disorders (ASD). According to Kathryn Bowles, a nursing researcher with a focus on informatics (i.e., the sharing and interpretation of information among health care clinicians),

There’s a pyramid for how you rate a study in relation to others. The highest level of medical research is the systematic review. Then the next level is a randomized clinical trial, and then it goes down to quasi-experimental, and then qualitative, and then expert opinion. This is the standard in the industry. It’s called the ‘evidence pyramid.’ There are also criteria that you can use to evaluate an individual study...by looking at the way the researchers gathered their information: the eligibility criteria of the patients in the study, how the researchers found their sample, how they approached their sample, how they enrolled their sample. Was there any bias in this design? (interview, October 31, 2016).

The Wakefield et al. study is a good example of poorly designed and poorly reported medical research, with a sample size of 12 children, considered too small to draw any robust

statistical conclusion. (Ironically, there were just as many co-authors on the paper.) The design was uncontrolled, as Wakefield et al. later admitted to having handpicked data and falsified results. The conclusions were entirely speculative, based on anecdotal testimony provided by the parents of the children in the study sample.

One might question why a reputable journal such as *The Lancet* would publish findings based on such a flawed study design. Dr. Bowles explains, "There is such a thing as publication bias, which means that studies that have positive results are more likely to be submitted to a journal by the [investigators]. Some journals may also introduce bias by only accepting studies with interesting results versus, 'Well, this doesn't show anything'" (interview, October 31, 2016).

In addition to the extremely problematic study design—in response to which, "A short retraction of the interpretation of the original data by 10 of the 12 co-authors of the paper [was issued because] 'no causal link was established between MMR vaccine and autism as the data were insufficient',"—the Wakefield et al. paper was later retracted by *The Lancet* because Andrew Wakefield was found to have a significant undisclosed financial conflict of interest (Sathyanarayana Rao and Andrade 2011:95). According to a 2004 investigative report by *The Sunday Times'* Brian Deer, Andrew Wakefield's role in the study in question was funded by lawyers representing families who were suing vaccine manufacturers for vaccine injury. He received more than £400,000 pounds to locate a link between vaccines and autism. In 2010, the General Medical Council of the United Kingdom revoked Andrew Wakefield's license to practice medicine.

Despite the scientific community's attempt to halt the spread of the idea that autism spectrum disorders are caused by vaccinations, the belief that a relationship exists remains widespread.

## The Pressure of Postmodernity

The issue of vaccine choice is not *just* an issue of vaccine choice, not just an issue of parents' rights, of risk, or of distrust in government regulation of the body. The current resurgence of anti-vaccination sentiments is the result of a collective postmodern panic attack. In her analysis of Richard Sennett's *The Corrosion of Character: The Personal Consequences of Work in the New Capitalism*, Sherry Ortner writes, "The crisis of the postmodern consciousness is once again a crisis of orientation within an uninterpretable, or what Sennett calls illegible, world" (2006:125). Ortner continues by illustrating Sennett's assertion regarding "the importance of narrative, of people being able to narrative their lives in a coherent and meaningful way" (2006:125). We are forced to acknowledge alternative and opposing worldviews and identities, and are thus are forced to question our own individual identity, to construct and to protect our notions of self.

Where non-vaccinating parents are concerned, it is important to understand, as Elisa Sobo argues, that "refusal is more about avoidance than active opposition," which would be resistance (2016:342).

Vaccine refusal often serves as a declaration of identification with the social setting of import to the individual. This kind of refusal is more about who one is and with whom one identifies than who one isn't or whom one opposes. While it is the case that vaccine refusal generally entails various important critiques (of the political economy, biomedicine, etc.), vaccine refusal is also, and for some parents more so, a highly social act—an act that, each time it is undertaken, reinforces social belonging by vitalizing community ties (Sobo 2016:345).

Non-vaccinating parents are using vaccine refusal to return to a more natural, local, community-based model of living. As I will later illustrate, the non-vaccinating parents I got to know personally are typically liberal and progressively minded. They are concerned with planetary climate change, with the overuse of synthetics in what they feel should be a more natural world, and with the loss of control over their children's experience and well-being. While

their right-of-the-aisle counterparts worry about the uncontrollable change foreign peoples might bring to the United States, non-vaccinating liberals are concerned with the juggernaut that is modernity. Vaccine refusal is just a piece of the narrative they have constructed in response to a postmodern world, where knowledge is both power and pain. When looking for ways to mitigate the overwhelming character of the postmodern world, ways to return to smaller scale localness, we focus in on the body. After all, what could be more local than the self? Furthermore, when examining the body, we conclude that the body itself is a complex system about which we know little.

Anthropologist Emily Martin discusses the modern interpretation of the body as a complex system within the context of other complex systems (local and international communities) in *Flexible Bodies: Tracking Immunity in American Culture—from the Days of Polio to the Age of AIDS*. Martin observes, "The first consequence [of thinking about the body as a complex system] might be described as the paradox of feeling responsible for everything and powerless at the same time, a kind of empowered powerlessness" (Martin 1994:122).

This is the result of the kind of hyper-interconnectedness that we are forced to recognize as a result of hyper-globalization, or the macro and micro interconnectedness of all things via commerce, international relations, and, of course, the Internet. If culture is a "part of [the] collective form of life, embodying [a] shared history and identity, worldview and ethos," then culture is a very difficult thing to pinpoint in a globalized society (Ortner 2006:114). If everything is connected and we have access to endless information and knowledge of all the different ways of being, it is increasingly difficult to build one's own identity. This produces a sensation of displacement and the only corrective is to counter hyper-globalization with hyper-localization: to shop locally, to eat locally, and to share ideas locally.

The issue of vaccine choice is thus an issue of social and economic power and control. It is yet another political battle being fought on both the figurative and literal grounds of the human body. The body is a battlefield and a weapon and the wars waged within and without the body are myriad.

Emily Martin analyzes the use of war metaphors in discussions of the body, especially with regards to the immune system. Martin writes that, "The notion that the immune system maintains a clear boundary between self and nonself is often accompanied by a conception of the nonself world as foreign and hostile" (1994:53). Thus, militarized language is employed: the body is "besieged," a wound is a "battlefield," the immune system deploys "armed forces," and, strategically engages in "intricate defenses" (1994:53). We have all heard a doctor, fictional or in our real-life experiences, say something to the effect of "We're going to fight this!"

"The borders of the body" are not as hermetic as we envision them to be, the same way international borders are not so hermetic, when we assume they should be impenetrable for the uninvited (Martin 1994:53). In recognizing the permeable nature of the body—both in the possibility of disease entering the body and the possibility that disagreeable ideologies (see field work data below) will enter the mind—we react with the what we see as the best "defenses."

The language that non-vaccinating parents and proponents of vaccine choice employ laments the loss of the simple and the natural. This model of purism is not the same as moral purism, which was a rallying cry for first wave anti-vaccinators (Biss 2014). This modern model of purism is also about control, but it is more so about control over one's space, one's world. The results of this study illustrates that many parents wish to control everything that enters their child's body, from medicine to food to ideology.

## Content Analysis and Ethnographic Methodology

When I looked to think pieces for help understanding the thoughts and experiences of non-vaccinating parents, mainstream media coverage was rarely flattering and even less enlightening: "Endangering the Herd: the Case for Suing Parents Who Don't Vaccinate Their Kids, or Criminally Charging Them" (*Slate* 2013), "Anti-Vaxxers Are Stupid and Contagious" (*HuffPost Living* 2014), "Dear Anti-Vaxxers, You Want Pure Nature? Okay, Die Young" (*Time* 2014), "7 Biggest Lies Spread by the Anti-Vaccine Movement, Debunked by Science" (*Mic* 2014), "Anti-Vaxx Insanity: New Study Highlights the Dangers of Science Denialism" (*Salon* 2014), "How to Argue with the Anti-Vaccine Crazyies: a Guide" (*Popular Science* 2013).

These articles did not aid in my understanding of the vaccine choice issue and did little to accomplish what Heidi Larson and Louis Cooper had encouraged, especially with regards to getting at underlying cultural beliefs (2008 and 2011).

In the autumn of 2015, Dr. Paul Offit, the Director of the Vaccine Education Center at the Children's Hospital of Philadelphia and a Professor of Vaccinology and Pediatrics at the School of Medicine at the University of Pennsylvania, spoke at a Columbia University School of Public Health symposium on "Vaccines and the Public's Health: History, Culture, and Science." During his talk, "The History of Vaccines and the Current Cultural Context of the Anti-Vaccine Movement," Dr. Offit posited that "vaccines were a victim of their own success." New parents did not fear the diseases, which vaccines have helped eliminate (specifically, polio, measles, and mumps) because these diseases were no longer visible to the average American—new parents have not seen someone suffer from these infectious diseases.

Despite the wide coverage of the "anti-vaxxer" issue in mainstream news media and by public health scientists, it was clear to me that there remained a gap in the literature, both mainstream and scientific (until the very enlightening research recently completed by Elisa



Sobo) exploring the theoretical framework with which non-vaccinating parents were operating as well as omissions of answers to some more fundamental questions: Who *are* the non-vaccinating parents in this country? Why *do* so many parents continue to reject vaccinations today, with so much evidence refuting the idea that they cause autism spectrum disorders? What is informing the non-vaccinating parents' decision? How do they decide to forgo vaccinating their children against potentially fatal infections? How do they feel about the science of vaccination and the government's role in vaccination mandates?

In an attempt to orient myself to the vaccine choice conversation, so that when I finally spoke face-to-face with non-vaccinating parents I was not completely ignorant of their decision-making processes or the reasons they decided to forgo vaccinating, I began my research with a content analysis of so-called "mommy" and "daddy blogs."

Rather than beginning by collecting primary data through in-depth interviews or traditional participant-observation, I collected data from online blog posts written by non-vaccinating or vaccine hesitant parents. Blog posts were identified and included in the sample if they appeared in the first ten pages of a Google search return for each of the following search terms plus the word "blog": vaccination safety, vaccine safety, immunization safety, vaccination danger, vaccine danger, immunization danger, vaccination objection, immunization objection, delayed vaccination, vaccine delay, delayed immunization, immunization delay, anti-vaxxer, and vaccine hesitant. Considering the relevance of vaccination issues (especially surrounding the 2014 measles outbreak) and the volume of recent coverage, all searches were limited to posts published between January 1, 2013 and November 15, 2015 (when I commenced my search).

I worried that the search terms above might bias the sample, as they depended on my etic understanding of the "anti-vaxxer" movement and limited mainstream media coverage of what non-vaccinating parents felt and thought. Throughout data collection, I made sure to look

for terms that vaccine hesitant or non-vaccinating parents used to describe themselves and the “anti-vaxxer” movement, with the intent of adding such a phrase to my search term list. In the end, the only phrase I added to the list was “vaccine choice,” which did not return any unique results.

Once I came across a blog, I read through to find the most relevant posts—articulations of the parents’ decision to forgo or delay vaccination. In an attempt to replicate the diversity in responses that might have been collected through in-depth interviews or participant-observation, all relevant raw data taken from non-vaccinating or vaccine hesitant parents were included in analysis; nothing was excluded based on the writer’s demographic profile. If they were American parents, they were included. Their current geographic location (i.e., which state they live in) and demographic details (i.e., race) were not used as inclusion or exclusion criteria.

In their content analysis of pro-eating disorder sites (which are websites that motivate people to successfully maintain their anorexia or bulimia by providing “thinspiration” and tips for self-control), Dina Borzekowski and her team followed internal links to find sites they would not have found through traditional database searches (e.g., Google) because of steps taken to hide the content from public health officials (2010). Where possible, I also followed these kinds of internal links and, where relevant, included the newly encountered texts in the sample.

By the end of my search, I had sourced data from blog posts written by 22 individual non-vaccinating and vaccine hesitant parents from January 1, 2013 through November 15, 2015. Because there was no feasible way for me to collect self-reported race/ethnicity data for all 22 individual parent bloggers, where possible I noted my *assumption* of the race/ethnicity of the parent bloggers based on family photos that were posted to the blog. I recognize that this methodology is inherently problematic, as research shows that phenotypic appearance is not always an accurate indicator of a person’s self-identification or genomic ancestry (Parra, Amado,

Lambertucci, Rocha, Antunes and Peña 2002). However, based on these visual assumptions, none of the parent bloggers were people of color.

Raw data (i.e., entire blog posts) were uploaded to the web-based qualitative analysis program Dedoose. Following the recommendations of Carl Auerbach and Louise Silverstein, relevant text was identified and recurring ideas and themes were noted, informing the development of a coding structure (2003). Qualitative data analysis is an iterative process, and as such, the coding structure evolved as data were analyzed.

After this content analysis was complete, having built a framework for understanding the issues surrounding vaccine choice, and securing IRB approval, I set out to get to know non-vaccinating parents in the Park Slope neighborhood of Brooklyn, New York, more personally. I chose Brooklyn primarily because it is the borough in which I grew up and still live, making the proposed study sample easily accessible. Secondly, the Park Slope neighborhood of Brooklyn has a reputation for being politically liberal and the neighborhood of choice for affluent and well-educated parents. There is a food cooperative on Union Street between 6<sup>th</sup> and 7<sup>th</sup> avenues, a local Waldorf pre-school, several other alternatively modeled schools, and highly-ranked public schools. The median sales price of a single-family Park Slope home (there are countless landmarked brownstones in the area), according to real estate site Trulia, is well over the million-dollar mark. Finally, Park Slope's P.S. 9 also has the lowest vaccination rate of any public school in the borough (WNYC 2015).

I recruited the parents for this second part of data collection using a "snowball" or "chain method," in which the researcher asks established acquaintances, contacts, and participants to recommend other participants (Auerbach and Silverstein 2003:18). I expected to be met with resistance by non-vaccinating parents because of how often they are vilified in mainstream media coverage. I expected that they would assume that I, too, would try to

convert them. To my surprise, I already personally knew several non-vaccinating parents and they were happy to help me understand their perspectives.

I asked the two mothers who volunteered as respondents for this component of my research to complete at least one one-hour-long in-person interview, answer any follow-up questions via telephone call or text, and allow me to either visit them at home or accompany them on some kind of routine outing (e.g., grocery shopping). I purposefully set out to limit the number of parents I spoke to because the beliefs, opinions, and experiences of fewer people can more easily be studied in greater depth (Morgan 1997). I spent approximately twenty hours, in total, with each of the volunteers, Delilah and Saxanne.<sup>2</sup>

I was able to apply the existing code structure arrived at during the blog content analysis seamlessly for the data collected from in-person interviews and participant-observation, which confirmed for me that I had reached data saturation—I was not hearing or learning anything new from the volunteers.

### **Information Flow**

To sufficiently understand the thoughts and experiences of non-vaccinating parents, from the first seedling of vaccine doubt to the ultimate decision of vaccine refusal, I began by tracing their decision-making processes: When and why did non-vaccinating or vaccine hesitant parents first think that they should forgo vaccinating their child according to the CDC's vaccination schedule? Where did parents go for information that would help them arrive at a decision?

The dominant narrative offered by parent bloggers is that once someone becomes a parent, they are forced to "do the research," to seek out the truth about what is best for their child in all arenas of the child's new life: safe bedding, the best toys for development, feeding

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<sup>2</sup> These are pseudonyms chosen by the respondents.

practices, and yes, vaccine safety issues (Adventures in Autism 2015). This need to gather all of the possible information is integral to the nature of parenthood in the modern, Internet-saturated, era. Because of the proliferation of information, the burden to make the *right* decision is overwhelming. Postmodernity means that we know too much to ignore how little we know about the world in which we live. In this sense, ignorance can both be blissful and anxiety provoking.

Non-vaccinating parents argue that they have taken the time to gather all of the information they need to make a decision they are comfortable with. One mommy blogger writes, "We opted out of vaccinating after intensive research and self-educating" (Circle of Moms 2013).

Delilah and Saxanne employ the same language when discussing their information sources. Delilah, 28, explains, "I have been researching and self-educating and practicing, you know, mostly from the Internet... But, it's self-education! Everything you need to know is out there, it's just a matter of finding it" (interview, August 28, 2016). Saxanne, 41, advises that expecting and new parents, "Do a lot of research definitely...the overarching answer is, the Internet is the place to go" (interview, April 28, 2016).

Another source of information for parents is other parents. Delilah's experience with anecdotal narrative evidence is typical:

A lot of children that I've worked with were functioning normally before having their immunizations, and their parents observed notable differences and difficulties following their immunizations. There was a distinct, abrupt change at the same time that their immunizations happened... [you] need to know people's real life experiences, to hear the stories of other parents (interview, October 22 2016).

In her study of parents at a Waldorf-Steiner school in California, Elisa Sobo observed the "socially cultivated nature of vaccine refusal" (2015:381). Vaccine hesitant parents share their thoughts and feelings with like-minded parents of a similar socio-cultural status. The receivers

of this information eventually adopt vaccine hesitant sentiments themselves. These parent-to-parent exchanges act as catalysts for Internet research.

Some of the primary Internet sources are, surprisingly (for this investigator), the websites of biomedical pediatricians like Dr. Bob Sears of California. Saxanne and the father of her children often went to talks by Dr. Larry Pannelsky and midwife Cara Muhlhahn (both of New York). Pannelsky and Muhlhahn promote naturopathy and holistic methods. Delilah also works as a pediatric occupational therapist and often collaborates with a large pediatric practice in south Brooklyn, where the head doctor promotes "gut health" as a means of ameliorating the symptoms of developmental disorders, including autism spectrum disorders (interview, October 22, 2016). The doctor prescribes strong probiotics and requires that parents provide their children with gluten- and casein- free meals; he believes that reducing inflammation in the gut, caused by candida and contaminated produce, will mitigate attention deficits and behavioral problems.

### **Scientific Discord**

In their research, parents thus encounter what appear to be two competing medical communities, instead of one unified discipline in which all members agree upon the cause and trajectory of developmental disorders and the usefulness and safety of vaccines. This apparent division only adds to the parents' uncertainty.

Siddhartha Mukherjee offers some explanation for the inconsistencies parents observe in the medical community. In *The Laws of Medicine: Field Notes from an Uncertain Science*, Mukherjee explains that in medicine, unlike other sciences (e.g., chemistry, physics) there are no fundamental laws. The laws of medicine are "laws of uncertainty, imprecision, and incompleteness," and "for every perfect medical experiment, there is a perfect human bias" (2015:6, 54).

I asked nursing researcher Kathy Bowles if she thought the medical community was at all to blame for the consistent doubt and confusion among parents. She responded,

I don't think we're doing it purposefully. I think science is science and you do get conflicting findings, depending on the population you're studying, the techniques you use for analysis...I bet a lot of what the parents are reading, what they call 'scientific evidence,' is case-study based...If an association is all that you've observed, that's the strongest argument you can make (interview, October 31, 2016).

Dawn Dowding, also a nursing researcher with a focus on informatics, offers some further insight into the conflicting reports from pediatricians, namely that they themselves are often not sufficiently trained to interpret research findings.

It was not until the mid-to-late nineties that evidence-based practice was introduced to medical school curricula in the UK. Such courses are, often, still absent from nursing and medical school curricula in the United States. I moved here in 2014. Before I arrived at [the University where I am currently teaching], there was no course on evidence-based practice, and students only briefly heard of the importance of such in their research methods class (interview, October 31, 2016).

If doctors and nurses themselves are unable to accurately interpret research findings, how are laypersons expected to? As sociologist Ulrich Beck remarks, "Herein lies the essential and momentous consequence [of modernity]: in definitions of risks the sciences' monopoly on rationality is broken. There are always competing and conflicting claims, interests and viewpoints of the various agents of modernity and affected groups, which are forced together in defining risks in the sense of cause and effect, instigator and injured party. There is no expert on risk" (1986:29).

### **Risk & Risk Avoidance**

Beyond a concern over a link between vaccines and autism spectrum disorders, there is fear of the ingredients in vaccines and concern about "introducing potentially dangerous chemicals to the undeveloped immune system of infant children" (The Matt Walsh Blog 2013).

Delilah expanded on this idea:

The chemical factor was the biggest deciding factor for me, not knowing what [vaccines are] made of... So, in living a life as natural and toxin-free as possible, believing that the body is a vessel and needs to be treated with the best care, the best food, the most nurturing, I don't see vaccines as a positive thing (interview, August 28, 2016).

Here are the ingredients listed by the CDC for the MMR vaccination as of June 2014:

"Medium 199 (vitamins, amino acids, fetal bovine serum, sucrose, glutamate), Minimum Essential Medium, phosphate, recombinant human albumin, neomycin, sorbitol, hydrolyzed gelatin, chick embryo cell culture, WI-38 human diploid lung fibroblasts." The PDF in which these ingredients are listed offers no simplified language or layperson-oriented explanation for what each of the individual ingredients is or from where they are sourced. The absence of this information, in the face of the current wave of vaccine refusal, is a failure on the part of the CDC.

Saxanne had a similar reaction to the obscure list of vaccine ingredients as a new mom:

There's an idea that what they put in these vaccines are, actually, poison. Not just the mercury, the mercury they've gotten rid of. It's more of the, whatever, frozen something, whatever it is, cow parts or something. It's sort of, huh? I think I got it in my head that vaccines were poison. And I didn't want to put poison in my baby's body (interview, October 31, 2016).

Non-vaccinating parents also take issue with the vaccine load, or number of vaccines administered early on, some of which they themselves were not given as children. A child born today will receive 22 separate shots immunizing them against 14 infectious diseases before their first birthday. "I think the number of vaccines is cause for question," Saxanne confided. "There's just so many! You know, when we were growing up, they didn't push a *flu* shot!"

The conclusion many parents make is that the unknown ingredients and not yet fully understood autism spectrum disorders are a worse fate than eliminated infectious diseases:

It just seemed to me that my kids had a greater chance of developing autism or of having a bad reaction to a vaccine than they did of acquiring one of these diseases they vaccinate for. If they did happen to get one of these diseases, the chances of them having serious or life threatening affects [sic] from them were low (All Natural Mom 2013).



“I mean, it may be a little bit like kidnapping,” Saxanne theorized (interview, October 31, 2016). “You know how we have this fear of our kids being kidnapped? I don’t know how many kids get kidnapped, but it’s not that many, right? But, the FEAR IS HUGE.”

Saxanne is on to something here. The work of Paul Slovic, a decision scientist, illustrates just how poorly we calculate risk. His 1987 study on risk perception shows that people believe the risk of dying in an auto accident is much higher than the risk of dying of disease and that more people are murdered than commit suicide. The truth of the matter is that disease and suicide are responsible for more deaths than accidents and homicide, respectively. This is perhaps because accidents and murder are more likely to be sensationalized and to grab our attention in person-to-person storytelling or on the nightly news. Whatever the reason, we are simply not very good at recognizing risk.

During a lecture at London School of Economics in 2006, sociologist Ulrich Beck posited that “being at risk is the way of being and ruling in the world of modernity; being at global risk is the human condition at the beginning of the twenty-first century.” So, what does modernity have to do with inaccurate risk perception? Is information overload (and, once again the Internet) to blame? If our attention is too easily drawn to the sensational, we are then desensitizing ourselves to the true dangers in the world.

In his seminal work, *Risk Society: On Modernity*, Beck offers this interpretation of modernity. He writes, “the knowledge is spreading that the sources of wealth are 'polluted' by growing 'hazardous side effects'...Risk no longer carries the connotation of individualized danger, but of “the threat of self-destruction of all life on Earth” (Beck 1986:21). This is exemplified in Saxanne’s discussion of the many things she is concerned about as a mother, which are all related to large industrial complexes.

We still don’t know what causing the prevalence of autism and cancer and all kinds of illness. I think a lot of it might be environmental factors. That’s my working theory.

When I say environmental factors, I mean Windex, I mean those chemicals that they put in all the cleaning stuff, I mean Raid. I mean those kinds of things, which I try not to have in my home. I make my own: washing soda, vinegar, liquid castile soap and some essential oils. I try to stay away from SLS, from—there's so many.

I think the other big thing might be how they treat the meat, because that I think is equivalent to slavery—I mean, that's a little harsh, but the way they treat the animals in huge agribusinesses, the cows and the chickens and the hormones. Sure there are some pockets of 'we want local and grass fed,' but the vast majority are eating—what is it, on Empire Boulevard? There's this huge WESTERN BEEF. I'm wondering, that beef is probably... I mean it's inhumane the way they treat those animals and it's so destructive on so many levels. I think that stuff is making people sick. It's not 'oh, I'm just going to have one thing and it's going to do it.' It's the constant of the chemicals and the bad meat and the pesticides and the herbicides, all the processed foods (interview, October 31, 2016).

In place of vaccines, anti-vaxxer parents use homeopathy, encourage natural immunity, and depend on nutrient protection via diet. The Paleo Mama advises her reader to,

Eat as organic as possible. Avoid GMO foods (they are known to cause intestinal problems). Make sure the child is getting adequate vitamin D. Give Fermented Cod Liver Oil [which] is loaded with Vitamin A. Give probiotics to help keep their immune system up (2013).

Delilah and Saxanne both shop at the Park Slope Food Co-op, the website of which advertises the following: "[We carry] a wide variety of products, including local, organic and conventionally grown produce; pasture-raised and grass-fed meat; free-range, organic poultry; fair-traded chocolate and coffee; wild and sustainably farmed fish." They both depend on biomedical doctors primarily for their diagnostic tools, but not for treatment. Instead, they self-treat:

When I'm sick I use essential oils. I dealt with my endocrine system recently being out of whack. And prior to that I had the flu. I used herbal medicine and essential oils...detoxing and getting whatever was in my system out: hot baths with salts, sweating, oregano oil which is an immune boosting antioxidant oil, clove is also an antioxidant oil, basically all the oils that support the immune system. So I used natural remedies to give my body what it needed to heal itself (interview with Delilah, August 28, 2016).

Some parent bloggers also cite their faith as protection from the illnesses vaccines are meant to prevent. "One more reason why we don't vaccinate and why I have little fear for my children catching one of these diseases: faith in God. God is in control of everything first and

foremost" (The Paleo Mama 2013). The use of faith as an alternative to vaccination was the singular difference between bloggers—who, as far as can be gathered, live mostly in the Midwest or California—and the Brooklyn parents, who identify as agnostics. Delilah and Saxanne do not teach their children from any dogmatic religious texts, but are believers in the good and bad energy of people and things.

### **The Burden of Parenthood**

Elisa Sobo, Ariana Huhn, Autumn Sannwald and Lori Thurman, "[locate] vaccine caution at the confluence of engaged, activated health care consumerism and the digital information commons of Web 2.0, which fosters a mindset radically appreciative of participatory dialog and diverse points of view," which is to say that, many non-vaccinating parents are, in fact, not stubborn and unmovable "anti-vaxxers," as the dominant mainstream narrative suggests (2016:15). Delilah and Saxanne often used ambiguous language to discuss their position regarding vaccinations. The murkiness of their arguments seems to be a common factor in the vaccine choice dialogue. Sobo, Huhn, Sannwald, and Thurman found, "Plurality, nonlinearity, and nonfinality ... [were] certainly evidenced in participants' narratives" (2016:13). While there are definitely some non-vaccinating parents that are steadfast in their conviction (Adventures in Autism), many vaccine refusers or vaccine hesitant parents are simply making a choice they see as fluid, with the potential for change.

We had vaccinated our first three children on an alternative schedule and our youngest four weren't vaccinated at all. We stopped because we were scared and didn't know who to trust. Was the medical community just paid off puppets of a Big Pharma-Government-Media conspiracy? Were these vaccines even necessary in this day and age? Were we unwittingly doing greater harm than help to our beloved children? So much smoke must mean a fire so we defaulted to the 'do nothing and hope nothing bad happens' position (Levi Quackenboss 2015).

Well there's definitely some concrete evidence to show that there's no link between vaccinations and autism. But there's also pretty good evidence to show that there is. I read something, I don't remember where it was, but it was basically breaking it down to say like, okay maybe vaccinations don't cause autism but vaccinations cause this

response in the body and this response in the body causes, you know, these mutations, and these mutations cause brain changes and these brain changes is what causes autistic behaviors (interview with Delilah, October 22 2016).

Yeah, I wish it was something that was a definitive. Like, you knew with complete and utter certainty that no vaccination is the best or the other way. Because, I think there's enough research out there from both sides to suggest something sort of nebulous. I would say, go with your gut, with what resonates most with you (interview with Saxanne, April 28 2016).

Elisa Sobo also contends that non-vaccinating parents' opinions on vaccines are developed on the basis of varying concerns. They see vaccines as being "variously unnecessary, toxic, developmentally inappropriate, and profit driven" (2016:381). There is no one reason for vaccine hesitance or vaccine refusal. A parent's decision to refuse or slow down vaccination is the result of the amalgamation of a variety of informational bullet points, gathered from the Internet and fellow parents, and the ultimate reasoning is unique to that parent.

Like all parents, non-vaccinating parents want to be able to control what happens to their child, because they feel the world is untamable.

I if I could control at least that, at least the vaccinations part...I will. Parents need to educate themselves, and have their own thoughts and opinions about it and don't go by what anyone tells you is right or wrong. Make the judgment call for yourself. Not many people realize that they have a choice! They go with what social norms are, and what everyone else does (interview with Delilah, October 22, 2016).

One blogger shared a similar sentiment: "You are the parent. You make the choice. Not the doctor. Whatever happens to your child—if they're unlucky enough to be injured by a vaccine, or get sick with a serious illness—who is responsible? You are. Not the doctor" (Modern Alternative Mama 2014).

Non-vaccinating parents' attitudes toward vaccines overlap with their attitudes toward education—they want to be able to engage with alternatives to the traditional, publically provided systems as a means to be better able to control what their children take in. Neither

Delilah nor Saxanne agree with the public school model and have chosen to pursue an alternative education for their children. By homeschooling or choosing a democratic school, they are able to control the messages their children receive about their role in and value to the world, just as refusing vaccinations help parents control the inundation of “toxins” going into their children’s bodies.

I’ll be homeschooling my children. I work for the Department of Education, that’s what I’m going based off right now. I don’t necessarily agree with some of the teaching methods they use in the City. They’re standardizing, and the pressure on children... Like, what they’re doing in kindergarten is really second-grade work. The curriculum does not allow children to be children (interview with Delilah, August 28, 2016).

My daughter was going to [a public school] in Brooklyn Heights. She’s now in a democratic school where everything is child-led. [The public school] has a reputation as a fairly good school...But, the teacher was totally authoritarian: ‘sit down and behave,’ ‘stop talking, we’re not supposed to be talking.’ You couldn’t interact with your friends in a normal way. She went from a really progressive Waldorf preschool where they’re like, ‘What’s your world? Child, what’s your world like?’ to a place where the kids are always being yelled at (interview Saxanne, April 28, 2016).

### **Privilege and Panic**

This most recent wave of vaccine refusal is undeniably influenced by the privilege afforded white non-vaccinating parents. Illustrated by CDC’s statistics on MMR coverage (where the rate of vaccination among non-white children has gone up while the rate of vaccination among white children has fallen), the modern vaccine choice movement is a white movement. The apparent absence of people of color in the vaccine refusal community and in the current narrative on vaccine choice is presumably a means of avoiding what Pem Davidson Buck calls, “the dangerous attention of the state,” in a 2014 article published online by *Anthropology News*.

Additionally, people of color in America face disparities in access to and quality of care. Minority groups likely trended upwards in vaccination rates between 2000 and the 2014 Disneyland measles outbreak, while non-Hispanic whites trended down, because these minority groups are facing a different health care reality than what is described by non-vaccinating

parent bloggers. A survey of healthcare coverage and access, completed by the Agency for Healthcare Research and Quality in 2010, found that blacks “received worse care than whites for about 40% of measures,” and had worse access to care than whites for one-third of the survey’s core measures.

There is evidence for the privilege of access to and quality of care in the United States in the justifications of white non-vaccinating parents. As one mommy blogger put it:

We have advanced medical care here in the U.S. The people that die from these diseases today are often dying because they live in third world countries where they don't have the access or money to get to a doctor for treatment. They also often are not able to practice good hygiene... (The Paleo Mama 2013).

Eula Biss captures the issue of privilege perfectly in her self-appraisal:

In Chicago, where 677 children were shot the year after my son was born, I still somehow manage to find myself more captivated by less tangible threats. While two-year-olds take bullets in other parts of the city, I worry over the danger embedded in the paint that chips off my child’s toys and the walls around him (2014:132-133).

While environmental hazards *do* exist, we must be careful to acknowledge the luxury inherent in the vaccine choice dialogue and the very wide gap that still remains in healthcare between whites and people of color in the United States.

Several parent bloggers also make the inaccurate assumption that “third world” infections cannot travel to the United States. Germs do not, in fact, require passports, only a living—and sometimes even a deceased—carrier. There is no filtering antiseptic force field enveloping America. The Disneyland outbreak, caused by the same strain found in the Philippines endemic, is a perfect example of the American inability to keep “third world” diseases out.

The ignoring of risks that are in any case imperceptible, which always finds its justification in the elimination of tangible need...is the cultural and political soil on which the risks and hazards grow, bloom and thrive. Avoiding small, less consequential risks is the exact behavior that exposes us to more serious risks...and for that very reason the risk society is ultimately victorious (Beck 1986: 45).

By choosing to avoid the now disproven risk of developmental delay in favor of greater control over their child's life and well being, non-vaccinating parents are gambling with the well being of the local collective, which is precisely what they claim to value, nurture, and hope to maintain.

## **Appendix I**

### **Interview Guide**

*I'd like to begin by telling you a little bit more about myself. As you know by now, I am a graduate student of cultural anthropology at Hunter College and I am studying the issue of vaccine choice. My research generally focuses on health and wellness, and the ways in which people access and use different forms of healthcare. For this project I'm particularly interesting in the ways in which parents make decisions that affect the lives of their children and the health and wellness of their families.*

*Before I start asking the more focused questions I've prepared, can you tell me a little bit about yourself? How many children do you have and how old are they?*

---

- 1) When did you first begin to consider whether or not you would vaccinate your child/children?
  - a. Can you remember what first made you think that you *wouldn't* vaccinate?
- 2) Did you research the pros and cons of vaccination before deciding not to vaccinate?
  - a. For how long did you research before coming to a decision?
  - b. Where did you look for information about vaccinations when making your decision?
  - c. Did you ask your pediatrician? What did they say?
  - d. Did you visit any websites?
  - e. Read any books?
- 3) What information most compelled you to NOT vaccinate?
  - a. Probe re: vaccine load in early life?
  - b. Probe re: "toxins"?
  - c. Probe re: fear of developmental disabilities?
- 4) What kind of exemption did you file, if any, and why?
- 5) Was there any information that made it difficult for you to decide? Did you come across any information that made you feel or think that you *should* vaccinate?
- 6) What advice would you give to new parents who are doing their own research and trying to decide whether or not to vaccinate?
  - a. What do you think they *need* to know?
- 7) What happened the last time your child got sick?
  - a. What did you use to treat or sooth them?
  - b. Did you take them to a doctor or some other healer?
- 8) What would you like to say to those who argue that parents who decide not to vaccinate are making the wrong decision?
- 9) What else should I know about the issue of vaccination choice? What question should I have asked?

**If mother begins to discuss her time while pregnant or in labor, probe for experience *with health care services and providers while pregnant, pre- or post-partum.***



## **Appendix II**

### **Demographic Questionnaire**

You may leave any of the responses below blank.

1) What is your age? \_\_\_\_\_

2) What is your current marital status?

- a. Single/Never married
- b. Married
- c. Domestic Partnership
- d. Divorced
- e. Separated
- f. Widowed

3) How would you describe your sexual orientation? (e.g. lesbian, gay, straight, bisexual, etc.)

\_\_\_\_\_

4) Which of the following best describes your gender identity?

- a. I identify with the sex that I was assigned at birth.
- b. I do not identify with the sex that I was assigned at birth.
- c. Other: \_\_\_\_\_

5) How would you describe your race or ethnicity? You may circle all that apply:

- a. American Indian or Alaska Native
- b. Asian
- c. Black or African American
- d. Hispanic or Latino
- e. Mixed: Indio/Criollo
- f. Mixed: Mestizo
- g. Native Hawaiiin or Other Pacific Islander
- h. White
- i. Other: \_\_\_\_\_

6) What is the highest educational degree you've earned?

- a. Technical Degree/Diploma
- b. High School Diploma/GED
- c. Associate's Degree
- d. Bachelor's Degree
- e. Master's Degree
- f. Doctorate (including PhD, MD, and JD)
- g. Other: \_\_\_\_\_

7) What is your usual/main job or occupation?

\_\_\_\_\_  
\_\_\_\_\_

8) Please tell me which group best represents your total combined household income for the past 12 months:

- a. \$0 – 4,999
- b. \$5,000 – 9,999
- c. \$10,000 – 14,999
- d. \$15,000 – 24,999
- e. \$25,000 – 34,999
- f. \$35,000 – 49,999
- g. \$50,000 – 74,999
- h. \$75,000 – 99,000
- i. \$100,000 and over

9) How many people live in your household, including yourself?

10) Is English the only language you speak at home?

- a. Yes
- b. No, we also speak: \_\_\_\_\_

11) In which country were you born?

\_\_\_\_\_

If USA: In which part of the country did you grow up?

Northeast Region

- a. New England Division: Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island and Vermont
- b. Middle Atlantic Division: New Jersey, New York and Pennsylvania

Midwest Region

- c. East North Central Division: Illinois, Indiana, Michigan, Ohio and Wisconsin
- d. West North Central Division: Iowa, Kansas, Minnesota, Missouri, Nebraska, North Dakota and South Dakota

South Region

- e. South Atlantic Division: Delaware, District of Columbia, Florida, Georgia, Maryland, North Carolina, South Carolina, Virginia and West Virginia
- f. East South Central Division: Alabama, Kentucky, Mississippi and Tennessee
- g. West South Central Division: Arkansas, Louisiana, Oklahoma and Texas

West Region

- h. Mountain Division: Arizona, Colorado, Idaho, Montana, Nevada, New Mexico, Utah and Wyoming
- i. Pacific Division: Alaska, California, Hawaii, Oregon and Washington

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