

**THE AUTISM SPECTRUM DISORDERS / VACCINE LINK DEBATE:
A HEALTH SOCIAL MOVEMENT**

by

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Autism and Vaccines: A Health Social Movement

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ABSTRACT

Over the past ten years, the parents and loved ones of thousands of individuals afflicted with Autism Spectrum Disorders (ASD) have mobilized around the idea that vaccines play a causative role in ASDs. The US Federal government and Western mainstream medicine refute this, claiming evidence refutes any causal link between vaccines and ASD. The result has been a heated dispute between ASD/vaccine link (ASD/VL) activists and mainstream medicine, both claiming legitimacy based on their own scientific research. To examine this controversy and why ASD/VL activists continue to mobilize around a scientific hypothesis that has been largely disproved, I surveyed and conducted in-depth interviews with ASD/VL activists and examined artifacts from the movement.

Utilizing the theoretical framework on Health Social Movements (HSM) developed by Phil Brown and theories on boundary work developed by Thomas Gieryn I examined how and why ASD/VL activists, in collaboration with politicians and scientists, organized a movement to prove there is significant evidence showing a causative link between vaccines and ASDs. I explored how mobilization occurred around several key events including the US Congressional hearings on vaccine safety, the Immunization Safety Review Committee hearings, reports published by the Institute of Medicine, and the release of the Simpsonwood Retreat transcript. I found that while ASD/VL activists became lay experts and used scientific evidence to build their

argument, they depended on their own experiential knowledge to inform their personal beliefs on ASD causation and treatment. My findings have significant impact for the study of health social movements and the study of contested illnesses.

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PREFACE

As a researcher, I came to study the ASD/vaccine link (ASD/VL) movement with no knowledge on vaccines and little knowledge on autism spectrum disorders. I came across an article by Robert F. Kennedy, Jr. in *Rolling Stone* on the controversy linking autism and vaccines. I immediately knew that this debate warranted a sociological analysis. It is truly a fascinating debate over definitions of knowledge, credibility, and truth and is a notable example of how health-related issues bring people together in social movements.

Science plays a central role in the ASD/VL movement. However, I purposefully do not go into detail about any specific research studies that have been conducted on vaccines and autism. Furthermore, I do not make any claims about the possible causation(s) of autism. I do not attempt to show who is “right” or who is “wrong.” Instead, my purpose is to understand how and why ASD/VL activists have come together to challenge the US federal government and to understand how the boundaries of science were contested and re-drawn in the ASD/VL movement.

The activists in this debate are extremely adept in producing, deconstructing, and analyzing research papers that deal with autism and vaccines; I’m sure I can look forward to hearing their feedback on my own work. Yet, while ASD/VL activists do use science to build their case, they largely trust their own experiences when it comes to beliefs about causation and treatment of ASDs. What started as a focus on specific vaccines containing thimerosal and specific outcomes including neurological disease turned into a larger terrain that couples theories of causation linked to vaccines in general with the idea that ASDs are treatable, reversible, and even curable. The ASD/VL movement inherently imbues activists with hope through the

following logic—if we know the cause (i.e., vaccines), we can work on the cure and the treatment (i.e., biomedical interventions), and what parent wouldn't want to believe in a cure? My finding that ASD/VL activists privilege their own experiential knowledge over scientific evidence will likely not be very popular and I anticipate a heated response from the ASD/VL activist community. However, if there is anything I have learned in the course of my analysis of this debate, it is that the scientific process must be rigorously followed, generalizations shouldn't be made beyond the data, and you have to be honest about your findings.

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1.0 INTRODUCTION

In 1997, the U.S. Food and Drug Administration (FDA) requested that vaccine manufacturers supply the agency with detailed information about products containing the mercury-based preservative thimerosal. Following data collection and analysis, the FDA discovered that through the administration of vaccines on the Center for Disease Control's (CDC) vaccine schedule, "some children could [have been] exposed to a cumulative level of mercury over the first six months of life that exceeds one of the federal guidelines on methyl mercury¹" (Notice to Readers 1999). For the past ten years, the parents and loved ones of thousands of individuals afflicted with Autism Spectrum Disorders (ASD) have mobilized around the hypothesis that mercury found in federally licensed vaccines is partially or completely responsible for their child's or loved one's ASD². The U.S. federal government, Institute of Medicine (IOM), and the American Academy of Pediatrics (AAP) have refuted this hypothesis and claimed there is little scientific evidence to support this causal relationship. Yet organizations such as SafeMinds, Generation Rescue, and Moms Against Mercury have used various political tactics, including public protests, lawsuits, and government lobbying, to publicize claims that mercury poisoning from vaccines causes ASDs and that the U.S. government is responsible and liable.

¹ Thimerosal contains ethylmercury; however, no safety guidelines for ethylmercury existed at the time of the joint statement. Therefore, methylmercury guidelines were used as a proxy.

² Autism is classified under the umbrella category of "pervasive developmental disorders" (PDDs). PDD refers to a continuum of related cognitive and neurobehavioral disorders that reflects the heterogeneity of symptoms and clinical presentations, and includes autistic disorder, childhood disintegrative disorder, Asperger's syndrome, Rett's syndrome, and pervasive developmental disorder not otherwise specified (PDDNOS, or atypical autism). The term "autistic spectrum disorders" (ASD) has come into common use (Institute of Medicine 2004)

Using the health social movement EHSM framework developed by Brown and Zavestoski (2004a), my research answers the question of how and why activists continue to mobilize around the hypothesis that mercury in vaccines triggers and/or causes ASD. Through the analysis of survey data, in-depth interviews, and archival documents, I examine how movement groups have challenged the cultural authority of Western mainstream medicine through an organized health social movement (HSM). Specifically this project a) outlines the challenges to Western mainstream medicine's cultural authority; b) describes and analyzes ASD/VL activists' organization and mobilization; and c) investigates how and why ASD/VL activists deploy personal experience to contest arguments that are scientific in nature.

Through examination of how the Western medical community has responded to the challenges levied by ASD/VL activists, this project contributes to the expansion and perhaps the revision of ideas about changing boundaries of legitimacy of knowledge, credibility, and authority in mainstream medicine. More broadly my findings also contribute to the methodological and theoretical understanding of HSMs.

Table 1: List of acronyms

Movement groups	
AAC	Autism Action Collation
A-CHAMP	Advocates for Children's health affected by mercury poisoning
ARI	Autism Research Institute
DAN!	Defeat Autism Now
MAM	Mom's Against Mercury
NAA	National Autism Association
NVIC	National Vaccine Information Center

Mainstream Medical and Governmental Institutions	
AAP	American Academy of Pediatrics
ACIP	Advisory Committee on Immunization Practices
BGMC	British General Medical Council
CDC	Center for Disease Control
DHHS	Department of Health and Human Services
EPA	Environmental Protection Agency
FDA	Food and Drug Administration
IOM	Institute of Medicine
NIP	National Immunization Program

Other	
ASD/VL	Autism Spectrum Disorders/Vaccine Link
EHSM	Embodied Health Social Movement
HSM	Health Social Movement
NVICP	National Vaccine Injury Compensation Program
VSD	Vaccine Safety Datalink

1.1 THEORETICAL FOUNDATIONS

Several bodies of literature inform my dissertation research. First, I draw on the sociology of health and illness, and more broadly on the sociology of science, to understand production of medical and scientific knowledge and cultural authority (Freidson 1970; Gieryn 1999; Starr 1982). Summarizing how practitioners of Western science and medicine have cultivated this cultural authority is necessary in order to understand the challenges being levied against it by ASD/VL activists. To understand how the boundaries of credibility are protected and challenged, I draw from the work of Gieryn (1999) and Hirschorn (2006). Secondly, I utilize the rich body of literature on HSMs, a framework built by Phil Brown and Stephen Zavestoski (2004a) and expanded upon by theorists Renee Beard (2004), David Hess (2004), and Sabrina McCormick (2007).

1.1.1 The Production of Cultural Authority

What is and is not legitimate science can be hard to distinguish; this is one of the main points of contention in the ASD/VL debate. To try and understand how to determine what is and is not legitimate science today, Gieryn (1999) developed the concept of cultural cartography and developed a “map” of credibility where boundaries are drawn around what is and what is not science. In the center of Gieryn’s map, is the Mountain of Knowledge, atop which sit the medical doctors and credentialed professionals working in scientific institutions like the Department of Health and Human Services, the IOM, and universities. These professionals belong to professional associations like the American Medical Association and the AAP. With these professionals and within these associations, ideas of rationality, logic, and rigorous science hold

the most influence on decisions about health and medicine. As we move further from the Mountain of Truth, we find the “soft” sciences – history, philosophy, and the arts. On the outskirts of the map, are the lands of religion, faith, anecdotal evidence, mysticism, quackery, and charlatans (Gieryn 1999).

This metaphorical map exists in the collective minds of a society and provides members with an image of who can be trusted and where real knowledge comes from. It is especially appealing because it takes the extremely complex, often overlapping, and at times contradictory relationships that happen between “territories” and maps them out in an overly simplistic manner. This is an effective, albeit overly simplified, tool for conceptualizing the terrain of the current ASD/VL debate as well as relationships between “real science” and “junk science” or “voodoo science.” The borders of this map are not static; challenges and loss of trust can quickly change the boundaries. As Gieryn (1999: 24) points out, “science truly has no concrete boundaries, just those drawn at any given moment in the courts and legislatures as well as scientific organizations.” Throughout the last century the scientific and medical establishments have carved out and protected their territory atop the Mountain of Knowledge.

Starr’s (1982) *The Social Transformation of American Medicine* thoroughly explores the *how’s* and *why’s* of medical authority. Through his historical and structural analysis, he finds the medical profession (and the scientific knowledge that it claims to represent) was able to achieve *cultural authority* in America by the 1930s. Cultural authority carries with it the ability to decide what truth is. It is, in effect, epistemic authority or the ability to define what is legitimate

knowledge (Starr 1982)³. Medicine and the larger institution of science achieved cultural authority through creating “two sources of effective control: legitimacy and dependence” (Starr 1982: 9).

Legitimacy is the acceptance of something (or someone) as credible, valid, and reliable. Professionals and the professions they represent create legitimacy by linking professional ethics to dominant cultural values, such as improving the health of the population, and forming a monopoly on a knowledge base that is built on rational, scientific grounds that is then validated by a community of peers (Hirschhorn 2006, Starr 1982, Abbott 1988). Once the profession has built legitimacy, they fight for autonomy. An autonomous profession or group has the right to conduct and supervise their work and training including the right to evaluate itself, to decide who is qualified to do what task and how that task ought to be done (Freidson 1970). To further legitimize a profession or institution’s right to authority and control over a specific territory, in this case health and science, it can seek protection from the state through licensure (Abbott 1988, Freidson 1970, Larson 1972). There are other means of restricting access to the practice of medicine and research which hinder lay involvement, such as Institutional Review Boards (IRBs), credential requirements to receive funding, and of course, professional board certification.

Once medicine was seen as credible and legitimate, it gained the trust of the population which then became dependent upon it, thus securing cultural authority (Starr 1982). Cultural authority is a very powerful force in American society. We often surrender our own judgment

³ For all intents and purposes, “epistemic authority” is synonymous with Starr’s conceptualization of cultural authority which he defines as “the probability that particular definitions of reality and judgments of meaning and value will prevail as valid and true” (Starr, pg.13). Both describe the power to define meaning, truth and knowledge.

when presented with professional opinion. As Starr (1982: 4) states, whether “it is the structure of the atom, the ego, or the universe, we generally defer to their judgment.” For the last century, we have turned to medicine for guidance on keeping us safe and healthy. Our food, water, air, national security, and our own physical and mental health are dependent upon this medical establishment. Indeed many people, including politicians, lawyers, judges, and lay citizens evoke the word “science” or “medicine” in arguments because they are so closely associated with legitimacy (Tesh 2000). Over half a century ago, Hofstadter (1963) recognized our reliance on experts in all fields and stated that there is no longer a suspicion about experts because they follow the scientific model and the positive paradigm of complete neutrality and objectivism. In order to maintain scientific legitimacy, however, they must act as watchdogs protecting the boundaries of what is and is not real science and who has the right to undertake legitimate science (Gieryn 1999, Starr 1982).

1.1.2 Boundary Work

Today’s society depends on science a great deal. Without the time or resources to study the world ourselves, we often must trust scientific experts and the research they produce and accept their claims as truth. Individuals alone cannot determine the safety of the products we consume. We depend on science to create for us a “trustable reality” as Gieryn (1999: 1) states, “If ‘science’ says so, we are more often than not inclined to believe it or act on it—and to prefer it over claims lacking this epistemic seal of approval.” However, rather than accepting that this type of trust is inherent, Gieryn (1999) problematizes this scientific epistemic authority and seeks to answer not what is inherent in science that makes it infallible but rather how people use science to make their claims credible. He finds this often involves one party claiming themselves

as credible by identifying and then distancing themselves from non-science—i.e. hearsay, speculation, religion, or “junk” science (Gieryn 1999).

Science holds cultural or epistemic authority which is extremely powerful, but as Gieryn (1999: 14) states, “the legitimate right to have one’s reality claims accepted as valid or marginally useful is no plum at all if everybody enjoys it all the time. Epistemic authority exists only to the extent that it is claimed by some people (typically in the name of science) but denied to others (which is what boundary-work achieves).” How those lines are drawn is a political endeavor involving different groups making claims for legitimacy in the state and to the public (Abbott 1988). This kind of line drawing is what Gieryn (1999: 4) calls “boundary work” which is “the discursive attribution of selected qualities to scientists, scientific methods, and scientific claims for the purpose of drawing a rhetorical boundary between science and some less authoritative residual non-science.” My research likewise seeks to identify how science was used in this debate, specifically how ASD/VL activists fought and used boundary work to have their own research and scientific claims seen as credible and legitimate and how their opponents responded.

Boundary work is used to pursue several different goals including: 1) expansion; 2) expulsion; and 3) protection of autonomy (Gieryn 1999). Expansion involves two parties competing for jurisdictional control of a contested or new ontological domain. In expansion campaigns, the struggle is not over who or what is more legitimate and credible but which party is the best to claim a specific territory for their own. This can occur when a new technology or practice is introduced into a professional arena. Expansionary issues do not come into play in the ASD/VL debate. More relevant to the ASD/VL debate are the practices concerning expulsion and protection of autonomy, which often go hand in hand. Where expulsion is the goal of

boundary work, one group wishes to expel another from a defined territory. This typically occurs when two parties are claiming they are the “more legitimate” party. In scientific disputes, such as historic debates between “regular” or traditional doctors and homeopaths in the early 1900s, both parties utilize the same tools of the trade, i.e., science, to make their case. Gieryn (1999) argues that the foundations of science are actually supported and reinforced in the course of scientific expulsion. He states:

...expulsion often pits orthodox science against heterodox, mainstream against fringe, established against revolutionary—but of course the issue in dispute is who and what belongs on which side. Neither side wishes to challenge or attenuate the epistemic authority of science itself, but rather to deny privileges of the space to others who—in their pragmatic and contingent judgment—do not belong there (1999: 16).

My research shows that public health officials from the CDC and IOM worked to expel ASD/VL activist researchers from the territory of respected science.

Expulsion reinforces autonomy, Gieryn’s (1999) third goal of boundary work, as it eliminates challengers from within a territory. However, it is also necessary to protect autonomy from challengers outside a protected boundary. This happens frequently when parties outside the legitimate realm of science attempt to use scientific language and design as a strategy to reach their own goals (Gieryn 1999: 17). In these cases members of the scientific community respond with harsh criticism against challengers and build a campaign to reassert the boundaries of legitimate and illegitimate science. My research shows that ASD/VL activists represented this kind of challenge to the autonomy and authority of Western mainstream medicine through the production and presentation of their own research linking vaccines and ASDs.

One form of boundary work that is integral to a group’s maintenance of cultural authority is the balance of their *technical knowledge* and *indeterminate knowledge* (Hirschhorn 2006).

Technical knowledge is knowledge that can be broken down into step-by-step procedures and delegated to many (Jamous and Peloille 1970). *Indeterminate knowledge* is the nuanced knowledge that comes only through “experience, ascription, or initiation” and the socialization of professionals (Hirschorn 2006, Jamous and Peloille 1970: 114). It is the *art* of medicine or the *craft* of practicing law. To maintain legitimacy and authority, the profession or organization must be able to prove that they are abiding by laws of rationality and logic by exposing some of their methods and procedures (technical knowledge), yet they must be able to maintain a degree of mysticism in their practice so that they do not lose autonomy to would-be technical encroachers or, even worse, to those who wish to challenge their constructions of legitimacy (Hirschorn 2006, Abbott 1988). My research will show that the professional experts working with the U.S. federal government and IOM have attempted to balance this technical versus indeterminate knowledge by controlling access to resources (like data and research) needed to take part in the scientific discussion of the ASD/VL debate.

Finally, time and space play a critical role in the ASD/VL debate and the movement it has spawned. Gieryn (1999) addresses the importance of time and space and asks where science is, rather than who is a scientist. To think about “where science is” forces us to think about where it is *not* and how that difference is used in boundary disputes. As Gieryn (1999: 27) states, “When considered as a cultural space constructed in boundary-work, science becomes local and episodic rather than universal; pragmatic and strategic rather than analytic or legislative; contingent rather than principled; constructed rather than essential.” My research shows that the contests over credible science in the ASD/VL debate are temporally and spatially bound around three anchoring events, 1) the Congressional hearings on vaccine safety, 2) the Immunization Safety Review Committee hearings that generated the reports published by the IOM, and 3) the

release of the Simpsonwood Retreat transcript. With this understanding of the terrain in which this debate takes place and the ways credibility contests are built, I move to a discussion of the content of the ASD/VL debate and the formation of a HSM.

1.1.3 Health Social Movements

In 1990, Phil Brown and Edwin Mikkelsen published *No Safe Place*, an ethnography of a community's lawsuit against two large corporations that polluted public water with toxic waste, resulting in numerous cases of childhood leukemia (Brown and Mikkelsen 1990). This study marks the beginning of what, over the next decade, would become a rich body of theoretical and conceptual work developed by Brown focusing on the intersection of illness and HSMs.

In the course of his ethnographic study of Woburn, MA, Brown developed the concept that is central to his work – “popular epidemiology.” Popular epidemiology is the practice of lay members of a community conducting independent research and then using that research to levy challenges against their opponents in the pursuit of social justice in health (Brown and Mikkelsen 1990). Popular epidemiologists use their empirically based findings as tools to fight institutions that are responsible for the injustice (Brown and Zavestoski 2004a, Tesh 2000, Brown and Mikkelsen 1990). Besides the residents of Woburn, other examples of groups practicing popular epidemiology and levying challenges in the pursuit of social justice in health include the environmental breast cancer movement (McCormick 2007, Klwaiter 1999), the Alzheimer's movement (Beard 2004), environmental illness and Gulf War syndrome (Brown and Zavestoski 2005), and human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS) movement of the 1980s (Epstein 1996).

Brown later incorporated the concept of popular epidemiology into the larger framework of HSMs (Brown and Zavestoski 2004a). HSMs are defined as “collective challenges to medical policy and politics, belief systems, research and practice that include an array of formal and informal organizations, supporters, networks of cooperation, and media” (Brown and Zavestoski 2004a: 52). In his framework, Brown adopts Della Porta and Dianai’s definition of social movements as “informal networks based on shared beliefs and solidarity which mobilize around conflictual issues and deploy frequent and varying forms of protest” (Brown, Zavestoski, McCormick, Mayer, Morello-Frosch, Altman 2004b:52). This general definition is useful because many competing definitions are quite specific in their scope restrictions, most notably in their requirement that the state be either a claimant or the opponent (McAdam, Tarrow, and Tilly 2001). As Brown points out, other institutions, such as private corporations, hold the same, if not more, direct power over communities and individuals. Moreover, by adopting such an inclusive and general definition, Brown encourages us to explore and even emphasize the cultural aspects of HSMs, where symbols and symbol systems may be the target for change. For example, challenging the cultural authority of Western mainstream science requires challenging not only the private sector and U.S. federal government but also changing what credible knowledge looks like, i.e., changing the authority attributed to scientific versus a lay activist’s knowledge claims.

Brown organized HSMs into three archetypes:

- 1) *Health access movements* address issues concerning increasing or gaining access to or provision of health care services.
- 2) *Constituency-based health movements* address disproportionate outcomes and oversights by the scientific community. For example, they are concerned with ending health inequality and inequity based on race, ethnicity, gender, class and/or sexuality.
- 3) *Embodied health social movements* (EHSM) are movements formed around the illness or disability experience and the “truth” that comes from embodiment.

Of the three archetypes, Brown’s conceptualization of EHSMs is the most developed and

is his largest contribution to the study of health social movements and indeed of social movements in general. EHSMs can usually also be framed in terms of a constituency/equality-based movement; however, not all constituency-based movements can be considered embodied. EHSMs “address disease, disability or illness experience by challenging science on etiology, diagnoses, treatment and prevention” (Brown et al. 2004b). They “include contested illnesses that are either unexplained or have purported environmental causes... and challenge existing medical/scientific knowledge and practice” (Brown et al. 2004b:54). Key in EHSMs is how “activists frame their organizing efforts and critique of the system through a personal awareness and understanding of their experience (Brown et al. 2004b:53). My research shows that the ASD/VL movement is a case of an EHSM.

The idea of embodiment can be rather ambiguous; embodiment in activism means that activists argue that their experiences and knowledge should be incorporated into the understanding, treatment, and decisions—including court decisions—concerning a particular illness (Brown et al 2004b). Traditionally the body has been absent from sociological theorizing (Turner 1992). This is because until recently the social sciences accepted the Cartesian model setting the mind and body apart from each other with no or limited interaction. As Turner (1992: 37) states: “sociology has neglected human embodiment, because it has implicitly accepted a Cartesian tradition, and because sociology has been fundamentally concerned at the level of values and beliefs.” Yet to truly understand social action, interaction and particularly issues of identity, human embodiment must be appreciated and explored (Turner 1992). This means looking at how the body interacts with the social environment and how it influences social action. Sociologists, such as Klawiter (1999) who studied the breast cancer movement, have made the role of the body central in their investigations into social actions and how the body

shapes activism. Klawiter found that how women interpret their illness experience is influenced by their views on femininity and directly translates to how they come together in social action. In her research, Klawiter (1999) found that some organizations moved to reinterpret the signs of illness, such as mastectomies or loss of hair, as signs of strength and survival, while other organizations celebrate advancements in plastic surgery and availability of wigs as a way to maintain an outward picture of normative femininity (Klawiter 1999). Her work illustrated how people come to embody their illness experience or how their physical experiences of illness directly impacts the formation of their values and ideas which are then translated into social action.

This rejection of the mind/body split and acknowledgement of the importance of the bodily experience is the foundation of the embodied health social movement framework. However, embodied health social movements may include not only those individuals who *have* the illness or disability but also those who are, or feel they may be, at risk for the illness or have intimate connections with those who have the illness. The Woburn community is an illustrative example of how individuals who are not diagnosed with illness come to embody the illness regardless: they developed the fear, anxiety, depression, anger, and despair associated with significant health hazards because they viewed themselves as vulnerable and/or had a family member who had died (Tesh 2000, Brown and Mikkelsen 1990).

Central in EHSMs is the role of activist's experiential knowledge. Experiential knowledge comes from living with an illness on a daily basis. Tesh (2000: 108) states that experiential knowledge "springs from the actual sights, smells, and tastes, the tactile and emotional experiences they encounter in their everyday lives." In her analysis of the activists affected by environmental pollution, Tesh (2000: 102) states that there was an "intensity of the

activists' conviction that the experience of living in polluted neighborhoods [gave] them special insights into the health effects of environmental pollutions." This special insight is then used to challenge their opponents who dismiss or ignore their claims and has the potential to generate or compromise legitimacy of political and scientific claims (McCormick 2007, Klawaiter 2004, Tesh 2000, Epstein 1996). For example, Epstein (1996) illustrated the power of experience in his analysis of HIV/AIDS activists' ability to demand a voice in policy-making concerning treatment plans and research in the HIV/AIDS community.

The use of experiential knowledge as a basis for assembling a challenge to established science is a specific case of identity politics. It is distinguished from persons with similar identities sharing experiences for non-political purposes such as emotional support (Tesh 2000). Broadly defined, identity politics refers to challenges based upon knowledge that comes from possessing a particular identity (Tesh 2000). Identity politics is often associated with issues of race, sexual orientation, and gender, but identity politics has also been used by groups who share environmental and health statuses (Brown and Zavestoski 2005).

Brown argues that the shared experience of illness and the further politicization of that illness results in a particular shared identity (Brown et al. 2004b). Drawing on work on oppositional consciousness, which "reflects a state of mind that binds members of a group against dominant ways of thinking by attributing problems and grievance to structural factors," Brown argues that the shared experience of illness and the further politicization of that illness results in *politicized collective illness identities* (Brown et al. 2004b:62). This politicized collective illness identity is what distinguishes EHSMs from self-help groups. The individual and collective illness identity is politicized in the activists' everyday lives, and the personal is made political through challenging current bio-scientific expertise, treatment approaches and

experienced injustice (McCormick 2007, Brown and Zavestoski 2004, Brown et al. 2004b, c). Brown et al. (2004b:60) states that “for a politicized collective identity to form, the collective illness identity must be linked to a broader social critique that views structural inequalities and the uneven distribution of social power as responsible for the causes and or triggers of the disease.” This concept represents the merging of illness identity and the notion of collective identity. The combination of these two is a powerful self-identification for individuals involved in EHSMs and an impressive foundation for political action. Activism and mobilization that result from a politicized collective illness identity based on experiential knowledge are the foundations of EHSMs (Brown and Zavestoski 2004a).

The characteristic that I find most distinguishes EHSMs, even from other HSMs, is the tendency for EHSM participants and activists to become *lay experts*. Brown and Mikkelsen (1990) first analyze and define this practice through their ethnography of the Woburn activists and their conceptualization of popular epidemiology. Becoming a lay expert means appropriating the tools and knowledge of biomedicine as well as becoming thoroughly familiar with the technical knowledge on the particular disease topic. The lay activists know as much as, if not more than, traditional or accredited experts (Brown and Mikkelsen 1990). In addition to becoming lay experts, activists produce their own knowledge through the practice of combining popular epidemiology with reflections on their own illness experiences. Lay experts also reach out to and form alliances with health professionals and credentialed scientists in pursuit of their movement goals including prevention, research, funding, and gaining access to restricted resources (Brown et al. 2004b, Brown and Mikkelsen 1990).

However, data collected and findings produced through popular epidemiology and used in HSMs do not carry the same credibility as results reported by Western mainstream medicine

and scientists for reasons covered in the above section on boundary work. The Woburn community members found it difficult to prove their credibility to the courts, even with the backing of Harvard University scientists. This practice of devaluing community action and data is part of a much larger framework that Brown terms the “dominant epidemiological paradigm” (Brown et al. 2004b). Brown explicitly defines the dominant epidemiological paradigm as “the codification of beliefs about disease and its causation by science, government and the private sector. It includes established institutions entrusted with the diagnosis, treatment and care of disease sufferers, as well as journals, media, universities, medical philanthropies and government officials” (Brown et al. 2004b: 61). The dominant epidemiological paradigm is the result of a century-long campaign by mainstream medicine for cultural authority as described above by Gieryn (1999), Starr (1982), Abbott (1988), and Freidson (1970). Essentially Brown is describing the group of professions and institutions that occupy the Mountain of Knowledge in Gieryn’s (1999) map. Throughout my thesis, I simply refer to this group as “mainstream medicine.”

Inherent in Brown’s framework is the democratizing nature of EHSM illustrated by the practice of lay experts mobilizing to challenge mainstream medicine, which includes gaining access to their territories, specifically access to data (McCormick. 2007). McCormick calls this “democratizing science,” which she developed using Brown’s HSM framework as a foundation. McCormick (2007: 609) states that expert knowledge “has begun to predominate in policy-making and be influenced by corporate entities,” and in response, “social movements around the world have begun to contest and control scientific knowledge.” Her work on democratizing science is relevant to the ASD/VL movement. My research shows that ASD/VL activists did

attempt to gain and succeed in gaining access to once restricted data and used it in the pursuit of movement goals linking vaccines to ASD causation.

McCormick (2007: 610) defines a democratizing science movement as cases that seek to have “lay understandings taken into account when scientific knowledge production is used to make political decisions.” She states that many of the HSMs today are seeking to democratize the scientific process and challenge the “scientization” that Habermas (1970) conceptualized as “the control of governmental decision-making by technical experts and bureaucracy, where citizens have little influence” (McCormick 2007: 609). McCormick looked at two situations: the Anti-Dam movement in Brazil and the Environmental Breast Cancer movement (EBCM). She found that both movements were initiated with the release of research by scientific experts alerting communities to new information. The communities appropriated the findings and developed their own perspectives and agendas. Once the EMBC activists gained access to research, they translated the information and framed it in a way that would be relevant and accessible to the lay population. McCormick further found that alliance building was critical in the initial phases of activism because scientific experts offered knowledge and resources not necessarily accessible to activists. Collaboration with scientific experts also gave them legitimacy, as McCormick (2007: 617) states, “these women knew that their interpretation of illness patterns and intuitive ideas about causation would have little credibility without such scientific authority.”

McCormick (2007: 611) argues that there is a potential and very real downside to the success of democratizing debates: institutions, including the government, can co-opt community perspectives in order to legitimize their own decisions. However, McCormick does not outline how we know when a perspective or plan has been co-opted versus legitimately taken into

consideration and adopted. Finally, McCormick calls for a new framework for the study of democratizing science movements. The framework requires an examination of how groups process and contest existing research, how they go about generating new research to counter the existing research, and how they reframe debates from technical language into meaningful information for the lay public. While McCormick makes some very insightful observations and provides us with the concept of democratizing science, there is no need for an entirely new framework. Rather, the idea of democratization fits nicely with Brown's framework on HSMs. Further, I am not entirely convinced that McCormick's data represents a successful democratization of science as her activists were still required to collaborate with "established" experts to gain legitimacy. A true democratization of science would allow equal access to data and would attribute equal credibility to lay data collection and analysis.

1.2 METHODOLOGY

I gathered data from three sources: questionnaires, in-depth interviews, and archival research. In collecting three separate data sets, I am practicing methodological *triangulation* (Denzin 1989). This approach of collecting different types of information (qualitative and quantitative, primary and secondary data), was developed to improve validity of results. By being able to compare survey data, in-depth interviews, and archival reports, I am able to see where there may be disagreements and inconsistencies, but more importantly, I am able to achieve richer, more comprehensive results.

1.2.1 Internet as a Site of Movement Mobilization and Action

The internet has provided a new arena for organizing social movements; it is the “new site of activism” (Earl and Schussman 2003). The internet allows for quicker, easier organization and mobilization of people because information is not bound to the physical world. People can read articles and access information, get connected with others, and share ideas with ease and convenience (Bonchek 1995). However, there are not many fundamentally new *methods* of organizing and activism online (Earl 2006)⁴. Most online tactics are the same or just slightly adapted from traditional movement tactics such as letter writing and collecting signatures for petitions (Earl 2006). Indeed, much mobilization and communication is concerned with carrying out offline political activities like rallies, protests, and vigils (Almeida and Lichbach 2003, Carty 2002, Van Aelst and Walgrave 2002, Eagleton-Pierce 2001, Rheingold 1996). Whereas people may have met and organized in the local church or community hall half a century ago, today they meet and organize online, particularly via message boards, making them an excellent site for recruitment and data collection. So while the setting is different (church versus message board), the underlying structure and purpose is the same.

There is a growing body of evidence showing that more and more parents, mostly women, tend to utilize internet message boards formed around parenting issues (Drentea and Moren-Cross 2005, Sharf 1997). Drentea et al. (2005) suggest that mothers turning to internet message boards, particularly for support and guidance, is a result of the growing social isolation

⁴ While I am using the internet to recruit participants and to collect data for my study, the scope of my project does not include making internet activism or internet communities a central focus of investigation. For information on communities and activism on the internet, see Diani (2000), Gurak (1999), Rheingold (1996), and Wellman and Gulia (1999).

of the modern mother. Evidence shows that the decline in birthrate (among certain socioeconomic statuses) and the fact that many mothers work outside of the home has left “fewer children in neighborhoods and family networks, thus creating a more adult-centered and less child-friendly environment” (Drentea and Moren-Cross 2005:921). To find support, share information, and fill social needs, parents turn to the internet and join communities or online message boards to

share with others in similar situations (Drentea and Moren-Cross 2005, Lin 2001). My research supports these findings as the internet has been the primary site for mobilization and organization of the ASD/VL movement.

1.2.2 Dataset 1: Survey Data

My first dataset is survey data collected via recruitment from internet message boards. The use of internet message boards as a site for data collection is a new yet quickly growing practice in research studies. There are several critical issues to consider when collecting data via the internet. Collecting data from internet users automatically excludes a number of groups—those who cannot read, those who do not know how to operate a computer, and those who do not have a computer or internet access. Internet access can therefore be considered as social capital, and like other forms of social capital (e.g. networks, money etc.), internet access follows unequal patterns of distribution (Drentea and Moren-Cross 2005, Lin 2001). Those in a higher socioeconomic status are more likely to have and use computers and an internet connection (Cotton and Gupta 2004, Schement 2001). Although computer and internet access is more obtainable today than twenty years ago (due to the decreasing cost of owning a personal computer or free access via schools, public libraries, etc.), a “digital divide” exists because those with higher socioeconomic status will be able to take advantage of technological advances more readily and easily (DiMaggio, Hargittai, Newmann and Robinson 2001). There are racial and ethnic disparities as well, with African-Americans having less access to computers (Attewell 2001). However, this is driven by income. “At higher levels of income and education, there are minimal ethnic or racial differences in internet access or computer ownership” (Attewell 2001: 253). The exclusion that is inherent in collecting data from internet users is not a concern for my

study. The ASD/VL movement formed and mobilized via the internet. As parents went online looking for information on raising an autistic child, they found each other and started a movement. As such, the internet users are the individuals I am looking to study, making message boards an ideal site for data collection.

1.2.2.1 Gaining Access

I identified message boards through internet searches using the Google search engine with keywords like “autism,” “autism and vaccines,” and “autism mercury message boards” independently. Google is the most extensive search engine in use internationally and contains the largest index of URLs (Earl 2006). It is also the most popular search engine and, as such, it is the most efficient tool to use for locating message boards and websites. As Earl (2006: 366) states, “Google mimics the two processes by which web site visitors identify web sites: a) using a searchable index of websites, or b) following links from a known site.”

Yahoo Groups and Google Groups resulted in the most message boards with the largest member lists. To choose the message boards on which to post recruitment information, I developed the following inclusion criteria. First, all boards must have a description of appropriate message board content. This is to ensure that I posted to appropriate boards. Second, all boards must have active posting, meaning at least one post within 24 hours of the search. This was to make sure I did not post to a “dead” board that no longer has active members. In total, I recruited from 40 separate boards. I obtained a waiver of informed consent from the University of Pittsburgh IRB for this portion of my data collection.

Most of the boards and groups I visited required membership and an explanation of why I wished to join the group. I was forthcoming in my reason. My statement read, “My name is Margaret Kerr. I am interested in learning more about the autism community.” I was denied

membership from one group, though they did not give me an explanation. I then posted my recruitment letter (Appendix B) in the message board welcoming members to take the survey on my website or to email me independently. This method was utilized by Nip (2004) with successful survey response rates.

Of the 40 boards I recruited from, I only received three direct emails from participants questioning my intentions. The first was from the board moderator who wanted to know more about my methods and my research agenda. I kept my responses to these inquires concise and direct as possible, and while I personalized each one to the recipient, I used the same text in each response. The other two emails questioned my research agenda and asked if I had any ties to pharmaceutical companies. They also contained critiques of my survey, for example stating that some questions were biased or that I should add different questions. With each of these emails, I repeated the language in my recruitment letter citing that I was a doctoral student with no ties to pharmaceutical companies, and I was interested in learning more about people involved in the ASD community. I also invited them to talk with me more in-depth and complete the informed consent so that we could speak more about the topic. None of those who criticized my survey or questioned my purpose agreed to an in-depth interview.

1.2.2.2 The Survey

I found the available survey hosting sites insufficient for my research and co-designed my own survey hosting site along with a programmer, www.socsurveys.com. My home page included an introductory letter and invitation to participate. It also included links to information about me so that participants could verify *my* credibility. Since the questionnaire was in electronic form, viewable questions were answer-dependent. This meant that the respondent's answers dictated what question appeared next. This is beneficial for two reasons: 1) the survey is tailored to each

respondent so that he or she did not feel they were “wasting their time” with questions that do not pertain to him- or herself, and 2) the survey produces more honest results. For example, if the participant responded that they were familiar with the IOM reports on vaccine safety, they were subsequently asked questions pertaining to the reports; if the participant responded that they were not familiar with the IOM reports, questions pertaining to the reports did not appear for them to answer. This is important because the respondent may have had opinions about the IOM that are separate from the vaccine safety reports, and if they were able to view the related questions even after answering no, they might be tempted to go back and change their answer to yes so that they could answer the corresponding questions. The survey included other questions assessing general opinions, so for these specific “if yes, then” questions, I wanted to generate as accurate results as possible.

1.2.3 Data Set 2: In-depth Interviews

I conducted 14 in-depth interviews with ASD/VL activists, and 3 with officials involved in writing the IOM reports on vaccine safety. To contact these individuals, I collected contact information for key informants from movement website pages, activists who expressed interest in the online questionnaire, and referrals from other informants. Since this movement has largely organized on the internet, activists, leaders and officials live across the world. I therefore conducted most interviews over the telephone unless it was feasible to travel to meet in person.

All conducted interviews went smoothly, and everyone who was interested in participating was eventually interviewed. Throughout the course of asking questions, I maintained an even and objective perspective. I was sensitive to the interviewee but made careful effort not to insert my thoughts and opinions into the conversation. As discussed by Babbie

(2001) and notable qualitative researchers, interviewer bias can skew and completely change the nature of an interview. I remained conscious of this throughout all 14 interviews to ensure that my data reflected the thoughts and opinions of those interviewed. I used the tool of reflecting often. Reflection is the process of repeating back to the person what they have said. It shows that he or she is being heard and understood and helps build rapport. For example, many of those I interviewed were very passionate about their child's health, to the point of tears at times. If they would say, "I love my child so much. I would just about do anything for them, and those bastards at the CDC could care less" (Sue, telephone interview, 18 Sep 2007). To show that I had heard what she had said, but to ensure that I not introduce any bias I responded with "Yes, I hear you saying that you really love your child and are furious at the CDC." This method was successful in creating a comfortable interviewing tone and ensuring the interviewee that he or she was being heard. The entire interviewing process was extremely positive, so much so that many of those I interviewed added me to their mailing list and referred other ASD/VL activists to my survey.

1.2.4 Data Set 3: Artifacts

I assembled and analyzed artifacts from the ASD/VL movement. This data collection was continuous over the past three years. Artifacts included media and text made available through ASD/VL movement websites, message boards, and official IOM reports on vaccine and thimerosal safety, media coverage, pictures and testimonials from protests and rallies, and statements from medical associations. To capture websites relevant to the ASD/VL movement, I used Google as the search engine and used a combination of the following terms: mercury, Autism, ASD, vaccine. I compiled a list of the top 20 sites from each search and exclude repeats. I used Googlebot, a "web spider," to go from link to link and copy and save the most popular

sites. This method of building an internet dataset has been successfully used by other internet researchers such as Earl (2006).

The amount of information in this debate is staggering, and I have had to make strategic decisions on what information to include and what to ignore. First, I looked at the documents, reports, and articles made available by the largest ASD/VL movement websites. The largest websites were those that have been the most active in the debate, determined by how often they post new information, make public appearances, and organize events. Second, I looked at reports, articles, and documents on ASD and vaccines made available through the CDC and IOM. Finally, I looked at the public media representation and discussion of the debate. The topic has gained such media status and presence that to include all coverage is impossible. To restrict the sources, I came up with the following criteria: the media outlet must be either national in distribution or specifically targeted to the ASD/VL movement community. The media must be available online—this is both a strategic decision and one based on convenience. This movement has developed over the internet with most of the information sharing occurring through the sharing of links to articles from newspapers and magazines online. Finally, I have restricted my time frame from 2000 to 2009.

1.2.5 Analysis

The qualitative data was the “meat” of my analysis. I brought in descriptive statistics from my survey to add context. Throughout the analysis of the qualitative data, I used a grounded theory perspective. Grounded theory, developed by Glaser and Strauss (1967), emphasizes systematic data collection and coding. Grounded theory, as Babbie (2001: 284) states, “attempts to derive theories from an analysis of the patterns, themes, and common categories discovered in

observational data and attempts to combine a naturalist approach with a positivist concern for a ‘systematic set of procedures’ in doing qualitative research.” Using this perspective, the researcher follows three key guidelines: 1) step back and ask if what the researcher sees is in line with the reality of the data, 2) maintain an attitude of skepticism—always check theoretical concepts and terms against the reality of the data, do not assume they are a fit, and 3) follow the research procedures (Strauss and Corbin 1990: 44-46).

Grounded theory often involves the creation of strict coding schemes in order to create and maintain a high degree of reliability and validity through data analysis. Coding schemes are created through an iterative process that includes going from theory to data and back again so that all emergent themes and deductive themes can be organized into specific codes. This process allows for constant monitoring of how the data fits the theory and hopefully reduces researcher bias. The grounded theory approach was the most appropriate approach for this study because of its emphases on systematic coding which produces high reliability and validity. It allows the researcher to analyze emergent themes, while also coding for preliminary themes identified initially through a literature review.

To analyze the audio-recordings from the in-depth interviews, I used a direct-from-audio coding system. This system works in the following manner: I uploaded the audio from in-depth interviews into the program Atlas ti Qualitative Data Software Package (Weitzman 1999), and while listening to the audio, I applied the codes that are then fed into a database. This allows for a richer coding as I was able to code for affect and tone (e.g. concern, empathy, frustration, and anger) as well as content.

I devised a coding scheme through an iterative process in which I moved between theory to data repeatedly to ensure that I organized all emergent and deductive themes into specific

categories, which were then broken down into specific codes. A code was applied to each semantic unit. The boundaries of a semantic unit are often hard to define but easier to identify. As Markoff and Shapiro (1998: 77) state, although a semantic unit “cannot be defined rigorously enough to be programmed, it can, with measurable and acceptable reliability, be identified, isolated, and categorized by human coders by virtue of their natural language competence.” I defined my semantic units as “occurrences” that happen each time a topic is brought up or addressed by the respondent. To achieve more than one occurrence per audio, the interviewee had to leave the topic and then return to it again later in the interview without interviewer prompting. The advantage of coding in this manner is that it gives the coder more options for analysis and a richer, deeper coding. With this level of coding, I was also able to conduct frequency counts to show what topics interviewees focused on the most. It allowed me to collapse data, combine codes, recode into new codes, and create composites. My composite groupings derive from theory and are more abstract, while the individual codes are concrete and relate directly to each speech “utterance.” The differentiation between concrete and abstract codes follows Markoff and Shapiro’s (1996) conceptualization which states that abstract codes should be kept in the theoretical realm while concrete codes should reflect the semantic unit. Through the process of organizing my codes into composite categories (Appendix A), I was able to get a better idea of the issues that were important to the movement.

To analyze the textual artifacts, I also used Atlas ti and followed the same process of grounded coding. For my textual analysis, my semantic unit was one artifact. Within artifacts (e.g. web-pages, advertisements, articles, etc.), phrases were tagged with codes, but the unit of analysis remained the artifact. While this was a more abstract level of coding, it was better suited to the diverse artifacts I collected and analyzed.

Because of the limited number of interviews, I was able to code my entire dataset twice to ensure that I had developed the best codebook possible. I re-coded each audio-recording, first allowing for emergent themes and codes, adopting the open coding method. Once the initial coding was completed, I analyzed my codebook and removed codes that had only one or two occurrences, or I tried to incorporate the code into a broader code. For example, after initially starting with individual codes “frustration” and “anger,” I later combined the two into “strong emotions.” Additionally, the codes “activist,” “plan of action,” and “getting information out” were combined into the broader “activism” code. Once this work on the codebook was completed, I conducted the second level of coding the data.

1.2.5.1 Reliability

To assess the reliability and validity of my codebook, a second coder co-coded all 14 audio-recordings. My coding procedure was to code each occurrence of each code each time. This would be a large, time consuming, and expensive project for a second coder; therefore, I instructed my co-coder to code “present” or “absent” for each code in each audio recording. This is a less resilient test, but it is still effective in testing the overall validity of the codes. I trained my co-coder extensively on how to code the audio-recordings using the definitions of each code. Not all codes were used to conduct reliability. For example, codes that were strictly used as flags such as “good quote” or “demographic” were not included in the co-coding. In order to calculate reliability, I recoded my own coding into “present=1” and “absent=0” and built a matrix of my own and my co-coders data organized by audio-recordings and used the Cohen's kappa to calculate agreement (Cohen 1960). There are advantages and disadvantages to using the kappa. In doing so, I have forgone the ability to show agreement on the frequency of codes per audio-recordings, but I have retained the ability to show validity of the individual codes

themselves. With such a large codebook and the restraints of time, this was the best option. A kappa of .811 or higher was achieved on all codes. See Appendix A for a table of results.

2.0 THE MOVEMENT BEGINS

The following sections are organized chronologically and then thematically as many events happened concurrently. I found that there were several anchoring events in this debate, namely, 1) the Congressional hearings on vaccine safety, 2) the Immunization Safety Review Committee hearings and publications by the IOM, and 3) the release of the Simpsonwood Retreat transcript. In addition to these lynchpin proceedings were a number of integral events. Therefore, to add clarity to the unfolding of events, I first provide a timeline. Following the timeline is a summary of how and why vaccines came to be associated with causing ASD. Next is a review of the demographic data from my survey and in-depth interviews. I then move on to a discussion of the mobilization and organization of the first movement groups.

Table 2: Timeline of events

Date	Event
1930	Thimerosal first added to vaccines and other products as a bactericide
1982	Barbara Lo Fisher founds the National Vaccine Information Center
1985	Barbara Lo Fisher writes "Shot in the Dark" linking DPT vaccines and autism
1986	National Childhood Vaccine Injury Act establishes the National Vaccine Injury Court and the Vaccine Adverse Event Reporting System
1997	FDA Modernization Act includes a call for the review of all mercury-containing biologics
1998	Andrew Wakefield publishes his study in the Lancet linking MMR vaccines and ASD
1999	National Autism Association founded (Liz Brit/focus initially on MMR and vaccines)
1999	Unlocking Autism founded (initially with greater focus on MMR)
1999	Joint statement from the AAP and the Department of Health and Human Services stating some children may have received excess mercury through the administration of their vaccines per the CDC schedule
1999	AAP and the FDA and EPA jointly advised the vaccine manufacturers to remove thimerosal preservatives from childhood vaccines
1999	The U.S. House Government Reform Committee, chaired by Congressman Dan Burton, held the first of a several-year series of investigative hearings on vaccine safety issues
2000	SafeMinds founded
Jun-00	Simpsonwood Retreat
2001	Thimerosal is voluntarily removed from standard childhood vaccines in the US by pharmaceutical companies.
2001	"Autism: A novel form of mercury poisoning" by SafeMinds is published in the journal Medical Hypothesis.
16-Jul-01	Verstraeten T. Vaccine Safety Datalink (VSD) Screening Study and Follow-up Analysis with Harvard Pilgrim Data. Presented at (IOM Meeting) Thimerosal-Containing Vaccines and Neurodevelopmental Outcomes; 2001 Jul Cambridge, Massachusetts
2001	SafeMinds obtains Simpsonwood transcript

1-Oct-01	Immunization Safety Review Thimerosal-Containing Vaccines and Neurodevelopmental Disorders The Institute of Medicine concluded that the hypothesis, while not proven, is "biologically plausible" and called for further research.
11-Sep-01	Terrorist attack on the World Trade Center in New York City. In the name of national security, Congress passed legislation giving emergency powers to federal and state public health officials which included liability shields for drug companies and vaccine administrators
2002	The CDC and US Congress declared an autism epidemic and "declared war" on the disorder.
20-Feb-02	Immunization Safety Review Multiple Immunizations and Immune Dysfunction
30-May-02	Immunization Safety Review Hepatitis B Vaccine and Demyelinating Neurological Disorders
22-Oct-02	Immunization Safety Review SV40 Contamination of Polio Vaccine and Cancer
Nov-03	Verstraeten and the Vaccine Safety Datalink Team publish the Safety of thimerosal-containing vaccines two-phased study of computerized health maintenance organization databases in Pediatrics
Dec-03	Dr. Halsey publishes letter to CDC titled "Comments on Verstraeten et al. Safety of Thimerosal-Containing Vaccines in Pediatrics
2003	Immunization Safety Review Vaccinations and Sudden Unexpected Death in Infancy
2003	Immunization Safety Review Influenza Vaccines and Neurological Complications
2004	NoMercruy.org founded
2004	The British General Medical Council announced it was launching an inquiry into allegations of serious professional misconduct by Andrew Wakefield.
9-Feb-04	Immunization Safety Review Committee hearing
17-May-04	Immunization Safety Review Vaccines and Autism The IMO published the report rejecting a causal relationship between thimerosal containing vaccines and autism.
2005	Moms Against Mercury Founded
2005	Advocates for Children's Health Affected by Mercury Poisoning (A-CHAMP) founded
2005	Generation Rescue founded

2005	Robert F. Kennedy, Jr., publishes “Deadly Immunity” in Rolling Stone
2005	Evidence Harm by Kirby published
2005	Power of Truth Rally
2006	Scene of the Crime Rally
2006	Geiers submit article to Autoimmunity that is later retracted “The biochemical basis and treatment of autism Interactions between mercury, transsulfurations, and androgens”
2006	US Congress passed the Combating Autism Act
2006	WHO committee reaffirms that there is no evidence of toxicity in infants, children or adults exposed to thimerosal in vaccines.
2007	Vaccine Injury Court hears the case of Theresa and Michael Cedillo, the parents of 12-year-old Michelle Cedillo, who claim their child’s autism was caused by vaccines
2007	Autism Omnibus vaccine hearing begins hearing three test cases.
2007	Simpsonwood Remembered Rally
2008	Toxic Lies, Toxic Children Rally
2008	Green our Vaccines Rally
2008	Hannah Polling case. The DHHS settled outside of court with the parents of Hannah Polling. The DHHS did not state that vaccines were responsible for Hannah’s mitochondrial disorder or her autism. Instead the settlement conceded that the vaccinations may have aggravated her underlying disorder.
2008	Paul Offit publishes “Autism’s False Prophets”

2.1 AUTISM AND VACCINES: MAKING THE CONNECTION

There are many reasons why parents or guardians may choose not to vaccinate their child. For example, they may consider it an intrusion on or a violation of their civil liberties and rights as a parent. This was the primary argument for the first anti-vaccine movement organized by the Anti-Vaccination League of London which formed shortly after the passage of the Vaccination Act of 1853. The Act mandated infant vaccination (at the time smallpox was the only available vaccine) and levied monetary penalties for non-compliance. The League gained support throughout the second half of the 19th century, and in 1885, over 100,000 people assembled in London to rally against the Vaccination Act (Wolf and Sharp 2002).

More recent vaccine debates have centered on the stigma of certain diseases for which vaccines were developed, for example the hepatitis B vaccine and, more recently, the human papillomavirus (HPV) vaccine. Since both diseases can be transmitted through sexual activities, they carry the connotation that only promiscuous individuals are at risk of infection. This is not the case, and despite the great benefits these vaccines offer public health, some groups have reacted strongly against them, citing concerns that vaccinating children against sexually transmitted diseases will encourage them to engage in sexual activity (Fisher, Darrow, Tranter, Williams 2008). While controversy over the HPV vaccine is continuing, both hepatitis B and HPV vaccines are on the recommended schedule. Finally, the decision not to vaccinate is increasingly attributed to a fear that vaccines are unsafe and cause autism.

Connecting vaccines with autism became publicized when, in 1985, a woman named Barbara Lo Fisher claimed that her son began regressing developmentally after he received his pertussis vaccine (DTP) vaccine. Eventually, he was diagnosed with autism. Fisher went on to co-author a book with Harris L. Coulter called *A Shot in the Dark* (1991) which brought public

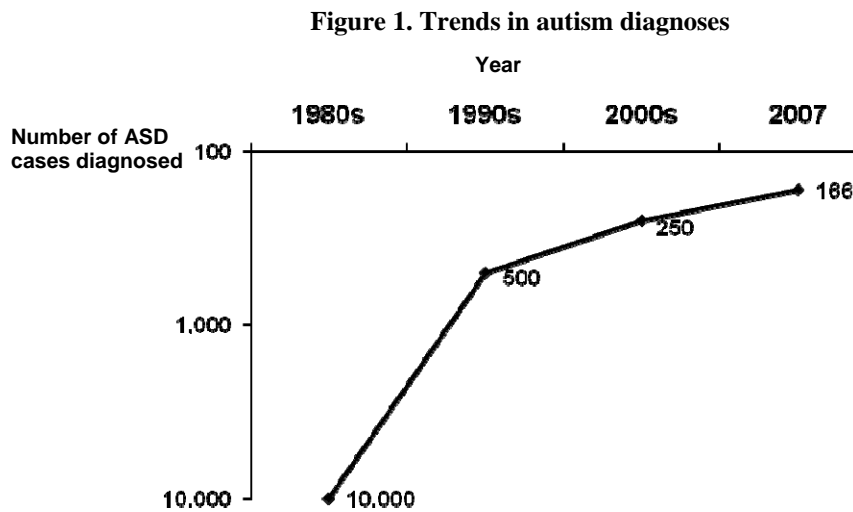
attention to the possible relationship between autism and vaccines. Adding support to the ASD/vaccine link is the work, and highly publicized and controversial life, of Andrew Wakefield, M.D.

Andrew Wakefield, a Canadian-trained surgeon, has become a central figure in the ASD/VL movement. His story begins in 1995 when he was approached by a parent of an autistic child with digestive problems. At the time, he was researching Crohn's disease, a disorder that causes inflammation in the intestinal tract. The parent who approached Wakefield, Rosemary Kessick, was head of Allergy Induced Autism, a group looking at the relationship of digestion, diet, and childhood behavior. The potential relationship between digestion and autism piqued Wakefield's interest, and he began his now infamous research leading to the controversial theory linking the measles/mumps/rubella (MMR) vaccination and autism. His paper, published in the *Lancet* in 1998 was titled "Ileal-lymphoid-nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children." The study only had 12 participants, 8 of whom he claimed started experiencing ASD symptoms after receiving the MMR vaccine. While the study stated explicitly that the link between MMR and autism had *not* been proven and at that point was just a theory that needed more analysis, Wakefield held a press conference and recommended that parents stagger the series of three shots by a year (one year for measles, the following year for mumps, and the final year for rubella).

Confidence in vaccination suffered greatly, so much so that Tony Blair (then Prime Minister of the United Kingdom) would not disclose whether or not he had vaccinated his own children, further contributing to the decreased faith in vaccine safety. Wakefield's cautionary press conference has been blamed for the drop of vaccination rates from 92% to below 80%, and the rates of confirmed cases of measles in England and Wales rose from 56 in 1998 to 1348 in

2008 (Deer 2009). Wakefield's study caused so much concern that the United Kingdom held a special meeting of the Medical Research Council to review the case. Amidst the controversy in 2001, Wakefield resigned from the Royal Free Hospital, stating “I have been asked to go because my research is unpopular.” His involvement with the ASD/VL movement was far from finished and will be further discussed as this story unfolds.

The connection of autism with mercury in vaccines was seen as related to the dramatic increase of children under the age of 18, not adults, diagnosed with ASD and the corresponding number of parents looking for answers. Throughout the past 25 years, the number of children in the US diagnosed with an ASD has grown exponentially: from 1 in 10,000 during the 1980s, to 1 in 500 in the 90s, 1 in 250 in 2000, and 1 in 166 as of 2007 (Figure 1) (National Immunization Program 2007, Kirby 2005).



The possible cause of this dramatic increase is highly disputed. It is widely assumed that at least a portion of the increase can be attributed to the changing, broadening definitions of ASD and a greater awareness on the parts of parents, doctors, and teachers of ASDs and their symptoms. While exactly how much of this increase is diagnostic in nature is disputed. The medical community largely accepts the fact that there is an *empirical* increase in actual incidence

of ASDs. Indeed, even CDC personnel have acknowledged it as “epidemic” (Kirby 2005, Simpsonwood transcript 2001).

Finally, the “connection” of autism, mercury, and vaccines came on the heels of a joint statement issued by the AAP and the Department of Health and Human Services (DHHS) in 1999 that revealed the overexposure of children to mercury in the form of thimerosal in vaccines. This discovery was made as a result of a congressional action in 1997 requiring the FDA to review mercury in drugs and biologics. Thimerosal is a 50% mercury solution that has been marketed as a preservative for vaccines since the 1930s. It is more economical to produce multi-use vials of vaccinations than to have single use vials. Thimerosal’s purpose is to kill any bacteria that exists or may be introduced through multiple needle sticks into a vial of vaccine. Thimerosal contains ethylmercury, which is different from the more toxic methylmercury that is found in fish. Pharmaceutical companies agreed to voluntarily remove thimerosal from vaccines by 2001. As of 2009 thimerosal is still used in flu shots but is absent from most childhood vaccines.

The joint statement and Wakefield’s press conference had brought attention to the issue and media outlets were beginning to cover the debate. Between 1981 and July 7, 1999, (the day before the joint statement was issued), 290 articles were published that contained the word “autism,” and only two of which contained both the words “autism” and “vaccine.” From July 8, 1999, to February 8, 2009, 950 articles contained the word “autism,” and 118 contained both the words “autism” and “vaccine.” This is an astounding increase in coverage. I conducted a similar search using *Time* magazine and found equally astonishing results (Table 3).

Table 3: Frequency of articles covering autism and vaccines

New York Times articles covering ASD and vaccines			Time Magazine articles covering ASD and vaccines		
	"autism"	"autism" and "vaccines"		"autism"	"autism" and "vaccines"
1981 - July 9 th , 1999	290	2	1948- July 9,1999	77	0
July 10 th 1999- Feb. 8 th 2009	950	118	July 10- Feb. 8 th 2009	147	35

2.2 THE MAKINGS OF A MOVEMENT

Fueled by Barbara Lo Fisher’s book, Wakefield’s article, the DHHS joint statement, and increased media coverage, parents and guardians of children with ASD began mobilizing and forming organizations focused on the ASD/vaccine link. The following section describes early organizing efforts. As I weave statistics from my survey and in-depth interviews into the remainder of the thesis, I first provide the necessary contextualizing demographic information of my population. Following the demographic information, I provide profile descriptions of some of the most prominent organizations that were involved with the debate early on. These groups have had significant impact on the development of the ASD/VL movement through their dissemination of information, mobilization of parents, and organizing research.

2.2.1 Demographic Data

2.2.1.1 Survey

A total of 205 individuals completed the online survey. When asked if they had a child or loved one with an ASD, 83% responded ‘yes, child’, 6% reported ‘loved one’ and 8% reported ‘no’ (Table 4). Furthermore, 78% reported being the primary caretaker of someone with an ASD (Table 5). When asked to estimate how many decisions require first taking into consideration the special needs associated with ASD, 70% reported most or all decisions made in an average week (Table 6). Finally, 56% reported that most or all of their time during a week is spent managing ASDs (providing or seeking care, managing behavior, etc.) (Table 7). This data shows the survey respondents consisted of a majority of parents who were primary caretakers and illustrates the extent to which their lives are dedicated to and embedded in issues related to ASDs.

Table 4: Relationship of survey respondent to ASDs

	Frequency	Valid Percent
No	17	8%
Yes, Child	170	83%
Yes, Loved One	12	6%
No Answer	6	3%
Total	205	100

Table 5: Percent of respondents that are the primary caretaker of someone with an ASD

	Frequency	Valid Percent
No	37	18%
Yes	159	78%
No Answer	9	4%
Total	205	100

Table 6: Percent of decisions during a week that are influenced by ASDs

	Frequency	Valid Percent
No decisions	13	6%
A few/some decisions	39	19%
Most/All Decisions	144	70%
No Answer	9	4%
Total	205	100

Table 7: Percent of time during a week spent managing an ASD

	Frequency	Valid Percent
Some/A Little	64	31%
All/Most	120	59%
None of my time	13	6%
No Answer	8	4%
Total	205	100

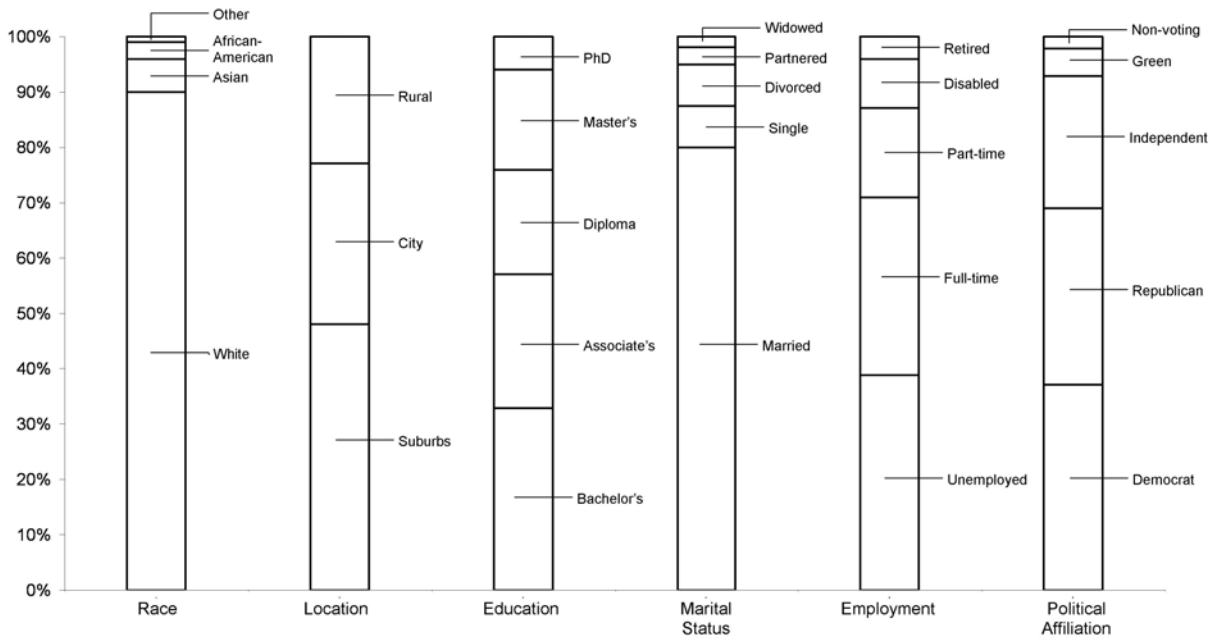
Of respondents who knew about the suggested link between vaccines and ASD, a majority were introduced to the idea through the internet (40%) or heard about it from a friend (17%). Only 3% heard about the link from their doctor, 4% from the newspaper and 6% from the television (Table 8).

Table 8: Source of introduction to the ASD/VL debate

Source	Frequency	Valid Percent
Doctor	7	3%
Friends	35	17%
Internet	82	40%
Newspaper	10	5%
Television	13	6%
No Answer	58	28%
Total	205	100

The demographic characteristics of my online survey respondents (Figure 2) place a majority in the white (90%), female (85%), middle to upper class, well educated, and financially stable sector of society.

Figure 2. Demographics of in-depth interviewees



The age range was clustered, with 76% being between the ages of 31 and 50. Ninety percent of respondents report their race as white, 1% identified as African American, 3% identified as Asian, and 96% report they were non-Hispanic. The majority of respondents lived in the suburbs (48%) with the remainder split between city and rural living (29% and 23% respectively). The respondents were well educated: overall, 76% had an associate’s degree or higher. More specifically, 19% held their associate’s degree, 33% had a bachelor’s degree, 18% had a master’s degree, and 6% had a PhD. About 40% of my population did not work outside the home. This is most likely due to the fact that they are primary caregivers and that caregiving is their “full- time job.” Thirty-two percent stated that they were employed full-time, 16% were employed part-time, 9% were disabled, and 4% were retired Most of the survey respondents were married (80%), and only 7.5% reported they were divorced. Three percent reported living with their partner, 2% were widowed and 7.5% were single. The distribution across political

lines was fairly evenly split with 36% reporting they were Democrats, 31% were Republican, 26% were Independent or other, 5% were the Green Party, and 2% stated they do not vote.

In terms of income (Table 9), this population was comparable to the national median income of \$50,233.00 (U.S. Census Bureau 2000). The two highest ranking categories were \$20,000 to \$40,000 (21%) and \$60,000 to \$80,000 (18%).

Table 9: Income distribution of survey participants

Income	Percent
\$0-19k	7%
\$20-39K	21%
\$40-59K	11%
\$60k-79K	18%
\$80-99K	10%
\$100K-129K	15%
\$130K-159K	6%
\$160K+	12%
Total	100

2.2.1.2 In-depth Interviews

Table 10 describes the demographic characteristics of my in-depth interviewees.

Table 10: Demographics of in-depth interview respondents

Name*	Age	Race	Relationship to child	Education Level	Work Status	Marital Status	Geographic Location	Political Party**	Notes
Joyce	62	W	Grandmother	Bachelor's	PT	M	Midwest suburbs	None	
Barb	35	W	Mother to son	Bachelor's	PT	M	Suburbs	None	Extremely active in her church
Clare	52	W	Mother to daughter	Bachelor's	Self	P	Southwest suburbs	None	
Desiree	30	AA	Mother to son	Bachelor's	FT	U	Midwest Major city	None	
Elizabeth	41	W	Mother to son	PhD in social science	SAH	M	West coast suburbs	D	
Hope	37	W	Mother	Master's	SAH	M	Northern Midwest suburbs	None	Head of her state's largest autism vaccine group
Jane	32	W	Mother to daughter	Master's student	ST	P	Rural northeast	D	Started her own group dealing specifically with girls and autism
Diane	33	W	Mother	Bachelor's	FT	M	Large city on the east coast	None	
Kara	43	W	Mother to son	Bachelor's	PT	M	East coast suburb	D	
Renee	40	W	Mother to son	Bachelor's	FT	M	Midwest suburbs	None	
Ryan	42	W	Father to son	Bachelor's	FT	M	East coast suburbs	D	
Sue	46	W	Mother to son	Bachelor's	SAH	M	Rural Midwest	None	
Tova	48	W	Mother to son	Bachelor's	SAH	M	Southern suburbs	I	
Veronica	39	W	Mother to son	Bachelor's	PT	M	East coast suburbs	D	

Abbreviations: W – white, AA – African-American, PT – part-time, FT – full-time, SAH – stay-at-home parent, M – married, P – partnered, U – unmarried, D – democrat, I – independent

* The names of my in-depth interviewees have been changed at their request.

** All interviewees stated they would vote for candidates who shared their views on ASD regardless of party.

2.3 MOVEMENT GROUP PROFILES: EARLY BIRDS

The following section profiles the most influential and active ASD/VL movement groups. Collectively, I argue, these groups comprise the ASD/VL movement. There are differences among the groups. For example, some are more focused on the connection between ASD and mercury while others focus on the link of MMR and ASD. But they all share several dominate goals that link them together under a movement umbrella; 1) they all believe vaccines play a causative role in ASDs; and 2) they identify the U.S. federal government, the AAP, and pharmaceutical companies as responsible for perceived injury due to vaccines. My research also shows that ASD/VL movement groups used the same strategies described in EHSM literature: forming around a politicized illness identity, producing their own scientific research, collaborating with scientific experts, and forming political alliances to challenge Western mainstream medicine and the U.S. federal government on issues of ASD causation, treatment, and responsibility.

All of the ASD/VL movement group founders that are profiled below are impressive. Through conducting a content analysis of ASD/VL movement group web pages, I found several common themes. First, they all were founded by parents or caregivers of children affected by ASDs. Social movement theorists McAdam et al. (2001) discuss three different pathways to leadership in a social movement organization: 1) a charismatic person *from* the group or base; 2) an intellectual from a different background; and 3) an oligarchic or routinized social movement leader, or someone who is distant from the group. As will be illustrated below, all of the ASD/VL activists that have been most involved came to this debate because they are passionate about the issue. They are charismatic and incorporate their personal stories into their mission. In fact, all but one (www.NoMercury.org) of the ASD/VL movement group websites contain the

personal histories of the group founders and their experience in raising a child with ASD on their home page.

ASD/VL movement groups go to great lengths to be seen as credible and legitimate. In fact, they follow standard protocols of professionalization—building a membership base, appointing leaders and advisory boards, building committees, hosting conferences, forming mission statements, and outlining specific goals and agendas. Through the following ASD/VL movement group profiles, I document the road to building a movement that seeks to achieve legitimacy and authority. Each group highlights their activities and makes attempts at mobilizing the resources necessary for an effective challenge. They have a board of directors filled with diverse professionals, parents, and celebrities, the majority of whom are parents of children with an ASD. They have scientific advisory boards containing credentialed professionals in health, law, and research. They work with public relations experts to manage their public image and get their message out. Further, they have alliances with state and federal politicians.

Finally, and perhaps most importantly, the founders of these groups and most of their members can be considered lay experts because they fund, design, and/or support independent research that they are either directly involved in themselves or do in collaboration with credentialed experts and professionals. ASD/VL movement webpages are full of quotes from founders criticizing studies, discussing research they sponsor or endorse, advising on treatment options, and sharing stories about their kids. This supports Brown et al.'s (2004b: 64) predication that ESHMs activists “transcend the scope of normal social movement activity by moving in-between lay and expert identities.”

2.3.1 National Vaccine Information Center and Barbara Lo Fisher

<http://www.nvic.org/>

The first organization movement group discussion starts with Barbara Lo Fisher's National Vaccine Information Center (NVIC). Barbara Lo Fisher co-founded NVIC in 1982. It is the oldest, "largest consumer organization advocating the institution of vaccine safety and informed consent protections in the mass vaccination system. NVIC is responsible for launching the vaccine safety and informed consent movement in America in the early 1980s" (www.nvic.org). NVIC is supported through donations, membership fees, and grants from philanthropic (non-federal, -corporate, or -state) foundations. Since its inception, it has been concerned with all things vaccine related, particularly informed consent. NVIC approaches vaccines from a civil liberties perspective. A quote on NVIC's home page from Fisher states: "If the State can tag, track down and force citizens against their will to be injected with biologicals of unknown toxicity today, there will be no limit on which individual freedoms the State can take away in the name of the greater good tomorrow." NVIC states that they are "pro-education, pro-science and pro-informed consent." They promote research, provide support to those injured through vaccines, and act as a watchdog over pharmaceutical companies and the government. In fact, the website's tagline is "America's Vaccine Safety Watchdog" (www.nvic.org).

Fisher advocates each person's right to choose whether or not to vaccinate, and that choice must be an educated choice. For Fisher, this means calling on the government and pharmaceutical companies to report ingredients and safety testing to all subjects. NVIC focuses on the broader issues related to vaccine. For example, they ask, "Is vaccination effective, safe and necessary for individual and public health and should all Americans be forced to use government recommended vaccines?" (www.nvic.org) NVIC is set apart from many of the other

organizations which focus solely on the outcomes of vaccinations and their safety. Instead, NVIC is taking a step back and asking whether vaccines are necessary to begin with.

NVIC has achieved great success in increasing the standards and accountability required of the government and pharmaceutical companies in regards to vaccine safety. For example, Fisher worked with congress in writing the National Childhood Vaccine Injury Act of 1986. This monumental piece of legislation set up the National Vaccine Injury Compensation Program (NVICP) and laid down the legal responsibilities of vaccine manufactures and providers, including 1) documentation and reporting of health problems following vaccines both in the patient medical record and with the federal Vaccine Adverse Events Reporting System, 2) providing risks and benefits to subjects, and 3) tracking lot numbers for vaccinations. Additionally, Fisher and NVIC also pushed government and manufactures to create a purified pertussis vaccine and an inactivated polio vaccine. Fisher has also served on multiple panels and committees including the Advisory Commission on Child Vaccines, the National Vaccine Advisory Committee, and the IOM Vaccines Safety Committee.

Fisher has been an active and prominent voice in the ASD/VL movement, and her website has acted as a jumping-off point for many organizations formed around ASD and vaccines. NVIC is also responsible for hosting the largest international conventions on vaccine safety. In the past, these conventions have provided a rich environment for ASD/VL movement group mobilization. They have served to bring parities together from across the nation and from different backgrounds. Indeed, it is where many future ASD/VL movement group founders, politicians, and collaborators met.

The National Vaccine Information Center program has remained consistent and active in their mission. While most ASD/VL groups evolved in response to the controversy, NVIC's

broad, all-inclusive agenda allows the organization to move in and out of vaccine related issues while remaining dedicated to education and informed consent. NVIC is a backbone of any vaccine safety related issue and a powerful advocate for informed consent in general. In fact, Fisher expanded her mission regarding the right of informed consent to the military where soldiers often do not have a choice in whether or not they want to receive a vaccine.

Fisher co-founded the Military and Biodefense Vaccine Project (MBVP) of the NVIC. The MBVP is sponsored by the NVIC and is dedicated to increasing the “the safety and effectiveness of vaccines that are being developed for routine use in the military or for use by military personnel and civilians in response to bioterrorism threats” (www.nvic.org). A primary aim of the MBVP is to inform the public and soldiers of “the benefits and risks of military and biodefense vaccines as well as federal and state legislation which authorizes mandatory use of experimental bioterrorism vaccines in military and civilian settings without voluntary, informed consent” (www.nvic.org). The founding of this sister organization represents the dedication and commitment Fisher has to the issue. It also illustrates how vaccine issues stretch beyond the concerns for child safety.

NVIC remains active and is currently organizing its fourth conference, scheduled for October 2-4, 2009, with the theme “Show Us the Science and Give Us a Choice.” The first three conferences were held in 1997, 2000, and 2002. The first conference was a landmark conference, bringing in over “500 doctors, scientists, health officials, lawyers, ethicists, journalists, and parents from 34 states and five countries to the U.S. Capitol to present new scientific data about vaccines and diseases and discuss the biological mechanism of vaccine-induced injury, death, and chronic illness” (www.nvic.org). This was one of the largest consumer-organized health conferences in history. The upcoming conference is designed to provide a “public platform for

examining the science, policy, law, ethics and politics of vaccination and holistic healthcare alternatives for maintaining wellness. It will also be a place for state and national vaccine safety and informed consent advocacy training and networking” (www.nvic.org). The conference includes a chartered bus ride to Washington, DC, to visit legislators and Obama administration officials.

2.3.2 Defeat Autism Now

Defeat Autism Now! (DAN!) is not an ASD/VL movement group but is an important collaborator and ally to the ASD/VL movement. DAN! is part of the Autism Research Institute (ARI), which was founded in 1995 when 30 physicians and scientists came together to discuss how to best diagnose and treat autism. The mission statement for DAN! is as follows: “Defeat Autism Now! is dedicated to the exploration, evaluation, and dissemination of scientifically documented biomedical interventions for individuals within the autism spectrum, through the collaborative efforts of clinicians, researchers, and parents.” DAN! takes the often contested and disputed perspective that recovery from autism is treatable through biomedical interventions. They take a step back from coming out and stating that it is possible to cure autism, but they do believe in treatment that removes different symptoms of autism. In 1996, ARI created the first version of the DAN! Protocol, which included biomedical assessments, and biomedical treatment protocols. The DAN! Protocol has continued to evolve and includes treatment procedures like chelation therapy (the leaching of heavy metals from the body), the use of dietary supplements, administration of B-12 shots, and adjustments in diet. The DAN! Protocol is not endorsed by mainstream medical practitioners, nor is it covered under medical insurance.

The ARI is part of a larger network of organizations that have joined together under a

Memorandum of Understanding. These groups include SafeMinds, Generation Rescue, The Shafer Autism Report, Talking About Curing Autism, the National Autism Association, Unlocking Autism, Autism One, and Treating Autism. All of these groups diverge from the mainstream treatments and protocols to varying extents and present a powerful counterforce to the reigning medical hegemony. All of the ASD/VL activists know about DAN! providers (as will be discussed at length in later sections) and view them as an alternative to utilizing mainstream medical doctors.

ARI and DAN! practice contested medicine and collaborate with ASD/VL movement groups and parents in the pursuit of scientific knowledge linking vaccines to autism, and proving ASDs are biomedically treatable. While the DAN! protocol is contested and not endorsed by mainstream medicine, to the lay public, the alliance of movement groups with doctors lends legitimacy to their arguments due to the cultural authority associated with the word “doctor” (Freidson 1970). This supports McCormick’s (2007: 618) finding that “collaborating with experts provides a space in which lay perspectives are legitimized and, therefore, used as a counter to official expert discourse.” DAN! provides this space and more. They give needed credibility to the parents’ claims, they give parents access to resources (lab testing, knowledge, access to research infrastructure including IRB’s and administrative support), and finally they provide a network of doctors trained in the controversial medical interventions who treat thousands of children with ASD. The role of DAN! medical providers will be discussed in more detail in a later chapter dealing specifically with medical providers.

2.3.3 National Autism Association

<http://www.nationalautismassociation.org>

The National Autism Association (NAA) was founded in 1999 by Liz Brit, and 6 other parents of children with autism that they believe was caused by vaccines. They additionally share the perspective that autism is treatable and even reversible through biomedical interventions. Brit became involved with the ASD/VL movement after her son was diagnosed with ASD and she read Wakefield's article in the *Lancet*. She began researching the link herself and returned to law school to further educate herself on the legal aspects of the issue. In addition to being a co-founder of the NAA, she helped found the Coalition for SafeMinds and started the Medical Interventions for Autism, which focused solely on the link between inflammatory bowel disease, immune disorders, and vaccines. In 2001, she went to work full time under U.S. Representative Dan Burton (R-IN) on the Committee on Government Reform where she reviewed data from the private and public sector (government and industry) on vaccine safety and conducted interviews with the FDA and CDC. Finally, she helped author the report to Congress titled "Mercury in Medicine – Taking Unnecessary Risks." Indeed, Brit was one of the most active workers in the ASD/VL movement until she passed away in 2005 after a tragic car accident.

The following co-founders of NAA represent the collaboration of "full-time moms" with impressive credentialed professionals, a common theme in ASD/VL movement groups: Robert Krakow and James A. Moody are both practicing attorneys of criminal and civil cases related to disabilities. Other founding members include Rita Shreffler, who holds a master's degree in library science; Lori McIlwain, who works in radio and television; Leslie Davidson, a biomedical researcher, Adrienne Rousseau, who works in a country club; Jo Pike, a full-time mom; and Wendy Fournier, a web designer. Fournier designed the NAA website which is by far the most developed of all the movement groups that I profile. Second only to Generation Rescue (profiled below) in terms of commercialism, the NAA website contains an online store where

viewers can buy supplements, art, and other autism related items. The website also posts advertisements for its sponsors, including several health and nutritional supplement developers that create and market supplements and treatments targeted towards children with autism.

The NAA board of directors and officers cover the spectrum of professions and expertise, which allowing them to achieve such high recognition and secure numerous sponsors. Also contributing to the organization's high profile status is the fact that celebrity radio personality Don Imus and his wife Deirdre sit on the board of directors. On his blog, Don Imus does not argue directly for or against the ASD/VL hypothesis; however, it is obvious through what he chooses to talk about on his show and in his blog and the guests that he interviews that he does support the ASD/VL hypothesis (The Imus Times). For example, he has given extended airtime to those who support the causal link and has been critical of big pharmaceutical companies and the CDC. Because of these efforts, he is seen as an ally in the debate. His wife is also an important ally not only through her involvement with NAA but also through her founding of the Deirdre Imus Environmental Center for Pediatric Oncology, which focuses on identifying, controlling, and preventing exposures to environmental hazards (www.nationalautismassociation.org).

The NAA has evolved along the same path as other ASD/VL movement groups, expanding their focus from mercury alone to include other environmental triggers over the past five years of the debate. While the NAA does provide information on the political and legal battles related to autism, their focus is primarily on educating parents and the public that autism is treatable and to increase research about biomedical interventions and causation. It is clear from their website that the organization believes vaccines are responsible for autism. They discount genetic theories stating, "It is important to note that in the past 10 years of looking for the autism

gene, none has been found, which leads many researchers to believe that something TRIGGERS the gene to turn on and cause autism” (www.nationalautismassociation.org). They believe that the trigger is vaccines and other environmental toxins. The NAA website includes a page on research projects. They are currently funding a project to study the effects of mercury exposure in the brain. They also have a detailed research plan to study autism and the gastrointestinal tract. This research trajectory stems from the work of Wakefield and his discovery of “autistic enterocolitis.” Wakefield is listed on the web page as a consultant for the study, while Arthur Krigsman, MD, Steve Walker, PhD, Jeffery Segal, MD, and other support staff at Wake Forest University are listed as researchers. The budget listed for their research plan is \$150-200K; however it is not stated whether they have these funds or need to raise them. Viewers are invited to donate to the research fund.

2.3.4 Unlocking Autism

www.unlockingautism.org

Founding member and president of Unlocking Autism, Shelley Hendrix Reynolds, became involved in the ASD/VL movement after her son was diagnosed with ASD in 1998. In 1999, she came together with Nancy Herndon Cale and Jeana Smith to form Unlocking Autism. Since then, Reynolds has been highly active through her appearances in front of Burton’s reform committee, her interviews with the *New York Times*, *Chicago Tribune*, CNN’s “Talk Back Live,” and the “Montel Williams Show.” Her interviews have primarily concerned the role of the MMR vaccine in causing autism rather than thimerosal. In 2005, she was named Person of the Year by *Spectrum Publications*, an autism-focused magazine, and in 2006 they named her one of the

“Top 10 Faces of Autism.” She also serves on the Department of Defense Autism Spectrum Disorder Research Program and is the director of State Advocacy Relations with Autism Speaks, a national autism awareness organization. Reynolds also notes that she is an active member of her church. Nancy Herndon Cale, vice president and co-founder of Unlocking Autism, also highlights her involvement with her church and community and youth ministries. She became involved after her grandson was diagnosed with an ASD in 1998, and her profile states, “Although she had never used a computer, she was determined to find help for Wynn. She obtained a hand-me-down Mac and logged on to AOL for the first time. Now, Nancy Cale is one of the most recognized members of the autism community on the internet” (www.unlockingautism.org).

Unlocking Autism is one of the oldest ASD/VL movement groups, though it does not aggressively advertise their belief that vaccines are the cause of ASDs. Members state simply that they believe vaccines could be one of many environmental triggers causing autism but that they believe there is also a genetic component. They also do not strongly assert the ability to “cure” autistic children, stating instead that it is “a lifelong disorder in most cases.” This places them on the more moderate end of activism as most other groups fight to have biomedical treatments of ASDs covered by insurance. While they do stress the importance of becoming politically involved and provide information on how to do so, their primary focus is on educating and supporting entire families of those with ASDs (www.unlockingautism.org).

As suggested in the last part of their mission statement mentioning a “spiritual outlet,” Unlocking Autism contains many Christian overtones. This point is woven through their web page most likely because the founding members emphasize their role in their churches and the importance of their faith. Unlocking Autism is entirely volunteer based, they view their activities

as “missions”, and they feel they have a responsibility to help the autism community and families.

2.3.5 SafeMinds

www.coalitionforsafeminds.org

The group that came forward early as proponents of the ASD/VL movement and who have achieved the most public recognition is the Coalition for Sensible Action for Ending Mercury-Induced Neurological Disorders (www.SafeMinds.org). Their mission statement is as follows:

The mission of the Coalition for SafeMinds is to end the devastation to human health and function from early life exposures to manmade sources of mercury, the second most toxic substance on earth. Our mission will be achieved through scientifically based internal and externally-funded research, increased awareness, and advocacy in the public policy and legal arenas (www.SafeMinds.org).

SafeMinds is the brainchild of two women: Lyn Redwood, a nurse practitioner, and Sallie Bernard, a Harvard graduate and market research entrepreneur. Both women have children with autism that they believe was caused by mercury in vaccines. Both women have been active in the autism community since their children's birth (Redwood's in 1993, and Bernard's in 1987), joined all the associations they could find, and explored all available ASD treatment options (Kirby 2005). Both took extremely active roles in educating themselves about the causes and treatments of ASDs. Bernard became involved with Cure Autism Now (CAN), an alliance of parents and researchers dedicated to finding a cure, not just treatment, for autism. Bernard was very impressed and intrigued with the idea of parents funding their own research (Kirby 2005)

and was excited about getting involved in activism for autism. She stated, “I’m going to be an agitator...I signed up for autism. You know, activism, advocacy, tearing down the halls of government. That sort of thing” (Kirby 2005: 24). She also connected with Albert Enayati, a chemical engineer with an autistic son. They later co-author a paper on the similarities of autism and mercury poisoning.

Their board of directors includes lawyers, doctors, nurses, and parents, all volunteers (although they pay for consultants), and all of whom have family members or friends they claim have been harmed by mercury in vaccines. SafeMinds became the most vocal proponent of the ASD/VL movement. Their achievements include: presentations at multiple hearings on vaccine safety hosted by Congress and the IOM, writing and publishing the now infamous article “Autism: A rare form of mercury poisoning,” (discussed below), building an alliance with the Geiers – a father and son team who have played an integral role in the movement, obtaining records from the U.S. federal government on vaccine safety through the Freedom of Information Act, and building one of the largest online resources for all things ASD and vaccine related. To date, they have funded over \$750,000 in research focusing on mercury and neurological outcomes, which they argue places them as the largest non-profit organization funding mercury-and-autism-related research (www.safeminds.org). The SafeMinds website is current and appears to be updated regularly as they continue to publish criticism, critiques, and highlight news articles related to autism, mercury, and any government actions related to autism and neurological disease in general. SafeMinds is also the focus and inspiration for Kirby’s book *Evidence of Harm* (2005).

Kirby’s book *Evidence of Harm* is itself an artifact of the ASD/vaccine debate. The way he has written about the events is important because it is perhaps the most well read

documentation of the ASD/VL movement. His book was referenced and quoted by all of my in-depth interviewees and is featured on all ASD/VL movement group websites. His book also spawned the creation of the Evidence of Harm (EOH) Yahoo newsgroup, the largest online group of ASD/VL activists. The message board is so big, in fact, that it has co-sponsored and helped organize rallies against the CDC and AAP. Kirby has achieved celebrity status. Every parent activist I interviewed trusts his judgment and his accounts. His book is one of the cornerstone documents of the ASD/VL movement. His book continues to draw attention: SafeMinds highlighted on their web page that they are excited about the news that “Kirby's book has since been opted for a movie by Participant Productions, which has produced such films as An Inconvenient Truth, Syriana, and North Country. This will bring the history of the politics of mercury in medicine and autism to an even wider audience” (www.safeminds.org).

A large part of SafeMinds’ mission, in addition to funding research, is aggressive surveillance “and vigilance on misinformation about this issue in the media” (www.safeminds.org). Their website is a “one stop shop” destination for anyone seeking information on the debate and its history. They focus on synthesizing and commenting on research related to autism in the hopes of informing the public and altering scientific agendas. Indeed, educating legislators and government representatives is one of their main goals. On their website, they state that their organization was founded

to raise awareness, support research, change policy and focus national attention on the growing evidence of a link between mercury and neurological disorders such as autism, attention deficit disorder, language delay and learning difficulties. Our mission is to end the health and personal devastations caused by the needless exposure to mercury, one of the most neurotoxic substances on earth.

We serve the scientific, health, governmental and advocacy communities by compiling and synthesizing the best evidence on

the mercury-human health issue. Our goals are to shape scientific thinking and priorities, alter medical practices to consider toxicants in health, raise public awareness and demands for action, and become an educational resource for regulatory and legislative bodies. We use a multifaceted approach in an effort to accomplish our goals (www.safeminds.org).

Bernard collaborated with Albert Enayati, an engineer by training and highly involved father of an autistic son. Enayati first began investigating thimerosal in 1998 after reading Barbara Lo Fisher's work and calling vaccine producer Merck & Co. to find out what components went into vaccine solutions. He was not able to find out what was in thimerosal then, but after reading the joint statement from the DHHS and AAP, his interest was again piqued and he began researching ethylmercury, the primary ingredient in thimerosal. He researched the effects of mercury poisoning and found that there were many similarities between mercury poisoning and autism. Together he and Bernard continued to work towards bringing awareness about the possible link between thimerosal and vaccines to the public. They also wanted the scientific community to take note. In a statement that highlights the degree of strategy Bernard knew was required to mount an effective campaign in the scientific arena, she stated, "These researchers will never give us the time of day, and no one will do anything about this unless we come out with something in their own language that speaks to the scientific world in a way they are used to being spoken to" (Kirby 2005: 60).

Bernard, Enayati, and Redwood went on to write and later publish in 2001 "Autism: A unique form of mercury poisoning" in the journal *Medical Hypothesis*. Before publication, it was distributed widely on the internet. The article detailed the similarities between ASD and mercury poisoning. They described behavioral similarities such as loss of speech, social withdraw, reduced eye contact, sleep disturbances, repetitive behavior, and biological similarities such as low sulfate levels, immune and neurological abnormalities (Bernard, Enayati, Binstock,

Redwood 2001). This article has become the foundation of the ASD/VL debate and, according to the authors, the article “was and remains recognized as a cornerstone document to the discourse on medical mercury exposure and toxicity and its effects on health” (www.safeminds.org). While the authors submitted the article first to the most respected journals, including the *Lancet* and *JAMA*, it was rejected and highly criticized by the AAP who argued point by point how mercury poisoning was *not* similar to ASD (Kirby 2005). This did not stop SafeMinds from disseminating their research by translating their findings into an accessible and relevant format for other parents and making it available over the internet. It is still one of the most widely cited sources as evidence of a link between thimerosal and autism.

The publication of this article illustrates a number of issues. First, it mirrors McCormick’s findings from the Environmental Breast Cancer Movement and supports the tenants of the EHSM framework that states activists recognize that they need more than their own intuitive ideas and experiences to levy a challenge that would be seen as credible. To overcome their lack of credible evidence, they go about collecting it themselves. The quote from Bernard about coming out “with something in their own language that speaks to the scientific world” (Kirby 2005: 60) shows her confidence that they could design and undertake their own independent research that would have to be treated as authoritative and legitimate.

In the production of their article, Bernard, Enayati, and Redwood used the same tools as their opposition, i.e. the scientific method. The scientific method is an example of a “boundary object” in EHSM (Brown et al. 2004b: 64). When an EHSM claims that its popular epidemiology is as legitimate as mainstream science, it is trying to cross the boundary into the scientific field. However, transcending the boundary from activist to lay expert is not easy, nor always possible. As Hirschorn (2006) notes, the validity of a claim is often judged by the status

or authority of the claimant. So while it may be easy to move from scientist to activist, it is more difficult to move in the other direction, as evidenced by the rejection of the article from mainstream medical journals and the criticisms from the AAP.

With the dissemination of the SafeMinds article and Wakefield's article, along with the joint statement from the DHHS, mobilization of the ASD/VL movement was well underway. ASD/VL groups were quickly growing in strength and numbers. The next step was reaching out to political allies.

3.0 MOVING TO THE FRONT LINES

As Gieryn (1999) pointed out, the constructions of science are spatially and temporally bound. The borders of scientific credibility have been constructed and reconstructed throughout this debate in deliberate and strategic ways. Gieryn (1999: 23) describes, “the border and territories of science will be drawn to pursue immediate goals and interests of cultural cartographers and to appeal to the goals and interests of audiences and stakeholders.” The following three sections investigate those spaces where the boundaries of legitimate science were negotiated and examine how ASD/VL movement groups mobilized and used resources, including information and data, to challenge mainstream medicine. In the first section I deal with the congressional hearings sponsored by Rep. Dan Burton. Next I take an in-depth look at the involvement of the IOM and their first report on thimerosal in vaccines and ASDs. Following the discussion of the IOM I present an analysis of the historical and famous Simpsonwood retreat and the article by Robert F. Kennedy, Jr., that set the ASD/VL movement on fire. I have identified these three sections as anchors of the ASD/VL movement as they provided cultural space around which ASD/VL activists organized and built their movement.

3.1 BURTON’S HEARINGS ON VACCINE SAFETY

In response to the growing concerns over vaccine safety, Rep. Dan Burton, then chairman of the House Committee on Government Reform, held a series of open hearings from 1999 to 2004 to

discuss the safety of vaccines and their relation to autism. Burton became involved after his grandson Christian was diagnosed with autism. He believes this was due to vaccination and states so explicitly in his opening statement to the Committee on Government Reform at the hearing on “The Status of Research into Vaccine Safety and Autism”:

I might have been like many of the officials within the public health community – denying a connection – had I not witnessed this tragedy in my own family. I might not have believed the reports from parents like Scott and Laura Bono, Jeff Sell, Jeff and Shelly Segal, and Ginger Brown, who came to me with pictures, videos and medical records. I might have been like so many pediatricians who discounted the correlation between vaccination and the onset of fever, crying, and behavioral changes. Because both of my grandchildren suffered adverse reactions to vaccines, I could not ignore the parents’ plea for help. I could not ignore their evidence.

My only grandson became autistic right before my eyes – shortly after receiving his federally recommended and state-mandated vaccines without a full explanation of what was in the shots being given. My talkative, playful, outgoing healthy grandson Christian was subjected to very high levels of mercury through his vaccines. He also received the MMR vaccine. Within a few days he was showing signs of autism (Burton 2002).

Burton’s statement includes themes expressed by most parents, most notably the “right before my eyes” statement that forms the bases of most ASD/VL activists’ beliefs about causation. His focus on his own personal experience and his validation of other parents’ experiences made him a strong ally in the movement. Burton’s hearings, largely attended by ASD/VL activists, were successful in bringing attention to the debate on a national level and increasing political as well as parental involvement.

Burton argued strongly against the use of thimerosal in vaccines and became the most involved politician fighting with the ASD/VL movement. In 2000, Burton wrote a letter to the DHHS asking the FDA to recall all vaccines containing thimerosal in a letter stating, "We all

know and accept that mercury is a neurotoxin, and yet the FDA has failed to recall the 50 vaccines that contain thimerosal and every day that mercury-containing vaccines remain on the market is another day HHS is putting 8,000 children at risk” (Burton 2000a). Throughout the hearings, Burton reiterated his opposition to the CDC’s proposal for a national registry system that would track children’s immunizations and issue vaccination due date reminders to parents. Burton stated that this was an affront to the public’s privacy and that “these systems would track people from birth to grave, something the public opposes.” He further stated that “we are going to be beating on this issue as long as I am chairman of this committee” (Burton 2000b).

The ASD/VL groups along with scientists, doctors, parents, and activists from all sides of the debate were in attendance at these hearings over the course of the years. The hearings were especially popular among activists and parents who felt they were finally able to voice their concerns and theories. For example, parents were allowed to speak of their experiences and beliefs about the cause of their child’s autism, as Burton had done in his own opening statement. Parents would often bring their children with them to the hearings as “evidence” of the harm they perceived to be caused by vaccines, a practice also seen at rallies and protest and one that would become highly criticized as exploitive by ASD/VL opponents. The practice of parents and guardians of children with ASD standing up and stating their beliefs that vaccines caused or triggered their child’s ASD reasssembled victims giving of testimonials of abuse against oppressors rather than presentation of scientific analysis, which is what the hearings were initially intended to do. For parents, however, their testimonies were truth, and they wanted their experiences and observations to carry the same weight as any scientific evidence.

Burton’s hearings were extremely emotional and received wide coverage. For example, an article titled “On Autism's Cause, It's Parents vs. Research” published in the *New York Times*

(Harris and O’Conner 2005: paragraph 1) covered one of the hearings and included an excerpt that was exemplary to the exchanges:

Kristen Ehresmann, a Minnesota Department of Health official, had just told a State Senate hearing that vaccines with microscopic amounts of mercury were safe. Libby Rupp, a mother of a 3-year-old girl with autism, was incredulous.

"How did my daughter get so much mercury in her?" Ms. Rupp asked Ms. Ehresmann after her testimony.

"Fish?" Ms. Ehresmann suggested.

"She never eats it," Ms. Rupp answered.

"Do you drink tap water?"

"It's all filtered."

"Well, do you breathe the air?" Ms. Ehresmann asked, with a resigned smile. Several parents looked angrily at Ms. Ehresmann, who left.

Ms. Rupp remained, shaking with anger. "That anyone could defend mercury in vaccines," she said, "makes my blood boil."

Burton’s hearings were effective in pressuring the government, specifically the CDC, to ask the IOM for an official investigation into the ASD/VL hypothesis. Because the hearings took place over the course of four years, their role in the ASD/VL debate and their significance in the political arena is interwoven with the story of the IOM hearings, SafeMinds, and the Geiers as discussed below.

3.2 THE INSTITUTE OF MEDICINE

Burton’s hearings, along with the joint statement from the DHHS, succeeded in bringing attention to the ASD/VL debate and pushing the CDC to move forward with organizing an official plan of action which was to appeal to the IOM to investigate what was quickly becoming the most controversial and gripping issue ever to face pediatric medicine. The IOM is one of the United States National Academies, part of the National Academy of Science. It is non-profit and

non-governmental, and its sole purpose is to provide independent, unbiased, and objective advice and service to the American people. Its researchers are all volunteers, experts in their fields, and subject to rigorous peer review. The IOM is a highly honorific and esteemed organization. It is the exemplar in medical research and, as such, is held to the most rigid standards. The IOM conducts reviews and research for a variety of reasons, including at the request of the CDC. In 2000, the CDC contacted the IOM and requested they conduct an in-depth review of autism and vaccines. In response, the IOM built the Immunization Safety Review Committee and planned projects that would review scientific research specifically addressing vaccines and autism. The IOM planned a course of seven publications dealing with vaccine safety. The topics were as follows:

1. October 1, 2001: Immunization Safety Review: Thimerosal - Containing Vaccines and Neurodevelopmental Disorders
2. February 20, 2002: Immunization Safety Review: Multiple Immunizations and Immune Dysfunction
3. May 30, 2002: Immunization Safety Review: Hepatitis B Vaccine and Demyelinating Neurological Disorders
4. October 22, 2002: Immunization Safety Review: SV40 Contamination of Polio Vaccine and Cancer
5. March 12, 2003: Immunization Safety Review: Vaccinations and Sudden Unexpected Death in Infancy
6. October 6, 2003: Immunization Safety Review: Influenza Vaccines and Neurological Complications
7. May 17, 2004: Immunization Safety Review: Vaccines and Autism

The reports that garnered the most attention from ASD/VL activists were the October 2001 report on thimerosal and the 2004 report on vaccine and autism. These two reports are the source of much contention, hope, and controversy in the ASD/VL movement. To examine the attitudes and events happening “behind the scenes” of the IOM’s Immunization Safety Review Committee, I interviewed several individuals involved. None of my sources allowed me to identify them in my work due to the threats and harassment they have already received for being

part of the committee and the potential for further retaliation. Their identifying characteristics have been changed to maintain anonymity, and they are referred to Eric, Beth, and Natalie.

The first report on thimerosal in vaccines and autism received mostly positive support from ASD/VL parent groups. The major findings that are most often cited from this report include confirmation that some children have died as a result of vaccines, though not due to mercury, and that the theory that mercury could be linked to neurodevelopment disorders is biologically plausible, but that there is simply not enough data to know for sure (www.iom.edu). The finding of biological plausibility came after the review of data from the Vaccine Data Safety link dataset. The Vaccine Safety Datalink (VSD) project, developed in 1990 to monitor immunization safety, is a collaborative effort between CDC's Immunization Safety Office and eight large managed care organizations (MCO). The VSD project includes a linked database with individual level data on vaccination (vaccine type, date of vaccination, concurrent vaccinations), medical outcomes (outpatient visits, inpatient visits, urgent care visits), birth data, and census data. Preliminary analysis screened for a relationship between thimerosal containing vaccines and neurodevelopment outcomes. The results revealed a potential link, but the result was inconclusive (Verstraeten 2001). This finding contributed to the IOM's report of biological plausibility – a concept that gave many ASD/VL activists, who were just beginning to organize through groups like SafeMinds, hope of finding a cause and possibly a cure. Eric, one of my IOM interviewees, reported that after the first report, the ASD/VL movement groups seemed to trust the IOM's findings. Eric stated, “We don't know, but they seemed happy that we said it was biologically plausible” (telephone interview, 15 Nov 2007). He reported that during the first review of research on ASD and vaccines, there was a general feeling of coming together and collaborating to try and find the truth, a feeling of partnership. Beth similarly noted, “After the

first report there was a huge relief on the part of parents” because they thought the tide was going in their direction or towards finding a definitive link between vaccines and ASDs (personal interview, 16 Oct 2007).

At the time (2000-2001), the most visible and vocal vaccine safety advocate was Barbara Lo Fisher. Eric reported Fisher was pleased after the first report and had said, “finally someone acknowledges that vaccines can kill babies.” Eric stated that the finding that some children have died as a result of vaccines (not due to mercury) was “scientifically not a big deal. Symbolically it was important because it dealt with the issue of death” (telephone interview, 15 Nov 2007). For the parents, it promoted trust in the IOM because they had acknowledged that vaccines can be harmful, which is what Fisher and fellow vaccine safety advocates had been trying to prove. Fisher was well known to the IOM and CDC from her work with the Congressional committee in writing the 1986 legislation. This previous collaboration contributed to a willingness on Fisher’s part to work together during the first hearings held by the IOM immunization safety committee, as Eric reported, “Barbara had a more compromising, ‘let’s work within the system’ [attitude]” (telephone interview, 15 Nov 2007). Eric stated that this compromising and collaborative attitude changed in the years following the first IOM report due to the information revealed by SafeMinds and the controversy stemming from the VSD link project, and the Simpsonwood Retreat.

3.3 SIMPSONWOOD

The Simpsonwood Retreat took place on June 7-8, 2000, at the Simpsonwood Retreat Center in Norcross, Georgia. The transcript of this retreat was not released until SafeMinds obtained it,

along with other previously unavailable information, through the Freedom of Information Act (FOIA) in 2001. SafeMinds had originally applied for the FOIA to gain access to the VSD data to investigate the possible link between vaccines and ASD. They had learned about the dataset after reading an abstract presented by Robert Davis and then CDC staff member Thomas Verstraeten to the AAP and the Pediatric Academic Societies in Boston in May of 2000 (Verstraeten 2001). The abstract, which calculated exposure to thimerosal through vaccination, was titled, “Infant exposure to thimerosal-containing vaccines and risk for subsequent neurological and renal kidney disease.” The abstract concluded there is no associated risk between thimerosal and neurological disease (Verstraeten 2001). SafeMinds, however, wanted to look at the data themselves and because the data was collected under the U.S. federal government and not a private institution, the public had a right to view it. SafeMinds won their appeal through the FOIA, and all information related to the VSD data and projects on vaccine safety were released to the ASD/VL group, including the Simpsonwood Retreat transcript. This transcript is critical for a number of reasons: 1) after SafeMinds posted it on their website and circulated it to other movement groups, it spurred even greater mobilization of ASD/VL groups who felt they had been denied critical information and data concerning their children; 2) it represents efforts to democratize science and supports Gieryn’s (1999) theories on how the boundaries of science are temporally and spatially constructed; and 3) it provides evidence of the uncertainty that characterizes this debate and how difficult it is to address public health concerns without scientific certainty.

3.3.1 Presenting the Case

The Simpsonwood Retreat was organized by Dr. Walter Orenstein, then the director of the National Immunization Program (NIP) at the CDC, to bring professional experts together to review the preliminary data analysis of the VSD database. The analysis of the VSD data was prompted by the DHHS joint statement in 1998 announcing that the mercury levels in vaccines were in excess of what was deemed safe by the Environmental Protection Agency (EPA). Additionally, preliminary analysis of the data had apparently raised concern of a potential relationship between thimerosal and neurological diseases, as Orenstein stated in his opening, “analysis to date raises some concerns of a possible dose response effect of increasing levels of methylmercury in vaccines and certain neurological diagnoses. Therefore, the purpose of this meeting is to have a careful scientific review of the data” (Simpsonwood transcript, 2001:11). It was made clear to the group that it was *not* a policy-making meeting but a meeting to have professional experts from different fields review the data and voice their opinion, which would be weighed by the Advisory Committee on Immunization Practices (ACIP). According to the Simpsonwood transcript, 50 experts from all areas of academia and government were present at the retreat including 11 consultants from the CDC, many members of the NIP, and representatives from (then) Smith Kline Pharmaceuticals and Wyeth Pharmaceuticals. The main speakers of the retreat besides Orenstein were Roger Berneir, Associate Director for Science in the NIP, Dr. Frank DeStefano, the project director for the VSD, and Verstraeten, who was at the time an NIP employee and had run the preliminary analysis.

The Simpsonwood transcript is a total of 286 pages. It is an exciting read, and when read as a standalone document or without the subsequent releases from the same group of people, the reader could possibly interpret that the government had indeed found a dose-response

relationship between vaccines and neurodevelopment delays and disorders. The data under analysis that day consisted of about 2 million children between the ages of 0 and 6 from four large health maintenance organizations. They conducted very careful analysis of the data and did indeed find a dose-response relationship between vaccines and several neurological outcomes.

Verstraeten stated:

We have found statistically significant relationships between the exposures and outcomes for these different exposures and outcomes. First, for two months of age, an unspecified developmental delay, which has its own specific ICD-9 code. Exposure at three months of age, tics. Exposure at six months of age, an attention deficit disorder. Exposure at one, three and six months of age, language and speech delays which are two separate ICD-9 codes. Exposure at one, three and six months of age, the entire category of neurodevelopmental delays, which includes all of these plus a number of other disorders (Simpsonwood transcript, 2001:40).

Interestingly, the same analysis that produced the results quoted above about general neurological problems also included a separate analysis looking only at autism as an outcome. That analysis did *not* show a statistically significant dose-response relationship specific to autism, something that is never highlighted by the ASD/VL activists. As Verstraeten stated, “This is the result for autism, in which we don't see much of a trend except for a slight, but not significant, increase for the highest exposure. The overall test for trend is statistically not significant” (Simpsonwood transcript, 2001:42).

Verstraeten stated that he has three hypotheses to explain the relationships they found. His first hypothesis was that it could be parental bias, meaning that parents who choose to have their children vaccinated are more likely to have their children evaluated for ASD. Multiple attendees pointed out, however, that this hypothesis does not hold up, since vaccination is mandated in most schools and daycares. His second hypothesis was simply that he does not

know. It could be various confounding variables or a bias in the data that he has not yet come across. Finally, he hypothesized that there could indeed be a relationship between the vaccines and the neurological outcomes.

The transcript also reveals how much was not known about the relationship between vaccines and health outcomes because there were many issues not addressed in preliminary analysis. For example, Verstraeten acknowledged that the analysis they had run was far from final because there were so many confounding variables and uncertainties that had yet to be accounted for. He further stated that he trusted that the group of experts assembled knew how to interpret the results and how to contextualize the findings; that is, that correlation does not equal causation and that there is still much unknown (Simpsonwood transcript, 2001). Indeed, in addition to highlighting the preliminary structure of the analysis and the need to control for confounding variables in the future, many in attendance warned that there was a the lack of knowledge or research addressing how thimerosal affects the body and interacts with other metals and additives. They also discussed the fact that it is difficult to accurately test for negative health outcomes when the diagnoses for neurological disease are not well defined and are often subjective. The analysis was dependent on International Classification of Diseases, 9th Revision (ICD-9) codes, but even ICD-9 codes that concern neurodevelopment delays can be ambiguous. These issues of uncertainty contributed to the concern over controlling the information discussed, as Bernier stated:

Let me just reemphasize if I could the importance of trying to protect the information that we have been talking about. As many of you know, we are invited here. We have asked you to keep this information confidential. If we could, consider these data in a certain protected environment. So we are asking people who have done a great job protecting this information up until now, to continue to do that until the time of the ACIP meeting. So to

basically consider this embargoed information (Simpsonwood transcript, 2001:113).

After the presentation by Verstraeten, most of the transcript includes experts trying to find better ways to analyze the data in order to get a more accurate idea of what, if anything, was happening. Dr. Philip Rhodes, a statistician for the NIP, was the most vocal about what the dataset could and could not show and was very adamant about stating that, with diagnoses that contain a great deal of “medical uncertainty,” it is difficult to come to any definitive findings, especially during the first round of analysis. Rhodes made many recommendations for future analyses. Suggestions included strictly controlling for how the diagnoses were made by including only children diagnosed by specialists rather than primary care physicians. Other suggestions included more narrowly defining which diagnoses were included in the analysis, i.e. breaking up the umbrella category of neurological delay into specific neurological outcomes.

The fact that the discussion was dominated by addressing limitations to the study and suggestions for better analysis is important to note because it does highlight the fact that the data presented at the Simpsonwood Retreat were preliminary, a point that is often overlooked by ASD/VL groups. The point of the retreat was to get feedback on how to progress with analysis. In fact, many of the problems and recommendations for correction brought up by Rhodes and other attendees were addressed and accounted for in the follow-up analysis, from selection bias to differences between medical care coverage to parental bias.

3.3.2 Where Do We Go From Here?

Following Verstraeten's presentation of the potential link between vaccines and neurological delays and the discussions of the serious limitations of the analysis, the group discussed how to handle the potential fallout of these findings. As Dr. Robert Brent states:

The thing that concerns me the most, those who know me, I have been a pin stick in the litigation community because of the nonsense of our litigious society. This will be a resource to our very busy plaintiff attorneys in this country when this information becomes available. They don't want valid data. At least that is my biased opinion. They want business and this could potentially be a lot of business (Simpsonwood transcript, 2001:191).

Brent expressed further legal concerns due to the difficulty associated with presenting scientific evidence in the court room; specifically that credible scientists will always err on the side of caution and rarely state absolutes because rarely, if ever, are there absolutes in science. He observed:

The medical/legal findings in this study, causal or not, are horrendous, and therefore it is important that the suggested epidemiological, pharmacokinetic and animal studies be performed. If an allegation was made that a child's neurobehavioral findings were caused by thimerosal-containing vaccines, you could readily find a junk scientist who would support the claim with "a reasonable degree of certainty." But you will not find a scientist with any integrity who would say they refute the data that is available. And that is true. So we are in a bad position from the standpoint of defending any lawsuits if they were initiated and I am concerned (Simpsonwood transcript, 2001:229).

As Brent predicted, the data presented during the Simpsonwood Retreat has caused a legal tsunami. After SafeMinds heavily circulated the document throughout the ASD/VL movement groups, parents and lawyers were more than ready to start building court cases against the federal government. In July 2002, the National Vaccine Injury Compensation Program (NVICP) formed

a Special Masters Panel of three judges to handle the thousands of claims coming in relating autism and vaccines. Today about 5,000 court cases are pending hearing in what is now called the Omnibus Autism Hearings.

Following the discussion of legal ramifications, the transcript ended with the attendees discussing what to do next. They decided to conduct two polls: 1) to determine whether or not more research should be conducted into the possible relationship between mercury and neurodevelopmental disorders, and 2) to determine attendees' level of concern from 1-6 (Simpsonwood transcript, 2001). The fact that a vote was needed highlighted the investigational, exploratory nature of this conference and that the findings presented were not conclusive or final. All attendees voted that more research needed to be done, though there was disagreement on the second vote of concern which will be addressed below. ASD/VL activists cite the fact that those in attendance voted for more research as evidence that the retreat attendees knew something was "going on" and kept it from the public. Reading the transcript, it is clear this is actually not the case. They called for more research not because they believed there was a link but because they were not convinced there was an association between vaccines and neurodevelopmental disease; however, they felt the issue was so important that it warranted more research. Dr. Paul Stehr-Green, an epidemiologist, summed up the sentiment of most of the experts there that day stating, "These preliminary results are not compelling, but the implications are so profound that the lead should be examined further" (Simpsonwood transcript, 2001:179). What followed is a meaningful exchange that the opposition has never highlighted:

Brent: So the reason for further investigation is not really from the data themselves? It's not on the strength of the data?

Stehr-Green: Not on the strength, no. They are intriguing, but certainly not compelling (Simpsonwood transcript, 2001:179).

The attendees struggled with how to voice both their concern for the plausibility of the relationship between vaccines and disease and its potential ramifications as well as their concern over what the data were actually saying. This is because of the seriousness of this issue and the concern over how it would be translated into both public opinion and public policy. Attendees were instructed by Orenstein that this retreat was *not* about public policy, but policy implications proved impossible to avoid, illustrating the inherently political nature of research. For example during the retreat, Dr. Bill Phillips from the American Academy of Family Physicians asked Verstraeten to express the findings from a public health impact perspective. Verstraeten refused to do so, instead he stated:

I have been a bit reluctant to get into such types of calculations. I think in lieu, the first place the whole face of this study was just to produce a signal, and what you are asking now is to extrapolate this to a public health level, which I have always been reluctant to do. I think in the first place that is giving credit where it is not due, and in the second place, it is giving more accuracy to this data than what they really have (Simpsonwood transcript 2001:146).

Yet policy implications continued to come into the discussion as the consequences of a potential link between vaccines and disease were horrendous. Dr. Dixie Snider was particularly explicit regarding policy relevance:

As someone was talking about what are the attributable risks, there are tremendous policy implications for this. Not only as the issue was brought up with compensation, and we haven't heard from John Clements, but for global immunization efforts and so forth. But I think we have to be very, very careful that we got it right when we decide to make a policy call on this (Simpsonwood transcript, 2001:155).

The second poll of attendees sought to quantify the level of concern raised by the data presented at the retreat. Attendees were asked to rate their level of concern from 1 to 6, this

proved to be difficult as attendees disagreed over what “concern” meant—did it mean concern over the accuracy of the data, concern over the importance of the issue, concern that would translate into an aggressive call for more research, or concern that would translate into immediate policy changes and government issued warnings? This resulted in one of the more interesting dialogues of the meeting between Roger Bemier, Susan Ellenberg, Orenstein, and David Oakes.

Bemier: Let me stop for a minute because I am trying to think about the point that you are raising, Walter, and it seemed that it wasn't helpful to just hear about the level of concern because to interpret that, it could have multiple repercussions. It could mean that it is concern, therefore that concern needs to be translated into a policy action or it means that the concern is that you don't think the evidence is strong, and therefore it is not worth doing more research. I mean just to measure people's level of concern without trying to get a handle on what does that operationally mean, I don't think is really helpful. So the reason we put this question this way was to operationalize what was meant by the signal. And likewise by the second question, it was to operationalize it by expressing it in terms of what you thought about how much this supported a causative relationship or not.

Ellenberg: I may be jumping the gun, but one of the ways you could frame it is the level of concern sufficient to have an urgent and immediate research plan to address the question. And the other one is the level of concern sufficient to instigate a chain of policy? I know that's jumping. The best way of measuring the magnitude of concern as opposed to measuring it related to causation, which I don't think anybody would be able to say that they know.

Bemier: They don't have to know, they just have to render. The way the question was written is that you render an opinion about the evidence as it exists. Does it or does it not support a causal relation? It is not a yes or no question, it is just that how much do you feel it does support it?

Ellenberg: But I think in terms of quantitative concern would at least may be able to determine what kind of action you can take.

Orenstein: I think you are talking about two qualifications. One is what is the level of concern of the need for action? I agree, I think I

would be shocked if everybody went around the room and said I'm just not sure. May be, but I think the issue is what is the level of concern.

Bernier: But what will that mean, Walter, if after this meeting everyone goes around and says I have a level of concern and it's high. What are you going to do?

Oakes: The other side to this is these data are now out. I mean they may not be public, but they will be. So this data exists, and then we can't go back to the state where this duty has not been done, so there is a need to understand the data we have. And that might be the way I would frame it. A better understanding of the results that we have (Simpsonwood transcript, 2001:186-7).

As the experts weighed in on their level of concern and thoughts about the presentations, it was clear that even among the attendees there were vastly different ideas about what the next steps should be (regardless of the data, particularly because it was unclear what exactly the data were saying). On the scale from 1 to 6, 1 being not a large concern, 6 being extreme, the average of all those present was 1.8. The opinions ranged from unimpressed to extreme concern. The group was unanimous in calling for more research, and, except for Dr. Bill Weil, unanimous in stating there was not enough evidence to support a finding of a causal relationship. However, one doctor, David Johnson, a state public health officer in Michigan and member of ACIP, voiced what many were probably thinking that day and what parents likely think when they read the transcript:

Then here comes an opinion, well it is all is [sic] opinion, but it expresses a favor, so I think it relates to what Dr. Bemier is trying to derive here. This association leads me to favor a recommendation that infants up to two years old not be immunized with thimerosal-containing vaccines if suitable alternative preparations are available. I do not believe the diagnoses justifies compensation in the Vaccine Compensation Program at this point. I deal with causality, it seems pretty clear to me that the data are not sufficient one way or the other. My gut feeling? It worries me enough. Forgive this personal comment, but I got called out at

eight o'clock for an emergency call and my daughter-in-law delivered a son by C-section. Our first male in the line of the next generation, and I do not want that grandson to get a thimerosal-containing vaccine until we know better what is going on. It will probably take a long time. In the meantime, and I know there are probably implications for this internationally, but in the meanwhile I think I want that grandson to only be given thimerosal-free vaccines (Simpsonwood transcript, 2001:199).

This quote, not surprisingly, is used among ASD/VL activists, and for many parents it is all they need to read to make their decision not to vaccinate their children. Part of what makes this quote so powerful is that Johnson takes the issue into the personal, “my child, my family” space, when most of the attendees at the retreat kept the discussion in purely abstract, scientific, and epidemiological space. Johnson’s statement, along with the struggle over how to quantify and define concern, highlights an important point – if a group of 50 doctors who are experts in the field have a hard time determining what is happening and what should be done, how should the general public deal with it? This is exactly the reason why efforts were made to keep the documents and discussion of that day private until more was known, not out of a desire to hurt or defraud the public, but because Simpsonwood attendees wanted to provide the public with a clear picture and a straight answer, something they were very far away from being able to accomplish.

Finally, at the close of the retreat, Dr. John Clements of the Expanded Program on Immunization for the World Health Organization, Geneva, was invited to share his thoughts on the research and proceedings. His comments are prophetic, and because of their weight, I have quoted them in their entirety.

Thank you, Mr. Chairman, I will stand so you can see me. First of all I want to thank the organizers for allowing me to sit quietly at the back. It has been a great privilege to listen to the debate and to hear everybody work through with enormous detail, and I want to

congratulate, as others have done, the work that has been done by the team. Then comes the “but.” I am really concerned that we have taken off like a boat going down one arm of the mangrove swamp at high speed, when in fact there was not enough discussion really early on about which way the boat should go at all.

And I really want to risk offending everyone in the room by saying that perhaps this study should not have been done at all, because the outcome of it could have, to some extent, been predicted and we have all reached this point now where we are leg hanging, even though I hear the majority of the consultants say to the Board that they are not convinced there is a causality direct link between thimerosal and various neurological outcomes.

I know how we handle it from here is extremely problematic. The ACIP is going to depend on comments from this group in order to move forward into policy, and I have been advised that whatever I say should not move into the policy area because that is not the point of this meeting. But nonetheless, we know from many experiences in history that the pure scientist has done research because of pure science. But that pure science has resulted in splitting the atom or some other process which is completely beyond the power of the scientists who did the research to control it. And what we have here is people who have, for every best reason in the world, pursued a direction of research. But there is now the point at which the research results have to be handled, and even if this committee decides that there is no association and that information gets out, the work has been done and through freedom of information that will be taken by others and will be used in other ways beyond the control of this group. And I am very concerned about that as I suspect it is already too late to do anything regardless of any professional body and what they say.

My mandate as I sit here in this group is to make sure at the end of the day that 100,000,000 are immunized with DTP, hepatitis B and if possible Hib, this year, next year and for many years to come, and that will have to be with thimerosal-containing vaccines unless a miracle occurs and an alternative is found quickly and is tried and found to be safe.

So I leave you with the challenge that I am very concerned that this has gotten this far, and that having got this far, how you present in a concerted voice the information to the ACIP in a way they will be able to handle it and not get exposed to the traps which are out there in public relations. My message would be that any other study, and I like the study that has just been described here very

much.[sic] I think it makes a lot of sense, but it has to be thought through. What are the potential outcomes and how will you handle it? How will it be presented to a public and a media that is hungry for selecting the information they want to use for whatever means they have in store for them? I thank you for that moment to speak, Mr. Chairman, and I am sorry if I have offended you. I have the deepest respect for the work that has been done and the deepest respect for the analysis that has been done, but I wonder how on earth you are going to handle it from here (Simpsonwood transcript, 2001:249).

Clement's fears did indeed unfold into reality much to the dismay of those in attendance. As he predicted, the data, analysis, and words in this transcript have been manipulated and used to serve the needs of who is quoting it. I have read the whole Simpsonwood transcript multiple times. The transcript can be interpreted differently: the ASD/VL groups highlight only those sections that state there is a significant relationship between vaccines and negative outcomes; they ignore the bulk of the 262-page transcript that is filled with scientists emphasizing what they *do not know*. Nearly every page has a professional expert stating that until they know more about a multitude of variables, nothing can be said definitively. Themes of uncertainty and skepticism dominated the retreat discussions. The public, however, links uncertainty with fear, a point that many of the attendees acknowledged. But quotes from this transcript should not be considered on their own, outside of the full text. It is often forgotten that this transcript is not a book or an article; it was a conversation, a dialogue between people. For this reason, I have not included any of the specific science discussed because it is possible to go through the 250+ pages and pull quotes that support whatever hypothesis one chooses. What we can discern from this transcript is how a group of people came together to try and understand a potentially horrendous public health disaster that could potentially lead to the return of previously controlled infectious disease if trust in vaccine safety is lost.

The issue of uncertainty comes to the forefront during this retreat, and how science is an imperfect practice. We see how difficult it is to make a decision when there is not enough evidence. We also see an example of Gieryn's (1999) discussion of science happening in a specific time and place as professional experts came together to negotiate the meaning of data and how it should be utilized. Finally, the public availability of this transcript and the summary reports that have been circulated through the ASD/VL movement groups represents the efforts of the ASD/VL activists to democratize science as they sought and won access to restricted territories. The publication of the Simpsonwood Retreat transcript by ASD/VL movement groups gave birth to a whole new wave of mobilization and attention. Aiding in bringing attention to this document was Robert F. Kennedy, Jr.'s article "Deadly Immunity" published in *Rolling Stone*.

3.3.3 Robert F. Kennedy, Jr.

In 2005, Robert F. Kennedy, Jr., published "Deadly Immunity: Robert F. Kennedy, Jr., investigates the government cover up of a mercury/autism scandal" in *Rolling Stone* magazine. His article spawned a wave of controversy and concern and led to massive mobilization by ASD/VL activists. While his article was not published until after the second IOM hearing, I will discuss it here as it directly relates to the Simpsonwood Retreat.

Kennedy is an environmental lawyer. He received a degree in American history from Harvard in 1976, his JD from the University Of Virginia School Of Law, and an LLM from Pace University School of Law. His work has primarily been in the area of environmental awareness and energy conversation, and in 2005, he choose to get involved in the ASD/VL debate. I read Kennedy's article before I read the Simpsonwood transcript and my immediate reaction was disappointment in the federal government for holding such a secret meeting. After reading the

transcript myself, my opinion of Kennedy's article changed drastically as I found it to be misleading. The article was sensationalized for a number of potential reasons: first, for the status and fame that comes with writing a controversial and inflammatory article. Second, it was printed in *Rolling Stone* magazine, where readers expect a good story – hardly a bastion of scientific knowledge or even cutting edge investigative journalism. Third, Kennedy may have purposefully sensationalized the events to bring attention to a debate he felt passionate about. Kennedy's article told a good story rather than presented facts. He began his article painting a picture of top government officials meeting “at the isolated Simpsonwood Conference Center in Norcross, Georgia... held at this Methodist retreat center, nestled in wooded farmland next to the Chattahoochee River, to ensure complete secrecy.” (2005:1) This extreme distortion set up an “us versus them” mentality, which is unfortunate when an issue is so contentious and significant. He further implied that this conference would have been a public event in the past but that this time the choice was to keep it closed, which was not the case. To expect a first-time meeting of this kind to be open to the public would ensure that nothing would be accomplished and discussion would dissolve into posturing and confusion. All those present at Simpsonwood were invited because they had necessary experience and knowledge in relevant subject areas. They were professionally socialized into the mainstream medical/scientific paradigm. Through reading the transcript, it is obvious they were all familiar with the scientific process. For example, the conversations regarding significance and control groups, toxicology, and epidemiology were understood by all without preamble. They were all working from the same map with the same language. It was important that everyone there understood the conversation, the methods, and the theoretical perspectives surrounding the data under consideration so that the most informed decision on how to interpret and move forward with the dataset could be reached. It is also

apparent from the transcript that advanced expertise in biostatistics was necessary to understand the presentation much less to recommend or advance additional analyses. Moreover, with a dataset this large, it is easy to come up with statistically significant findings that are not meaningful. For these reasons, it is absurd to think this meeting should have been a public hearing.

Whether for journalistic flair or because he truly believed it, Kennedy interpreted all cautions stated by professional experts during the retreat as the attempt to hide findings. “The officials and executives at Simpsonwood spent most of the next two days discussing how to cover up the damaging data.” This is not true. As discussed above, they were trying to build better statistical models. It is frustrating, to say the least, to see how Kennedy twisted and used the quotes to imply that most in attendance were in some way trying to defraud the public. Throughout the article, Kennedy states that the CDC paid the IOM to “whitewash” the risk of thimerosal and that numerous attempts were being made to bury the link. Kennedy’s implications are insulting and completely untrue, as proven by a special House committee that convened, in part due to his accusations, to look into the potential bias of the IOM panel (Eric, telephone interview, 15 Nov 2007). Further, Kennedy viewed statements like Clement’s mentioning concerns about the data “getting into the wrong hands” as an attempt to keep the public from finding out the truth. I do not believe this was the case. Rather, the concern was related to the potential harm to the public’s trust were someone not skilled in the technical knowledge of biostatistics to run inappropriate analyses with the same dataset and come up with false findings. This is exactly what ended up happening as I will discuss in a later chapter.

In his article, Kennedy also covers the history of thimerosal and reveals financial and political connections between various vaccine manufactures, politicians, and health scientists.

This discussion is a compelling rational call for greater monitoring of conflict of interest; however, it should not overshadow the fact that the conclusion reached by attendees at Simpsonwood was one of concern and the need for more research, not a call for a cover up. Vigilance and monitoring of public officials and politicians is absolutely necessary in order to ensure public safety and wellbeing. However, sensationalizing the Simpsonwood events, which have such massive public health ramifications is equally as damaging, if not more so, as evidenced by recent increases in morbidity and mortality due to decreased vaccination rates (Deer 2009). No one at the retreat tried to cover up any findings. All attendees voted for more research. As scientists and researchers, they were seeking the most appropriate ways to get the best, most accurate picture of what was happening in the dataset. That is a far less appealing story to sell if one is seeking fame, however. Instead, Kennedy focuses on the few scientists who were in disagreement and the now famous quote from Johnson about his gut feeling.

The fire that continues to drive Kennedy's story is the fact that a relationship was found between thimerosal and neurological problems at the closed Simpsonwood Retreat, but by the time the data and findings made their way to the public in the research article written by Verstraeten and published in 2003 (discussed below), the relationship was insignificant (Verstraeten 2003). Therein lies the foundations of conspiracy and paranoia as people try to determine why the relationship found between thimerosal and neurological problems was omitted. Competing interpretations include: 1) everyone at the Simpsonwood Retreat and involved with the data has lied; or 2) all the advice and issues raised at the retreat, such as what to do with confounding variables, sample sizes, control groups, and other methodological issues were actually taken into consideration and adjusted for, and a more rigorous analysis was rerun. Unfortunately, the later explanation is not the story that was told by Kennedy. Instead, Kennedy

painted a picture of lies and secrecy and delivered it to the public, causing controversy because some agreed with his interpretations. Who wouldn't agree after reading his article? It was a beautifully written, accessible, and compelling story. Since its publication, Kennedy has become a celebrity spokesperson for the ASD/VL movement.

4.0 CONTESTS IN SCIENCE

Following the release of the Simpsonwood Retreat transcript along with the hundreds of other CDC communications obtained through the FOIA concerning vaccine safety, there was an increase in intensity and activism throughout the ASD/VL movement, both on the part of the opposition and the ASD/VL movement groups. The following chapter provides an analysis of the ASD/VL movement's attempts to access the CDC's resources as an instance of democratizing science. I then discuss the contests over credible science leading up to the second hearing on immunization safety hosted by the IOM on February 9, 2004, and finally the aftermath of the heated boundary dispute over credible science.

4.1 GAINING ACCESS

Following the release of the Simpsonwood transcript, SafeMinds became even more aggressive in their quest to gain access to the VSD data themselves. To do so, SafeMinds knew they would need to collaborate with credentialed doctors who had access to the necessary resources to carry out such a feat. This strategy supports the EHSM framework which states that movements often “involve activists collaborating with scientists and health professionals in pursuing treatment, prevention, research and expanded funding” (Brown et al. 2004b:55). The collaboration with renegades from mainstream medicine who have crossed over to join ranks as “expert activists” is

something unique to EHSMs. Indeed, collaboration with expert scientists and doctors is often defined as a resource and definitely as an aid in mobilization. Recognizing the benefit of collaborating with professional experts, SafeMinds built a relationship with the Geiers, a father and son research team. Dr. Mark Geier has worked on vaccines since the early 1970s under the direction of the National Institutes of Health and is now a self-employed geneticist. Over the last thirty years, he has published widely on vaccine safety related issues, or more specifically the link of vaccines to injury, including autism. Together, the Geiers have presented at hearings in front of the U.S. House and in front of the IOM Immunization Safety Review Committee and have testified in over 90 vaccine cases. They are ardent believers in the ASD/VL hypothesis, but their research is hotly contested and, as will be discussed later, they have recently been expelled from Western mainstream medicine.

SafeMinds met the Geiers in 2002 at an NVIC-sponsored conference. The Geiers were presenting research linking vaccines and autism from data collected from the Vaccine Adverse Event Reporting System that consisted of complaints filed by parents stating their children had been harmed (in any way) by vaccines. They argued that the number of complaints related to vaccines and autism increased in conjunction with the increase of thimerosal in vaccines, suggesting a causative link. Seeing a potential ally for their cause, SafeMinds recruited the Geiers, who became the group's "expert activists."

From this point on, SafeMinds and the Geiers often worked hand in hand aggressively promoting the ASD/VL hypothesis and gaining access to the actual VSD dataset so that they could run their own analysis. Access to the VSD dataset was strictly guarded, but Burton, U.S. Rep. Dave Weldon (R-FL), and SafeMinds worked with the Geiers to gain access. Weldon, who served in Congress from January 1995 to 2009, was a political ally in the movement. Weldon

was introduced to the issue through his friend Dr. Jeff Bradstreet and became a believer in the ASD/VL hypothesis. Bradstreet believed his son's autism was triggered by the MMR vaccine. Weldon and Bradstreet, along with Burton, were essential in getting the Geiers access to the VSD dataset by using their political clout and resources (Kirby 2005).

An example of politicians using their political clout can be seen in the evolution of Burton's vaccine safety hearings through the House Committee on Government Reform. Burton had been using his position as chairman of the committee to support the ASD/VL activists. He provided them a space to voice their concerns and diligently made demands to the CDC to open access to the VSD dataset. Over the first two years of his hearings, he grew increasingly frustrated with what he perceived to be stalling, blocking, and intentionally keeping information from the public (Burton 2002). Burton explicitly articulated the argument for gaining access to the VSD in his opening statement to the House Committee in 2002. He stated:

Up until this year, access to data from the VSD has been limited to researchers affiliated with the CDC and a few of their handpicked friends. This "good old boy's network" practice has predictably led to questions about the objectivity of the research and the fairness of the results.

The VSD data should be made available to all legitimate scientific researchers so that independent studies can be conducted and results verified... The Committee first raised this issue with the CDC two years ago. For two years the CDC delayed. Six months ago, we were informed that the CDC was developing a plan to expand access to the database. In preparation for today's hearing, Committee staff asked the CDC why the plan described to us in February had not yet been put into effect. The staff was informed that the plan had been put into effect. However, there had been no public announcement. How are researchers supposed to know about the availability of the data if there is no announcement? It took two years of prodding by this Committee to get the CDC to open up access to the database. For four months it appears that the CDC didn't inform anybody but this Committee of the data's availability.

That doesn't make it appear that the CDC is making a good faith effort to open up this database. It looks to me like the CDC is trying to do the bare minimum that they have to do to get us off their backs. That's not acceptable (Burton 2002).

Burton threatened to subpoena the VSD dataset from the CDC. The act of subpoenaing data from the CDC, which is charged with protecting public health, represents a challenge to that institution's autonomy, credibility, and cultural authority. It was a very powerful symbolic action reflecting the decline in trust of the CDC. Burton's aggressive statements and threats are characteristic of his approach throughout his hearings; he was always direct and insistent. Burton also provided a space for other parents and caregivers to express their experiences. This helped make the hearings the central location of organizing and planning as attendees came together and shared their theories and arguments. In the course of these hearings, parents and caretakers of children with ASD were constructing a politicized illness identity. Through working with politicians and gaining a controlling voice at these hearings, the movement groups were, as McCormick notes, "engaging in or creating participatory state structures and generating new knowledge" (2007: 621), which they would then use to challenge mainstream medicine, a truly powerful political action.

This increasing mobilization of concerned parents and caretakers of children with ASD and the growing call for access and transparency from Burton caused tension within the committee hearings. U.S. Representative Henry Waxman (D-CA), the minority representative on the committee, started as, and continued to be, a supporter of more research into the ASD/VL hypothesis, but he did not like how the tone of the hearings was shifting from one of honest investigation to conspiratorial accusations and unsubstantiated allegations from scientists he perceived had questionable standing. He states in his committee response:

There have also been negative consequences to your approach. You have repeatedly provided a forum for unsubstantiated allegations about vaccine safety that have alarmed and confused parents...This is a potentially dangerous development because it can lead to lower immunization rates and more disease (Waxman 2002).

Waxman felt it was time for Burton and the committee to move on from the vaccine safety issue. His argument was that because the CDC and IOM were involved in the debate, there was no further need for the hearings and that they were providing a forum for fear and misunderstanding to flourish. Waxman strongly stated his concerns about the consequences of allowing the trust in the system to diminish, namely, the increased rates of morbidity and mortality due to the return of acute infectious disease such as pneumonia. He noted that the CDC has predicted 224 deaths, 8500 cases of pneumonia, and 26,000 hospitalizations if child immunization rates drop below levels achieved in 1989. This statement brought to the forefront a critical issue: parents losing trust in the system could mean that child vaccination rates would fall resulting in increased childhood morbidity and mortality rates. This problem is something that the ASD/VL activists and Burton do not often mention or attempt to solve. .

Besides Waxman's harsh indictment of Burton's handling of the hearings, he was extremely upset with the threat Burton made to subpoena the raw data from VSD. He stated "You have an alternative to a subpoena. CDC has worked with the HMOs to create a process for allowing independent researchers access to the data. I continue to urge you to accept this solution and renounce your subpoena threat" (Waxman 2002). However, Waxman also pointed out an interesting irony; Burton threatened to subpoena the entire VSD project, which would violate the privacy of 6 million patients by sharing patient medical records. Such a violation of privacy is exactly why Burton opposed the national registry he referenced in the earlier hearings. This

illustrates the difficulty involved with negotiating the public wellbeing against individual's rights.

Waxman also expressed concern over the lack of credible science present during the hearings, specifically the involvement of Andrew Wakefield. Wakefield had become a target for vaccine safety activists in the U.S. since his 1998 publication in the *Lancet*. Barbara Lo Fisher invited Wakefield to present his data on the relationship of the MMR vaccine and ASD at the IOM in 2001, which he did. However, it was Wakefield's written testimony in the Burton hearings that incited a great deal of unease among politicians and government public health officials, illustrating the heated controversy over who is a legitimate, credible researcher and who is not. In Wakefield's testimony providing evidence of the link between MMR and autism, he suggested that a fellow presenter, Dr. Michael Gershon, had perjured himself when stating that Wakefield's lab was inappropriate for research of this kind. In response, Wakefield alleged that Gershon's wife had a financial stake in the chickenpox vaccine, and as such, Gershon had a conflict of interest and was not credible (Waxman 2002). Wakefield's claims caused a rift within the House Committee as Waxman came to Gershon's defense and gave a scathing indictment of Wakefield. He stated, "Gershon's testimony last year was quite lengthy, and he raised many scientific issues, but Wakefield has not refuted any of them. Instead, he resorts to name-calling, which does not move these scientific issues along and is unproductive" (Waxman 2002).

Waxman's statement was meant to act as a strong wakeup call to representatives, particularly Burton, who were perceived as fanning the fires of fear and concern in the minds of parents with autistic children. The statement was an attempt to solidify the boundaries between responsible, credible scientists and charlatans. And it did have an impact; Wakefield's reputation suffered, and Burton did not follow through with the subpoena of the raw dataset. Instead, the

Geiers worked with Burton and Weldon in accessing the data through the channels authorized by the CDC, a process which, according to the Geiers and Weldon, was quite arduous and unnecessarily difficult. In short, the CDC required the Geiers to go through seven separate IRBs, would not provide the full dataset to the Geiers, required the Geiers to be monitored by a supervisor, and restricted the time and space the data would be available. They were also, according to Weldon, supplied with “inadequate computers” that made the Geiers’ attempts at analysis difficult and at times impossible (Kirby 2005, Weldon 2004).

In his book, Kirby describes in detail the events that occurred over the few days in 2002 when the Geiers were allowed access to the VSD data to conduct their own analysis. Kirby wrote that, once on-site, the Geiers gained access to the data only through the aid of a “rogue” CDC monitor who was sent to “keep an eye on them” while they were at the CDC’s Research Data Center. The story unfolds like a mystery novel, with Kirby building suspense as he walks readers through the Geiers’ obstacles in accessing the data starting with the frustration over learning new computer software programs, recruiting knowledgeable statisticians who could help them to run the analysis, and the dead end they hit when the computer they were working on did not contain the correct software. The following excerpt from an interview with the Geiers illustrates the “mystery-novel” tone of the book and covers the events of the day the Geiers went to the CDC site to access the data and were confronted with the fact that they did not know how to run a data analysis using the software provided by the CDC. Also included in this excerpt is the “heroic effort” of the “rogue” employee who wanted to help because she was related to a child with an ASD:

“How on earth can this be happening?” Mark[Geier] muttered, shaking his head. “Once again, they got us.” Silence filled the room. There would be no number crunching today. The men stared at the screen.

“Wait a minute.” It was the female monitor. She rose from her chair, peered out into the hallway, and closed the door. She sat down and took a deep breath.

“Do *not* tell anyone this,” she said in a low voice. “But I can help you.”

The woman explained that she had an “affected child” in her family. Nervously, she sat at the terminal and began banging away in the computer code (Kirby 2005: 281).

The findings the Geiers uncovered that day will be discussed in the next section, but first it is critical to discuss the symbolic importance and meaning of the Geiers gaining access to this restricted data. The story of the Geiers and SafeMinds gaining access to the VSD dataset can be seen as an attempt at democratizing science. The ASD/VL activists and expert activists viewed the barriers from mainstream science and the government as purposeful manipulation, misdirection, and pressure to force the Geiers to give up their attempts. To the CDC, the Geiers represented “unqualified encroachers” (Hirschorn 2006). However, to the ASD/VL activists, gaining access to the data symbolized the reclaiming of information that was rightfully theirs. In their eyes, the data belonged to the people since it was collected by the U.S. federal government for the benefit of the public. They were attempting to tear down the boundaries, giving citizens access to useful data about themselves because they truly believed it should belong to everyone. The CDC denies they were trying to manipulate or misdirect the Geiers; however, they did eventually acknowledge they were resistant to allowing access. This is an example of mainstream science trying to protect their autonomy and their boundaries in order to maintain their cultural authority.

The CDC did not believe that the Geiers should have access to the VSD data because they believed that only qualified professional experts (defined by them) should be allowed to handle it or were capable of handling it. As discussed by Hirschorn (2006) and Abbott (1988), in order to maintain legitimacy and authority, institutions must be able to balance technical versus

indeterminate knowledge. The CDC attempted to balance this ratio by providing information to the public through their publications and presentations of the studies from the VSD dataset. Usually publications in mainstream journals that expose methodology and design are sufficient to retain credibility and legitimacy. This was not enough for the ASD/VL movement as they sought and won greater access, thus challenging the CDC and their cultural authority.

4.2 DATA WARS

The Geiers reported that they found significant associations between thimerosal and vaccines in their analysis of the VSD data and shared it with SafeMinds, who then circulated their findings to other ASD/VL movement groups. The Geiers also took their findings to Dr. Walter Spitzer, an epidemiologist, and politicians Weldon and Burton, all of whom advised them to submit their findings to the *Journal of the American Medical Association (JAMA)* for publication. The article was eventually submitted and rejected in 2004.

The Geiers' findings contributed to the growing evidence circulating on the internet linking vaccines and ASDs, and according to my IOM informant Dan, officials from the CDC and the NIP were "getting beat up" on Capitol Hill and in state legislations as bills calling for the ban on all mercury in vaccines were being submitted and parents were filing more court cases in the NVIP court. Eric reported that there was a real concern about the declining trust in the CDC. He stated that Rick Rollins, who at the time was a powerful California state legislator speaking out about the harm done by thimerosal, told Rodger Bernier, chief of NIP, that any studies coming from the CDC were not going to be viewed as legitimate. According to my survey data and interviews with ASD/VL activists, the lack of trust in the CDC continues to be a major issue.

To re-instill faith and trust in the government and to counter attacks from ASD/VL groups, Bernier set up a meeting that would bring people from all sides of the issue together to have a “real dialogue” about the vaccines and autism. The meeting, called Wingspread, took place in June 2003 and, according to my IOM informants, came to be seen as a real shift in the relations between the IOM and Barbra Lo Fisher, who had been invited to the meeting because of her active role as spokesperson and her collaboration with multiple organizations. The IOM reached out to Fisher because, as Eric stated, she understood progress could be tedious and she was “someone who had worked slowly and diligently towards change” (telephone interview, 15 Nov 2007). But my informants reported this all changed with the Wingspread meeting.

Eric reported that during the meeting Fisher “stated that ‘there is a new breed of vaccine safety advocates out there. You don’t know what they are like, and they will kill you’ or something like that” (telephone interview, 15 Nov 2007). Reflecting back on the meeting, Eric stated he understood that Fisher was actually trying to warn the officials, researchers, and IOM volunteers about the new movement groups. Unfortunately, as Eric reported, others in attendance did not see it that way, and her words were taken as a threat rather than a warning. Eric stated that after that point, the tension was far greater between the ASD/VL activists and those working with the IOM. He also stated, in a remorseful way, that everything Fisher had warned them about during the meeting came to pass in the last six years. He stated that after the Wingspread meeting “there were all these groups clamoring. The autism moms are another thing altogether” (telephone interview, 15 Nov 2007). He stated that the groups seemed to be composed of either “libertarians, crunchy back-to-nature types, or conspiracy theorists. But they were all armchair scientists, armchair epidemiologists really” (telephone interview, 15 Nov 2007).

To try and counter the growing roar of concerned parents and ASD/VL activists, the CDC released results from the second analysis of the VSD data. The article titled “Safety of thimerosal-containing vaccines: a two-phased study of computerized health maintenance organization databases” was published in *Pediatrics* in 2003, first authored by Verstraeten. The article reported no link between thimerosal and autism. ASD/VL activists were quick to point out that the findings reported in this article, using the same data, differed from the 2001 findings reported to the IOM. As discussed earlier, the 2001 presentation to the IOM on the VSD data did include a statistically significant association between thimerosal and neurodevelopmental delay, which contributed to the IOM’s finding that it is biologically plausible (Verstraeten 2001). The new analysis took into consideration the feedback and recommendations from the attendees at Simpsonwood, which included dividing the data by specific neurodevelopmental delays, controlling for age and diagnostician. The result was the finding that there was no significant relationship between thimerosal and ASD (Verstraeten 2003). This article was hotly debated and what followed was no less than scientific warfare as each side accused the other of various infractions in the practice of good science in an attempt to prove their argument and, in doing so, drew lines of what is and is not legitimate science.

The CDC and the Geiers along with SafeMinds all claimed the other was manipulating the data in deceitful or inappropriate ways. The CDC officials claimed that the data collected and analyzed by the Geiers was not the full dataset and that their findings were not reliable or valid. Meanwhile the Geiers, Burton, Weldon, and SafeMinds stated that the CDC manipulated the VSD data to hide any relation between vaccines and ASDs. SafeMinds was given access to the results that would be published in *Pediatrics* and preemptively published on their website “An analysis and critique of the CDC’s handling of the thimerosal exposure assessment based on

vaccine safety datalink (VSD) information” (www.safeminds.org). In this article, posted a month before the *Pediatrics* article, SafeMinds did not simply state that the data was manipulated, they included tables, charts, and outlined exactly how it had been manipulated, illustrating the scientific sophistication of the ASD/VL activists and their close collaboration with expert activists.

Directly following the November publication of the *Pediatrics* article, SafeMinds issued a press release with the following heading: “CDC Manipulated Data in Study on Link Between Children’s Vaccines and Autism, CDC’s Earlier Results Showing Significant Link Covered Up—Exposed by Freedom of Information Act Documents” (www.safeminds.org). SafeMinds focused on the manipulation of data to show that there was no link between vaccines and autism and on the political connections between Verstraeten, the CDC and GlaxoSmithKline , who had several vaccinations containing thimerosal. Specially, SafeMinds argued that after Verstraeten began work at GSK, “the data, sampling, and methodology of the study were altered so that results would point to enough inconsistencies to cast doubt that mercury in vaccines causes autism,” and further that “Verstraeten had not been named as a GSK employee in the study and was misidentified as an employee of the CDC” (Kirby 2005:286). Mark Geier contested the findings as well, and in an interview for a three-part television series that aired in Detroit following the publication of the CDC data, stated:

You gotta understand this is the biggest doctor-caused catastrophe that has ever happened. The AAP who attacked us—they just don’t want anyone to know the horrendous thing they allowed to happen. We discovered that children were twenty-seven times more likely to get autism” (www.wxyz.com).

The aggressive campaign to discredit the CDC included ASD/VL activists writing letters to respected vaccine safety specialists in the hopes of recruiting them to express ASD/VL

activists' concerns over the credibility of the Verstraeten data (www.safeminds.org). Their efforts were successful. Dr. Neal Halsey, a vaccine expert and advocate from Johns Hopkins University, along with several colleagues posted an open letter in the December 17th issue of *Pediatrics* calling into question the Verstraeten publication, specifically asking why the results that were presented in 2001 to the IOM differed from what was eventually published (Halsey 2003). Halsey disagreed with some of the changes made to the analysis design and stated that this “may have substantially reduced the power to find important relationships” (Kirby 2005: 291).

The continued pressure from both sides of the debate pushed the CDC to ask the IOM to conduct further investigations into the thimerosal-autism link. This is yet another example of how EHSMs bring together doctors, scientists, and activists to challenge cultural authority. Indeed, the collaboration and work of groups like SafeMinds, the NAA, Unlocking Autism, and Barbara Lo Fisher and the NVIC and the many activists seemed to have paid off. They had doctors, researchers, politicians, and many media outlets on their side willing to support their cause. They had breached the walls of the CDC and gained access to the VSD data and, over the next few years, drafted and passed legislation banning mercury in vaccines in several states. By any measure, this EHSM could claim success in their goal of voicing their argument that ASDs and vaccines are linked thereby posing a formidable challenge to Western mainstream medicine.

4.3 THE SCIENTIFIC SHOWDOWN AT THE IOM

Amidst the continue media coverage and controversy, the CDC contacted the IOM again in 2003 requesting yet another review of vaccine safety. As Eric stated “the groups weren’t going away.” The IOM agreed to form another panel to look at more studies, which was not an easy undertaking. Those I interviewed at the IOM stated that it was an emotional, difficult time. As Natalie stated, “I really did understand and was exposed to the emotionality” (personal interview, 04 Oct 2007). This side of the story is rarely heard in the media or from the ASD/VL movement groups. There has not been much investigation or dialogue with those who were responsible for actually looking at the data and going through the process of analyzing multiple scientific studies examining vaccines and ASDs. It is an important side to consider, however, since this debate focuses on the personal experiences of parents and caretakers. If the parents want their voice and experience to be heard and validated, the same should be allowed of those involved on the other side of the debate. Therefore I asked my IOM informants what they felt while working on the debate, and how they look back on their experiences. Natalie stated:

It's a politically charged issue and a very emotional issue. It was emotionally draining to go through all the reports and so now I kinda stay out of it. It was a really hard time. I might check out a few articles to see if they mention vaccines, but it was an emotionally draining time for me to go through all of that (04 Oct 2007).

My IOM informant report that everyone involved with the Immunization Safety Review Committee was very passionate about their work and achieving their goal while upholding the mission of the IOM. One informant described the goal of the IOM as bringing people and information together; Natalie stated that “the IOM invited individuals to have a voice, and they held public hearings so everything was on record. It provided more, revealed more of the issues

that are going on, in general” (personal interview, 04 Oct 2007) She applauded and felt honored to work for the IOM. She was proud of its efforts to bring more people into scientific discussions and not to keep people out. Natalie compared the IOM to the CDC where she states people like

the Geiers would never have had a voice at the CDC. [We] opened a dialogue about what it means to have more vaccines, what it means to have them mandated, and the IOM made a space for that. We never shut out anyone. We always had a public time and space to voice concern to the committee. Those are things that we never take lightly (personal interview, 04 Oct 2007).

Eric also was proud of the openness and willingness of the IOM to hear all sides of the debate. He stated that there was wide representation at the immunization safety hearings hosted by the IOM from parents and lawyers. When Barbara Lo Fisher exerted pressure to have Andrew Wakefield speak right after he had published his controversial paper in 2001, the IOM was willing to give him a platform. Eric further stated, “I think we gave people opportunities to give us information” (telephone interview, 15 Nov 2007). Unfortunately, the ASD/VL movement groups did not view the IOM in the same way. In fact, my review of the movement websites reveals that many of the groups felt that the IOM was restrictive and manipulative in their practices.

Preparation for the Hearing

In preparation for the second panel meeting to take place on February 9, 2004, the IOM committee discussed the relevant issues at public advisory committee meetings. However, the date for the final committee hearing, where multiple researchers would be brought in and where all the relevant data would be presented, was set without input from the public or groups like SafeMinds. This did not sit well with the ASD/VL activists who then asked the IOM repeatedly to change the final hearing date. They, particularly SafeMinds, wanted to have a more active role

in the hearing and in choosing what studies would be reviewed. Eric described how events unfolded:

It was public what we were doing, the topics were discussed at public advisory committees. I mean it was public but it wasn't, well. ..but basically SafeMinds got pissed when they found out in December that we were having a meeting on it in February. They started a mass email and phone campaign to get us to cancel it because there was all this stuff that was coming out in the next few months that wouldn't be available. So we invited them, we wouldn't normally invite them because it was bad science, but we did. And that's when the emails with what we interpreted... well the aggressive emails with the death threats happened. We did the report, and they were ballistic and Barbara Lo put out a hateful press release. She loved us when it was working for her!" (telephone interview, 15 Nov 2007)

Eric's hesitancy over describing the planning process as public and stating that "it wasn't" shows that he was aware that what they were doing was officially supposed to be public but that they did not go out of their way to inform people of their next steps. The ASD/VL movement groups interpreted this as manipulation and let the IOM know through emails. Eric reported that most emails were from ASD/VL activists complaining about not being informed or included on the setting of the meeting date. He further stated that they were strongly worded but not threatening. Only one email was threatening and it was actually directed at a presenter scheduled to speak, not at the IOM.

SafeMinds felt that they were being pushed out of the IOM proceedings (Kirby, 2005). SafeMinds desperately wanted several specific studies they had been involved with to be included in the presentations to the IOM. These studies focused on research into the biological mechanisms behind the supposed genetic predisposition that left some children susceptible to mercury poisoning through vaccines. The studies included three research projects conducted independently, by 1) Richard Deth, a pharmacology professor and Marvin Boris, a private

physician; 2) Allan Goldblatt, a researcher and 3) Jill James, a professor of pediatrics. Collectively these three studies “provided a cohesive genetic and metabolic explanation for why children with autism may be more vulnerable to mercury—and why they may be less able to excrete the mercury in vaccines” (Kirby, 2005: 295). This research was presented at a DAN! Conference in October 2003, but it was not published in peer review journals, and the IOM did not invite any of the researchers to attend the hearing. However, Weldon and the ASD/VL activists were able to convince the IOM to allow more time in the proceedings for competing theories. Specifically the IOM invited Bradstreet’s group, the International Child Development Resource Center. In a collaborative spirit, Bradstreet decided that he would include notes from the 3 biological studies SafeMinds requested. The Geiers were also invited to present their findings at the IOM proceedings on February 9, 2004.

In preparation for the follow-up panel hearings by the IOM, the Geiers wanted to gain access to the VSD data once again. To do so, they worked through Weldon’s office. Dr. Julie Gerberding, the director of NIP, agreed the Geiers could have access to the VSD data, again only on-site with a CDC monitor, for two days. According to the Geiers, their attempts were sabotaged—first by the two CDC monitors who would not help the Geiers with access to the room where their data would be printed (and who were later accused by the Geiers of tampering with their output by whitening out data) and second by being given access through a faulty, inadequate computer that crashed halfway through the day (Kirby 2005). The Geiers left the CDC with no “useable” data, which could mean they were unable to run analysis or that they were unable to find the results they were looking for. The Geiers would only be able to present the data and findings from their first VSD analysis.

The Hearing

Kirby described the meeting that took place on the eve before the February 9th IOM hearing. Present at the meeting was Lyn Redwood, Liz Brit, and Sallie Bernard from SafeMinds along with Jim Moody, their lawyer and consultant, parent activists Scott and Laura Bono, Jo Pike, Lori McIlwain, Albert Enayati, Richard Deth, and the researchers who had been invited to present data on the link between thimerosal and autism (including Lloyd Haley, Jeff Bradstreet, and the Geiers). Kirby stated that everyone came prepared for a showdown and was ready to argue their hypothesis linking ASD and vaccines the next day.

Present at the public hearing were over 60 parents of children with ASDs, who my IOM informants stated were very active, even clapping when speakers they knew and liked presented. Kirby (2005: 308) similarly wrote that “sometimes it felt more like a political debate than a scientific inquiry.” The hearing included an assessment of causality, which relied on epidemiological studies, and biological mechanisms, which were largely assessed through biological testing. Dave Weldon was invited to give an opening statement. He stated that he was “very disturbed by the continued number of reports I receive from researchers regarding their experiences. It is past time that individuals are persecuted for asking questions about vaccine safety” (Kirby,2005:309). I also asked my IOM respondents what they thought of Weldon’s speech. Natalie said:

Weldon spoke at the last meeting. And that's just something, ya know if a congressman wants to talk, he takes up 30 minutes and says nothing, but you just kind of have to, and some say well isn't that conflict of interest, but you know these are really smart scientists. They know how to separate out (personal interview, 04 Oct 2007).

Natalie’s quote shows that while politicians are useful in passing legislation and mobilizing support, their opinions on science are not always respected in the scientific territory.

The first presenter, Dr. Mady Hornig, presented data linking mercury to biological harm in mice. This study, funded by SafeMinds, was highly applauded by ASD/VL activists. However, according to Eric, this study has yet to successfully be replicated.. Dr. Robert Davis, a pediatrics professor from the University of Washington, presented data from the VSD that he and Verstraeten had worked on, and preemptively included in his presentation criticisms of the Geiers' work. He walked the panel through the analysis of the VSD data and stated that there were indeed differences found in the data, namely that those who had been exposed to more mercury were more likely to have a diagnosis of an ASD. However, Davis explained that the difference has to do with age—those in lower exposure categories were younger and, therefore, had fewer opportunities to be diagnosed. When the analysis controlled for age, the statistical significance disappeared, thus adding evidence that there is no link between mercury and ASD.

An additional researcher hoping to prove the link between mercury and autism was H. Vasken Aposhian. Aposhian presented data that suggested autistic children have a “mercury efflux disorder,” which means they cannot excrete mercury thus leading to neurological damage (Kirby 2005). Other research showing a link between mercury and ASD included the work of Holmes, Blaxill, and Boyd, who used evidence from hair samples (Holmes, Blaxill, and Haley 2003). This study was applauded by the ASD/VL activists and has often been cited as indisputable evidence that mercury and ASD are linked. This sentiment was not shared by the IOM. When asking my IOM informants about this research, Eric stated, “So what, they think that one stupid study where you cut snippets of hair off a baby’s head means more than 5 epidemiological studies?! I just don’t understand. They’re very anti-science” (personal interview, 15 Nov 2007). This quote shows that Eric felt they were anti-science because of the kind of study that the ASD/VL movement relied on and trusted. For the movement, Hornig’s study

provided enough evidence to call for drastic changes in vaccine protocol, but according to Eric, bench science with possible anecdotal outcomes is not what carries the most credibility when deciding public safety issues. Rather, the large epidemiological studies carry more authority.

As this unfolding story illustrates, the practice of scientific research is often a political endeavor. Those who produce data, those who interpret data, and those who benefit from particular interpretations can have political agendas. In the ASD/VL movement, the argument over bias and political agenda is made by each side. Both sides bring bias and agendas when deciding what studies to present, what studies to criticize, and what studies are deemed legitimate. The political agendas influence how research is designed. As the comment from Clements in the Simpsonwood transcript points out, even deciding to ask a question can make a political statement. But politics works its way into research in a more nuanced way as individuals decide what constitutes a significant risk. Brown et al. (1990) describes this decision over significance in his discussion of public health significance versus statistical significance. Brown et al. (1990: 134) states that “an increased rate of disease may be of great public health significance even if statistical probabilities are not reached.” This happens when epidemiologists, who prefer false negatives or type II errors, falsely claim there is no relationship between variables when one does exist (Tesh 2000, Brown et al. 1990). This is contrasted to the clinical practice of preferring type I errors, which means doctors choose to “err on the safe side” by claiming there is a relationship when there is none. An example of this is seen in the practice of “defensive medicine,” where doctors over-prescribe antibiotics or tests just in case (Brown et al. 1990).

In the ASD/vaccine debate, the dispute over what “evidence of harm” means is a dispute over type I versus type II errors, or public health significance versus statistical significance. For

parents, even the suggestion or plausibility of harm due to vaccines is enough to call for change. They would rather “err on the safe side” (type I). The studies the IOM based their findings on, however, were the large epidemiological studies which choose type II errors. This difference is important because it illustrates the philosophical differences between the parent and research activists and the IOM.

Finally, the Geiers presented their epidemiological data from their first analysis of the VSD. Kirby’s retelling of the presentation is presented in true journalistic fashion, accentuating the political fervor and frustration.

Mark Geier’s face hardened in anger. “This is not a scientific issue, this is about as proven an issue as you are ever going to see,” he said, feeding off the rising applause from parents in the audience. “What is occurring here is a cover-up, under the guise of protecting the vaccine program. And I am for the vaccine program. If you keep covering it up, you are not going to have a vaccine program” (Kirby 2005: 318)

As the quote illustrates, ASD/VL expert activists presented with zeal and confidence. They were passionate and renegade in their approach, and they were saying things that were in line with the activists’ experience. While this was an effective mobilizing strategy in the media and among the public, it was not effective in front of the IOM. The Geiers’ accusations and performance in front of the panel did not work to their benefit. Rather than adhering rigidly to the standards of what a credible research presentation should sound like, they made their presentations personal and political. This only lost the ASD/VL movement credibility in the eyes of the IOM and most of mainstream medicine. As Natalie stated, “They [the Geiers] grandstanded. They didn’t speak about what they were supposed to speak about. They complained they didn’t have enough time, but they spent 30 minutes complaining about politics. They were really difficult. They’re difficult, very difficult” (personal interview, 15 Jan 2008).

The Result

The IOM did not respect the Geiers' findings. Beth stated that they were ill-prepared and did not organize their presentation meaningfully. Indeed, they brought 101 slides for a 30-minute presentation (although the IOM did allow them to go over their time limit). The IOM stated that the Geiers' work was "uninterruptible," that they used inappropriate statistical modeling, and that they used terms like "attributable risk" incorrectly (Harris and O'Conner 2005). Even Kirby conceded that the Geiers' presentation "may have hindered their credibility" (2005:317). The Geiers aside, Eric did state that he was impressed that day with Sallie Bernard and Lyn Redwood, stating, "SafeMinds, yeah they are incredible people, pretty impressive. The heads of that, Sallie and Lyn, well Sallie is more savvy, Lyn is more emotional" (telephone interview, 15 Nov 2007).

The outcome of the February 9, 2004, panel hearing resulted in the IOM rejecting the hypothesis that vaccines are linked to autism. Their findings were published in the IOM's 2004 report titled "Immunization Safety Review: Vaccines and Autism." The IOM primarily based their findings on five large epidemiological studies conducted in the U.S., Britain, Denmark, and Sweden. They boasted large numbers (from 109,000 to over 400,000 medical recorders reviewed) and none reported an association between thimerosal and vaccines (IOM report 2004). The IOM also reviewed 14 epidemiological studies concerning the link between MMR and autism and found no relation (IOM report 2004). They further reported that the studies attempting to prove the biological mechanisms linking vaccines and autism were flawed, theoretical, and lacking sufficient proof (IOM report 2004). The ASD/VL groups were not happy with the findings, and a new resurgence of mobilization began.

5.0 RESURGENCE OF MOBILIZATION

The controversy surrounding the VSD data and the results published in the IOM report on vaccines and autism (IOM report 2004) acted as a catalyst for the founding of new ASD/VL groups. The following chapter analyzes the newly formed organizations that have a decidedly greater intensity than the first wave of groups. This chapter describes how, in addition to producing and funding research, this second wave of ASD/VL groups organized and participated in rallies and protests, taking the movement to a new level of activism. Groups like Generation Rescue, A-CHAMP, NoMercury.org, Moms Against Mercury, and Unlocking Autism came together to fight for recognition, retribution, research, and treatment. What follows is an analysis and description of the main organizations that have formed following the controversy over the second significant IOM hearing and the VSD studies.

5.1 THE NEXT GENERATION

5.1.1 Generation Rescue and Jenny McCarthy

<http://www.generationrescue.org>, <http://www.putchildrenfirst.org>

Generation Rescue was founded in 2005 by Lisa and J.B. Handley, the parents of a child they believed was damaged by vaccines resulting in autism. The organization has grown and changed radically as the controversy developed. Originally, the group's main focus was on exposing the harm they believe thimerosal has caused and what they believe was a major cover

up by the CDC. Beginning in May 2005, they began an aggressive ad campaign promoting the link between mercury, vaccines, and autism. They took out full-page ads in the *New York Times* and *USA Today*. The first introduced the idea that autism is “preventable and treatable.” In their first ad appearing *USA Today* on May 5, 2005, they stated that

It is critical that we have all the facts about this epidemic (autism), including the recent developments about autism’s relationship to mercury poisoning and how the right detoxification treatment can entirely reverse this disorder. To find out more about this life changing news go to www.generationrescue.org. Generation rescue was founded by parents for parents. We are dedicated to empowering parents with the truth to help their children (www.GenerationRescue.org).

This message is extremely inflammatory and some have said irresponsible as it creates false hope for a cure. Doctors and scientists across the country responded, warning parents that no cure or detoxification has been found (www.cdc.gov). The use of full-page ads focusing on parent involvement, research, and hope for effective treatment and a cure has been an extremely effective strategy for Generation Rescue, and the group has become one of the most well funded and well known ASD/VL groups.

Their next full-page advertisement came out one month later on June 8 in the *New York Times* and included the description of mercury poisoning and ASD, pointing out the similarities in symptoms stating “Mercury and Autism, It isn’t a Coincidence” (www.generationrescue.org). In this ad, Generation Rescue quoted Robert F. Kennedy, Jr., John F. Kennedy, Dan Burton, and Dave Weldon. They also advertised David Kirby’s book. Next, they followed up with a full-page ad in the *New York Times* on November 14, 2005 that thanked all the researchers who had worked on the ASD/VL hypothesis stating, “For those of you who have done groundbreaking research on the connection between mercury and autism, we thank you..” (www.generationrescue.org). It was a positive upbeat ad of thanks, but it was strategic too;

through thanking researchers for research on ASD and mercury, they implied that the link had been proven. The next full-page message was published in *USA Today* on September 25, 2007, and highlighted an article suggesting children today receive too many vaccines, some of which (like chickenpox) are unnecessary. The image was extremely powerful as it depicted the image of a very long needle with the statement ‘Are we Over-vaccinating our Kids’ (www.generationrescue.org). The next ad ran in *USA Today* on February 12, 2008 and called for the CDC and AAP to listen to parents’ anecdotal evidence. It stated, “Given the dramatic rise in autism to epidemic levels, isn’t it time for the scientific community to seriously consider the anecdotal evidence of so many parents?” They also stated, “The Centers for Disease Control and The American Academy of Pediatrics dispute this [link], but independent research and the first-hand accounts of parents tell a different story” (www.generationrescue.org). Again in this add the theme of privileging the parental perspective and experience was highlighted with the statement “Thousands of parents believe their child’s autism was triggered, if not caused by over-immunization with toxic ingredients.” (www.generationrescue.org).

These advertisements are very expensive but Generation Rescue brought in thousands of dollars through sponsorship from places like Global Health Trax, which makes and markets the nutritional supplements advocated for use in the treatment of autism. They also achieved perhaps the highest level of recognition among ASD/VL movement groups, particularly since recruiting the sponsorship of celebrities Jenny McCarthy and Jim Carry, both of whom sit on their board of directors. Celebrity involvement in medical issues is not uncommon—actor Michael J. Fox, who suffers from Parkinson’s disease, has donated his time and energy to fight for stem cell research in the hopes of finding a treatment or cure, and actress Christina Applegate has become a central figure in cancer awareness and research following her double mastectomy after a diagnoses of

breast cancer. But never before has a medical controversy attained such celebrity attention as the ASD/VL debate. Indeed, the debate became a classic celebrity feud when fellow celebrity Amanda Peet had some less than friendly words for McCarthy.

Peet has come forward as a vaccine advocate working with Dr. Paul Offit, one of the most outspoken opponents to the parent activists. Peet is now the spokesperson for Every Child by Two, which is a non-profit group promoting childhood vaccination. She stated in an interview with *Spectrum* magazine that parents who do not vaccinate are like parasites, to which McCarthy later responded sarcastically, “I’m so proud to be a parasite” (<http://spectrumpublications.com/october/november-2008/i-am-a-parasite.html>). Now many popular columnists portray the debate surrounding vaccines as a face-off between Peet and McCarthy. For example, Rosemary Black wrote a headline in the *New York Daily News* in September 2008 that read, “Jenny McCarthy and Amanda Peet duke it out over childhood vaccines and autism.”

To most of the activists I interviewed, McCarthy is seen as both hero and trailblazer. Born in 1972 in Chicago, Illinois, to a courtroom custodian and a steel mill foreman, she helped pay for nursing school by sending photos into *Playboy* magazine and in 1993 became an official Playboy Bunny. From there, she went on to achieve celebrity status. She was an MTV dating show host, the star of her own sketch comedy show “The Jenny McCarthy Show” and an all around “whacky type comedienne” who starred in numerous Hollywood films.

In 2005, her son was diagnosed with autism, which she believes has been cured through the use of biomedical interventions. Since then, she has been a very vocal, influential ally to the ASD/VL movement. McCarthy has written five books to date on curing autism and the role of vaccines, including *Mother Warriors—A Nation of Parents Healing Autism Against All Odds*. She has done book tours and appeared on nearly every popular national talk show including

“Oprah” and “Larry King Live.” McCarthy is highly involved in Talking about Curing Autism (TACA) and works with DAN! medical providers. She has gone from “sexy, whacky comedienne” to respected movement activist. As Larry King stated after her appearance on his show “she held her own and knew her stuff” and told her “You’ve been very impressive here, Jenny” (McCarthy 2007).

The attention McCarthy has received and the degree to which people have been impressed with her is at least partially due to her media image. Up until her involvement with the autism community, she was primarily seen as a sexy young starlet. She does not try to distance herself from that image—in fact she continues to embrace her role as a sex symbol as evidenced in her appearance with World Wrestling Entertainment (WWE) and writing a movie called “Dirty Love” with Carmen Electra, also a Playboy Bunny. While McCarthy embraces her sexuality, she also fights to be heard and have a voice. My interviews with ASD/VL activists revealed that they seem to empathize with the struggle McCarthy has gone through to be taken seriously, as they feel they have gone through the same struggle to be heard and seen as a legitimate source of knowledge. In McCarthy, ASD/VL activists have found someone they can relate to, a parent who struggles against mainstream science to have her voice heard.

Because McCarthy has played such an active role in mobilizing ASD/VL activists and parents, I wanted to analyze exactly what she has been saying. Her most debated and “no holds barred” interview was with Larry King in 2008. I analyzed the transcript from the interview which included McCarthy, her friend and fellow Hollywood actress Holly Robinson Peete, and a DAN! pediatrician, Dr. Jerrold Kartzinell, whose practice is devoted to studying autism and other neurodegenerative disorders. Kartzinell is also the father of an 11-year-old boy diagnosed with autism.

McCarthy's interview conveyed an overall message to ASD/VL activists to not lose hope and to keep fighting. While reading the "Larry King Live" transcript, the dominant theme became the use of metaphors. Metaphors in medicine has been widely studied and explored, most notably by Susan Sontag in her piece *Illness as Metaphor* and her 1988 piece *AIDS as Metaphor*. Metaphors are popular in medicine because they take complex, jargon-laden, biomedical terminology and turn it into something we can relate to and understand easily. Abbott (1988) likewise argues that when mobilizing support, it is best to keep messages to the public simple. We can "fight" cancer and "wage war" on heart disease, which are very powerful motivators, but Sontag's message is that this should not be the case. Sontag states, "Illness is not a metaphor, and the most truthful way of regarding illness—and the healthiest way of being ill—is the most purified of, most resistant to, metaphor thinking" (Sontag 1978: 3).

Metaphors can be seductive because they reduce the uncertainty inherent in illness to a simple idea. The first metaphor that McCarthy repeated was that of autism being like a car accident. She stated, "It's like getting hit by a bus. You don't become cured, but you can recover" (McCarthy 2007). She repeated the metaphor again later in the interview saying, "I'm not saying cured. It's like getting hit by a bus. But you can recover, and there will be some bruises" (McCarthy 2007). This is a message of hope to parents, which she is excited to share. Her mission, she stated, is to "bring hope, hope and hope." In fact, McCarthy uses the word "hope" a total of 11 times in the one-hour interview.

The second metaphor McCarthy and Peete used repeatedly is the idea and image of a window, getting an ASD child out and through the window. McCarthy states she was "pulling Evan out of the window" (McCarthy 2007). Later Peete states she was in "the trenches working to get this kid out of this window" and then later stated she was working on "getting him

through the window” (McCarthy 2007). Again McCarthy states, “There is this window. You can pull him out” (McCarthy 2007). The window metaphor evokes possibilities, again brings hope for effective treatment and a cure to the forefront. It is powerful for parents of autistic children specifically because ASD symptoms often include lack of eye contact and lack of social skills. Children with an ASD may seem disengaged and distant, so “bringing them through a window” means restoring those connections, bringing them back in a very literal sense. As Peete stated, “...get in there and try to help pull this child out of this world” (McCarthy 2007).

Another meaningful metaphor involves the difference between looking at the forest versus looking at the trees. This was introduced by Dr. Jerrold Kartzinel and is often used by DAN! medical providers and the Geiers (Kirby 2005). Kartzinel states that the CDC and government are “looking at a forest” while they (DAN! medical providers and ASD/VL activists) “are looking at the trees.” This is a simplistic way of explaining the difference between large epidemiological studies and small lab-based studies.

The use of such metaphors resonates with parents of autistic children. It offers hope for treatments and cures, along with information in an oversimplified and easy-to-understand manner. DAN! medical providers and ASD/VL activists like McCarthy describe the issue from a non-threatening stance that gives credit to parents’ experiences and puts the power to help their children in their hands. These metaphors are even more powerful because of who they are coming from—celebrity and mother Jenny McCarthy.

During the interview, McCarthy stated that she supports the use of vaccines, she just feels it needs to be more “green,” meaning the toxins and additives need to be removed; however, when asked if she would vaccinate her child today, McCarthy said no (McCarthy 2007) Recently however, McCarthy seriously damaged her credibility and influence. In an interview she

conducted with *Michigan Avenue Magazine* in March 2009, she stated, “Since the increase in vaccines there’s been an increase in autism. I can understand why the other side won’t admit to it” (Negovan 2009: 84). She further re-iterates that she is not anti-vaccine but pro “greening” of the vaccines. This is in line with her usual interview repertoire, but then when asked for her view on plastic surgery and Botox she said, “I love Botox, I absolutely love it. I get it minimally, so I can still move my face. But I really do think it’s a savior” (Negovan 2009: 84). The irony of her statements is almost too obvious to even elaborate. Botox is the botulinum toxin, a neurotoxic protein that essentially paralyzes the muscles injected. The fact that McCarthy is perfectly fine with injecting Botox into her face but not with the administration of vaccines because of their toxins has caused quite an uproar as scientific journalists and bloggers point out the logical inconsistencies. Even if McCarthy stated she had conducted an in-depth analysis of the ingredients in Botox and decided it was safe, this would not protect her from criticism for failure to recognize the impact such a statement would have on her credibility. Generation Rescue has yet to address the quote or the attacks to her credibility.

Despite the Botox controversy, McCarthy is a powerful ally for Generation Rescue, which they frequently highlight. They even state on their home page that Generation Rescue is “Jenny McCarthy’s Autism Organization” and has links like “Go Shopping with Jenny.” Indeed, McCarthy has brought a tremendous amount of attention to the group. For example, she recruited the help of the WWE in raising funds to support Generation Rescue and donations to help autism research.

While the organization’s mission focuses on autism and vaccines, they have stepped back from focusing only on mercury and from directly attacking the CDC. Today their message is more of hope and recovery and, as McCarthy says, “greening” vaccines. This process of

expanding their focus to include removing toxins from the environment illustrates the hybrid nature of many EHSM's, as they "merge individuals, cultures, and strategies of various movements" (Brown et al. 2004b: 62).

While the Generation Rescue website has turned to the more politically correct and broader message of "Green Our Vaccines," which supports vaccination and focuses on treatment and hope, the underlying belief that the U.S. government is to blame and is involved in a cover up has not changed. Instead it was transferred. In 2005, the founders of Generation Rescue started a separate website called PutChildrenFirst.org. This website became the home of a full out attack against the CDC and the U.S. government. The site is dedicated to Liz Brit, founder of the NAA and Alan Clark, founder of NoMercury.org (profiled below). This was an extremely smart strategic move for Generation Rescue. By separating out their arguments for safer vaccines from their blame of the CDC and the U.S. government, they were able to appeal to the full autism community. Generation Rescue can bring in thousands of dollars by promoting the "safe," non-extremist cause of greener vaccines while still funding and promoting the conspiracy theory that the government actively buried any link between thimerosal and autism. Generation Rescue's message is made explicitly clear in the advertisement PutChildrenFirst.org published in *USA Today* on April 6, 2006 which quotes Kennedy as stating "It's time the CDC came clean with the American public" under a large print message that reads: "If you caused a 6000% increase in Autism wouldn't you try to cover it up too?" (www.generationrescue.org).

5.1.2 NoMercury.org

<http://www.nomercury.org>

NoMercury.org was founded in 2004 by Lujene G. Clark, a former elected official, and her husband Alan Clark, a physician with over 30 years of experience in medicine and research who also serviced on the scientific advisory board of the NAA. They believe their child developed an ASD as a result of thimerosal in vaccines. The founders of nomercury.org felt betrayed and lied to by not being informed about mercury in vaccines. They state on their website, “As parents and as a medical family, we felt blind-sided. We wanted to prevent this from happening to other families” (www.nomercury.org). However, the founders of NoMercury.org do not state who exactly they felt was to blame for not informing them of the mercury in vaccines.

NoMercury.org places heavy emphasis on peer-reviewed, credible research into the ASD/VL hypothesis. Their website contains one of the most comprehensive collections of scientific research, clinical, toxicological, and epidemiological articles, government documents, and interestingly, information and documents that cover “the political and financial aspects of public health policy making” (www.nomercury.org). This organization places a greater emphasis on educating not only parents but also medical doctors and policy makers. According to their website, NoMercury.org is “a philanthropic based venture whose mission is to educate policy makers, physicians and the public regarding the dangers associated with the use of thimerosal, a mercury containing preservative used in vaccines” (www.nomercury.org). NoMercury.org is unique in that it does not accept donations or seek financial support. They state that their organization “is a labor of love, in honor of our mercury poisoned child” (www.nomercury.org).

The founders' professional experiences in medicine and public policy greatly influence the strategy and mission for NoMercury.org. They only provide information on the debate from journals like the *British Medical Journal* and *JAMA*. They do not include media from tabloids or inflammatory blogs. They state:

As a former elected official, Lujene is familiar with the political process and recognizes the importance of factual information when making vital public policy decisions. Alan, as a physician with more than 30 years' experience, recognized the importance of peer-reviewed, published studies that are timely and unbiased. Scientific literature is heavily relied upon by physicians to make sound clinical decisions that are in the best interest of the patient. Just like most organizations involved in the debate (www.nomercury.org).

NoMercury.org states that they are not anti-vaccine but pro safe vaccine. They highlight the benefits of vaccines from a public health prospective while calling on policy makers and medical doctors to step up to their responsibilities and make safer vaccines. This is in line with NoMercury.org's overall tone of positive change rather than negative blame. They acknowledge the importance of trust and faith in public institutions and paint a picture of citizens and the institutions that they depend on, i.e. NIP, working together rather than as adversaries, which is characteristic of other groups like SafeMinds and Moms Against Mercury.

NoMercury.org heavily advocates becoming politically active in the ASD/VL movement. The website serves as a clearing house for information and resources for those who wish to pursue activism in their home states. They provide details for each state's current and pending legislation and how to get involved. Through their efforts, they have become one of the most recognized sites in the ASD/VL movement and are among the most cited resource by my ASD/VL activists and those who took my online survey. In 2006, Clark passed away due to cancer. NoMercury.org reports that one of his final wishes was for NoMercury.org to continue

providing credible information and resources to those researching mercury in medicine. A memorial research fund was also created in his name “to provide grants to physicians and researchers striving to prevent and reverse the devastating effects of mercury, particularly when used in medicine” (www.nomercury.org). This research fund is separate from NoMercury.org however, as Clark wanted to keep NoMercury.org a strictly philanthropic resource with no financial ties or donations.

5.1.3 Advocates for Children's Health Affected by Mercury Poisoning and Autism Action Collation

<http://www.a-champ.org>, <http://www.autismactioncoalition.org>

Advocates for Children's Health Affected by Mercury Poisoning (A-CHAMP) was founded in 2005 as a political action group dedicated to the ASD/VL movement. Their mission statement is as follows: "To be a strong and unified voice for children with neurodevelopmental and communication disorders so that each child may be provided the support necessary to live a full and productive life." Like most of the ASD/VL movement groups, A-CHAMP was founded by parents of autistic children. Unlike other prominent organizations, A-CHAMP does not provide an extensive profile of the founders or the founder's stories, a tactic that has been effective for rallying support for groups like Moms Against Mercury, No Mercury.org, and SafeMinds. By keeping the organization impersonal, the tone of the website remains focused on legal action and advocacy.

Additionally, A-CHAMP does not use the word “autism” frequently. Instead they use the umbrella of “neurodevelopmental and communication disorders.” This illustrates their ideological perspective that children damaged by mercury experience a host of symptoms not

necessarily bound by the autism spectrum. This is similar to many ASD/VL movement groups that view the symptoms as evidence of poisoning and damage rather than a specific disorder. They seek to raise awareness, but their primary aims focus on ensuring that the material and financial needs of children with ASD are met and that the local, state, and federal systems are complying with laws written to protect the needs of children with ASD. The language they use throughout their mission, vision, and goals statements is consistent with a group focused on rights—they use phrases like “protecting human rights” and “fighting for legal and civil rights of children damaged by vaccines.”

In 2006, A-CHAMP changed their name to Autism Action Coalition (AAC) and launched a new website under that name. However, they did not remove the A-CHAMP website, which is now entirely outdated. AAC now highlights that they are non-partisan and support candidates that share their goals and hold “accountable those in government who do not act in the best interest of our children” (www.autismactioncoalition.org) A large part of the AAC vision is dedicated to the legal end of the ASD/VL movement, working towards legislation and government that works towards protecting and increasing the rights of children they believed were damaged by vaccines. For example, AAC campaigned against the “Vaccine Accessibility for Children and Seniors Act of 2005” on the bases that it would limit the ability to hold pharmaceutical companies liable for damage in court. Their website is full of “one-click” options to get involved politically through the visitor’s own state. It is extremely user-friendly, providing monthly action plans and contacts for state coordinators. They provide “Action Alerts” for users to be aware of, supporting documents for pending issues, and information on how to navigate the National Vaccine Injury Compensation Program (NVICP).

It is not readily obvious that AAC was once A-CHAMP, and they do not state the reason for the revision. Through analyzing the differences between A-CHAMP and AAC, it is clear that this re-launching was an effort to expand their focus and their base of support. Through re-launching, they were able to distance themselves from the negative press associated with some of the rallies A-CHAMP co-sponsored against the CDC and AAP. This practice of broadening their focus away from mercury alone to include all environmental triggers is consistent with the national trend of ASD/VL groups. The above ASD/VL groups I profiled all came together to sponsor rallies organized by Mom's Against Mercury.

5.1.4 Moms Against Mercury

<http://momsagainstm Mercury.org>

Moms Against Mercury (MAM) has been perhaps one of the more volatile groups. They have organized aggressive rallies and campaigns specifically targeting the CDC. MAM was founded by Amy Carson in 2005. Carson is the mother of an autistic son she believes was damaged by vaccines. Personal experience is extremely important and is highlighted in the MAM mission statement and in its practices. In fact, in the About Us section of their website, it states proudly that Carson's "passion for eliminating mercury and thimerosal in vaccinations stemmed from personal experience" (www.momsagainstm Mercury.org). This is in contrast to the outwardly stated focus on science and research by SafeMinds which draws attention to the varied approaches in this debate. For MAM, they believe their voices should be heard and taken seriously not only because they believe they have the scientific evidence to back it up but because they are the parents of these children and therefore have the most knowledge.

MAM has organized two large-scale rallies to raise awareness and accountability to the CDC. The first rally, called “The Power of Truth Rally” (Figure 3), took place in Washington, DC, on July 20, 2005, in front of the Capitol Building. Other collaborating groups were A-CHAMP, Coalition for Mercury-free Drugs, Dad’s Against Mercury, Educate Before You Vaccinate, Generation Rescue, NAA, NVIC, NoMercury, SafeMinds, and Unlocking Autism. The rally featured several speakers including Dan Burton, Dave Weldon, Diane Watson, and Carolyn Maloney along with author David Kirby, Dr. Boyd Haley, president of the AA, Wendy Fournier, and MAM co-founder Amy Carson. The keynote speaker was a five-year-old “recovered” child, Zachary Barsamian. Andrew Wakefield was also present. There is no final headcount available; however, the NAA claims over 700 people registered. The photos in the figures below were taken at the rally and posted for the public on www.momsagainstm Mercury.org (no individual photo credit given on the website, all posted under momsagainstm Mercury.org).

Figure 3. Power of Truth Rally



Photo credit: www.momsagainstm Mercury.org copyright 2005-2007

Figure 4. Power of Truth Rally



Photo credit: www.momsagainstm Mercury.org copyright 2005-2007

Figure 5. Signs and shirts from the Power of Truth Rally

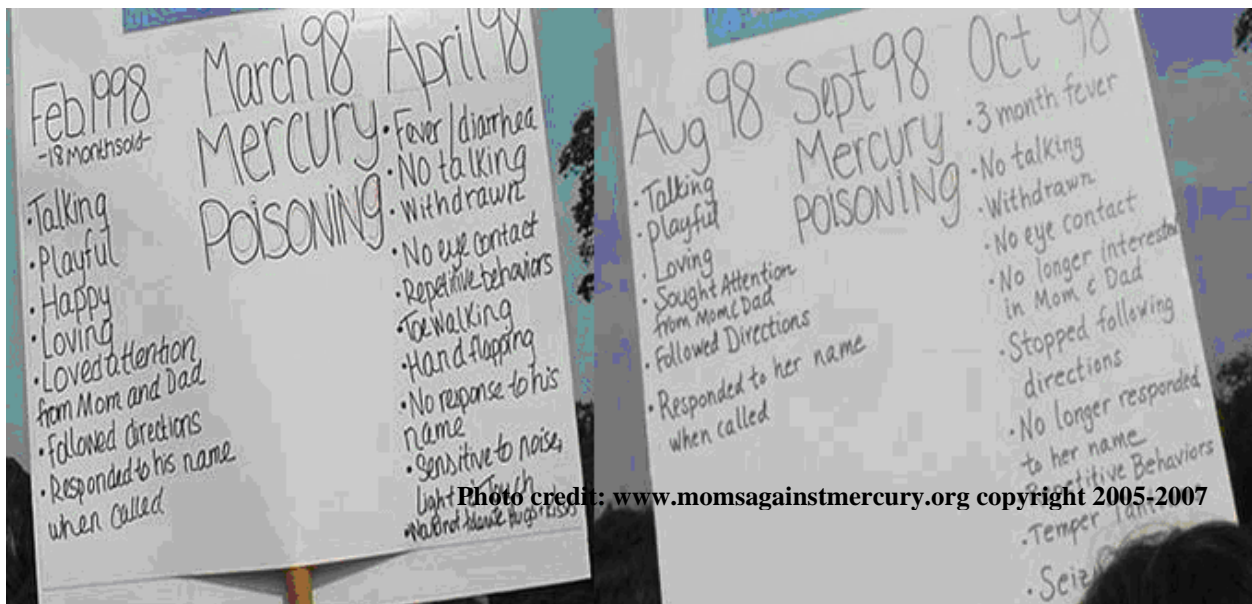


These photos express the anger, frustration, and blame the parents feel towards the CDC, government, and the pharmaceutical companies.

Photo credit: www.momsagainstm Mercury.org copyright 2005-2007

Many photos included parents and children carrying charts with specific mercury levels in shots, lab results from testing hair and urine, and cumulative exposure to mercury totals. These types of signs were meant to highlight the medical evidence proving their children were poisoned by mercury in vaccines. Other popular types of signs included “before and after” scenarios, either through pictures of children before their vaccines or with descriptions of their child’s behavior before and after their vaccinations (Figure 6).

Figure 6. Before and after signs from the Power of Truth Rally



These photos illustrate that for the ASD/VL activists, the evidence of harm is found in their observation of their child before and after vaccines. The photos also represent a strategy used in this debate, though most ASD/VL activists would deny it is a strategy and consider calling it such insulting, and that is the use of their children. Many parents brought their children to these rallies, to the hearings, and even to the panel before the IOM to show everyone how “damaged” they were. The use of children with ASD by ASD/VL activists is an extremely

volatile subject. On the one hand, it can be condemned by the ASD/VL opponents as tasteless and exploitive. On the other hand, it can be viewed by the ASD/VL activists as their attempt to force their opponents to see the reality of their situation and confront the people they believe to be responsible with the evidence of their harm. From my interviews with the IOM, I do not think that using children with ASD has been a successful strategy. Indeed, it has had the opposite effect and has only bolstered the ASD/VL opponents' arguments that the ASD/activists are extremists because, as Beth stated, "Who would use their own child in such an exploitive way to make a political point?" (personal interview, 16 Oct 2007)

The second rally organized by MAM occurred on Thursday, June 29, 2006, but this time it was held in front of the CDC in Atlanta, Georgia. This rally was very direct and aggressive in its purpose: to target and protest against those that they held responsible for their children's ASD, namely, the CDC. Their mission for this rally was to "send a message to the CDC that we will no longer tolerate their cover up, lies, and deception about mercury in vaccines!" (www.momsagainstmercury.org). This rally was also an effort to bring attention to the Simpsonwood Retreat and the "criminals" that were present, as MAM describes them. The name of the rally was "Scene of the Crime," and the logo, which was an image of a needle, was printed on t-shirts and bumper stickers with the phrase: "Scene of the Crime Rally: Our Children, Your Crime....It's Prison Time!." The photos from this rally are similar in message and style to the ones taken at the Power of Truth Rally only with a more specific focus on blaming the CDC.

Figure 7. Scene of the Crime Rally



Photo credit: www.momsagainstmcury.org copyright 2005-2007

The above poster designates Marie McCormick of the IOM, Paul Offit of the CDC, and William Eagen, deputy director of the FDA as “terrorist.” The word “terrorist” was used by both sides to frame the other as corrupt and evil. It is a simplistic word used to bring to mind images of the most disdained and morally reprehensible people and acts. It is an unfortunate choice of word, as both sides of the ASD/VL debate genuinely did and continue to have the interest of the public as their foremost concern, which is quite the opposite of terrorism. The use of the word “terrorist” does show, however, the extreme emotions that characterize this debate.

Again, I could not find total headcount estimation for this rally, but MAM claims it was “a huge success despite the CDC’s efforts to make it very difficult for us to succeed with it” (www.momsagainstm Mercury.org). They further state:

We cannot thank you all enough for coming together with us and letting the CDC know that we will no longer tolerate their lies. We will continually send cards to the Simpsonwood criminals each year to remind them of those hateful days in June that they all agreed to continue poisoning America’s children (www.momsagainstm Mercury.org).

The next rally organized by MAM took place on June 7, 2007, again in front of the CDC. This one was titled “Simpsonwood Remembered Rally” and focused on exposing “the infamous, secret Simpsonwood meetings.” MAM was able to recruit the United Methodist Women Division as a co-sponsor of the rally, which they were very proud of and excited about, as they stated on the rally advertisement, “This is a huge victory for our movement! This is the first time a global organization has decided to support our fight for our mercury injured children!” (www.momsagainstm Mercury.org). During their rallies at the CDC, MAM has always made certain that they followed ordinances set by Homeland Security and the county police, meaning they could not (and did not) trespass on the CDC property nor did they plan violence, arrests, or disorderly conduct. They also did not allow megaphones and advised everyone to abide by all rules and regulations. Interestingly, they also advised attendees not to bring the American flag to the rally. Though not explicitly stated, I believe this was due to MAM’s desire to avoid any kind of potential for allegations of anti-American or anti-patriotic behavior that could happen with an attendee carrying the flag upside down, burning it, or dragging it on the ground.

Next, MAM held a rally titled “Toxic Lies, Toxic Children” at the steps of the AAP contesting their continued support of thimerosal in vaccines. This rally also had a focus on curing autism. Interestingly, in their flyer for this rally, MAM called for ASD/VL activists to send in

their prophyrin test (tests for heavy metal content in body), urine, or fecal toxins lab results to use as evidence of mercury poisoning. The goal was to connect the idea that ASD was biologically caused and could therefore be biomedically cured with treatments such as chelating (the process of excreting heavy metals from the body), diet, and supplements. This is another excellent example of ASD/VL activists collecting their own data to be used as a tool to challenge mainstream medicine.

This rally had much more involvement from other vaccine awareness groups, including Generation Rescue, TACA-Chicago chapter, World Mercury Project, Illinois Vaccine Awareness Collation, and the Evidence of Harm Yahoo Group discussion board. The broader collaboration shows how the movement has expanded its focus from just mercury in vaccines to mercury harm in general, vaccines in general, and the belief that autism can be cured. This was the last rally that has been hosted and put together by MAM, though they have gone on to sponsor other rallies, such as the “Green Our Vaccines” rally organized by Generation Rescue.

5.2 DAMAGE CONTROL

Following the campaigns of the ASD/VL movement to discredit the CDC, IOM, and mainstream medicine, opponents of the movement acted to frame their movement as anti-science, fringe, and radical. Opponents of the ASD/VL movement also sought to expel the Geiers and Wakefield from mainstream medicine. The following chapter discusses Western mainstream medicine’s use of boundary work to protect their autonomy and the boundaries of credible science. This chapter

also explores how the response to the challenges brought by the ASD/VL activists can be understood as a countermovement.

5.2.1 Boundary work: Expulsion from the Ranks

Gieryn notes that during boundary disputes, the lines of credible territory are contested, and the outcome of the dispute results either in “purifying” the scientific territory or the opposite. Generally, boundary disputes over the power to define meanings and control techniques and practices result in a tightening and solidification of boundaries, thus purifying the territory (Gieryn 1999). Yet boundary work can also result in an impurification. When resources are at stake, particularly material resources such as funding, instruments, and personnel, the boundaries are stretched and sometimes diluted to appeal to the greatest audience and appear the most beneficial for larger society (Gieryn 1999). ASD/VL boundary dispute causes the potential for impurification as researchers on both sides struggled to argue their case, even if it meant selectively critiquing research or stretching beyond the boundaries of what their research could support. For example, while impressed with ASD/VL activists’ ability to deconstruct studies, my informant Eric found their efforts one-sided. He stated that ASD/VL activists are always on top of tearing down studies proving no link between ASD and vaccines but would rarely say anything negative about studies that did suggest a causal relationship. As Eric stated, “They pick apart every study that says there's no link. But when a study, well they made so much hay over the Hornig mouse study, I didn't hear a peep when a study came out that said they couldn't replicate any of that. And it was done at the Mind Institute! So, fair's fair right?” (telephone interview, 15 Nov 2007) However, after stating this, Eric did concede that some of the mainstream scientists working to discredit the link are not free from the same biased scientific

criticism. Eric sided with SafeMinds on the criticism of one particular study claiming to provide evidence that MMR vaccines were not related to autism. Eric was disappointed in professionals who stretch beyond what their findings actually supported in order to discredit the theory. He stated, "I'm sorry, when the people who should know better fall into the same traps, they should know better. That study really did not say anything about vaccines and autism." This type of selective criticism and trumped up findings is an example of boundary work as parties try to have their theories validated.

Throughout this debate, mainstream medicine has actively sought to shore-up its boundaries in an attempt to distinguish legitimate from illegitimate science. This has meant expelling those deemed non-credible. To accomplish this, mainstream medical institutions including the AAP, the CDC, and the IOM set out to blacklist the Geiers and Wakefield. The arguments that mainstream medicine used against the Geiers included their lack of peer review process, working outside their expertise area, lack of qualifications, and accusations of outright "voodoo" science. As quoted in the *New York Times* (Harris and O'Conner 2005: paragraph 30), "The problem with the Geiers' research is that they start with the answers and work backwards," said Dr. Steven Black, director of the Kaiser Permanente Vaccine Study Center in Oakland, California. "They are doing voodoo science."

The Geiers have also been blacklisted in the court system. Indeed, the Geiers have acted, or attempted to act, as expert witnesses arguing in favor of a causative link between vaccines and ASDs in hundreds of vaccine damage cases. However, judges across the nation have agreed that

their data was not sufficient and that they failed to meet the Daubert standard⁵. As quoted in the *New York Times* in 2003, a judge ruled that Mark Geier was "a professional witness in areas for which he has no training, expertise and experience" (Harris and O'Conner 2005: paragraph 30) In other cases, judges have called Mark Geier's testimony "intellectually dishonest," "not reliable" and "wholly unqualified." (Harris and O'Conner 2005: paragraph 30). This did not deter the Geiers from continuing their search for more data nor from their belief that mercury and ASD are directly linked.

In 2006, the Geiers submitted an article to the journal *Autoimmunity* titled "The biochemical basis and treatment of autism: Interactions between mercury, transsulfurations, and androgens" asserting the link between thimerosal and vaccines. The article was scheduled for publication and announced on the journal's website, but then interestingly the journal chose to retract the article without stating a reason. Brain Deer, a journalist for the *Sunday Times* in England, has played a significant role in the Geier and Wakefield cases. In 2007, he exposed in a scathing article titled "What makes an expert" that the retraction of Geier's article came after the journal editors were made aware that the Geiers' "institutional" review board consists of Mark and David Geier, along with Dr. Geier's wife, two of Dr. Geier's business associates, and two mothers of autistic children, one of whom was a patient of Dr. Geier while the second parent has

⁵ In *Daubert*, the Supreme Court held that federal trial judges are the "gatekeepers" of scientific evidence. Under the *Daubert* standard, trial judges must evaluate proffered expert witnesses to determine whether their testimony is both "relevant" and "reliable", a two-pronged test of admissibility. (1) The relevancy prong: The relevancy of a testimony refers to whether or not the expert's evidence "fits" the facts of the case. For example, you may invite an astronomer to tell the jury if it had been a full moon on the night of a crime. However, the astronomer would not be allowed to testify if the fact that the moon was full was not relevant to the issue at hand in the trial. (2) The reliability prong: The Supreme Court explained that in order for expert testimony to be considered reliable, the expert must have derived his or her conclusions from the scientific method. The Court offered "general observations" of whether proffered evidence was based on the scientific method, although the list was not intended to be used as an exhaustive checklist: (Wikipedia.com)

pending vaccine injury claims (Deer 2007). Institutional review boards are designed to ensure patient safety, and investigator bias are addressed and accounted for, therefore an IRB consisting of relatives and patients is highly inappropriate.

Andrew Wakefield has also faced expulsion from the ranks of credibility. After his testimony at Burton's hearing, the next integral event in the Wakefield debate surfaced in March 2004 when the British General Medical Council (BGMC) announced it was launching an investigation into Wakefield's conduct and research. At the same time, the editor of the *Lancet* came under increased scrutiny for allowing the publication of the Wakefield article. He subsequently stated it never should have been published due to methodological shortcomings and ten of the thirteen authors retracted their support for the conclusions that suggested a link between MMR and autism. The remaining three authors, including Wakefield, became the target for the Ethics and Conduct in Research investigation headed by the BGMC (Deer 2007).

Deer was integral in bringing allegations against Wakefield to the BGMC, claiming he had violated research ethics by exposing the 12 children in the study to excessive, invasive testing, specifically colon biopsies and lumbar punctures. This was only the beginning of claims against Wakefield. Over the course of the next five years, evidence was collected and presented against him in a 2007 hearing before the BGMC including dishonesty in subject recruitment and failure to disclose financial incentives – some of the children were recruited through a lawyer representing their parents in a case against the MMR vaccine manufactures and were paid for their involvement. Neither fact had been disclosed to the IRB (Deer 2009). Second, Wakefield did not disclose that he and the hospital hosting the research were paid by the lawyers representing study subjects in the case against the MMR vaccine manufacture. Specifically, the Royal Hospital received £55,000 from the UK Legal Board to pay for research, and Wakefield

himself had been paid over £400,000. Next, Wakefield ordered and administered invasive tests on subjects without “the requisite pediatric qualifications” and against the children’s best interest, in effect putting their health needlessly at risk (Deer 2009). Additionally, he was charged with conducting the study in a manner not approved by the hospital’s ethics committee, including purchasing blood samples from children while they attended his son’s birthday party. Finally, Brian Deer argued that Wakefield applied for a patent on a single measles vaccine. Even if Wakefield had not applied for a patent on a single dose vaccine, the degree of conflict of interest, from subject recruitment, to payment from the lawyers to the hospital, and to Wakefield himself, is inexcusable.

The proverbial nail in Wakefield's coffin came just recently as information surfaced that he *suppressed and falsified data* to support the MMR/ASD link. Evidence presented to the GBMC included testimony from Dr. Stephen Bustin and Dr. Nicholas Chadwick, interviews with participants and witnesses, and a review of the medical records of the children who were listed as participants in the study. This evidence was reported in the *Sunday Times* by Brian Deer in February 2009 under the headline “MMR doctor Andrew Wakefield fixed data on autism” and stated explicitly that Wakefield “changed and misreported results in his research, creating the appearance of a possible link with autism” (Deer 2009). Specifically, investigation found that the symptoms of the children presented in the *Lancet* article were not the same symptoms that their medical records report. The *Times* states in most cases, the symptoms were noted in the child’s charts before they received the vaccine, that in only one case did onset of symptoms occur within days of the vaccination, and that the reports of abnormal gut or bowel did not hold when reviewed by pathologists (Deer 2009). The final decision by the GBMC has not yet been made, and Wakefield continues to deny the allegations against him. In response to the accusations made by

Deer, Wakefield wrote a 58-page letter to the editor contesting Deer's article, claiming slander and misrepresentation. In the meantime, as the executive director of Thoughtful House for Children in Texas, Wakefield continues to treat children who he claims have "autistic enterocolitis," which he states is a new disease but is not accepted within mainstream medicine.

In addition to the expulsion of non-credible scientists, opponents of the ASD/VL movement have undertaken an aggressive framing campaign to protect their autonomy and the boundaries of legitimate science.

5.2.2 Framing tactics

The attempts of mainstream medicine and its supporting institutions to protect their autonomy, the borders of credible science, and to "purify" the territory was accomplished not only through expelling the Geiers and Wakefield but through an aggressive framing campaign of the entire movement as anti-science and extreme. As Eric stated, "They don't use the scientific process. It's this struggle. The shifting hypotheses that happen... as soon as you say there's nothing for X [they say] oh, it could be Y. They're not going to give up, they're really not" (personal interview, 15 Nov 2007). This sentiment was also expressed in a quote from the 2004 chairwoman of the IOM, Dr. Marie McCormick, who stated, "It's really terrifying, the scientific illiteracy that supports these suspicions" (Harris and O'Conner 2005: paragraph 7).

The "anti-science" frame is a purposeful attempt by a group to paint the opposition as fanatic and jeopardize its credibility while at the same time reinforcing its own. As Hunt, Benford, and Snow state, frames "condense aspects of the world out there...in ways that are indented to mobilize potential adherents and constituents, to garner bystander support, and to demobilize antagonists" (1994:198). This indeed was the goal of mainstream medicine. The

New York Times quoted Dr. Melinda Wharton, the deputy director of NIP as stating, "This is like nothing I've ever seen before. It's an era where it appears that science isn't enough" (Harris and O'Conner 2005: paragraph 5). And Ms. Kris Ehresmann, the Minnesota immunization official stated, "It doesn't seem to matter what the studies and the data show. And that's really scary for us because if science doesn't count, how do we make decisions? How do we communicate with parents?" (Harris and O'Connor 2005: paragraph 56)

In addition to framing the movement as anti-science, they also framed the movement as radical and fringe. The "terrorism" characterization began when, prior to the second IOM hearing, one of the IOM researchers received a threatening email that stated: "Forgiveness is between them and God. It is my job to arrange a meeting" (Harris and O'Conner 2005: paragraph 50). McCormick shared with the *New York Times* that she and the CDC had also received threatening emails. The *New York Times* then filed for a release of records and gained access to an email sent to the CDC that said, "I'd like to know how you people sleep straight in bed at night knowing all the lies you tell and the lives you know full well you destroy with the poisons you push and protect with your lies" (Harris and O'Conner 2005: paragraph 50). These are barely enough to characterize an entire movement as terroristic. Indeed, when I asked my IOM informants about the emails, they reported that they did not view them as real threats. But CDC officials and others in mainstream medicine continued to try and frame the entire movement as a group of fanatical parents, particularly Paul Offit.

Offit is the chief of staff of Infectious Diseases at the Children's Hospital of Philadelphia. He is also the co-inventor of the vaccine against rotavirus and perhaps the most outspoken vaccine advocate and ASD/VL opponent. Offit has spoken out against the parents who have organized around the ASD/VL movement for years. His book *Autism's False Prophets*

summarized his arguments on why the entire ASD/VL movement is not only false but dangerous. The picture he painted of the opposition is grim. He generally characterized the ASD/VL activists as terrorists and stated to the *New York Times* he will not be doing a book tour because of the death threats he has received. “I’ll speak at a conference, say, to nurses...But I wouldn’t go into a bookstore and sign books. It can get nasty. There are parents who really believe that vaccines hurt their children, and to them, I’m incredibly evil. They hate me. Opponents of vaccines have taken the autism story hostage” (McNeil 2009: paragraph 3).

His harsh characterizations, along with those of his celebrity spokesperson, actress Amanda Peet, are strategic in that they are hoping to connect the anti-vaccine, or even vaccine skepticism, with fanatical extremists. Peet called parents who do not vaccinate “parasites” because they rely on the vaccination of other children to protect themselves (McNeil 2009). It is exactly this gross exaggeration of the activism that the parents themselves wish to distance themselves from and why they are hesitant to call themselves activists as discussed in a later chapter. I have not found any evidence of this extremism or even terrorist characteristics among the ASD/VL activists I interviewed. SafeMinds, along with most of the movement’s groups, stated that this is not typical behavior nor advised practice among group members. They are politically active and they do practice standard strategies employed by any social movement such as letter writing, protest rallies, and phone calls. But rather than framing these activities as political actions, their opponents characterize them as terrorism.

5.2.3 Movement/Countermovement Dynamics

The responses and reactions, including the use of boundary work strategies, from opponents of the ASD/VL activists resemble movement/countermovement phenomena described by Meyer

and Staggenborg (1996). The data collected for this project did not include a plan for collecting countermovement group presence or organization, which unfortunately limits a full exploration of how Meyer and Staggenborg's rich theoretical framework may apply to this case. However, there are key elements present in this analysis of the ASD/VL debate that can be enhanced through engaging with the discussion of countermovement emergence and movement/countermovement interaction. Meyer and Staggenborg (1996: 1630) state that "any social movement of potential political significance will generate opposition." This opposition can be described as a countermovement, which they define as "a movement that makes contrary claims simultaneously to those of the original movement" (Meyer and Staggenborg 1996: 1631). Movements that have the potential for success, that present a potential threat to some population, and that have political allies who oppose movement goals are more likely to see a countermovement emerge (Meyer and Staggenborg 1996: 1635). All three of these conditions are met in the ASD/VL debate; the ASD/VL activists achieved success in mobilizing support for their argument and influencing political agendas which in turn presented a threat to Western mainstream medicine's credibility and authority. Finally, the political allies of the IOM, and indeed the CDC itself strongly oppose the arguments of the ASD/VL activists, providing a foundation for a countermovement to form.

Countermovement activities happen simultaneously, which is critical as each side is influenced and in some cases forced to respond and adjust to the actions of the countermovement, thus changing the movement environment (Meyer and Staggenborg 1996). The strategies employed by public health officials and opponents of the ASD/VL debate to discredit the opposition and protect the boundaries of credible science as described above were carried out in response to the arguments and challenges brought by ASD/VL activists. This

offense/defense action then led to ASD/VL activists countering with their own media campaigns, protests, rallies, and research. Aiding the emergence and continuation of movement/countermovement processes have been the utilization and creation of opportunities to engage in movement interplay. Meyer and Staggenborg (1996:1638) state that “When movements effectively create or exploit events, they are likely to encourage countermovement mobilization at the same time that they advance their own causes.” In the ASD/VL movement activists took advantage of (and created) key events to advance their cause including the congressional hearings held by Burton, the IOM panel review hearings, and the release of the Simpsonwood transcript. Displeased with the arguments presented during and after these events, opponents formed their own strategies to counter ASD/VL activists. More research on potential countermovement formation at a grassroots level is needed to more fully explore how countermovements may have taken advantage of these events.

The ability of a movement to stay relevant and active is related to its ability to change and utilize various venues for action (Meyer and Staggenborg 1996). ASD/VL movement groups and their opponents have been extremely adept in their utilization of multiple institutional sites for action, including the media, federal and state legislatures, and the courts. Meyer and Staggenborg (1996: 1649) state that when a movement “enters a particular venue, if there is the possibility of contest, an opposing movement is virtually forced to act in the same arena”. This forced engagement is seen in this debate as ASD/VL movement groups have used the media and celebrity spokespersons to argue their points, forcing their opponents to enter the same venue and even utilize the same tactics, such as securing celebrity support, to counter the claims.

Meyer and Staggenborg (1996: 1647) posit that the movement/countermovement action and response dynamic can only go on for so long. They state: “in the long run, neither side can

maintain itself without victories; the side that fails to win any victories over many years will decline”. Both sides have seen victories and defeats in this debate which, according to Meyer and Staggenborg (1996) contributes to movement longevity. Further, with the numerous pending court cases and the broadening in focus of the ASD/VL activists groups, the potential for the continuation of this cycle of protest and response is great.

This section has merely touched on the movement/countermovement dynamics that may be at work in this debate. Meyer and Staggenborg (1996) offer a full framework for exploring movement and countermovement dynamics and their work would be a valuable guide for future research into how opponents of the ASD/VL argument have organized to counter the movement’s influence.

6.0 IN THEIR OWN WORDS

The following chapter brings in the voices of those ASD/VL activists I interviewed along with data from my online survey to contextualize the events detailed above. The first section addresses ASD/VL activists’ response to the idea that they are anti-science and scientifically illiterate. The second section discusses the lack of trust in institutions responsible for public safety, followed by the third section examining who ASD/VL activists do trust and how they determine what is trustworthy and credible.

6.1 DON'T CALL ME ANTI-SCIENCE

ASD/VL movement groups have emphatically not been terroristic and definitely not anti-science; indeed through the practice of popular epidemiology and the funding of research, they have been extremely pro-science. However, by framing the parents as anti-science, mainstream medicine has hoped to retain the position of cultural authority and reinforce scientific boundaries. In response and to prove they should be heard and viewed as credible, ASD/VL activists have worked towards becoming lay experts.

To become lay experts, ASD/VL activists read as much literature on ASD and vaccines as they could. My survey data showed parents read new research and sought out new research weekly. In fact, I found that the majority (64%) read literature related to autism daily and were passionate about gaining as much knowledge on the subject of vaccines and ASD as possible, as the following quotes illustrate:

I have been looking really rigorously at the studies. Of course, like any study, there is always a weakness (Elizabeth, telephone interview, 6 Nov 2007).

I read a lot of medical journals (Clare, telephone interview, 15 Jan 2008).

I get the newsletters from everyone. I like to read all the information, anything I can get my hands on (Tova, telephone interview, 13 Sep 2007).

I'm lucky to have access to the libraries and the journals through my university since I'm an employee, so I can get into the databases and do the research on what's been done (Veronica, telephone interview, 28 Nov 2007).

As the quotes demonstrate, ASD/VL activists claimed to constantly keep up with research and literature on vaccines and ASD. They were also critical readers. Hope stated, "I have it in my notes but there was a statistic released that for elderly people who have received at

least five consecutive flu shots, their chances for Alzheimer's increase exponentially...which to me makes sense if metals do have a correlation" (telephone interview, 31 Oct 2007). This quote illustrates how ASD/VL activists have adopted and incorporated scientific language such as "exponentially" and "correlation" into their vocabulary and use it to their advantage. Furthermore, the research they are becoming familiar with is not just on autism. It is on the link between autism and vaccines and the possible biological mechanisms that may be at work. This is important because it shows that they are interested not only in treatment for their own child but in being part of the larger conversation on vaccines and autism. Further, it shows that they know that to be part of this conversation, they have to be seen as credible which requires they learn the language..

ASD/VL activist brought their own studies to the table and criticized studies they felt were biased or problematic. They tried to push through the boundaries of mainstream medicine using the language of science as their tool. They worked with scientific advisory boards, went through IRBs, and used the same kind of scientific language to discuss complex biological mechanisms. To the casual observer, and to some fellow researchers, they were equally as reliable and valid as any other mainstream scientist. Yet the ASD/VL activists did not accept the findings of the IOM panel nor the research showing no link. Why? The problem was not that they were anti-science; the issue was that they did not trust the institutions producing the science.

6.2 TRUST IN INSTITUTIONS

The aggressive framing of ASD/VL activists as fringe and dangerous only seemed to have strengthened the opinion of the activists that mainstream medical institutions cannot be trusted. If

the research institutions producing the findings are not trusted, then it does not matter how much scientific literacy one has. The recommendations based on those findings will not be followed.

According to my survey and interview data, members of the ASD/VL movement have little to no trust in the government and mainstream medical institutions. The CDC tried to assure the public that they could be trusted. Dr. Julie L. Gerberding insisted there was absolutely no attempt to hide information or manipulate data. She was quoted in the *New York Times* as saying, "There's certainly not a conspiracy here... And we would never consider not acknowledging information or evidence that would have a bearing on children's health" (Harris and O'Conner 2005, paragraph 46). My IOM informants were also disheartened with the lack of trust attributed to the IOM. Eric stated in a rather defeated voice, "They don't trust us. They had it in their head we were in cahoots [with the CDC and pharmaceutical companies]. We were cleared from the House committee of being in cahoots, but they assumed we were" (telephone interview, 15 Nov 2007). Eric recalled the discussion with Barbara Lo Fisher after the final report as evidence of their distrust:

Barbara Lo said "How can you say this is an unbiased committee?" and I said, "What more do you want?" and she said, "Don't you think that because they're all from schools of medicine and public health that they're indoctrinated into being pro-vaccine?" and I said anyone who wasn't pro-vaccine we would consider to be scientifically indefensible. It isn't pro-vaccine or anti-vaccine, it's about one vaccine and one side effect. Meanwhile, they will never acknowledge that *they* are biased, that some of their experts are financially conflicted. They won't see it (telephone interview, 15 Nov 2007).

This quote highlights the fact that the movement's lack of trust extended beyond just the IOM, it extended to the supporting institutions and entire field of mainstream medicine. To investigate this further, I included measures of trust in my survey and asked ASD/VL activists

how they felt about different institutions. When asked how trustworthy respondents felt the CDC was, 40% felt it was not at all trustworthy, 24% felt it was “a little,” 22% felt it was “mostly” trustworthy, and 1% felt it was “extremely trustworthy” (12% don’t know).

The CDC has been a primary target of the activists in the ASD/VL debate. In fact 43% of survey respondents felt that the CDC is responsible for allowing the levels of mercury in vaccines to surpass safe levels. This is most likely due to the greater expectations of protection and responsibility the public has entrusted to the CDC; with greater expectation comes greater disappointment. As Sue states, “I didn’t believe it at first. I thought there’s no way, there’s no way this could be happening. There are so many safeguards in place” (telephone interview, 18 Sep 2007). For the activists I interviewed, it was not simply a lack of trust, but the belief that the CDC is calculating in their efforts to undermine and slander the works of the activists, as the following quote from Hope illustrated:

After the whole Jenny McCarthy press tour, I saw then that the CDC immediately put out this study. But ya know, no one looks past the headline, including the fact that the doctors get so much of their “continuing education” from pharmaceutical companies, and so it’s really frustrating and upsetting (telephone interview, 31 Oct 2007).

Likewise, Barb stated, “The sad thing is right after that [Jenny McCarthy on Larry King], the CDC released that study that didn’t even have anything to do with autism but... the headline was thimerosal doesn’t have any bad side effects... That’s been very frustrating – the way the press takes what the CDC says and so many don’t question it at all, and it comes across as ‘this is the authority’” (telephone interview, 4 Nov 2008). This quote highlights the fact that parent activists have withdrawn their support of the CDC and mainstream research as the cultural authority on health and science. It demonstrates how cultural authority can be degraded and lost. Furthermore, these two quotes highlight how arguments circulate through movements. All of my participants

interviewed after McCarthy’s interview with Larry King referenced the fact that the CDC released an article directly after McCarthy’s appearance in an effort to discredit and slander the ASD/VL movement. This illustrates how connected members of the ASD/VL movement are and how quickly information is shared and shaped into repertoires that are then circulated to movement members.

My survey also asked respondents about their trust in the FDA, EPA, IOM, and presidential administration, the results of which are summarized in Figure 8.

Figure 8. Levels of trust by agency

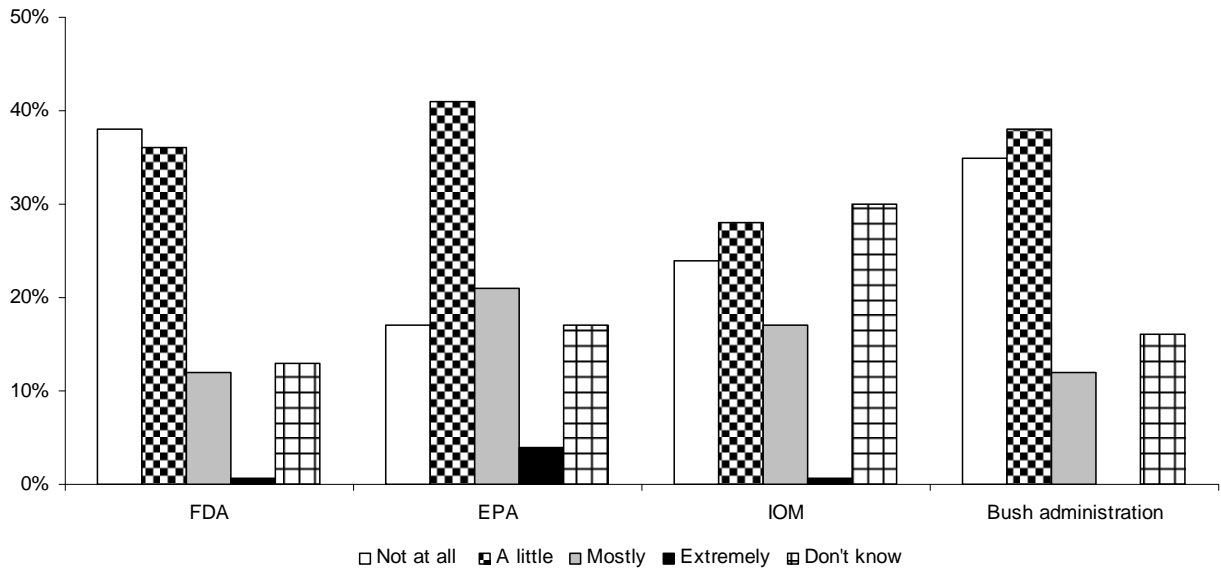


Table 11: Correlation of trust by institution

Institution	IOM	FDA	Pharma	EPA	BUSH
CDC	.875*	.770*	.818*	.751*	.821*
IOM		.770*	.760*	.751*	.789*
FDA			.778*	.696*	.790*
Pharma				.668*	.810*
EPA					.723*
*p<.000					

To examine the strength of association among the trust variables I constructed cross tabulation tables and used the Goodman and Kruskal's gamma test for ordinal variables. Results show that all the trust variables are significantly associated; meaning a person who answered 'extremely trustworthy' for one institutional trust variable is likely to answer 'extremely trustworthy' for the other institutional trust variables (Table 11). While measures are significant at $p < .000$, it is interesting to note that the weakest levels of association are among the EPA, suggesting the survey population may consider this institution slightly separated from rest.

I also examined the relationship between activism and trust in institutions. I hypothesized that those who are less trusting in the above institutions would be more likely to participate in activist activities. Because all of the 'trust in institution' responses are highly correlated, I used 'Trust in the CDC' as a proxy measurement of trust in institutions and re-coded the variable into "a little/not at all trustworthy" and "mostly/extremely trustworthy." Using the responses (yes/no) to the question "Do you make it a point to share your thoughts on the relationship between ASDs and mercury with others"⁶ as a proxy for ASD/VL activism, I constructed a 2X2 table and used the Phi-coefficient to measure association between the two variables; the results are reported in Table 12. Results show that the two measures are significantly associated, meaning those who are less trusting in the CDC are more likely to talk to others about their beliefs regarding ASD and vaccines.

⁶ This question is also significantly associated (Contingency coefficient is .720, $p < .000$) to the question "Would you ask your doctor to speak to friends, families, or the public about the ASD/VL link" meaning those who answered 'yes' to the speaking about others about the ASD/VL are also likely to answer 'yes' to asking their health care provider to speak about the ASD/VL.

Table 12: Trust in institutions by activism

Symmetric Measures Trust in Institutions by Activism			
		Value	Approx. Sig.
Nominal by Nominal	Phi	0.407	0.000
N of Valid Cases		125.000	

a Not assuming the null hypothesis.

b Using the asymptotic standard error assuming the null hypothesis.

The EPA appeared to command the most trust of all institutions (Figure 8); this is perhaps due to the fact that they maintain the most stringent estimations of what is considered a harmful amount of heavy metals like mercury. I also asked respondents specifically about the trust in the George W. Bush administration, which resulted in majority trusting the administration either a little or not at all. My in-depth interviews provided more context to the lack of trust in the Bush administration. It seems that within the ASD/VL activist community there are several reasons for distrusting the administration and all are linked to the connection of the Bush family to Eli Lilly. According to Joyce, George H.W. Bush chose Dan Quail as a running mate because of his connections with Eli Lilly. She stated, “I never understood why Bush, Sr. chose Dan Quail as his VP when he was running for president but here the connection is the Quail family at that time had controlling interest in Eli Lilly, who of course was a big Bush supporter. It’s all about money” (telephone interview, 4 Oct 2007). The most often cited reason for distrust of the Bush administration among ASD/VL activists is the special protection written into the Homeland Security Bill to protect Eli Lilly. According to Sue:

In 2002 when they were passing the Homeland Security Bill, in the 11th hour when Congress was about to vote on this bill, they slipped in riders that would have protected Eli Lilly, the makers of thimerosal, against litigation. And there’s this new study out that shows there’s no connection to the vaccines, and these studies are funded by the government, and they’re always put in journals that are funded by the pharma companies. And ya know, it always

comes back to it if there is no connection, then why in the name of God did they feel the need to put those riders into the bill to protect the drug company? (telephone interview, 28 Nov 2007).

Veronica and Kara similarly stated their lack of trust and their disappointment in the U.S. government. “I have completely lost trust in the government. I don’t believe they’ve really got our best interest in mind, especially with the current [Bush] administration” (Veronica, telephone interview, 28 Nov 2007). “I don’t turn on the TV anymore. I used to very actively keep in touch with politics and news, and I don’t anymore. It’s just too upsetting” (Kara, telephone interview, 1 Nov 2007). Hope decided to abandon her political party ties and now votes for those who share her views on the ASD/VL. “I’ve become independent primarily because this whole thing. All these toxins that are thrown at us without any protection by the government, and in fact so much of it encouraged by the government, and it’s all really upsetting to me, and it’s swayed me politically. I pretty much go to anyone who courts me on this issue, so to speak” (telephone interview, 31 Oct 2007).

By far the least trusted of the institutions in question were the pharmaceutical companies, here described collectively as “Big Pharma.” Trust in Big Pharma was as follows: 53% felt they were not at all trustworthy, 29% felt they were a little trustworthy, 9% felt they were mostly trustworthy and 2% felt they were extremely trustworthy (7% don’t know). Big Pharma is a primary target for many of the activists, particularly Eli Lilly and Merck due to their relationship with the Bush administration, as Joyce stated:

What bothers me the most are these drug companies knew about the dangers of thimerosal. Merck knew way back in 1991. They knew, they did nothing. And as far as I’m concerned, these people are criminals and should be charged with crimes against humanity, and they deserve to be in jail. I don’t think we will ever see that kind of justice because there’s too much conflict of interest, there’s too much cover up on a federal level from the CDC all the way up to the White House. You know Bush had a chance to sign a bill to

ban thimerosal in all vaccines, which he said he would do during his bid for re-election, but what did he do but veto it (telephone interview 4 Oct 2007).

Kara similarly stated, “They [Big Pharma and the Bush administration] are definitely hiding a lot. The truth comes out sooner or later. I just hope I’m alive to be able to relish in and put it back in the faces of those who say there is no connection” (telephone interview 1 Nov 2007).

Many of the activists expressed that their feelings go beyond distrust to the belief that Big Pharma is not interested in protecting and serving the health of the population and is knowingly and purposefully putting unsafe products on the market, as Joyce and Diane expressed below:

Once these companies know about the dangers, they know about the risks and continue to use it. I just don’t know how they live with themselves (Joyce, telephone interview, 4 Oct 2007).

They want us as sick as possible because if we’re healthy, they don’t have any customers (Diane, telephone interview 27 Oct 2007).

Among ASD/VL activists I interviewed, the distrust and anger towards Big Pharma often translated to a refusal to use prescription drugs to manage their child’s autism. As Sue stated, “I refuse to use drugs to manage my son’s autism. For the very reason that [pharmaceutical companies] are the people responsible for this. I am not going to trust them with my children’s lives or my life again. I take nothing that comes from a drug company other than Advil” (telephone interview, 18 Sep 2007). However, all of the ASD/VL activists I interviewed did employ other forms of bio-medical treatments, such as special supplements, B12 shots, and dietary restrictions. Their reluctance to use interventions from Big Pharma yet their willingness to use alternative bio-medical interventions suggests that they distinguish between which interventions are considered “good” and which are considered “bad.” It appears that those treatments that are advocated by Big Pharma are “bad” while those advocated by DAN! medical

providers and other parents are “good.” Yet many of the supplements and biomedical treatments advertised through ASD/VL movement groups are subject to the same, if not worse, oversights in regulation, testing, and marketing as drugs marketed by the FDA and Big Pharma. Indeed, there is greater opportunity for abuse in the marketing of supplements due to lack of standardization and testing. This contradiction or lack of insight seems to stem from the distrust, anger, and resentment the parents hold towards Big Pharma. To investigate this seeming contradiction, along with the broader question of who, if not mainstream medicine, they *do* trust for information, I asked the ASD/VL activists I interviewed how exactly they determine credibility.

6.3 DETERMINING CREDIBILITY

When discussing credibility, it became clear that parents put a lot of trust in the experiences of others who have already tried an alternative method. This is in part a result of, and contributes to, being a part of a community founded on a collective illness identity. When I asked if they worried about the honesty of the parents reporting their experiences with different methods, most reported that they did not think anyone would lie. They give the benefit of the doubt to the parents because they trust others they view to be in the same situation as themselves. As Ryan stated:

I don't know, I just form my own opinions. The internet is scary; you can read completely opposite points of view. I just try to make the best sense that I can, ya know, talk to other parents. Over 95% of these parents believe in the diet and no vaccines, some with recovered kids. I find it hard to believe they're under this false hope on a mass level (telephone interview, 23 Jan 2008).

Parents of children with an ASD turned to each other and their online community for guidance on treatments, what works and what doesn't, as the following quotes illustrate:

I find parents I trust too. This specific woman gives just really great detailed advice on what has worked with her, and I tend to follow her. I mean she's not the word of God or anything, but it's very detailed. (Elizabeth, telephone interview, 6 Nov 2007).

I also look at, ya know, is it more than one parent suggesting it, how many people have tried it? (Kara, telephone interview 1 Nov 2007)

It appears that parents are more willing to trust each other and are more comfortable with the uncertainty that is associated with anecdotal evidence than they are with the same type of uncertainty presented by mainstream doctors. This ties back to the lack of trust in the institutions that they feel have betrayed them. So while parents are avid and sophisticated consumers of scientific research, they often disregard or are not influenced by findings that show alternative treatment options to be ineffective or untested so long as it has "worked" for someone else. The hope for a successful treatment or even cure is too great, as the following quotes show:

There hasn't been that much rigorous science, rigorous studies on autism. Of course, there is so much going on right now, but since it is all almost anecdotal, so I know it's anecdotal, but I feel like I'm going to try it anyway (Diane, telephone interview, 27 Oct 2007)

Again, as a social scientist, I do try to look up what studies have been done through the academic journals. But, will the lack of them stop me from spending money? I don't think so because I want to try whatever I can (Elizabeth, telephone interview, 6 Nov 2007).

While they are willing to try untested and unproven treatment options, they are discerning in their decisions, as Tova stated, "But I don't try everything. You have to pick and choose. So much of it is a bunch of crap, so you have to be careful" (telephone interview, 13 Sep 2007). So while they do not try everything that is recommended, the reasoning on how they decide what

they will try is unclear and seems to direct back to their personal experience. When I asked how she decides what to try Desiree stated “I know by watching what I do, what my son does. I believe it can be changed by diet. It makes sense” (telephone interview, 15 Nov 2007). For Desiree, being able to “see” the changes in her son was the best evidence, along with her belief that it “makes sense.” When asked why she thought it made sense, Desiree retold the story of her mother who made a full and quick recovery from breast cancer with the help of a good diet. She extended this logic to the treatment of her son’s ASD.

Reflecting on how they determine credibility turned out to be a difficult question for the ASD/VL activists. Many were unable to really articulate how they decide what is legitimate, though they did recognize that there is misinformation out there, as implied in the quotes above. Ryan stated he just tries to read as much as possible to make sure he has all the information. He stated, “I read all the emails. I don’t believe everything I read, but there is some good information” (telephone interview, 23 Jan 2008). When asked how she determines credibility, Kara stated, “I think there is not a simple answer; I think it’s a tricky thing” (telephone interview, 1 Nov 2007). Tova similarly stated, “I don’t know how to answer that. Um, I just know some things sound way ‘out there’ or they wouldn’t work with my kid. I just *know*” (telephone interview, 13 Sept 2007).

In my online survey, I also tried to capture what different types of sources ASD/VL activists find credible in an attempt to understand the foundations of their belief system and who they do trust. The question stated, “What information has contributed most to your beliefs about ASDs and mercury in vaccines?” Respondents chose personal experience (54%) and scientific literature and research (38%) as first and second sources of credibility. My in-depth interviews with ASD/VL activists supported this finding. Interviewees stated that their own experiences and

the reported experiences of other parents were the deciding factor on credibility. Below, Renee summed up in descending importance how she determines credibility:

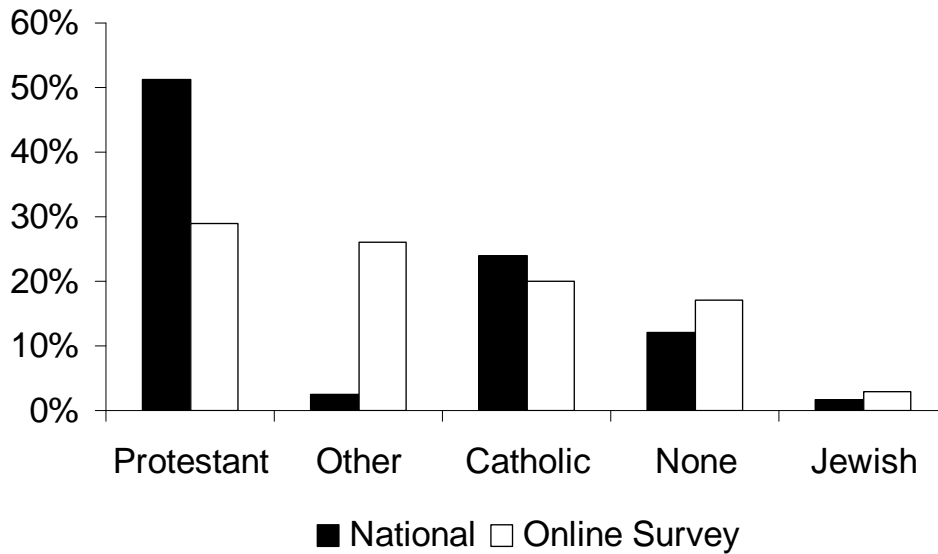
...just from what I know from my son and the things I've read from the legitimate websites and the books, the *Evidence of Harm*, and some of the other biomedical ones I've read. And then just having to treat him on my own (Renee, telephone interview, 10 Oct 2007).

Joyce further illustrated the importance of experiential knowledge in belief formation:

You know, something happened to him. When it's your child, or your grandchild, and you watch it happen after a vaccine, I don't care what they say, you know what you saw. You know the child you had the day before, you know the child you had the day after (Joyce, telephone interview 4 Oct 2007).

In an attempt to further understand what may contribute to activists' construction of credibility and belief system, I included questions about religion. I did not have any expectations about the role of religion in my interview and survey datasets. Analysis shows that ASD/VL survey respondents are less religiously inclined when compared to the general population as summarized in Figure 9.

Figure 9. Religion demographics of survey respondents



In addition, 5% of those surveyed identified themselves as atheist, though national rates were not available for this category. None of the survey participants identified themselves as Muslim. I also asked all of my ASD/VL interviewees about religion. Specifically, I asked, “What role, if any, does religion play in your life in general?” followed by, “Has religion influenced your decisions regarding care and involvement in the ASD community?” The responses were mixed, but for the majority, religion was not a dominate force (79%). For those who stated that religion did play an important role, it seemed it acted as *the* reason; the purpose of their child’s autism. For example as Desiree stated, “God’s got a plan, and I’m gonna try it, and this is what we’re gonna do” (telephone interview, 15 Sep 2007). Sue believed this happened because God wanted to give her a “wake up call.” She stated:

I think God gave me my son because we were a little too complacent, a little too happy-go-lucky, and He wanted to give us a wake up call, and He wanted to do it in such a way that we were going to be able to improve at least our son’s situation. And in the process, we’ve been told by numerous parents we’ve probably saved their children (Sue, telephone interview, 18 Sep 2007).

Previous studies have examined the possible connection between prayer and cure from illness (citation), I asked separately about prayer, and if they ever pray. Only one responded. Renee reported prayer as a crucial part of her parenting. “I know prayer helps because, I mean, he got into a school that he never should have gotten into, and I was in a mom’s group, and they were all praying for him” (telephone interview, 10 Oct 2007). But for the majority of the ASD/VL activists I interviewed, religion did not play an important role, as Veronica stated:

[laughs] It’s hard to say. I guess probably not, we talked about getting him more involved in the church and they encouraged that but it never ever happened. They didn’t make an effort and we didn’t really make an effort (telephone interview, 28 Nov 2007).

Others simply answered “No, no not really” (Diane, telephone interview, 27 Oct 2007). Though they may not be religious, many have used the religious exemption when avoiding the vaccination requirement in schools. Not all states have religious exemptions, but most do. In fact one of Unlocking Autism’s primary goals has been to maintain the right of religious exemption to vaccination requirements. The ASD/VL activists I interviewed discussed the ease of getting a religious exemption (for those states that allow it). Ryan and Kara stated:

You can join churches, and it sounds hokey, but if that’s what I need to do, I’ll do. There are churches that you can send a \$75 donation, and they’ll send you back a certification. All the parents around here have done it and have them (Ryan, telephone interview, 23 Jan 2008).

Well, I went to a Buddhist minister and had him sign off on it. He understood where I was coming from (Kara, telephone interview, 1 Nov 2007).

The finding that so few parents cited religion as an important force in their life highlights the fact that ASD/VL activists trust their experiential knowledge to guide their decisions in ASD

treatment, their arguments against their opponents, and as the foundation of their belief system regarding ASD causation.

6.4 ACTIVISM WITHOUT ACTIVISTS

As is illustrated above, ASD/VL activists have gotten involved in politics through state and federal legislation aiming to ban mercury in vaccines, they have engaged in letter writing and phone call campaigns, and they have recruited the support of powerful politicians. They have also worked through the legal system, filing court cases against school districts, pharmaceutical companies, and through the government National Vaccine Injury Compensation Program. As a politician and movement activist, Becky Lourey, Minnesota state senator and a sponsor of a proposed thimerosal ban, said to the *New York Times*, “We're not looking like a fringe group anymore,” (Harris and O’Connor 2005: paragraph 6). This next chapter discusses how the parents became involved in the debate and how they framed their own activism.

6.4.1 Don’t call me an activist

The narrative of how ASD/VL activists came to this debate was the same for most of my in-depth interviewees as well as the founders of the ASD/VL movement groups I profiled above. First, they became aware that something was “not quite right” with their child in terms of development, so they sought professional help from their pediatricians and specialists and came away with a diagnosis of ASD. Feeling disheartened with the little information and treatment options provided by their medical doctors, they started their own research and began reaching

out through the internet to other parents of children with ASDs. Finally, they discovered the potential link to vaccines, became angered and turned to political action and mobilization. They are parents of children with ASDs who refused to accept what they felt was a lack of information, lack of services, and lack of responsibility by the government, their doctors, their schools, and pharmaceutical companies. They became ASD/VL activists for their own children and ended up becoming trailblazers and leaders in a unique EHSM.

Surprisingly, the ASD/VL activists I interviewed were not quick to call themselves activists. I first asked my study participants about their history in politics and whether or not they had always been politically active. I suspected that those who were already predisposed to involvement in activist activities would be more likely to get involved as an activist in the ASD/VL movement. According to my interviews, this was not the case. While some (21%) did state they were “political” in college, a majority (79%) did not become political until after their child or loved one was diagnosed with an ASD. These individuals became ASD/VL activists by what they considered a necessity. They unanimously expressed that if they did not fight for services, education, treatment, and information, no one would. Jane stated, “My school district didn’t have anything. They had an [Association for Retarded Citizens] program, but that was for the more developmentally disabled, so I had a lot of work to do. It was hard” (telephone interview, 13 Oct 2007). Elizabeth recalled her introduction to the debate as a sort of light bulb that went off. She stated, “It was like a realization of ‘oh, we have to begin this fight’ and what has continued to be this constant battle to get services and figure things out and what to do” (telephone interview, 6 Nov 2007). Words like “battle” and “frustration” were often used by my study participants. As Desiree told me her story of coming into the debate, her frustration with the perceived lack of support from medical doctors was obvious. The tone of Desiree’s voice

while stating this implied she became a reluctant but committed activist for her own son with an ASD. She stated:

I was the one who asked for the psychological evaluation, I was the one who asked for the referral, I was the one who said he needs to be in speech and occupational PT, I was the one who asked for the OT. His pediatrician did not take any initiative in any of those areas, I had to do it all on my own (telephone interview, 15 Sep 2007).

Renee mirrored Desiree's sentiment, stating, "His [traditional] pediatrician wasn't really proactive, I had to really pursue everything myself. He didn't take any initiative" (telephone interview 10 Oct 2007). The frustration with mainstream medical doctors was also an important theme and will be addressed in-depth in later chapters.

My survey data also shows that 77% of respondents would not identify themselves as activists. However, when asked specifically about activities they have participated in throughout their involvement with the ASD/VL movement, 71% said that they do make it a point to talk to others about their ideas about mercury and vaccine, 45% participate in writing letters and emails and making phone calls to representatives to support ASD legislation, and 75% would vote outside of their party to support a candidate who held the same beliefs about the ASD/VL debate. Furthermore, 64% stated they would ask their medical doctor to speak to others about vaccines and autism. Finally, 28% have been involved directly in research focused on ASD. My in-depth interview data show similar results. All of the ASD/VL activists I conducted in-depth interviews with were involved politically. When asked if they had ever written letters or made telephone calls on behalf of ASD and vaccines, they all answered yes. When asked if they would vote outside of their political party if the opposing candidate share their views on vaccines and autism, they all answered yes. All have been to either state and local vaccine hearings or

rallies and most have attended events in Washington, DC, or at the CDC in Atlanta. So while most do not identify as activists, they are taking part in activist activities.

This insistence, and persistence, in the seeking of care and services on behalf of their children was the start of the parent activists' careers. Rather than taking a passive patient role and accepting the limited options and information that is presented to them from either doctors, the school district, or the legal system, they went about fighting for not only the minimum they felt they deserved as parents with disabled children, but for more—more services, more treatment, more research, and more awareness. In fighting for their own children, ASD/VL activists ended up changing entire institutions, yet the ASD/VL activists I interviewed were hesitant to call themselves “activists.”

My in-depth interviewees provided insight into this reluctance. They stated they did what they did because they felt they had to for their children in order to be “good parents.” They did not deny that they “fight” and “battle” for their cause, as Kara stated, “Well no, we didn’t get lucky – we fought” (telephone interview 1 Nov 2007), but they did not label what they did as a form of activism. When asked about their political activities, the ASD/VL activists I interviewed described their actions in a nonchalant way, as though they were things that any parent would do for their child. For them, being a good parent meant being an activist. For example, when asked if she had been to any national meetings or rallies concerning ASD and vaccines, Diane stated in a very matter of fact, casual way, “Oh sure, when Dan Burton was doing the vaccine hearings, I used to go to that quite frequently from 2001, 2003, and 2004. I haven’t been to any of the rallies because we can’t afford it though” (telephone interview, 27 Oct 2007). At these hearings, Diane took part in holding posters and handing out fliers, but she did not think of herself as an activist. Similarly, Renee, a veteran in the debate who holds a leadership position in an ASD/VL

movement group, stated that she got involved but “doesn’t go out looking for stuff. I mean, we had a meeting with new state senators, and we went to that and talked to quite a few of them about what was going on with our kids” (telephone interview, 10 Oct 2007). Talking with state senators is an important activist activity, one that many movement activists struggled to gain access to be able to do, yet Renee discussed it as though it were easy and nothing outstanding. This is most likely due to the increased social capital that comes with being well educated, financially stable, and white. For Renee, walking up and speaking to senators did not feel like stepping outside of her normal social or cultural network because she viewed herself as occupying the same cultural space as her representatives.

Hope is the head of one of a Midwestern state’s ASD/VL movement group and has worked tirelessly in her state on legislation and ASD awareness. Hope recognized that she worked hard for the ASD/VL movement, but she did not see herself as an activist. Part of her involvement included recruiting the support of a local senator and forming a legislative task force to draft a bill that would require medical doctors to inform patients when they were being given a shot that contained mercury. The DHHS came out against it, along with many doctors. This was a kind of wakeup call for Hope as she realized she had become involved in a hot political debate. In her mind, she was just trying to protect children. When it went to a vote, she was shocked at the response from the opposition and realized they would need more resources and support to pass the bill. Hope stated:

I had a bill with my state senator last spring to require doctors to tell patients, especially with children or pregnant women. I was particularly concerned about the flu vaccine. It’s pushed like crack cocaine. In any case, it was fought by the doctors and the Health and Human Services. I didn’t realize how much power they had and how much effort I should have put into it (telephone interview, 31 Oct 2007).

My research suggests that the reluctance to consider their activities as activist in nature or even to consider themselves activists is due to the difference in meaning attributed to the word “activist,” which to them seems to connote militantancy and fringe activities. For example, Ryan has started an employee network group, applied to be on the board of trustees for the early intervention collaborative in his state, and participated in letter writing and phone call campaigns, but in response to being asked if he considers himself an ASD/VL activist, he stated, “I don’t really, only to the point of making phone calls and writing letters, but I mean, I’m so proactive. I have to be involved in every way, but I’m not militant” (telephone interview, 23 Jan 2008). Ryan then followed up with the fact he and his wife are the couple that “is involved in everything.” He further stated that he now has to stay away from the local hearings on vaccine schedules and mandates because he gets too upset and refuses to stay quiet. He cited his most recent outrage with New Jersey’s four additional mandated vaccines that have been added to the well-baby schedule. But for Ryan, the term “activist” brought to mind radical militants rather than passionate parents, which is how he defined himself.

Ryan expressed a tension I heard in most of the interviews, a tension between wanting to be as vocal and involved as possible with getting information out, passing legislation, and gaining services, but not seen as “one of those crazy internet people” or obsessed (as many have been accused through an aggressive framing campaign by their opposition). This fear of being viewed as “fringe” is what keeps the parents from considering themselves as “activists.” The ASD/VL activists wanted to be taken seriously and seen as legitimate. A way to accomplish this was by distancing themselves from any characterization of radical. All the ASD/VL activists I spoke with, many of whom are in leadership positions in groups and organizations in the

ASD/VL movement, sought to distance themselves from those they considered fringe. As

Veronica stated:

I think some people are a bit too much. You start to lose sight of your life, you know, it becomes an obsession. Which I can understand because I'm involved in litigation with the vaccine court now, but I don't want to argue with other parents of kids with autism. I don't want to get into it. I'm happy that the more aggressive groups are there, but they're not for me (telephone interview, 28 Nov 2007).

Joyce further elaborated the same sentiment,

Yeah, the folks that go way out on the fringe, get too far out there, hurt in the long run. I understand they're angry, I understand they're frustrated, but they make us look like a bunch of nuts, and we're not nuts. So I wish they would rein themselves in and think about how it sounds and find a more constructive way to get their point across or get their message out and get some action (telephone interview, 4 Oct 2007).

Joyce connected fringe activism with hurting their movement because she felt it draws attention away from the more legitimate activists in the debate, like Robert F. Kennedy, Jr. Joyce stated, "It's very disappointing to keep having things like Robert F. Kennedy, Jr., stepping out and saying, 'Hey people, look at this' and being ignored" (ibid.) The fact that Joyce considers Kennedy *not* a part of the fringe illustrates that it is the frame of fringe and radical that the parents seek to avoid but not the actual practices.

6.4.2 Getting the Word Out

Through the analysis of my interview data, I found that the ASD/VL activists framed their activism through the lens of public education or "getting the word out." This framing went along with their reluctance to call themselves activists. Rather than thinking of their actions as political action, they saw it as education and helping their community. This is in line with all of the

movement groups profiled above, and an effective strategy (it is difficult to argue with someone who states they just want to share more knowledge and information).

This frame also emerged because it ties back to the issue that brought them to the debate to begin with, namely, the refusal to accept the limited information and treatment options offered through mainstream medicine. All of the ASD/VL activists I interviewed expressed the difficulty they experienced in finding answers when their children were first diagnosed, and it moved them to do something about it. Hope stated:

It takes over. And for me, I'm sort of a, sort of a save-the-world kind of person and always have been. I can't even just take the information and use it and keep it to myself. I have to get the word out and try and stop this thing. I just can't.. can't just sit still with it. So, ya know, I'm starting a special needs ministry at my church and leading a book group, trying to do all these things to help other people just because that's the way I know how to deal with that (telephone interview, 31 Oct 2007).

One veteran debate activist, Barb, went so far as to adorn the side of her van with her son's mercury load and the effects of mercury positioning side by side with the symptoms of autism. In this respect, their activism is not restricted to only predefined political actions, like rallies, or only when in the company of other ASD/VL activists. Barb's activism was part of her identity as a parent of a child with ASD. For example, Barb took the job of informing the public very seriously, and very personally. She stated:

I'm very proactive on making people aware that (1) these kids are here, (2) they're not being bad, they're not spoiled, they have issues going on, and (3) the cause of this epidemic "autism." I don't even call it autism anymore. It's called autism for educational and insurance reasons, but in my mind's eye, this is strictly mercury poisoning (telephone interview, 4 Nov 2007).

Renee, also a movement veteran, worked hard to get the latest information out to the public. She was actively involved with her state's autism association and routinely sent information to local

medical doctors on issues concerning vaccine safety, heavy metal poisoning, and information on different biomedical approaches to treatment. Renee stated:

If any, if anybody says anything [about autism], I'll tell them what we're doing with our son and try to get them on that...And you know, I was told when I moved here "When you go to get him diagnosed with the developmental pediatricians, don't mention anything about vaccines!" There was like this code. "Don't say anything about vaccines, don't say anything about any of this or you will be thought of as 'crazy' or whatever or one of those 'internet people' or whatever (laughs)." But I refuse to stick to that. We've had great success, ya know. I'm not going to be quiet about these things because, in my opinion, doctors need to be aware of these things that helped (telephone interview, 10 Oct 2007).

Another debate veteran, Kara, viewed her refusal to censor her son who has an ASD or to apologize for his behavior as a learning opportunity for a society that needs to become more educated and accepting. She stated, "I'm not going to sequester my son in my own home because society doesn't understand what autism is. It's time they learned, and I was hell bound and determined to be one of the teachers" (telephone interview, 1 Nov 2007).

Sue was also determined to get the word out. She has the longest history of involvement with the debate of all the ASD/VL activists I interviewed. Sue is the parent of a son diagnosed with ASD, which she believes was caused by mercury poisoning through vaccine administration. She came to this conclusion after reading Sally Bernard's "Autism: A Unique form of Mercury Poisoning" which she found online. It was through reviewing the symptoms of mercury poisoning and autism that she "saw they were exactly the same, and that's when the bells started ringing" (telephone interview, 18 Sep 2007). In 2001, she started her own online newsgroup because she was frustrated with the lack of available information from fellow parents. Sue stated, "In the beginning, I wasn't getting any information from parents. All the information I was getting was from papers online" (ibid). She started the group as a place parents could come and

discuss their experiences with ASD and the connection with vaccines. In the beginning, she used it simply as an information distribution site, sharing research and articles, and later discussing different kinds of treatments. Sue stated,

My goal is to reach the masses before they become victims. My goal is to educate parents so they have all the information, not just what the drug cartels tell the pharmaceutical reps who tell the doctors. I want everyone to have everything. Then and only then can they make an informed decision on whether to vaccinate their child (ibid).

Sue was also particularly interested in hearing other parents' experiences so that everyone could learn from each other. Now, her newsgroup is a tremendous resource for parents of children with ASDs looking for answers. She observed that her membership has changed over time, and she was pleased with the shift, stating,

A lot of people who are joining now are parents or about to be parents who are questioning the safety and effectiveness of vaccines before they start, which ultimately is my goal. I want to get to these parents before they end up becoming victims of all this like we were. So, ya know, it's like my group is starting to achieve the goal that I set out for it six years ago, and it's taken that long (ibid).

Even those who are new to the debate, like Jane, often become involved in trying to spread information. Jane has a daughter diagnosed with autism, and she became frustrated and disheartened with the lack of information available that is specific to girls. She took it upon herself to start her own newsgroup online and a local support group to bring parents of girls diagnosed with ASD together to share information and try to increase awareness and support services. Similarly Ryan, whose son was recently diagnosed, started an employee network group in his office for parents of children with any type of disabilities. Through this venue, he hoped to increase awareness and support.

Part of getting the word out is “educating” medical doctors on the new treatments and research that parents of children with ASDs and DAN! medical doctors have been practicing. Many activists stated that it is the norm to inform their online community when they find a medical doctor who is open to listening and working with parents who are interested in non-traditional treatments for ASDs. The goal is to then inform the medical doctor in the hopes of recruiting him or her to the cause, thus enlisting the doctor as an ally to challenge western mainstream medicine from the inside. In one example, Renee stated, “And a lot of the parents on our group started going to him after what I posted, and one of the moms really started working on him, giving him books and things like that” (telephone interview, 10 Oct 2007). This brings us to the role of the providers in the ASD/VL debate which I examine in the following chapter.

7.0 THE ROLE AND INFLUENCE OF MEDICAL PROVIDERS

The discussion of physicians was notably absent throughout the description of movement organizations, activism, and scientific debate, but through the course of the analysis of my in-depth interviews, I found that medical doctors and the treatments they do or do not provide play an extremely important role. In the following sections, I first discuss the current trends among clinical practices and the broader profession of medicine followed by ASD/VL activists’ attitudes towards mainstream medical doctors. I then discuss the Defeat Autism Now! (DAN!) medical doctors and the use of alternative medicines and experimental treatments as a form of activism.

7.1 GOODBYE TO THE GOLDEN AGE

Primary care physicians and pediatricians play an interesting and pivotal role in this debate. As Jenny McCarthy stated on “Larry King Live” (2007), “But for some reason the pediatricians do not know how to treat these kids.” This quote was repeated back to me during numerous interviews with ASD/VL activists. Indeed, the sentiment towards medical doctors expressed by ASD/VL activists is a far cry from the cultural authority and respect Freidson (1970) and Starr (1982) described doctors as possessing. This may not solely be due to the ASD/VL movement. Many theorists argue that the field of medicine is going through a drastic transition as parts of the profession are becoming “proletarianized” and outsourced to non-physicians. At the same time, partner professions, such as nursing and psychology, are gaining more autonomy (McKinlay and Marceau 2002, Hafferty and Light 1995).

Since the 1970s, the American Medical Association (AMA) has been rapidly declining in their ability to pass favorable legislation due in part to the growing power of Health Maintenance Organizations (HMOs), pharmaceutical agencies, rising cost, and the tendency for doctors to join specialty professional associations rather than the AMA. Today only half of all doctors are members of the AMA, dramatically decreasing the power that comes with numbers and the funds that come from dues (McKinlay et al. 2002). This decrease in power has contributed to the success of legislation expanding the professional scopes of non-physician clinicians over the last decade (Hafferty et al. 2000). The Intergovernmental Health Policy Project (1994) reported there has been a doubling in the number of non-physician clinician training programs. Finally the doctor-patient relationship has suffered as the private and public sector continues to make decisions that favor more profitable illness treatments for the few rather than population-wide health concerns such as pollution (McKinlay et al. 2002). These trends are making it more

difficult for doctors to convince society that they are the only legitimate sources for health care (Saks 2003, Hartley 2002).

The ASD/VL activists I interviewed were also unhappy with the degree of influence health insurance companies have over the practice of medicine, specifically what is and what is not paid for, and they get frustrated when their medical doctors do not work for them in trying to fight for services. The ASD/VL activists' sentiments are supported by McKinlay et al. (2002) who state the increasing involvement from private corporations and the government has created a massive bureaucracy where medical doctors are acting more as administrators concerned with the bottom line rather than the practice of medicine. McKinlay et al. (2002) refer to this as the corporatization of medicine, which is essentially the expansion of capitalism into the medical domain. This corporatization turns the treatment of illness into a commodity rather than a human right and contributes to the erosion of the ethical basis of medicine. This makes it impossible for medical doctors to consider patient concerns first and foremost when making decisions, thus creating a shift from what Light (2000) calls the provider driven era to the consumer/buyer driven era. The ASD/VL activists I interviewed validated these concerns. They all expressed frustration and anger over the lack of support and partnership with their medical doctors, but they also expressed a lack of trust.

7.2 ATTITUDES TOWARDS MEDICAL PROVIDERS

When the ASD/VL activists I interviewed discussed their feelings regarding their doctors and why they had strayed from or completely abandoned mainstream medicine, it became clear that many of the activists associated Big Pharma, the CDC, and the Bush administration, who they

claimed are responsible for harming their children, with mainstream medical doctors, particularly the American Academy of Pediatrics (AAP). MAM and other ASD/VL groups have been and continue to be upset with the AAP due to the reversal of their position on the safety of thimerosal. Originally in 1999, they recommended the removal of all mercury from childhood vaccines. They have since reversed their decision on this and state that it is safe. The AAP is also prominent in blocking and lobbying against any and all legislation inspired, written, or supported by vaccine awareness groups. This has built up resentment among parent activists. As mentioned before, an entire rally titled “Toxic Lies, Toxic Children” was organized by MAM against the AAP on February 20, 2008. It focused on the role of the AAP in the continuation of the use of mercury in vaccines, as MAM’s website (www.momsagainstm Mercury.org) states:

Are you sick and tired of the AAP? Their endless lies? Their spineless refusal to stand behind their 1999 recommendation of removing thimerosal from childhood vaccines? Their tireless effort to stop state legislation for mercury-free vaccines? Their demanding of the cancellation of the Eli Stone premier? It is time we let them know we will no longer stand for their Toxic Lies.

McCarthy also contributed to the declining trust of medical doctors. In her media appearances, she continually stressed the lack of faith she has in mainstream medical doctors to treat children with ASDs and the lack of trust the medical doctors extend to parents. She stated on “Larry King Live:”

You know, I called the American Academy of Pediatrics this week, because I've been complaining about why isn't the medical community behind this treatment so they can teach it to every pediatrician across the country, so parents don't have to go looking for a specific DAN! doctor. They can go right to their doctor and go, “These are my son's symptoms. They resemble Jenny's son's symptoms. Can you help me?” They don't know how to treat these kids. That's a fact (McCarthy 2007).

This sentiment was repeated by the ASD/VL activists I interviewed as well. It was a common narrative among the parent activists that 1) mainstream pediatricians are not aware that autistic kids can be treated with biomedical interventions, and 2) they don't listen to the parents' experiences or trust them. The belief that mainstream medical doctors do not know how to treat autistic children was fervently stated by almost all of the ASD/VL activists I interviewed as illustrated in the following quotes:

There's something [traditional] doctors aren't hip to, and the natural doctors are and really seem to know what's going on (Diane, telephone interview, 27 Oct 2007).

My son has two doctors, one for the general. Ya know, they're traditional, they don't have a clue, they don't care or they don't want to learn about the vaccines. They know that we're not vaccinating. They don't press us about it, but they don't either have a clue, don't believe it, whatever the case might be (Sue, telephone interview, 18 Sept 2007).

Unfortunately, the primary care doctors and pediatricians don't know anything, and what else is terrible is that everything is so compartmentalized. No one wants to coordinate the information into one and see the big picture (Barb, telephone interview, 04 Nov 2007).

I get past the point where I even want to deal with most doctors, and it's frustrating. And they do seem, and it sounds arrogant but, it is at a point where they seem really ignorant. And it's like, I cannot listen to you. You don't know what you're talking about (Hope, telephone interview, 31 Oct 2007).

We've come to not trust peds at all. We hop around to different peds. We don't like any of them. No matter what they say, it's all nonsense, and there's no evidence. They won't even hear my story. Sometimes developmental peds like we go to, she's very... I don't know if she does it [listens] because she's being compassionate or believes it, but she's supportive while others are just push, push, get your kid vaccinated, you're depriving your child, ya know." (Ryan, telephone interview, 23 Jan 2008)

The ASD/VL activists I interviewed felt that their mainstream medical doctors “didn’t have a clue” because the medical doctors were not talking about the bio-medical and alternative ideas the ASD/VL activists had read about through their involvement with the movement and their own research. Traditionally, we look to medical doctors to be the experts on the health concern we have, but when a parent goes in and feels they know more than the doctor, the parent experiences a loss of faith and trust, and the relationship is subverted. The medical doctors the ASD/VL activists did eventually trust were more likely to be from the naturopathic and homeopathic traditions. For example, when asked what made one interviewee leave her mainstream medical doctor for a homeopath, Clare responded, “because the conventional doctors didn’t know what they were talking about. I went and did my research and saw this person had been cured and this person had been cured and came to the conclusion that my doctor just didn’t know what he was talking about” (telephone interview, 15 Jan 2008). Barb similarly left her medical doctor in favor of a homeopath stating, “that doctor didn’t seem quite as up on things, and um, she was a little bit behind in her understandings and in some of the research, so we switched over” (telephone interview, 04 Nov 2007).

The next point of contention with many of the ASD/VL activists I interviewed was the degree of hostility and disrespect they felt from mainstream medical doctors. As Barb stated:

I was seeing a [rheumatologist] and even when I expressed concern about the mercury and shots, he said in a condescending way, “Oh, have you been on the internet?” ya know. And that’s kinda a common thing, like “oh these moms are spending too much time on the internet just soaking up all kinds of crazy information” like we don’t know how to discern what is accurate and what is not. And ya know, he really didn’t then seem to treat me for what I was coming in for. And so – a bad thing – but I stopped seeing him for a reason I need [to see a doctor], but I just can’t deal with it (telephone interview, 04 Nov 2007).

Other interviewees had similar stories:

The doctor just kept putting us off, not listening. It was always, “We’ll refer after the next visit,” and it was always the next visit, and she just kept putting us off... We got rid of her. We tried working with her, but we found a doctor who was more open towards [bio-medical treatment] and would talk with us about the vaccines (Renee, telephone interview, 10 Oct 2007).

That’s one thing I think a lot of [pediatricians] don’t understand. They may not even see there is an autism epidemic because we don’t go to them. We don’t. They have nothing to offer our children, and they have nothing to offer us except hostility and condescending attitudes, and that’s something important to note (Hope, telephone interview, 31 Oct 2007).

We received a lot of help through our DAN! doctor, and typically it seems like traditional pediatricians for the most part not only are not knowledgeable and not helpful but actually somewhat hostile towards this (Tova, telephone interview, 13 Sept 2007).

For the ASD/VL activists, a medical doctor was perceived as “not listening” when they disagreed with their ideas. This was also interpreted as disrespect. They wanted their experiential knowledge to be heard and taken legitimately. Many ASD/VL activists I interviewed had never experienced this kind of discontent with their medical doctors before having an autistic child and a controversial viewpoint. Hope shared how her views of mainstream medical doctors have changed since having a child with autism and seeing how few medical doctors were open to listening to parent input:

So I asked another doctor who is on board and asked who to see, and he said there is no one in this area. No one listens to their patients. And... I used to do whatever the doctor says and think they’ve got it all under control, ya know, like I’ll just do whatever my doctor tells me, and I’ll be fine. But we’re just kinda past that point (telephone interview, 31 Oct 2007).

Kara also lamented the lack of respect and willingness to listen she has experienced from mainstream medical doctors since having a child with an ASD:

It seems like they either go with it and are listening, or they just stick with what they're taught and [are] willing to sink with that ship. They just don't seem to listen to what works. They say it's a placebo effect on the part of the parents or other things like, "Oh, it's a coincidence." But not everything works. I've tried some things I had high hopes for but that didn't work at all (telephone interview, 01 Nov 2007).

Kara's last sentence in the quote illustrates that she did not blindly believe everything she learned from fellow parents in the ASD/VL activist community. Her acceptance of the failure of some treatments is evidence that she is not just a hopeful parent of a child with an ASD who sees what she wants to see; rather her beliefs are based in critical observations.

Contributing to their frustration towards the activist/doctor relationship is their resentment of and discontent with the fact that they have to go to mainstream medical doctors at least occasionally due to the many co-morbidities that are often associated with ASDs, specifically allergies and digestion problems. Brown addresses this in his research as well, noting that activists have often or continue to undergo medical treatment and, hence, are dependent upon the very system they are challenging. This sets up an inherently combative relationship between medical doctors and patients and constrains some of the tactics of EHSMs (Brown et al. 2004b).

In reaction to this perceived betrayal of trust and harm done by these institutions, ASD/VL activists rely on their own experience in treating their children and tend to align themselves with DAN! medical doctors, other parents in the ASD/VL activist community, and alternative medicine and experimental treatments outside the mainstream. Choosing a medical doctor was a major decision for all of the ASD/VL activists I interviewed. They were not just choosing someone to go to for treatment, they were choosing a partner, someone they could trust,

someone that would agree to try experimental and medical interventions, and more importantly, someone who would listen to and respect their experiences. As Veronica described:

I was lucky to find good doctors through talking to other parents. You know, you can't get a referral through a hospital. You have to talk to other parents, ya know, find out who's sympathetic, who's going to help, who's going to be open to the medical interventions. And we had to go online and do some research (telephone interview, 28 Nov 2007).

My in-depth interviewees reported that when one person finds a medical doctor that they like, they share it with the group in an effort to help each other, and it does help. Desiree stated "I put the word out. I said, 'Ok group I need your help, I need to find a doctor here.' And I got several responses back, and it was great. Cause you know, I didn't know anything about it" (telephone interview, 15 Sept 2007). Desiree went on to find a medical doctor through her ASD/VL community and right away took a liking to him.

I love him dearly. We went for our initial visit, and he said, ya know, he was like the first thing out of his mouth was, "How can I help David?" And I was like, great you're going to listen to me! And he began to tell me all about the different things it could be. He talked about autism but also talked about other options (telephone interview, 15 Sept 2007).

The important issue for Desiree, and all of the ASD/VL activists I interviewed, was listening. If a medical doctor did not listen and respect their wishes, they would not go back. More often than not, the ASD/VL activists I interviewed found what they were looking for in a DAN! medical provider. DAN! doctors are appealing because they offer hope of treatment and even a cure for ASD. The ASD/VL activists I interviewed all expressed disappointment and sadness when their traditional, mainstream medical doctors informed them that there was no cure for ASD and that the only treatment options available are not always effective. They conveyed a sense of abandonment and even betrayal, whether it was from a medical doctor, a representative,

or the entire federal government. DAN! medical providers offer alternatives, partnership, hope, and an ally in their cause, as the following quotes illustrate:

I like the websites that really convey a message of hope, like the DAN! websites. They say, ya know, “Let’s help these kids to heal.” There’s that message of hope. Let’s heal our kids, let’s work with trying to get them healed, let’s get them to where they’re not considered autistic anymore (Desiree, telephone interview, 15 Sept 2007).

They’re in the same battle we are, they’re wonderful people. At least they’re looking at these children and willing to try different things and see what works, ya know, instead of being afraid (Joyce, telephone interview, 04 Oct 2007).

They’ve all been on the quest with me to find the answers (Clare, telephone interview, 15 Jan 2008).

The ASD/VL activists I interviewed felt like they were partners with their DAN! medical providers and that these medical providers trusted and listened to their ideas and experiences. Kartzinel, the medical doctor that appeared with Jenny McCarthy on “Larry King Live,” illustrated all the characteristics the ASD/VL activists I interviewed stated they liked about their DAN! doctor. First, he constantly referred back to parents’ experiences and listened to them. When King asked him if he thought vaccines were a problem, instead of referencing studies and reverting to medical jargon, he immediately turned to parental experience, stating, “Well, I think we have to ask, first of all, is the vaccine a problem? I keep hearing from parents it is” (McCarthy 2007). He did not confirm nor deny what research was saying but instead deferred to parental experience. Kartzinel later explained:

If you tell me that your child woke up with ear pain and 102° fevers, and I look in the ear and see an ear infection and prescribe an antibiotic, you’re right. If you tell me that your little guy had tummy aches in the right quadrant and can’t walk, and he ends up having appendicitis, your right. Now you come in and tell me that your son has lost eye contact and language and is screaming all night, and this happened a week ago right after a vaccine, all of the

sudden you're wrong? I think the first thing we have to understand as a medical community is we have to listen to the parents tell us what's going on (McCarthy 2007).

ASD/VL activists responded positively to Kartzinel's entire argument, which was exemplar of the DAN! doctors' attitudes and practices described by my interviewees. The DAN! approach confirms parental experiences, gives them voice, legitimizes their concerns and gives them hope for a cure and recovery.

Among the ASD/VL activists I interviewed, being a DAN! medical provider was not always a requirement for their chosen provider. For some, the relationship the medical doctor has to ASDs and the debate was more important. Clare asked of her medical doctors, "Why is this doctor practicing this, doing this research? Ya know, that's what I want to know. Is it because he or she is really invested?" (telephone interview, 15 Jan 2008) For others, if ASD/VL activists found a medical doctor that was trusting and respectful and open, that was sufficient. As Elizabeth stated, "I liked him cause he wasn't attacking us for not doing vaccination" (telephone interview, 06 Nov 2007). Sue further elaborated that the relationship with the medical doctor and the doctor's relationship the ASD community is key.

Dr. – is just a regular family practitioner, not a DAN! doctor. But, and this is key, for any doctor that's going to work with these kids, whether they're a DAN! doctor or not, Dr. – happens to have a child who is on the spectrum. And in my opinion, that's more important than being a DAN! doctor. Because to become a DAN! doctor, all you have to do is go to one of those conferences. That's it, and you're a DAN! doctor. And that's not enough. I like Dr. – because anything he recommends for my son, he's tried himself, so even if it's not going to be effective, I'll know it's not going to be dangerous (telephone interview, 18 Sept 2007) .

Sue brings up a critical point and also another question. Becoming a DAN! Provider is very easy and does not require stringent examinations or certifications, nor does it require having a medical

degree (DAN! medical providers can be naturopaths, DOs, homeopaths). The goal for many parents is to find a certified MD who is also a DAN! provider, as Hope illustrated:

I have two DAN! doctors, both MDs. I don't always know the qualifications of the straight naturopathic doctors, and so I don't know, I think some degrees are more difficult to get than others. So what I prefer to find is an MD who just happens to have actually listened to parents. What a concept right? And then who has educated themselves looked at research, attended the DAN! meetings (telephone interview, 31 Oct 2007).

As Hope stated above, knowing that her medical providers have their MDs was important to her, as it was for most of the ASD/VL activists I interviewed. This would suggest that they have faith in what the MD stands for; however, that faith and trust is not automatic. Rather their medical providers have to earn their trust and respect. From the above quotes, a picture emerges that paints conventional or mainstream medical doctors as condescending, patronizing, and negligent in keeping up with research. These medical doctors are then juxtaposed with medical providers who are proactive in both research and treatment. Medical providers who listen are respectful and legitimate parents' experiences. While the ASD/VL activists stressed knowledge of current research as being extremely important, what actually seems to be happening is that ASD/VL activists are drawn more to medical providers who, like the parents themselves, are unwilling to accept the limited number of options available to treat ASD. ASD/VL activists seemed to disregard the medical doctors who only offered the mainstream treatments. Instead, they preferred medical providers who offered hope in the form of new or different options and were on board with alternative methods and up-to-date on experimental research.

8.0 THE MAKING OF POLITICIZED COLLECTIVE ILLNESS IDENTITY

The mobilization and activism described in the ASD/VL movement was possible because the parents shared similar experiences and created a politicized collective illness identity. This chapter explores that process. I begin with a discussion of the creation of a shared illness identity. I find that the experiences that have brought ASD/VL activists together include the stress of being a caretaker, the effects on their interpersonal relationships, and their experiences in trying to get the best treatment for their children diagnosed with ASDs. The chapter concludes with a discussion of how my ASD/VL activists politicized their shared illness identity and their thoughts and observations of the larger movement community.

8.1 SHARED IDENTITY: YOU FEEL THE SAME WAY?

As stated above, EHSMs are dependent upon the creation of a collective identity (McCormick 2007, Brown et al. 2004b, Tesh 2000, Benford and Snow 1986). Collective identity is necessary in order to mobilize internally, (i.e., creating solidarity, loyalty, nurturing feelings of empowerment, confidence, esteem) as well as externally (i.e., promoting a public image). Brown calls the collective identities that EHSMs create “politicized collective illness identities” and argues that the illness experience is different from the experiences of people with ascribed or socially labeled identities. Brown (Brown et al. 2004b: 55) states that the “disease process

happening within the body results in the development of a particular disease identity...this identity represents the intersection of social constructions of illness and the personal illness experience of a biological disease process.” This process is not limited to only those who have the illness. Even though the parent or caretaker is not the one suffering the biological impact of the disease, their lives and identities changed when they became parents and caretakers of an autistic child. They too experience very real consequences that come with a diagnosis of ASD. Moreover, the parents view themselves as part of a shared identity created around the ASD/VL movement. ASD/VL activists have expressed their feelings of solidarity as though they were the ones experiencing the disorder, and in many ways, they have been. For example, the parent activists have always used collective pronouns like “we” as Joyce stated, “We’re an inconvenient truth, the canary in the coalmine, and no one is listening” (telephone interview, 04 Oct 2007). Joyce does not have an ASD, but she has so fully embraced the identity that she considers herself part of the population harmed by vaccines. As Desiree similarly stated, “I was actually on the website one night just searching, trying to find another parent out there who understood what I was going through emotionally” (telephone interview, 15 Sept 2007). So what were they going through emotionally? The next section explores the themes that emerged when I asked ASD/VL activists about their personal lives and the socio-emotional impact of being a caretaker.

8.1.1 Stress on Relationships

To understand the ASD/VL activist’s collective illness identities, which as stated above depend on shared experiences, I asked all participants open-ended questions regarding their family relations, friendships, and interpersonal lives. My questions included, “What are your friendships like?” followed by, “Have any friendships changed since you became involved in the ASD/VL

issue?” I also asked, “How are your family relations?” All of my participants reported strained friendships and strained family relationships. All had lost at least one friend due to their involvement with the ASD/VL movement. As Joyce stated, “I can’t go to lunch today (with normal moms), so all the sudden you are by yourself. So we have to support each other, we go to meetings” (telephone interview, 04 Oct 2007). It is important to restate here that the ASD/VL activists I interviewed are those that are active in the movement not only as information seekers but as leaders, so their experience of friendship loss may not be generalizable to the population of parents who support the ASD/VL movement. In fact only 25% of all survey respondents reported losing a friend due to their involvement in the ASD/VL debate.

It is in the analysis of the relationship fractures and stress on friendships that the uniqueness of this movement presents itself again. Friends may argue over the politics of institutions, finances, or political parties, but many times these differences can be laid aside to create space for a friendship. For the ASD/VL activists I interviewed, this did not appear to be the case. For some, the distancing from friends happened slowly as play dates were cancelled. For others, it was more abrupt as friends outright expressed their disagreement with their position. But the ASD/VL activists all described similar narratives. Their child would be diagnosed, their friends would be supportive and helpful, the ASD/VL activists would begin researching ASDs, they would learn about the possible relationships with vaccines, they would start trying different treatments all the while sharing with their close friends who would then began to grow more and more distant until finally the activists would stop trying to reach out. One ASD/VL activist even stated she does not “have any friends left from before” (Kara, telephone interview, 01 Nov 2007). This loss of social connections was obviously painful for the activists. Their voices carried a tone of frustration, but also sadness, as Elizabeth expressed. “I

think some parents are afraid ‘Oh, I don’t want my kid picking up habits,’ so whatever. It’s been hard, it’s been really, really hard” (telephone interview, 06 Nov 2007 Joyce, the grandmother of a child on the spectrum and a leader in a ASD/VL movement group stated, “Her [Joyce’s daughter] own family, they don’t want them to come to the house ‘cause they might break something or jump on the couch. It’s heartbreaking” (telephone interview, 04 Oct 2007). Kara further illustrated how her activism has affected her interpersonal relationships, noting that her family is not always thrilled at her dedication.

My dad made a comment once to my husband said he was sad because he said, “Kara used to send us funny jokes and stuff and now all we get is the latest autism and vaccine. She’s so serious now, so focused,” and it has, it just takes over (telephone interview, 01 Nov 2007).

Veronica and Ryan also expressed the mix of disappointment, frustration, and isolation that comes with not only raising a child on the spectrum but being involved as an activist in a heated debate. Both quotes also highlighted the role of being involved with other parents who hold the same ideas and are in the ASD/VL groups. The quotes below further illustrate the strain on relationships:

I don’t think family and friends want to hear about it. They may say they do, but you just think they’re just not going to get it, so you reserve that conversation for other parents and group members. But just going to family for Christmas is an ordeal, going to someone’s house is an ordeal. (Veronica, telephone interview, 28 Nov 2007).

We don’t go out with other typical kids his age or parents. They don’t set up play dates because I think they’re freaked out by it. Most of our friends are in – [movement group], and we have play dates that way, and we go to birthday parties with a bunch of kids, autism kids rather than typical kids, ‘cause that’s who we know now and that’s who we hang out with (Ryan, telephone interview, 23 Jan 2008).

Others stepped back from relationships because “they (friends and family) just don’t get it, and they don’t want to get it” (Diane, telephone interview, 27 Oct 2007). “Not getting it” was a common theme, and referred to friends and family not understanding the relationship between vaccines and ASDs, or the alternative treatments and interventions they practice. Indeed, “not getting it” was a repeated phrase by all of my in-depth interviewees, as Barb stated, “My parents, my husband’s parents, all our siblings, all of them they just don’t get it” (telephone interview, 04 Nov 2007), and as Ryan stated, “Um, the hard thing is our parents, both sides of the family, and other siblings of ours, they have no clue. They don’t get it. You try to explain, and they just have no idea” (telephone interview, 23 Jan 2008).

The distancing and cutting of ties was not always initiated by the friend or family member. Many of the ASD/VL activists expressed becoming extremely careful and selective of whom they spent time with once their child was diagnosed. Deciding who did “get it,” and who the ASD/VL activists would spend time with, surprisingly came down to one thing: diet.

While analyzing the discussions under the family and friendships grouping, I discovered an interesting theme. All of the ASD/VL activists passionately focused on how their child’s dietary restrictions changed the dynamics in family relations and friendships. Whether or not the ASD/VL activists could trust someone to respect their child’s diet became a kind of litmus test for determining if they could trust them as friends. Disrespect of their parental decisions regarding diet was enough for my ASD/VL activists to cease socializing with family and friends. This is not only because my ASD/VL activists believed diet was a critical treatment for ASDs but because it represented a broader disrespect for the ideas and core beliefs surrounding their child’s treatment and their involvement in the debate, which shaped a good deal of their personal

identity. Disrespecting decisions regarding diet brought out anger and frustration for my in-depth interviewees, as the following quotes illustrate:

On my husband's side, there are people I try to avoid because I don't like the way they treat her. They won't respect our diet, so we just don't see them (Tova, telephone interview, 13 Sept 2007).

We just found out a few months ago my mom, my husband's mom and sister, and I don't know who else, apparently they all talked one day and said they haven't seen any improvements in Kevin and they don't agree. Like, my mom says she feels sorry for him because he can't eat all the crap the other kids are eating, so it's always, "When is he going to get to eat normal food?" So you know...food gets brought up a lot. Even before we knew anything, they tried sneaking him stuff. It's a pain in the neck (Renee, telephone interview, 10 Oct 2007).

Like, when I say I stopped giving our kids milk, it's like they think I'm depriving them of essential vitamin D or something, even though we give them calcium supplements and everything else. Matter of fact, our tests show their calcium levels are high. But like, ya know, when you tell family members, they're just like mortified. And when you tell them about vaccines, they don't understand. They're like, "Well the CDC says..." They can't possibly imagine why I wouldn't vaccinate. It's just too frustrating (Ryan, telephone interview, 23 Jan 2008).

Try this – you need a babysitter, and you can't trust your own parents because they simply don't get or don't believe it. You tell them they're on a gluten/casein-free diet and the gluten molecule can stay in the system for six months. They can't even have a cookie. So it's like parents come over and they're, "Oh well, it's one cookie. What could that hurt?" It's more obvious with casein. If Chase drinks a glass of milk with dairy, he'll wig out for a couple of days. Needless to say, we don't see them too much anymore (Kara, telephone interview, 01 Nov 2007).

I also asked all my ASD/VL activists about their relationships with spouses. Taking care of a special needs child introduces increased stress into marriages. The majority (79%) of my in-depth interviewees were, in fact, married and in self-reported stable and supportive relationships. In fact, only two of my in-depth interviewees were divorced or separated, and only one had never

married. Indeed, the level of support and partnership present in my interviewees' relationships suggested strong evidence that a supportive spouse is an important pre-condition to holding a leadership position in the ASD/VL movement, but more research is needed to confirm this. The following quotes describe how their marital relationships have provided support with raising an autistic child:

My wife quit her job. She was a full time real estate agent, but she quit her job so she could be a full-time therapy mom (Ryan, telephone interview, 23 Jan 2007).

We are a team. I'm the one doing most the work, but he is supportive. We will look at things together and decide if it's worth doing (Veronica, telephone interview, 28 Jan 20008).

At first my husband and teenager were going, "Okay, have you lost your mind," but yeah, at first he was kinda going, "Okay, I'm not sure about mercury" and saying, "You're a crazy woman." But as soon as he saw the dramatic changes after the food testing and dietary and supplements, he has more and more fallen in line. He even wrote a letter to his office management about the flu shot and that they need to, ya know, to warn of mercury in them (Hope, telephone interview, 31 Oct 2007).

Spouses were not always completely supportive, however, and some stated that it had initially been very difficult and trying on their relationship as Hope stated:

He [husband] gets a little frustrated if I'm away too much, which I need to monitor too cause I'm always thinking, "Oh, I've got to go to the capital, I've got to go here." If it interferes with my primary duties, I've got be aware, but he is supportive (telephone interview, 31 Oct 2007).

8.1.2 Self Blame

Many of the ASD/VL activists I interviewed expressed the struggles they have undergone on a personal and emotional level after finding out their child's diagnosis. All parents struggle emotionally when they hear their child is ill. This struggle is more complicated for parents with a

child on the spectrum due to the history of parental blame. In 1949, Leo Kanner stated that autism was the fault of mothers who were cold and distant; thus, the term “refrigerator mother” was born. While the theory is entirely discredited, it still haunts the mothers of autistic children, as evidenced in my interviews. Hope shared a story involving a former pediatrician.

I had it with this doctor. He would say things like, “Sensory issues are really a parenting issue.” Um, wow, okay! I didn’t know it was *my* fault that my child is afraid of air brakes on a truck, and how exactly did I cause that? So yeah, things like that, I just don’t need that. I have enough on my plate, so I switched to one I knew was a little more up on things, but we really don’t see her for anything (telephone interview, 31 Oct 2007).

Elizabeth also shared that her mother-in-law told her that her son’s problems were a result of her not talking to him enough and being too distant. Elizabeth knew this was not true, but as she stated, “It’s hard not to internalize these things and blame yourself, especially since you know the research initially was like, the kids have these issues because the moms aren’t compassionate enough. Anyway, so I have all this self guilt, ya know” (telephone interview, 06 Nov 2007). Similarly, when Barb’s son started showing signs of developmental delay, the first thing she did was blame herself. She stated, “I really started seeking help and asking myself, ‘What am I doing wrong as a parent? What is going on here? What am I doing?’” (telephone interview, 01 Nov 2007). Ryan believed that he passed on a genetic predisposition to his son which made him susceptible to damage from the mercury in the vaccines. He and his wife both struggled with the diagnoses, as he stated:

I was ADHD growing up, so I think [genetic predisposition] directly came from me. My wife has two kids from a previous marriage, and they’re fine, so that reinforces that it’s probably coming from me. So it hit hard. When I found out, it was pretty overwhelming. Ya know, I would come home from work and lock myself in my room and just cry, and one time I came home and my wife was in the van, just with the kids, in the van crying. Stuff like that would happen. But once we got on depression meds, and the

right amount of depression meds, we got back to “What can we do to help?” instead of just doomsday (telephone interview, 23 Jan 2008).

Feelings of self-blame and changes in interpersonal relationships are powerful, emotional experiences. Reaching out to other ASD/VL parents who experienced the same thing provided a great deal of comfort and aided in the parents coming together politically.

8.2 COMING TOGETHER IN POLITICAL ACTION

Sharing experiences with other parents in similar situations creates a shared illness identity, but, as Brown states, that identity must become political (Brown et al 2004a). The ASD/VL activists have followed Brown’s conceptualization by linking their identity as a parent with the politics of the debate, as Barb stated, “Because we’re all parents, we’re grassroots” (telephone interview, 04 Nov 2007). They have come together and shared their experiences and taken it further to challenge the institutions they feel are responsible for their child’s ASD. The shared identity in this movement is so strong that many of my interviewees considered fellow members as close as family. As Joyce stated, “It’s great. You can go to a rally, and it’s like a family reunion. It’s like finally people here who understand you” (telephone interview, 04 Oct 2007). The degree of collective solidarity appears to be strong. While speaking about her fellow ASD/VL activists, Joyce stated, “I love them. They just won’t give up, you can’t. If these kids want to function in society, we can’t wait 20 years. We got to get them the services they need right now” (ibid). Sue further stated, “As long as we’re all on the same page, there’s no problems, we’re all friends.

We've been more connected more lately. We're trying to help the families" (telephone interview, 18 Sept 2007).

The ASD/VL movement community is not totally cohesive of course, as Barb stated, "It's like a soap opera sometimes" (telephone interview, 04 Nov 2007), and Jane stated, "Well, most of the [online] groups are okay, but in others, they feel very strongly, and if you get on there and say something they don't like, well, they're really kinda mean" (telephone interview, 13 Oct 2007). When I asked what improvements or things they would like to see change in the ASD/VL movement community, they mostly expressed a desire to bring all the smaller groups together or to help each other. As Kara stated, "We don't want to reinvent the wheel. If one group's doing it, we ask can we help them out or do something different" (telephone interview, 01 Nov 2007). Hope expressed a similar sentiment to work together and collaborate:

I don't know why all the groups are separate. I wish they would get together. I think we could accomplish a lot more if we get together, ala Autism Speaks. I think it divides the money and the effort to have so many pocket organizations. I wish they could unite under one banner. That's my main desire. But I've found that, especially when you're dealing with women, that, ya know, "I don't want to work with her." But when we're dealing with this, such an important issue, I just want to say get over it! I just wish they would come together (telephone interview, 31 Oct 2007).

While the movement cannot be considered one cohesive unit, there exists a strong sense of solidarity among ASD/VL groups and activists. The expressed struggles and experiences that came with being a caretaker for or relative of a child with an ASD highlights how illness truly is a social phenomena that effects not only those diagnosed but also those who are directly involved. The internal and interpersonal issues that parents struggled with were shared by others in the movement, and this emotional connection aided in the building of solidarity. Concerns over self-blame and struggles with family and friends were a direct result of the introduction of

an illness, in this case an ASD. When parents went online and found out that others were going through the same thing and held the same views about the causal relationship between vaccines and ASD, the foundations of a politicized collective illness identity were made.

9.0 HEALTH SOCIAL MOVEMENTS

My data supports and contributes to the validity of theoretical foundations of HSMs in that ASD/VL movement activists used the special insight gained from their experiential knowledge to organize and create solidarity and challenge their opponents. This chapter moves the discussion forward to address the recommendations and implications for the HSM framework, the impact of the ASD/VL movement, the evolution of the movement, and finally the future of HSM studies.

9.1 IMPLICATIONS FOR THE HSM FRAMEWORK

Brown's framework of HSMs includes three archetypes: constituency, access, and embodied (Brown et al 2004a). While he acknowledges that HSMs often cross these categories, I find that the degree of overlap in the first two categories is so complete that it makes distinguishing the two as separate categories inefficient. Furthermore, there are components of all three types in just about all HSMs. In most cases, the word "access" can be replaced with "equality" without losing meaning. For example, racial minorities in a HSM can be identified as a constituency-based movement, embodied movement, and also an access movement. The same goes for class, gender, even disease. Another example would be environmental illness activists fighting for recognition that theirs is a real illness. This is both a constituency-based movement and an access movement because they are seeking access to make or influence decisions on medical diagnoses. My

research also supports the dissolution of these three categories and simply using embodied, access, and constituency as descriptive characteristics rather than organizing strategies. The ASD/VL movement can be described as a constituency based movement because the majority of participants and leaders are parents and caretakers of children with ASD. The movement can also be viewed as an access movement because movement leaders sought access to data and a 'seat' at the decision making table. And finally it is an embodied movement because their experiences so heavily informed their actions and decisions.

My research supports Brown's theory that HSMs are also "new" social movements. New social movement theory developed in response to what some movement theorists argued was an overemphasis on economic and political explanations of collective action and an observed shift of focus to issues of culture and identity (Johnston, Laraña, Gusfield 1994). However there is debate over whether or not 'new' social movements are really new (Tarrow 1989, Melucci 1994, Rose 1997, Picardo 1997), or if issues of culture and identity are finally receiving the attention in social movement theory that they deserve. Theorists such as Inglehart (1990) suggest that prior to the 1960's social movements were more concerned with economic well-being as evidenced in labor movements, while today social movements are often centered around issues of empowering identity and symbolic action as evidenced in movements organized around race, class, and gender (Picardo 1997, Rose 1997, Johnston et al 1994). This shift in focus from economy to identity is theorized as being a result of postindustrial development and the rise of a post materialist society. Inglehart (1990) argues that new social movements are developing as a result of a "generation discovering new values given their freedom from material want" (quoted in Rose 1997: 471). The 'post materialist' argument posits that "the population in industrialized

countries is being liberated from preoccupation with economics and survival and shifting attention towards the search for personal meaning and quality of life” (Rose 1997: 471).

However, the argument that economic concerns are less central to collective action today fails to recognize that issues concerned with identity and quality of life can be directly tied to material and economic concerns (Rose 1997). Furthermore, issues of identity and symbolic action were important in collective action prior to the 1960’s (Rose 1997). Therefore rather than thinking of new social movements as significantly different from movements of the past (though not denying potential differences), the conceptualization of new social movements is suited to analysis of collective action with a focus on identity and culture (Johnston et al 1994). As Johnston (1994: 6) states: “the concept [new social movements], however, refers to an approach rather than a theory; it is not a set of general propositions that have been verified empirically but just an attempt to identify certain common characteristics in contemporary social movements and develop analytic tools to study them.” In line with Johnston’s recommendation, ASD/VL can be considered a ‘new’ social movement because it shares key characteristics of new social movements.

New social movements bring culture, personal experience, and issues of identity to the center of arguments and adopt tactics other than violence, protest, strike, and revolution (Brown et al. 2004a). Rose (1997) further argues that new social movements often, whether intentionally or not, promote middle class interests and include professional middleclass members. He cites large numbers of professional middleclass membership in the mainstream peace, environmental, and women’s movement as evidence (Rose 1997). The ASD/VL movement contains many characteristics of new social movements. As evidenced in my survey data, members and leaders come from the middle to upper middle class. Further, new social movements adopt the adage of

the “personal is political,” which is evidenced in this debate as parent activists personify their agenda in everyday, mundane life experiences like going to the grocery store in a car adorned with ASD/VL material and handing out informational fliers to their doctors, neighbors, and anyone else who will listen. Indeed, ASD/VL activists’ personal decisions regarding treatment of ASD, such as deciding to utilize alternative, non-licensed treatments for their children, is a political statement and form of activism as it goes against accepted protocol and implies (explicitly or implicitly) that they do not trust or have complete faith in mainstream medical treatment options. Finally, the ASD/VL activists involvement in this debate is directly influenced by their personal experiences of raising and caretaking for a person with an ASD.

Brown notes that HSMs introduce the biological body to social movements (Brown et al. 2004b). My research emphasizes that the person exposed to a social movement may not be the one directly diagnosed with the illness or disorder. Instead, those who are closely tied to the diagnosed individual also experience the effects of illness in a physical way. Many of the ASD/VL activists I interviewed experienced depression, fatigue, and anger due to the introduction of autism into their lives. The parents used this experience in the same way Brown (2004a), McCormick (2007), and Hess (2004) describe those who are diagnosed with illness do, i.e. they deployed their personal experience as a challenge to mainstream medicine. Therefore, I would argue that it is not necessarily that HSMs are introducing the biological body to social movements but that the body, and the experience of the body, is the central site and source of knowledge in HSMs.

One issue that Brown does not explicitly discuss is the question of measurement of HSM success and impact. For example, how do we measure when an HSM has successfully gained legitimacy and equality in the biomedical world? Another significant issue is whether the

movement has achieved success in their contests for credibility. One way to evaluate movement success is to look at the trajectories of HSM organizations; i.e. have they grown more institutionalized, bureaucratized, and/or mainstream? Have they evolved? The following two sections address issues of movement impact and evolution.

9.2 MOVEMENT IMPACT

Some sociologists and political scientists have suggested that social movements have little impact (Burstein 1999). Others, however, have argued the opposite, that social movements can and do have an impact (Giugni, McAdam, Tilly 1999). The ASD/VL movement has had a significant impact on several sectors of society which can be interpreted as evidence of its success. Another measure of the success of a movement is to look at its goals and then determine if it has achieved them (Gamson 1975). While this seems like an easy task, it presents several challenges, Giugni (1999) notes: 1—lack of movement homogeneity; 2—assessment of success can be subjective; and 3—consequences are not always intended. First, as evidenced in the profiles of the movement groups, not all groups have the same goals: some are more interested in pursuing research to prove the ASD/VL link while others are more interested in acting in the court rooms, and still others prefer to act more directly through political rallies. Second, what one ASD/VL group may consider a success, another may see as a failure. For example, while five states have banned the use of thimerosal, at least eleven others have had similar legislation voted down. Therefore the question of legislative success overall is subjective. Finally, some of the successes of this movement may not have been originally intended, for example obtaining the

Simpsonwood transcript was never an explicit goal, the original goal was access to data, yet the impact of Simpsonwood transcript proved to be pivotal.

Bearing in mind that ASD/VL movement organizations may hold different views on success and failure regarding their specific goals, the ASD/VL as a whole has made an impact in several arenas. Impact in the political arena is evidenced by the ASD/VL movement's success in enlisting the support of elected officials such as Burton, Waxman, and Weldon. Political advocacy included the congressional hearings organized by Burton that provided a space for ASD/VL movement activists to meet and mobilize; political advocacy generated pressure on the CDC to comply with Freedom of Information Act application, and advocacy forced the CDC to allow the Geiers access to the Vaccine Safety Data link, and, finally advocacy created support in state legislatures for banning mercury in vaccines. Burstein (1999) argues that part of a social movement's ability to have an impact is dependent on the participation of political allies who are concerned with either getting elected, or re-elected. That is, if it is politically beneficial for elected officials to partner with a movement group, they are more likely to do so. While my data did not explore the potential for the ASD/VL political advocates motivation possibly stemming from a desire for re-election, social movement literature and theory support the idea that concern over future political careers would play a significant role in their involvement (Burstein 1999). Burstein's (1999) theory would suggest that ASD/VL movement groups which are able to take advantage of politicians' desire for electoral support are able to create a mutually beneficial relationship, exchanging advocacy for votes. However, further research into the political careers of elected officials supporting the ASD/VL movement is needed to fully explore the motivations behind their involvement.

Rucht (1999) argues that social movement mobilization rarely translates into direct policy outcomes. His reasons for this include social movements' lack of direct access to the decision making process and the effect of countermovement actions (Rucht, 1999). The ASD/VL movement is evidence that movement efforts *can* translate into direct policy outcome. With the aid of political allies, the ASD/VL movement successfully persuaded legislators to ban the use of thimerosal in vaccines in five states. As of February 2009, one additional state is awaiting signage to pass a bill into law that would ban thimerosal and 14 states have comparable bills introduced to the state legislature. Legislation banning mercury has been aided, and indeed promoted, by ASD/VL movement organizations that supply templates dealing with the 'how-to' of introducing bills to the state (e.g. Moms Against Mercury, NoMercury.org, AAC all have resources for legislative actions).

The success of the mercury bans, especially in the face of countermovement activity by the CDC and American Academy of Pediatrics which opposed all bills banning thimerosal, highlights the movement's ability to directly impact public policy. Burstein (1999: 4) states that social movement impact is restricted in democratic politics due to the "limits on the ability of citizens and legislators to pay attention to many issues at the same time." The ASD/VL success in state legislatures illustrates the movements ability to hold the attention of policy makers and present an argument strong enough to succeed in getting their legislation passed.

Part of the ASD/VL movements ability to keep the attention of the public is due to their success in utilizing the public media. They have been able to keep the ASD/VL debate in the headlines over seven years through the use of strategic advertisements, collaborations with authors like David Kirby, journalists like Robert F. Kennedy, Jr., and celebrities like Jenny McCarthy. Future research into this debate should examine what other factors contributed to the

success of the mercury ban initiatives in some states but not others. Possible factors include political ally involvement and positions, and the nature of potential competing legislative agenda items.

In addition to influencing state legislation, the ASD/VL movement has made an impact and seen some success in the US federal court system. In March 2008, after I had completed my interviews with parents and closed my online survey, the ASD/VL groups celebrated what they viewed as victory in the National Vaccine Injury Compensation Program (NVICP) and a step towards vindication. The case centered on 9-year-old Hannah Poling, daughter to Dr. Jon Poling, a neurology resident at Johns Hopkins University and Terry Poling, a registered nurse and trial attorney. The Polings filed a case in the NVICP claiming vaccines damaged their daughter. Their argument stated that Hannah had been developing normally until she received five shots on the vaccine schedule at 19 months of age. In the next 72 hours, they argue Hannah began to regress drastically—crying, fever, and refusal to walk (Terry Poling V. DHHS). Within a year, she received a diagnosis of autism. The Polings found that Hannah had a mitochondrial disorder that affects the body's cell metabolism. This case never made it to court, as the DHHS decided instead to settle the case out of court and awarded damages to the family. The DHHS did not state that vaccines were responsible for Hannah's mitochondrial disorder or her autism. Instead, the settlement conceded that the vaccinations may have aggravated the underlying disorder, which can lay dormant for years. The Polings were awarded financial compensation to be used to care for Hannah and to cover her health expenses (Poling v. DHHS).

As stated above movement success is subjective and the interpretation of the Poling settlement is contested. The ASD/VL activists see it as the government acknowledging that vaccines cause autism; in the ASD/VL blog 'Age of Autism' Kent Heckenlively, claimed, "It's

official. The sky has fallen! The fat lady has sung. Pigs are flying. We all know what happened here, and we know what this settlement means. The government just dropped its pants” (www.ageofautism.org). However this was explicitly contested by the VICP and the CDC. As Dr. Julie L. Gerberding, director of the CDC stated to the *New York Times*, “Let me be very clear that the government has made absolutely no statement indicating that vaccines are a cause of autism... That is a complete mischaracterization of the findings of the case and a complete mischaracterization of any of the science that we have at our disposal today” (Harris 2008: paragraph 5). This did not change the mind of most ASD/VL organizations, including SafeMinds who followed Gerberding’s statement with their own press release claiming that the Poling settlement was more evidence that thimerosal is indeed dangerous and responsible for the ASD epidemic. MAM, the NAA, Autism United, and countless other ASD/FL groups stated this validated their concerns over vaccines, and they were encouraged by the finding, believing it would set a precedent for the upcoming Autism Omnibus trials that were going under review.

The success in the court system has not been consistent and recent court actions appear to be taking a turn against the ASD/VL hypothesis. In June 2007, the VCIP heard the first of the more than five thousand cases claiming vaccine damage causing autism. The first case, *Cedillo v. Secretary of Health and Human Services (Case#98-916V)* was finally decided on February 12, 2009. The Cedillos’ case argued that their daughter’s immune system had been compromised and weakened by thimerosal, which resulted in her inability to “clear” the measles virus vaccine she received at 15 months of age. This case, along with two others, argued this thimerosal-MMR combination was a “one-two punch” to the immune system resulting in ASD. The Special Masters disagreed with the argument, but rather than placing the blame on lawyers or parents, Special Master George Hastings, Jr., blamed the physicians and scientists he believed were guilty

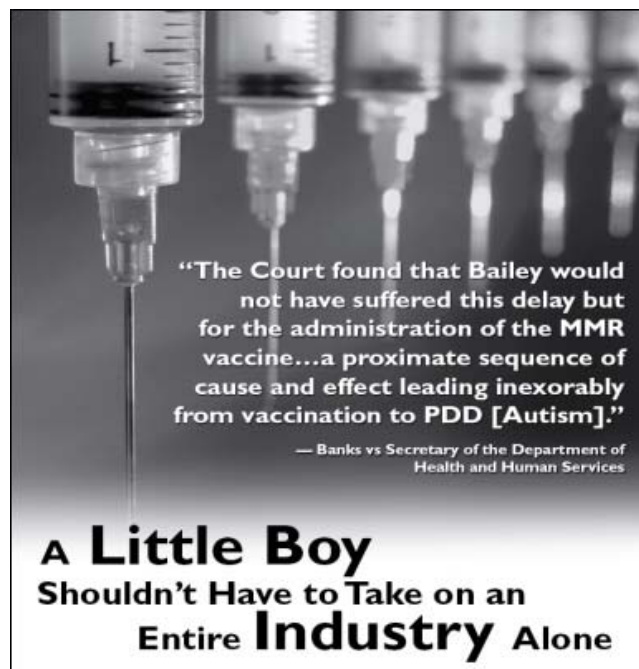
of gross misjudgment. He stated in his closing decision, "Unfortunately, the Cedillos have been misled by physicians who are guilty, in my view, of gross medical misjudgment" (Cedillo vs. DHHS). Implicit in his closing statement is the message that there are honorable and dishonorable medical professionals and that parents must be careful who they trust. While he did not state explicitly that DAN! providers were responsible for the misinformation, it is a safe assumption that he was referencing medical providers who believe in and practice the alternative biomedical interventions, including practices to excrete heavy metals.

Through this boundary drawing, Hastings strengthened the dominance of Western mainstream medical professionals who continue to assert there is no link, and he pushes those doctors who continue to argue the ASD/VL further to the edges of credibility and legitimacy. This finding was a blow to the ASD/VL movement community. The prominent ASD/VL groups argued bias, dishonesty, and misconduct on the part of the special masters while applauding the parents for their efforts (www.ageofautism.com). ASD/VL activists commended the families stating, "These families blazed the legal trail for children with autism in the omnibus autism program. These brave families and their children are our heroes" (www.ageofautism.com). The ASD/VL organizations have not lost hope, however. There are many more cases to be tried. Right now the court is hearing testimony in three test cases on the link of thimerosal only and autism. If these three test cases find in favor of the parents, all remaining cases will be heard, and the potential payout from the VCIP would likely exceed its \$2 billion budget.

In what some argue was an attempt to mitigate and draw attention away from the decision in the Cedillo case, and a nice example of movement/countermovement action and reaction, Generation Rescue chose to highlight a court case from 2007 they claim was evidence of government admission of the ASD vaccine link (<http://leftbrainrightbrain.co.uk/2009>). The case

in question concerned Bailey Banks versus the DHHS in which the plaintiff argued that Bailey developed autism as a result of the MMR vaccine. The finding of the court was that “Bailey would not have suffered this delay but for the administration of the MMR vaccine...a proximate sequence of cause and effect leading inexorably from vaccination to PDD [autism]” (www.generationrescue.org). The finding in favor of Bailey did not confirm the direct causal link between MMR and autism. Instead the MMR vaccine was found to set off a series of adverse events in Bailey leading to a developmental delay. Nevertheless, Generation Rescue sought to publicize this event two years later to, as some argue, draw attention away from the finding of the Special Masters court decision against the ASD vaccine causal relation. To draw attention to this finding, Generation Rescue took out another full page add in *USA Today* which ran on February 25, 2009 (Figure 10). This advertisement again highlights the media savvy of ASD/VL movement groups as they attempt to remain relevant and hold the attention of the public.

Figure 10. Feb. 25, 2009 Generation Rescue ad published in *USA Today*



While ASD/VL activists have seen success in the political, media, and judicial arenas, they have not won credibility within mainstream medicine, as evidenced by the expulsion of the Geiers and Wakefield and the aggressive framing campaign. Further evidence of their lack of success in achieving credibility in mainstream medicine is the denial of coverage for alternative biomedical interventions promoted under the DAN! protocol. This represents the continued dominance of mainstream medicine in the treatment domain because it maintains the cultural and legal monopoly over determining which treatments are valid and effective, as well as which are justified for medical insurance coverage.

This section briefly covers the impact of this social movement. However a more in-depth analysis is needed to fully assess the movement impact. As Tilly (1999: 268) discusses, many factors shape effects and outcomes of social movements, such as the independent actions of authorities, interventions of other interested parties, environmental changes, and non movement politics. Thus, the potential for outside factors and third party actors to influence the mobilization and outcome of this debate has been great. For example, the role of financial interests in this debate has not been fully explored in my research, yet may be a critical factor in the mobilization and involvement of politicians, lawyers, and journalists.

There are many stakeholders who could stand to benefit from the continuation and success of the ASD/VL debate. First and foremost are lawyers who, if they either win or settle their cases, could earn millions of dollars. Second are the expert witnesses who are paid to testify in vaccine related court cases and to appear as guest speakers at conferences. Journalists are also stakeholders in this debate because they can capitalize on the visibility and relevance of the movement by writing inflammatory articles to grab headlines and increase their own status. Alternative medical practitioners have also benefited, and will continue to benefit, from the

ongoing dispute over causation. They stand to benefit because the theory that vaccines are linked to ASDs goes hand-in-hand with alternative treatment plans that advocate using costly supplements and biomedical interventions like hyperbaric chambers, ointments, creams and procedures to excrete heavy metals from the body. The popularity of these alternative treatments has undoubtedly been financially beneficial for providers willing to offer these services and treatments. In addition, the companies manufacturing alternative, naturopathic supplements and ‘treatments’ can also benefit. Several movement web pages, such the National Autism Association and Generation Rescue, allow these manufactures to advertise on their sites, providing direct access to a captive population of parents searching for treatments.

On the opposite side of the debate there are great financial losses that could result from legal success of the movement. First, the federal government would owe parents of vaccine damaged children literally billions. This would most likely bankrupt the Vaccine Injury Compensation Program. Second, vaccine manufactures would see increases in production and insurance costs if policy required more rigid safety standards and testing. Vaccine manufactures would also suffer a decrease in their stock prices as concern over vaccine safety grew. While more research is needed to fully explore the financial stakes in this debate, financial concerns appear to play an important role. Future research should explore the stakes these third party players hold in this debate and attempt to track their involvement in movement outcomes.

To aid in this endeavor and to fully understand social movement impact Tilly (1999: 270) suggests a six step approach:

- 1) to formulate clear theories of the causal processes by which social movements produce their effects;
- 2) to limit investigations to the effects made plausible by those theories;

- 3) to work upstream by identifying instances of the effects, then seeing whether the hypothesized causal chain was actually operation;
- 4) to work down stream by identifying instances of the causal chain in operation, then seeing whether and how its hypothesized effects occurred;
- 5) to work midstream by examining whether the internal links of the causal chain operated as the theory requires, and;
- 6) to rule out, to the extent possible, competing explanations of the effects .

While full utilization of this framework is beyond the scope of this project, future research on the ASD/VL debate would benefit from adopting this approach in order to untangle the effects that are a result of direct movement activities from those that are unintentional outcomes. An additional research project looking specifically at the social movement impact in an organized, systematic framework such as Tilly's (1999) would add more depth and understanding to the successes and failures in this debate.

9.3 MOVEMENT EVOLUTION

The ASD/VL movement groups have gone through a broadening of focus as the debate evolved. The first groups held a primary focus on thimerosal in vaccines and the MMR vaccine while more recently they, along with newer groups, have evolved to include a more comprehensive concern over vaccines in general. Furthermore, the first wave of mobilization consisted of groups focused on gathering information, gaining access, and arguing their case (SafeMinds, NVIC, NAA). The second wave, consisting of groups who believed they were defrauded and ignored, was more contentious and used more aggressive tactics (MAM, Generation Rescue). The third

wave consists of these same groups continuing to focus on research and information dissemination, but these groups have broadened their base by including general vaccine safety and focusing on treatment and other possible causative links.

By becoming more inclusive and expanding beyond a focus on the possible causative link between thimerosal, MMR, and ASDs, movement groups can continue to stay relevant and mobilize support. When movements are forced to adapt in the face of insurmountable obstacles, such as the mounting evidence against the ASD/VL hypothesis, they have three options; they can disband entirely, become co-opted and appropriated into existing institutions, or adjust their movement goals and focus (McAdam, Tarrow, and Tilly 2001). This last option has proved to be the most popular among ASD/VL movement groups. Many groups have expanded their mission from just focusing on one cause and one outcome to include multiple causal theories, alternative treatment options, and other issues associated to vaccination like informed consent. Generation Rescue and A-CHAMP's evolution over the course of the past four years is an example of this.

The movement's frame expansion is achieved through innovation (McAdam et al. 2001, Snow and Benford 1992). As discussed, both sides have practiced various framing techniques to gain support, but the need to adjust movement frames in order to maintain support now is more critical. As expressed by the ASD/VL activists I interviewed, they are aware that they have been framed as fringe, radical, and anti-science. Further, autism rates continue to increase (Figure 1) and more research is emerging showing thimerosal had no influence on ASDs. These are serious obstacles the movement must deal with. It appears they have dealt with these obstacles through innovation and adjusting their repertoires to include other causative theories. This practice is well documented in movement literature, as McAdam et al. (2001:49) states, "Repertoires evolve as a result of improvisation and struggle." To distance themselves from the fringe and radical image,

ASD/VL movement groups focus on treatment, healing, and messages of hope. Finally, to prove they are not anti-science, they put even more effort into funding and conducting research.

These innovative efforts have resulted in a broader base that includes environmental activists, patient rights activists, and alternative medicine activists, allowing the groups to remain relevant as the focus moves away from thimerosal. The foundations of the core movement groups' arguments remain the same, i.e. vaccines cause autism, but now they have won the support from multiple organizations with similar interests in the "greening" movement, which includes groups organized around environmental awareness, global warming, pollution, air and water quality, and environmental illness.

9.4 THE FUTURE OF HSM STUDIES

Now I would like to turn to a discussion of some of Brown's (2004b) predictions concerning HSMs as my research can directly address their accuracy. First, Brown predicts that those illnesses that are less legitimate, i.e. do not have biomedical backing, and that are more uncertain will have more difficulty mobilizing a collective illness identity and, hence, a more difficult time launching an EHSM. He cites examples such as multiple chemical sensitivity (MCS), fibromyalgia, and chronic fatigue syndrome. These kinds of diseases present difficulties because an essential part of forming a political illness identity is having a name for the illness. If there is no medical recognition, then it is up to sufferers to name the illness, as is the case with MCS, which also goes by "environmental illness." My findings do not support this prediction. Indeed it appears that uncertainty and lack of accepted medical knowledge of a disease contributes to mobilization. As outlined above, ASDs are one of the most medically uncertain disorders today,

and my research establishes that the uncertainty *contributed* to the forming of illness identity and the political activism due to the desire to find answers. Mitigating my dismissal of his prediction, however, could be the drastic increase in ASD rates, which makes ignoring the problem impossible.

This prediction also fails to acknowledge the powerful mobilizing force of the internet. With the growing use of the internet, people with diverse and unknown disorders can easily find each other and start their own groups with little to no resource expenditure. All that is required is one person to start a web page or newsgroup discussing a particular group of symptoms, name those symptoms, and register the web page with a popular search engine such as Google. Another challenge to this prediction is that often those groups who view themselves as outsiders, as ignored, and looked down upon, have *more* passion to mobilize and fight for justice than those who already have mainstream acceptance. Many of the quotes from the ASD/VL activists I interviewed support this point, as they work activism into their everyday lives and confront those who stigmatize children with ASDs.

The next prediction Brown makes concerns the extent to which an HSM learns and assimilates from other social movements or are open to social movement spillover (Brown 2004b). This proves true in the ASD/VL movement as groups broadened their focus and collaborated with environmental protection groups. Brown also predicts that the “sheer number of people experiencing a disease should translate into broader public awareness and greater mobilization” (Brown 2004b:74). My research supports this prediction as it is undeniable that the drastic increase in number of children diagnosed with ASD contributed to greater mobilization.

Brown (2004b) predicts that groups who are already oppressed will be more likely to experience their illness in politicized terms. This is due to the fact that oppressed people are

already sensitized to what it feels like to experience injustice. On the one hand, my data cannot really speak to the effect of race or class oppression because my population was largely white middle class. While my own data cannot address this prediction, there are counter examples which may challenge it. For example, the lack of mobilization among the impoverished population that is experiencing “epidemic” rates of diabetes mellitus. The relationship between poverty and obesity, and poverty and type 2 diabetes is remarkable, yet this population that is already experiencing injustice does not seem to view their disease through a political lens.

10.0 CONCLUDING THOUGHTS: THE INFLUENCE OF UNCERTAINTY

The most consistent theme across all my datasets, and indeed the dominate characteristic of this entire debate, is uncertainty. Uncertainty is almost always a characteristic of HSMs. In fact, uncertainty alone can be sufficient to generate a HSM. But why is it that some diseases are hotly contested and the source of great controversy while others are not? The deciding factors appear to be uncertainty of an illness in causes, symptoms, and population. Brown et al. (1990) describes the various reasons why uncertainty influences whether or not a particular illness or disease will be contested: 1) uncertainty of the body's past exposure, 2) uncertainty in knowledge of dose-response relationship, 3) uncertainty of synergistic effects, 4) etiological uncertainty, and 5) diagnostic uncertainty.

The ASD/VL debate contains every possible uncertainty listed above. ASD/VL activists have tried to estimate their child's past exposure to mercury through vaccines. In fact, many of the group websites contain "mercury calculators" where parents can enter in their child's vaccines and get a total mercury exposure. But there is no way to know the total mercury exposure as other sources can contribute, as so bitterly noted by Kristen Ehresmann during the vaccine safety hearings held by Burton. And as pointed out in the Simpsonwood transcript, we do not know what the dose-response relationship is with mercury nor the body's threshold of tolerance. This uncertainty is problematic not only for the ASD/VL debate but all environmental health debates. Because we cannot experiment on humans and the knowledge gained from animal testing is not directly transferable, we do not know the effects chronic low-dose exposure of chemicals on health (Tesh 2000). Going along with this is the lack of knowledge concerning

the mechanisms that the body goes through when processing different chemicals or the uncertainty of synergistic effects. This is something that the Simpsonwood scientists and ASD/VL activists agreed should be studied more carefully—i.e. looking at how the body processes mercury and heavy metals.

One of the biggest issues in the ASD/VL debate is what Vyner (1998) calls the etiological uncertainty—what is the *cause*. Because we do not know what the body's threshold to ethylmercury is nor what the dose-response relationship is, it is almost impossible to effectively prove that exposure to mercury in vaccines causes specific diseases. As Vyner states, “Even more basic is the uncertainty of how the different levels of organization – from molecular to sociocultural – are related to health and illness at the individual level. For example, what role do genes have in predisposition, ‘vulnerability,’ and even causation of disease vs. environmental?” (Brown, 1990: 38) This is what the IOM attempted to establish. However, in the end, due to the nature of the scientific debate, they could only say that the data supports a rejection of the hypothesis, which is far away from claiming that mercury is safe. Finally, there is diagnostic uncertainty—how do we know that symptoms X cause disease Y? More importantly, how do we know that all diagnosticians are using the same criteria consistently? This problem is difficult even in dealing with diseases that have 99% effect testing mechanisms, so the problem of reliable and valid rates of diagnosis of ASD is highly contested. Many argue that the dramatic increase in ASD diagnoses documented is not a matter of actual increase in occurrence but a reflection of changing definitions and increased awareness among practitioners. With the abundance of uncertainty, it is no wonder that there is a high level of contestation and debate.

Uncertainty was also a reoccurring and dominate code in my content analysis of articles that discussed autism and vaccinations from the *New York Times*. The following is an example of

a statement in an article that would lead to an “uncertainty” code: “Dr. Tom Insel, director of the National Institute for Mental Health, said, ‘Is it cell phones? Ultrasound? Diet sodas? Every parent has a theory. At this point, we just don't know.’” (Harris and O’Connor 2005, paragraph 21). When the *New York Times* first starting covering the debate, they gave equal weight to both sides, but in 2005, “two reporters investigated every scientific study and thousands of documents from parents convinced of a link between autism and vaccines and came down pretty clearly on the side of the scientists” (Hoyt 2008:2). After this review, the *New York Times* prefaced each article related to the debate with a note that science supports the finding that there is no link. It is interesting to note that the author stated they came down on the side of “scientists,” implying that evidence suggesting a link comes only from non-scientists. But the message of uncertainty was still pervasive in the articles. This may have something to do with the way each side presented their cases.

The quotes from government officials refuting the link were couched in scientific language and difficult to understand. This is for two reasons: 1) top government officials, who were the only ones allowed to speak to the media, had to be careful of what they said in an attempt to stay true to what the data can say, and in acknowledgment of the uncertainty characterizing the issue (as mentioned by Brent in the Simpsonwood transcript), and 2) to protect themselves and their boundaries from accusations and encroachment. For example, rather than saying vaccines do not cause autism, the IOM stated “evidence supports a rejection of the causal hypothesis,” a watered-down, much less powerful declaration. Meanwhile, the parent activists do not have the same responsibility or consequences attached to their statements and are able to make very bold, very direct claims as exemplified in the Generation Rescue advertisements. This was pointed out in a recent article, published after I had already analyzed my data. Dr. Peter

Hotez, president of the Sabin Vaccine Institute and father to an autistic daughter, was quoted in the *New York Times*, “If the surgeon general or the secretary of health or the head of the CDC would come out and make a really strong statement on this, I think the whole thing would go away” (McNeil 2009: paragraph 9). Yet government officials continue to couch their language in scientific jargon and “supports of rejection of casual relationships.”

That ASD/VL movements have the freedom to make direct aggressive claims while government officials are limited to tight-lipped, scripted answers that are often too obtuse for the public to understand works to the movement’s benefit, a point also brought up by Brent in the Simpsonwood retreat. This is supported by Abbott (1988), who noted that it is better to keep messages in the media simple and direct because the audience is not as aware of particular precursors or the detailed issues needed to put the specifics in context. Also, keeping the messages simple allows those involved to have a better handle on how its image is constructed in society. In the ASD/VL movement, activists are able to keep their messages simple and direct, in a way ignoring and denying the uncertainty that pervades the issue, while the government and health officials take the safer, more restricted approach, honoring the scientific uncertainty.

I believe that this difference between how the ASD/VL movement and mainstream medicine handle uncertainty is key to understanding why the theory that vaccines and ASD are linked has endured through the multiple attempts to disprove it by the CDC. This happens because parents, overwhelmed with the uncertainty of ASD and their children’s futures, are hungry for answers and explanations. According to my data, it is how they came to be involved in the debate in the first place. Therefore, when someone presents them with a hypothesis in a direct and concise manner that appears to be scientifically sound and that comes from someone who appears sincerely concerned, and most importantly, if that theory supports *their own*

personal experiences, they are more willing to accept it as credible. It is a much more pleasant package to believe in when compared to mainstream medicine's offer of inconclusive research, ineffective behavioral therapies, and no hope for a cure.

11.0 EPILOUGE

Parents and caretakers of children diagnosed with ASDs came together, formed a politicized, collective illness identity, became lay experts, produced their own scientific research, and used science as a tool in a heated boundary dispute. They formed a powerful, and in many ways successful, HSM organized around the hypothesis that vaccines play a causative role in ASDs. In this debate, ASD/VL movement groups, sometimes working together and sometimes independently, used science and research to build legitimacy because they know the authority science holds. As Toumey in his work *Conjuring Science* states, “the prestige of science is so great that it... is believed to possess such authority and be able to answer any of life’s questions... Thus to invoke the symbols of science is to make policies sound, commodities desirable, and behavior legitimate” (Gieryn 1999: 6). But science was not the foundation of the movement activists’ beliefs. Rather, their experiential knowledge and advice from others they trusted in the movement proved to be the most credible source of information.

I admit I was surprised by my findings. I did not expect the influence of experiential knowledge to be as prominent as it was. I thought that ASD/VL movement members would come together *because* of their shared experiences, but I did not expect that those experiences would weigh so heavily in their decisions regarding causation and treatment. However, by trusting their experiential knowledge and ignoring the research rejecting a causative link, parents can continue to hope for vindication, for compensation, and most importantly, for a cure. With this in mind, mainstream medicine should adjust its approach in this debate and, rather than

framing the movement as fringe or radical, attempt to reach out and offer support and understanding and, most importantly, hope.

APPENDIX A

A.1.1 Codebook

1. **Strong Language:** composite grouping to capture any language that is particularly strong or incendiary. It contains the following codes: anger, frustration, war fare, redemption.
2. ***Activism:** Plan of action and Getting word out, discussions of strategy, planning, mobilization, and activism this code is applied whenever the discussion of any kind of activity or action or involvement as a means of achieving political or other goals, sometimes by demonstrations, protests, letter writing, advocacy on behalf of an agenda, etc. Applied whenever the respondent discusses the spread of information.
3. ***Allergies:** any discussion of allergies
4. ***Alternative causative theories:** discusses alternative theories of ASD causes
5. ***Alternative medicine:** discusses the use of alternative medicine
6. ***Strong emotions:** (Warfare-language, anger, frustration): expressing that he or she is upset, frustrated, annoyed, moved to anger, connotes images of war, reference to war
7. ***Big Pharma:** discusses anything having to do with pharmaceutical companies
8. ***BIOMED:** discusses the various biomedical treatments for ASD
9. ***Bush administration:** Bush administration and/or Homeland Security Bill is mentioned
10. ***Civil Liberties:** discusses their rights as parents, as citizens
11. ***ASD Community:** any discussion of opinions and thoughts of other ASD organizations discusses the ASD community, support groups, organizations, their opinions on how the organizations function or do not function together
12. ***Collaboration with other groups:** discusses collaborating with other groups, either other ASD groups or non ASD groups (example working with environmentalist groups)
13. ***Credibility:** whenever the topic of credibility comes up, often how respondents determine credibility
14. ***Cured:** discusses the ability/possibility/hope that a cure will be found or has already been found state they have heard of ASD being cured
15. ***DAN:** any mention to the DAN! doctors
16. **Demographics:** demographic data on the participant
17. ***Diet:** any discussion of diet as it relates to ASD

18. ***Discussion of doctors:** any discussion of doctors
19. ***Discussion of treatment:** any discussion of treatment
20. ***NIH/GOV/CDC:** any discussion of the NIH, DHHS, or government
21. ***Distrust/trust of doctors:** expresses trust or distrust in their doctors
22. ***Epidemiology:** mentions population studies or any epidemiological research or data
23. ***Family health status:** any discussions of respondent's family's health
24. ***Family members' support:** any discussion of family support
25. ***Fringe activism:** discusses fringe or extreme activism
26. **Good quote:** to denote and flag good quotes
27. **How got involved:** narrative of beginning/entering into the ASD world
28. ***Influence of other parents/people who work with ASD:** any discussion of the influence of others in the respondent's involvement in the ASD community
29. ***IOM:** any discussion of the IOM
30. ***Media:** discussion of media portrayal of the ASD/vaccine dispute, celebrity involvement
31. ***Mention of other health:** any discussion or mention of other health issues the respondent or the respondent's loved one with ASD is dealing with
32. ***Mercury load:** any discussion of mercury load, in vaccines, in lab reports, etc.
33. ***MMR:** any mention of the MMR vaccine in particular
34. ***Money:** any discussion of the financial end of ASD, activism, collaboration, treatment, etc.
35. ***Morals of others:** discussion of the values, principles, perspectives and worldviews of others in or outside of the ASD community
36. ***Online:** any discussion of their online involvement or interaction/readings on the internet
37. ***Politics/bills:** discussion of specific legislation, bills, politics in general
38. ***Prevalence of ASD:** discussion of the rates of ASD before and after 2001 and just in general
39. ***Redemption:** discussion of what "winning" would look like
40. ***Religion:** discussion of the role of religion in the respondent's life
41. ***Research literature, labs, data (combined):** any mention of data, any discussion of tests and lab data by the respondent, data on their own child or others, any discussion of research and literature as it pertains to the ASD debate
42. ***Self-blame:** statements that indicate the respondent is responsible for his or her loved one's ASD
43. ***Services treatment:** discussion of treatment for ASD
44. ***Services education:** discussion of education for ASD
45. ***Services insurance:** discussion of insurance and payment for treatment of ASD
46. ***State vaccine policy:** discussion of state vaccine policy
47. ***Handling stress:** stress on friendships, discussion of the influence ASD has had on friendships and relationships, stress of care, discussions of stress and how it is handled
48. ***Symptoms:** discussion of ASD symptoms

49. ***Vaccinate child**: statement that they did or did not and will or will not vaccinate his/her child
 50. ***Vaccine court**: discussion of vaccine court
- * Tested for reliability

A.1.2 Composite Groupings

1. **Activism**: This composite grouping contains the following individual codes: Activism, Plan of Action, Getting Info Out, and Fringe Activism.
2. **Treatment**: This composite grouping contains the following individual codes: BIOMED, Diet, Alternative Medicine, discussion of treatment, services-treatment
3. **ASD Community**: This composite grouping contains the following individual codes: Cohesiveness of ASD Community, Collaboration with Other groups, Thoughts on Other groups
4. **Doctors**: This composite grouping contains the following individual codes: DAN, trust/distrust, discussion of doctors
5. **Research**: This composite grouping contains the following individual codes: Epidemiology, Data, Labs, Research/literature, Prevalence of ASD, Mercury Load, IOM, Distrust of CDC, and Credibility
6. **Stress**: This composite grouping contains the following individual codes: Handling Stress, Stress of care, and stress on friendships
7. **Government**: This composite grouping contains the following individual codes: state vaccine policy, politics/bills, Bush Administration, Vaccine Court, NIH/GOV, IOM, distrust of CDC
8. **Health Status**: This composite grouping contains the following individual codes: Symptoms, Allergies, mention of other health, family health status, Cured, Vaccinate child
9. **Services**: This composite grouping contains the following individual codes: Services-education, Services-Treatment, Services-Insurance, and Money
10. **Family**: This composite category contains the following individual codes: Family Health Status, Family Support, Self-Blame
11. **Introduction Narrative**: This composite grouping contains the following individual codes: How got involved, Influence of others, parents of ASD kids, people who work with ASD, online

A.1.3 Reliability

Table 13: Inter-coder reliability

Code Name	Kappa	P-Value
Activism	-	Constant
Allergies	1	.000
Alternative Causative Theories	.857	.001
Alternative Medicine	.759	.003
Strong Language/Emotion	.851	.001
Big Pharma	1	.000
BIOMED	1	.000
Bush Administration	1	.000
Civil Liberties	1	.000
ASD Community	1	.000
Collaboration w/Other	1	.000
Credibility	.811	.002
Cured	1	.000
DAN	1	.000
Diet	1	.000
Discussion of treatment	1	.000
Discussion of Doctors	1	.000
Trust/Distrust of Doctors	1	.000
Epidemiology	1	.000

Family Health Status	1	.000
Family Support	1	.000
Fringe Activism	1	.000
Influence of Others	1	.000
IOM	1	.000
Media	1	.000
Other Health Problems	1	.000
Mercury Load	1	.000
MMR	1	.000
Finances	1	.000
Morals of Others	.837	.001
GOV	1	.000
Online involvement	1	.000
Political	.857	.001
Prevalence of ASD	1	.000
Redemption (insufficient n)	-	-
Religion	1	.000
Research	1	.000
Self Blame	.811	.002
Services-treatment	1	.000
Services-education	1	.000
Services-Insurance	1	.000
State vaccine policy	1	.000

Stress	1	.000
Symptoms	1	.000
Vaccinate Child	1	.000
Vaccine Court	1	.000

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