# UNSETTLED SLEEP: THE CONSTRUCTION AND CONSEQUENCES OF A PUBLIC HEALTH MEDIA CAMPAIGN

by

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# Abstract

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Public health media campaigns involve more than simply transmitting information to its audience: they advocate deep social change that involves the embodiment of specific values, lifestyles, and behaviors. Social factors are involved in what issue becomes a public health media campaign and how the messages are created and communicated. Once presented, there are implications and expectations for how these messages are to be received. There are also consequences of public health media campaigns that may cause harm as well as good. This dissertation examines what is underlying the creation, implementation and dissemination of a public health campaign. The *Back to Sleep* campaign to reduce the risk of Sudden Infant Death Syndrome (SIDS) is used as a case study. A multi dimensional methodology of interviews, participant observation, and content analysis diagnoses the underlying factors that go into constructing a national public health media campaign, as well as the campaign's intended and unintended consequences.

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# Acknowledgements

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# CHAPTER 1

How do we know what we know about health? Films in class warn us not to start smoking. Safer sex advice appears on posters. Television commercials tell us to "just say no" to drugs. Magazines are filled with recommendations on how to eat right. On the subway, television, radio, in print and the internet, media messages educate, inform and warn us about health issues from AIDS to obesity. They are created to change individual attitudes or behaviors through the techniques and language of advertising and marketing--but instead of buying a burger, the audience is being persuaded to buy a behavior change. Though at first glance they appear useful, there are more to public health media campaigns than meet the eye. Public health campaigns are not just simple solutions to a health problem. Social factors influence what issue will be the focus as well as how the messages will be created and communicated. Once presented, there are expectations for how these messages are to be received. Public health media campaigns involve more than simply transmitting information to their audience--they advocate for the embodiment of specific values, lifestyles, and behaviors. There are also unintended consequences of public health media campaigns, some of which may cause as much harm as good.

This dissertation examines the social forces underlying the creation, implementation and reception of a public health media campaign, using the *Back to Sleep* campaign as a case study. *Back to Sleep* is a national public health campaign sponsored by the National Institute of Child Health and Human Development, the Maternal and Child Health Bureau, the American Academy of Pediatrics and others, that began in 1994 and continues to today and is named after its primary recommendation that infants be placed on their backs to sleep in order to reduce the risk of Sudden Infant Death Syndrome (SIDS). *Back to Sleep* offers a potentially powerful insight into a successful public health media campaign[1] and this analysis of its construction and consequences will illuminate how the dynamics of power, gender, race, social class, and the role of context shape what is often seen as benign health advice.

## Background

Sudden Infant Death Syndrome (SIDS, also known as crib death) is a leading cause of non-accidental death in the United States for infants from one month to one year of age (AAP Policy Statement 2000). SIDS, the sudden and unexplained death of an infant under a year old, is defined as the cause of death only after all other possibilities have been eliminated by autopsy, an investigation of the death site, and an examination of the infant's medical records. Though these types of sudden deaths in infants have been observed for centuries, a definitive cause or causes of SIDS are still unknown. A SIDS death is unexpected, silent, and takes place during sleep.

By the 1960s in the United States, the search for the answers to the source of these sudden infant deaths and how they could possibly be prevented was fueled by those who had the most interest—parents of babies who died. Mothers and fathers who lost children to crib death (as it was known then) started to form local organizations to help other parents cope with their loss and feelings of guilt. These groups soon discovered that

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[1] In public health, promotions often have many components. Though these other aspects (e.g. community education, professional training) are significant factors in promoting health, the dissertation will focus on the *Back to Sleep* mass media campaign.

scientific research to prevent these deaths was unfocused and uncoordinated. Eventually these mostly upper middle class, white "crib death parents" fused local support groups into a powerful special interest lobby (Bergman 1986). The activism of these SIDS support groups contributed to the passage of the Sudden Infant Death Syndrome Act of 1974, which authorized millions of dollars for state-run support programs and scientific research (Johnson and Hufbauer 1982). Studies supported by these funds discovered many possible physiological causes of SIDS without proving any definitive causal relationships[2].

By the late 1980s, a turning point in the approach to SIDS risk reduction arrived. Studies from the Netherlands, Australia, England, and other countries implicated the prone sleeping position (face down) as being associated with a greater risk of SIDS (DeJonge et al 1989, McGlashan 1989, Flemming et al. 1990, as cited in Guntheroth 1995). Public health campaigns that encouraged the issue of the supine sleep position (on the back) and SIDS risk reduction were carried out in the United Kingdom, Holland, and New Zealand and five other countries. These campaigns were judged to have significantly reducing the number of SIDS deaths (Mitchell et al. 1991, Engelberts et al. 1991, Wigfield et al. 1992, as cited in Guntheroth 1995). American SIDS researchers were initially skeptical of the validity and applicability of a health campaign for something as simple as the supine position to reduce the risk of SIDS in the United States. Moreover, the decision to recommend the supine position for sleep was in conflict with what pediatricians had been recommending to parents since the 1950s—that

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[2] Studies over the past 30 years have found possible causes to include: abnormal genes, virus, apnea, prenatal trauma, irregular heartbeat, defects in the nervous system, inherited metabolic disorder, protein levels in the blood, fumes from mattress chemicals, brain abnormalities and child abuse.

it was safer for infants to sleep on their stomachs[3].

Despite these concerns, the advisory group of American Academy of Pediatrics eventually felt that they could not ignore the dramatic reduction in SIDS deaths in the countries that promoted the supine position. On April 15, 1992 the AAP issued a statement recommending that "normal infants, when being put down for sleep, be positioned on their side or back" (Pediatrics 1992). By 1994, this recommendation was expanded to a national public health campaign. The U.S. Public Health Service, in conjunction with SIDS Alliance, the Association of SIDS and Infant Mortality Programs, and the American Academy of Pediatrics launched the *Back to Sleep* media campaign[4].

The saturation of the campaign's message is associated with a change in how many parents put their babies to sleep. Between 1992 and 1998, among U.S. infants, prone sleeping decreased from more than 70 percent to approximately 20 percent. During that same time frame, the number of SIDS deaths declined by over 40 percent (Willinger et al. 1998, AAP 2000, NICHD 2001). Most researchers, policymakers, and SIDS professionals agree that this significant decline occurred largely as a result of changing sleep position (AAP 2000).

This dissertation will trace the implementation and impact of the *Back to Sleep* (BTS) media campaign to reduce the risk of Sudden Infant Death Syndrome from 1994 (the year the campaign began) to 2006. The *Back to Sleep* media campaign is an

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[3] Pediatricians were successful in convincing parents that the prone position was the best for babies, though it was based on inconclusive studies regarding asphyxiation on vomitus in premature infants. Before this push in the mid 20th century advocating for the prone position, most infants, particularly those who were nursed by their mothers in the same bed fell asleep on their backs.

[4] The *Back To Sleep* media campaign also recommends avoiding soft bedding surfaces, tobacco smoke exposure, bed sharing, and overheating or over wrapping.

important case study for several reasons: It is a national campaign that has had a uniform presence highlighted by local and state programs; it focuses on infant mortality, a topic in public health that has been addressed for over 100 years in the United States; and it is considered one of the most successful public health campaigns in recent history. *Back to Sleep* also provides an entry into examining how issues of power, gender, and race dynamics become embedded into the creation of a public health campaign and its unintended consequences.

What follows in this chapter is a review and analysis of the literature that has steered my research and that I have considered to be integral in understanding the sociological aspects of public health media campaigns and Sudden Infant Death Syndrome. This review provides a background on the study of the social forces behind public health media campaigns that places my project within this and other relevant literature; establishes the theoretical framework that I am using in this study; and outlines my research design and methodology.

Chapter Two looks at how SIDS was constructed as a public health problem. This includes an analysis of how the sudden death of infants shifted from an unfortunate accident to an official medical condition. This chapter uses qualitative content analysis of media reports, books, and educational pamphlets as well as data from interviews with SIDS health educators and other professionals to create the narrative of this transformation of SIDS to a significant public health issue. The chapter concludes with an analysis of the creation of *Back to Sleep* campaign in 1994.

Chapter Three looks more deeply into the *Back to Sleep* campaign itself and examines how media were used to communicate the SIDS risk reduction messages from

1948 to 2006. This chapter will examine how scientific research was translated and negotiated into health advice by the campaign's creators, how the messages changed over the time period, what values the campaign communicated (both directly and indirectly), and how different media interpret the campaign's messages to its audience. This chapter uses the methods of qualitative content analysis and analysis of interview data.

Chapter Four looks at the interpretation of the *Back to Sleep* campaign for a specific audience: African American mothers and caregivers. Here I look more deeply into campaign materials produced to target African Americans, who have a rate of SIDS that is two times higher than that of whites in the United States in order to discover the campaign's underlying values and its relation to power, gender, and class. In this chapter I suggest that efforts to make the campaign culturally competent so as to target African Americans for behavior change may have backfired, creating resistance based on race and class. I use qualitative content analysis, interview data, and participant observation data to develop my findings.

Chapter Five examines the unintended consequences of the *Back to Sleep* campaign. This includes consequences for parents based on conflicts with the campaign's underlying values and assumptions, consequences that arise from scientific research into the causes of SIDS, and consequences for the campaign itself and SIDS as a public health issue. This chapter uses qualitative content analysis of newspaper articles, electronic listservs, parenting bulletin boards, and websites, interview data, and participant observation analysis to discover these unintended consequences.

The final chapter serves as a conclusion of my findings and presents their sociological significance. I also present the implications of my findings for health policy and health communication and recommendations of how they can be applied. Finally, I suggest the next steps that I will take with this research and how other scholars can build upon my findings.

## Sociological Rationale

This dissertation looks at the *Back to Sleep* media campaign to reduce the risks of Sudden Infant Death Syndrome from a three dimensional perspective: its creation, production, and interpretation. The public experiences a health campaign by interaction with its external products on television, in newspapers on billboards and signs, often unaware of the social forces that were mobilized to create them. Evaluations of the effectiveness of recently completed or ongoing campaigns are standard operating procedure in the public health field, and they usually focus on the changes and influences on health behavior rather than the social outcomes. Though these campaigns are predicated on raising awareness of significant health issues and improving health outcomes, the context in which they are developed, presented, and interpreted demands that they also be examined from a sociological standpoint.

Today, the leading causes of death in the United States are brought on by ailments such as heart disease and Type 2 diabetes (NCHS 2006)--illnesses that have causes rooted outside of the body, in the environment, in the social setting, and the so-called "lifestyle choices" of individuals. The types of chronic conditions that have the greatest impact on the health and well being of the population in the United States are also deeply connected to other factors outside of the body: issues of class, race, and gender. Disparate denominations of illness are outlined by these demographic factors;

women live longer than men, whites live longer than blacks, and the poor have worse health outcomes than the rich. Though these apparent dichotomies have more nuances in reality, they remain a fundamental axiom of the greatest public health issues in this country. What I am interested in looking at in this dissertation is how a sociological approach to the study of health and illness can be applied to the study of public health campaigns and the role they play in society.

### *Sociology of Medicine*

Much of the work that has influenced my perspective to studying the *Back to Sleep* campaign *as a social product* is in the field of medical sociology, an area with a rapidly expanding literature and interest from researchers around the world. Over the past 40 years, there have been negotiations of the focus of study within medical sociology in terms of what approach to take to the topic of health, illness, and society. One of the major distinctions comes with the definitions of sociology "of" medicine.

The approach known as sociology of medicine looks at how social factors affect health and well being, and critiques the medical establishment's increasing power and influence (Syme 1999). As a further development, there has been a move within the past couple of decades towards a more critical view, known as sociology of health and illness. This perspective looks at what conditions are present to create health situations for those who experience them. Sociology of health and illness explicitly looks at "how social factors such as the political economy, the corporate structure, the distribution of resources, and the uses of political, economic and social power influence health and illness and society's response to health and illness" (Conrad 2001:2). Also included within this critical perspective is not only an examination of a particular disease or cause of death—like AIDS, a heat wave, and breast cancer—but of the values, norms, and assumptions that helped to shape our understanding of them (Lupton 1996, Kleinenberg 2001, Kasper and Ferguson 2000).

In sum, sociology *of* medicine is concerned with the social factors that lead to the creation, understanding, and continuation of notions of health and illness. I am interested in pursuing the line of thought present in the sociology "of" medicine perspective and how it can also be applied to the study of public health. How this sociology of medicine perspective will be specifically interrogated in this dissertation follows in the theoretical framework section.

### *Sociology of Public Health*

The field of public health has traditionally been concerned with protecting and improving the health of a community. Public health's history from the colonial period to today have several reoccurring themes, many of which reflect the sociological perspective described above. According to a comprehensive history of American public health by the historian John Duffy, these themes include the ebb and flow of what is considered to be a public health crisis and what are the norms of everyday life, such that in the colonial period smallpox was considered to be the most pressing health menace, though malaria and respiratory infections actually caused more sickness and death (Duffy 1990). Other reoccurring themes include the "fight to replace ineffective traditional ways of maintaining health with more effective ones," the conflict between government regulation of individual conduct to protect the health of the community, what the prevailing medical concepts of the time were, and the influence of social attitudes in determining public health policy (Duffy 1990:3-4). Indeed, the history of public health in the United States has been influenced by issues of power and control, the struggle between the rights of the state and the rights of the individual and evolving notions of modernity and technological advance. These conflicts are still present today in public health and represent a sociological entry point into the creation of public health problems and their consequences.

The history of public health campaigns is connected to the story of the growth of the city. Immigrants came to the United States, migrants arrived from rural areas, and African Americans moved into northern cities to labor in the new industrial system. These populations lived in overcrowded city slums that were plagued by poor sanitation, living conditions and nutrition, and growing cities housed rising threats to the public's health. Communicable diseases like dysentery, tuberculosis, scarlet fever, smallpox, diphtheria and typhoid fever had high mortality rates, especially among the poor (Duffy 1990). The connection between poverty and ill health was clearly seen during this period and actions on the community activist and state level worked to address these problems together. At this time, health departments were concerned with the control of these diseases through quarantine and proper sanitation.

The decades between 1900 and 1930 marked the first major period in public health campaigns to deal with problems caused by industrial expansion and urban poverty. Specifically the strategies and tactics to prevent and control a deadly disease like tuberculosis used biological, socio-economic and cultural factors in its health campaigns. Publicity was used to educate the public about how the disease was spread through contact, campaign focusing on personal hygiene, fresh air, proper nutrition was used and forces were mobilized on the state level to pasteurize milk (Rosen 1977).

Today it is recognized that the largest contributors to poor health outcomes are related to behavioral and social factors (McKinlay and McKinaly 1977, Syme and Berkman 1976, McCord and Freeman 1990) and as a result, the role of social science theory and practice has become increasingly important in the public health. Non-communicable health conditions influenced by tobacco smoke and obesity are identified as the largest public health threats (CDC 2006), and these are increasingly being addressed by behavioral and social interventions. According to the World Health Organization,

> "A distinction has been made in the health campaign literature between public health and a 'new' public health for the purposes of emphasizing significantly different approaches to the description and analysis of the determinants of health, and the methods of solving public health problems. This new public health is distinguished by its basis in a comprehensive understanding of the ways in which lifestyles and living conditions determine health status and recognition of the need to mobilize resources and make sound investments in policies, programs and services which create, maintain and protect health…" (WHO 1998:3).

This approach within the "new" public health can be seen for the purposes of this study as "sociology *of* public health". One of the examples of this sociology of public health perspective is seen in the efforts in many public health departments across the United States and their focus on the "health campaign". This is a concept that in its ideal form is a social and political process that empowers communities to advocate for change in their social, political and economic environment in order to improve their health outcomes and prevent disease (Ottawa Charter for Health Campaign 1986).

In reality, health campaign activities on the part of public health professionals often consist of simplistic messages directed to individuals that are designed to embody the latest scientific information about disease prevention, which is subject to change. Common health campaign messages to prevent heart disease, the number one cause of mortality in the United States, include smoking cessation, exercising and eating "right", which at various times could be a diet low in fat, high in fiber, low in the bad type of cholesterol, and high in the good type of cholesterol. The health campaign approach has been critiqued by medical sociologists who see it as a site worthy of scholarly attention. Marshall Becker, in a speech to the American Sociological Association's Medical Sociology section, suggested that the health campaign/disease prevention movement, for all of its virtues, has created or exacerbated a number of undesirable developments including "a public generally confused and skeptical with regard to public health advice; a scientific community that rushes tentative findings into print; a mass media community that abets this process and often independently worsens the problem; and an introspective approach to health that fosters victim-blaming and stigmatization, ignores critical social, economic, and environmental issues that have major impacts on health" (Becker 1993:5). The sociology of health campaign and public health takes into consideration that sociologists have contributed historically to the creation of public health campaigns and health campaign, but have not looked at them as areas for inquiry, and most sociological research has been used to create public health campaigns rather than critique them (Burrows, Nettleton & Bunton 1995). It is from the sociology of public health perspective that this dissertation uses as its starting point, using critical theory to inform how we should look at the creation, dissemination and interpretation of a public health campaign like *Back to Sleep*.

## Theoretical Framework

### *Critical public health*

The sociology of health campaign or the critical public health approach is a little more than two decades old, but provides an alternate perspective in which to view public health media campaigns. This body of literature provides analysis and debate beyond bio-medically oriented public health concerns, and highlights the social and political aspects of public health (Bunton and Wills 2004). This perspective investigates the nature of the relationship between the state *vis a vis* public health and the 'regulated body', highlighting concerns about power, agency, and risk (Peterson 1997, Lupton 1994). These concerns about the role of the state in public health intersect with issues of privacy and surveillance. Surveillance by the government in public health matters sometimes cross the line between privacy and public health knowledge that is 'needed', like with HIV registries, TB monitoring and control, and STI notification. These concerns reflect the uncertain role the state has played in transmitting knowledge that proscribes (and sometimes enforces) practices related to family life and the private sphere.

Critical public health is influenced by the theories of Michel Foucault, who offers that as early as the Eighteenth Century a medico-administrative knowledge begins to develop concerning society and its health and sickness that create a hold on a population given a "series of prescriptions relating not only to disease but to general forms of existence and behavior" (1984:280). Health campaigns in this light are viewed as the tools of the state that establish power through advice on how individuals should conduct themselves, which culminates with regulating the human body and personal identity

(Foucault 1980). Viewed through this lens, public health media campaigns raise issues about the social values that influenced the creation of the campaign messages and how they affect their audience. These campaign messages are also a part of processes that are 'creating' their audience through subjectivation.

The work of Deborah Lupton, an Australian sociologist, has had great influence in the field of critical public health, using a Foucaultian approach. In her book The *Imperatives of Health: Public Health and the Regulated Body* (1994), Lupton presents a historical approach to the questions of how the health of populations first emerged as a problem, how certain 'rational' strategies, apparatuses, and discourses were constructed to deal with this problem and how, in turn, the subject of public health has been constructed and reproduced. My dissertation uses a campaign as a case study for how the public health discourse gets created and developed around a health issue. The focus of this dissertation remains consistent with the work of Lupton's, which aims to:

> "…undermine and contest accepted understandings and assumptions about public health and health promotional practices, to incite critique and ask questions about dominant belief systems; in short, to disrupt the complacency of these knowledge/discourse systems and to open up the space for alternative 'truths' and realities." (Page 14)

By looking at the *Back to Sleep* campaign from this perspective, public health can be presented as a product of its social setting and context, one that is not immune from the complex environment that created it.

### *Health Campaigns and Locus of Responsibility*

Another thread that the critical public health perspective pursues is an ongoing tension in public health practice: between individual and social responsibility for health.

As was discussed above, modern public health campaigns began as interventions on the state level to ameliorate the negative health consequences of urban life. Changes in laws and policies to improve sanitation, housing conditions, food safety, and vaccinations were responsible for some of the greatest successes in public health, including a massive reduction of infant mortality. The next stage of public health campaigns was based on increasing scientific knowledge of microbiology and epidemiology, which discovered multiple factors involved in the causation of chronic disease. Now the focus of public health campaigns was no longer on controlling the spread of, but on the active *prevention* of disease. By the early 1940's, campaigns concentrated on the correlation between poor health and certain behavioral practices. As scientific research connected unhealthy lifestyles to increased risk for certain types of cancer and heart disease, public health campaigns began to focus on changing these behaviors—which included diet, exercise, and smoking (Becker and Rosenstock 1989). As a result of this shift, the public had been increasingly encouraged to take responsibility for their health. Knowles (1977:58) stated bluntly: "over 99% of us are born healthy and made sick as a result of personal misbehavior and environmental conditions. The solution to the problems of ill-health in modern American society involves individual responsibility". However, with the burden of responsibility placed on the individual for cause and cure, complex health problems like infant mortality and obesity are often given ineffective solutions.

Indeed, infant mortality has long been considered to be a socially determined factor. The United States currently has the second worst newborn mortality rate in the developed world due to substantial disparities in race/ethnicity, education, and income within the population (Save the Children report 2006). In New York City, for example, infants born to black non-Hispanic mothers have an infant mortality rate more than twice the rate of those born to white non-Hispanic mothers (NYCDOHMH 2004). This difference is especially stark in communities that have a high percentage of black residents. The factors that contribute to these disparities are difficult to isolate as they interact with each other, but some areas studied include: the overall health of the mother, socioeconomic status, and the stress of the marginalization associated with racism (Rich-Edwards et. al. 2001, Kramer et. al. 2001). It is probable that these stressors can have an effect on women throughout the life course--before conception as well as during pregnancy, which may contribute to poor birth outcomes. Focus on not only the individual behaviors that a woman engages in, but also the community she lives in, her economic standing, and her social status since women who become pregnant at any one moment in time are affected by many factors that influence the health of her baby (Starfield et. al. 1991, Chomitz et. al. 1995). However, public health interventions that would address these multiple layers of risk for infant mortality (which would involve changes to institutions, social structures, and attention to social justice) are rarely attempted.

The critical public health framework challenges the assumptions that personal health related behaviors are discrete and independently modifiable; that anyone can decide to alter his/her behavior and then go on to do so successfully; and the notion that everyone has a personal responsibility to live well through self-discipline and behavior modification. Critical public health posits that the social environment provides an important locus for interventions to modify health behaviors and promote health (Levine 1981; Syme 1986). This theoretical framework is useful in examining why and how the

*Back to Sleep* campaign focused on individual level behavior change rather than larger social issues that are stronger predictors of infant mortality.

### *Medicalization and the social construction of illness*

The medicalization thesis traces medicine as an increasing area of social control over problems not traditionally considered to be medical in nature. Irving Zola (1972) saw medicine becoming the new place of truth, where absolute and often final judgments are made by supposedly morally neutral and objective experts in the name of health. This medicalizing of daily life Zola saw as being rooted in our increasingly complex technological and bureaucratic system and the reliance on the expert. As a result of this reliance on the medical establishment, regular life events like birth and death have become medicalized in society (Rothman 1989, Timmermans 2000). Also, this approach analyzes how different historical constructions of disease shape knowledges about diseases like AIDS/HIV over time (Fee and Krieger 1993).

Since the 1980s, the sociology of health and illness has been increasingly influenced by the social constructionist perspective. The social constructionist approach offers that society—people and their actions—is in an ongoing process of becoming, and that society is a constant negotiation of reality (Blumer 1986, Berger and Luckmann 1966). Based on the symbolic interactionist approach to society established by G.H. Mead and William James in the early 20th century, individuals are seen to be knowledgeable actors in a structure that is created through this process of on going negotiation. Social constructionism is positioned to discover the ways social reality and social phenomena are constructed. How is a social phenomenon created, institutionalized and made into a tradition? What constructs these concepts of “reality” is the flow from macro to micro levels of how situations are defined. The social construction of illness perspective posits that health matters are like social problems in that some exist and are not yet problems, and some don’t exist until they are turned into problems. The definition of something as a problem involves the social conflict between those who would gain and those who would lose from such a perception (Katz Rothman 1991, Brown 1995). Looking at public health campaigns with this type of a social lens allows for a more complete picture of how a campaign is created and allows for a broader way to measure its effects.

Today this constructionist perspective draws on post-structural approaches (e.g. Foucault, Derrida), building upon the theories of sociology of knowledge (Berger and Luckman 1967), and social constructionism questions the notion of ‘facts’ and the nature of the truth in general. This perspective argues that all knowledge is the product of conflict, negotiation, and struggles for power and is therefore never objective. Examining the social aspects of medicine, how discourses and practices shape experiences with health and illness, and social context that determine how medical knowledge is created are some of the themes the social constructionist perspective brings forward. With this approach, medical power is seen as not only from the top down as with previous medical sociological perspectives, but that it is “deployed by every individual by way of socialization to accept certain values and norms of behavior” (Lupton 2003:13).

Critiques of the social constructionist perspective are present within medical sociology. Critics argue that social constructionists talk ‘around’ disease, which may appear to be denying that the disease itself exists. By writing about the social aspects of what created conditions of health and illness, they argue, there is no acknowledgment of the very present reality and embodiment of those conditions (Williams 2001). Social constructionists tend to agree that there is a very real biological entity at work in the manifestation of health and illness, but that the *experiences* of them are influenced by cultural and social processes, and that these need to be examined in order to influence change (Lupton 2003).

Another critique of how health issues are presented as societal concerns is known as disease mongering (a theoretical perspective will not be the focus of this study) which posits that those in power tend to define problems in a way that is “fixable” in their terms, whether it is pharmaceutical companies involved with physicians to sponsor the definition and campaign to consumers of new illnesses and diseases that can then be treated by drugs that are already on the market. This trend is described as “the social construction of illness is being replaced by the corporate construction of disease.” (Moynihan, Heath, and Henry 2002:866). Another way the disease mongering perspective presents how those in power are seen to “fix” health problems is by not challenging the status quo, an approach which is relevant to this study. As an intervention to reduce infant mortality, changing an infant’s sleep position does not threaten the structure of society the way that other ways of decreasing infant mortality, like ending income inequality would.

### *Social Problems Construction*

Thirty years ago, Spector and Kisuse (1977) identified a social problem as a product that has been produced or constructed through social activities, particularly through claims-making, where groups make claims with respect to some condition that needs action. The constructionist view examines what claims-makers say about conditions, and how they ‘typify’ them, which is how they shape our sense of just what the problem is (Schneider 1985). Especially in modern times, the media play a significant role in the development of these issues. Best (1990) calls the media a “social problems marketplace” where many claims-makers are competing to attract press coverage and bring their cases forward, and there is often a struggle to develop rhetoric that will draw attention and lead to action.

When does a social problem become a public health concern? Indeed, the history of medicine consists in large part of how, and by whom, disease has been defined in society. The framing and reframing of the cause and care for diseases from tuberculosis to ‘women’s problems’ were influenced by shifting scientific paradigms as well as changes in the structures of society (Rosenberg and Golden 1997; Katz Rothman 1991; Ehrenreich and English 1989). The media represents a public forum for raising concern over these newly discovered problems, which facilitates the ever quickening process of medicalization (Pitts 2003). The decision to sponsor public health campaigns for a particular social condition involves a number of political as well as medical factors (Conrad and Schneider 1994/1980).

Public health media campaigns are often thought of as practical solutions to serious health problems that can affect the public. This dissertation argues (similarly to those from the critical public health perspective) that public health campaigns are a form of social intervention prompted by a determination that some situation represents a social problem meriting social action. By defining certain situations as in need of change and then prescribing efforts to change individuals and groups, public health professionals attempt to control the process of change and in doing so often adapt its political, social or economic environments in a manner which is deemed desirable by the change agency (Salmon 1989). The media campaign emerges as the "solution" to something some organization has defined as a "problem". Many chronic problems exist, but only some are granted problem status.

Constructionists note that claims in the media attract notice when they "are presented in a dramatic way" (Hilgartner and Bosk 1988:71) and have "cultural resonance" (Gamson and Modigliani 1989). The sudden death of infants is an example of this type of a dramatic, culturally resonant issue. Though the sudden death of an infant is undeniably tragic, it has not always existed as a social problem or a matter of concern for public health. This transformation occurred through a series of events and actions taken by those who had an interest in having these deaths be taken seriously: physicians, medical researchers, and most importantly, parents of babies who died. The negotiation of what we now know as Sudden Infant Death Syndrome as a social problem, and specifically a public health problem in the United States, culminated within a period of a few decades in the mid 20th Century.

Traditional social problems theory has viewed the progression of social problems through a series of stages, using the framework of the 'natural history' model (Blumer 1971, Spector and Kisuse 1973, 1977, Mauss 1975), which described how social problems would begin, exist, and end. However, the model proposed by Hilgartner and Bosk (1998) goes beyond this framework and examines the 'rise and fall' of social problems through the lens of public arenas. This new model stresses the 'arenas' where social problems definitions evolve in an environment where public attention is a scarce resource and issues compete for social problems status.  The public arenas model examines the effect of those arenas on both the evolution of social problems and the actors who make claims about them.  This approach improves upon the natural history model by looking at "the combination of background and events which cause an issue to be defined as a social problem in a particular time and place" (Rittenhouse 1991) and not merely identifying the stages a social problem goes through. This dissertation will show how public attention over SIDS, and *Back to Sleep* in particular went through a rise and fall as a public health problem within the social context of the times, and how this had an influence on the messages of the campaign and its audience.

## Relevant Studies

There have been several significant strands of research in the sociological and social science literature that particularly inform the direction of this study.  In the following section I will review a selection of the existing literature in the areas most broadly addressed in my work: the use of media to promote public health messages, the unintended consequences of public health campaigns, public health campaigns directed towards mothers and the well being of their infants, and non-medical studies of SIDS.

### *Public Health Media Campaigns: Using media to promote health*

Over the past century, mass media campaigns have disseminated messages about hundreds of different health topics to the United States.  The definition of a mass media campaign has been found to focus on four key areas: it is purposive and seeks to influence individuals, it is aimed at a large audience, it has a defined time limit, and it involves an organized set of communication activities (Rogers and Storey 1988). Numerous government agencies and health associations have sought to educate and persuade the public to adopt healthy practices or to avoid behaviors that pose a risk to health. Public health practitioners have an extensive record of using available mass media to communicate health information to the general population. Historically in the U.S. there has been a strong belief in the ability of the media to communicate information, transform public opinion, and potentially change individual health behavior (Paisley 1989).

One of the most famous early studies of the use of mass media to promote changes in health behavior took place in the early 1970s, known as the Stanford Three-City Study. This intervention was designed to improve cardiac health in three California communities through widespread exposure to prevention messages that would encourage people to seek out health campaign activities. The study found that media messages alone did not significantly change health knowledge or behavior, but could be successful when reinforced with other types of interventions (Stern et. al 1976). Health campaign itself assumes that there is something that can be done to improve health outcomes and reduce the risk of disease (Becker and Rosenstock 1989). Campaigns like the Three City Study and others may appear to benefit the public good, but are not value-free. As Wallack (1981:221) has observed:

> "…these campaigns do not take place in a vacuum but confront strongly vested financial interests and deep-rooted well-established values…campaigns…are inherently political in that they require processes of compromise and conciliation of potentially volatile issues affecting interests not necessarily consistent with public health."

As a result of their inherently ideological conception, public health media campaigns have the dubious honor of being critiqued by both liberal and conservative political players.

The liberal critique is based on the ‘new’ public health perspective, which sees media messages as not doing enough or doing the wrong thing altogether. The argument states that campaigns focus on individual behavior change, blaming the victim for health issues that stem from inequalities in the social structure. This then becomes an issue of the ethical nature of public health communication campaigns which focus on personal responsibility for solving health problems (Guttman and Ressler 2001). Liberals argue that change must come not from a campaign message, but from the larger structures of society that are connected to poor health outcomes like poverty, poor housing, crime, and a polluted environment (Freudenberg 2002, Yen and Syme 1999, McCord and Freeman 1999). Public health problems are seen as being “ill suited to the type of information that mainstream mass media typically provide” (Wallack 1991).

Conservatives criticize that public health media campaigns challenge individual liberty and are wary of state involvement in, and regulation of, personal decisions (Sullum 1998). This increased regulation of one’s lifestyle habits have led to public health campaign being labeled “the nanny state” that is too concerned with the health choices people make (Davies 1991). These critics are especially concerned with public health media campaigns that call for government regulations on the macro level, for example: limiting trans fats in the fast food industry for contributing to obesity and enforcing environmental safety laws. As a result, conservative entities have opted for mass media public health campaigns that address health issues generally, with the hope of individual behavioral change. Partnership for a Drug Free America, ("Just Say No"), the campaign of abstinence over condoms to prevent pregnancy, and the "Truth" anti smoking campaigns used mass media to un-sell a behavior on an individual level.

Public health media campaigns use the techniques of commercial advertising to promote awareness of risks to health and to provide information to improve health and have had some level of success in communicating this information. Recently, a Kaiser Family Foundation survey of the Black Entertainment Television/Viacom campaign on African-American HIV/AIDS found that almost three quarters of respondents saw the campaign and that a majority of them said that they have learned "important information" from them (KFF 2004). Campaigns based on these theories focused on taking information on health and illness and transmitting it to the public, who would then receive this knowledge and act accordingly, a feat difficult to imagine without any other support.

Another example of a media campaign that has had success recently is the national "truth" campaign targeted to teens to discourage tobacco use. This series of television commercials and website presents the facts behind the harms of cigarettes in a matter of fact and stark way that undermines the appeal of smoking. A recent study has found that this campaign is associated with a decrease in teenage smoking prevalence by 22% (Farrelly, Davis, Haviland et al 2005), a major accomplishment for a public health campaign. However, the "truth" campaign was funded for millions of dollars by the Master Settlement Agreement, the result of a class action suit by 46 states and the tobacco companies, and this result may be hard to replicate with other media campaigns that have smaller budgets.

The idea of using the paradigm of commercial advertising to communicate health messages relies on a long standing belief about the power of mass media. Health communication texts base the idea of public health campaigns on the advertising model (Rice and Atkin 1981, Backer et al 1992). In these texts, how the message is constructed, the choice of language, how to 'target' the audience and get their attention are emphasized. The theory behind using the media to communicate important information has a long history in the United States--from pamphlets used during the Revolutionary War to Abolitionist's literature to posters used during both World Wars. As these techniques and technology became more sophisticated over the years, so did the approaches to communication theory.

Early communication researchers saw these "media effects" as particularly forceful and something to be feared. Media messages were seen as being a tool to force a point of view on its audience. By 1917, World War I led President Wilson to bring together Progressive journalists to create the Committee for Public Information (CPI). The CPI was to produce propaganda for the war and demonstrated a shift from a journalistic paradigm to an advertising paradigm to unite the American people. There was also a shift in the language of public communications from rhetoric of the word to the image (Ewen 1996, Bernays 1964). These campaigns used the psycho-social theories of Sigmund Freud and Gustav Le Bon in the early 20th century to create messages that would have a presumed direct effect on the "mass mind". These techniques of propaganda were successful in their attempt to win over public opinion and to support an unpopular war. Lippmann (1922) saw a vast potential for "controlling chaos" through the framing and managing of public opinion and the manufacturing of consent based on the success of those campaigns.

After World War II, studies by social scientists on how to use media to communicate messages to the public furthered theories of ‘propaganda for social objectives’ (Lazerfeld and Merton 1948). These investigations, (known as the Process School) attempted to quantify how information could be used via the mass media to communicate social values to the public. The theories used scientific, often quantitative methods to support their hypotheses, and were the basis for the success, especially in researching voting and political campaign issues (Klapper 1960). Public health campaigns have often relied on the Health Belief Model which is based on these theories (Becker 1977).

Today, campaign creators now recognize that the relationship between a public health message and an audience is more complex. However, researchers still rely on the idea of the audience as a monster to be conquered, if only the right weapon could be found. There has been much research dissecting the race, ethnicity, socio economic status and education of the intended audience (Backer 1992; Salmon 1989). Often this boils down to “cultural sensitivity” to the groups that are seen as having barriers to receiving the intended messages. This includes the use of appropriate language, symbols, and visual images that would be the most effective to target “hard to reach” groups. These approaches still privilege behavioral models as well as isolating and stigmatizing these groups (often the poor, the young, and minorities). The underlying assumption is that these messages contain knowledge that a uniformed public needs to be made aware of so that “at risk” individuals can change their behavior, as prescribed by the creators of the campaign (Lupton 1994). All of these have the effect of seeing the public as apathetic, ignorant and passive.

In contrast to the behavioral models of public health media campaigns employed by health educators, the critical public health perspective utilizes cultural studies approaches, based on the work of the Birmingham School in England in the 1980s. In particular, the work of Stuart Hall is often cited as providing a useful framework for looking at mass media in society that has been applied to public health media campaigns (Lupton 1994, Seale 2003, Peterson 2001). Hall's model of 'encoding' and 'decoding' gives an alternative perspective to not only analyzing how public health messages are produced and the meanings of the text, but also how these messages are received (Hall 1980). Cultural studies approaches to the media like Hall's are based on the Frankfurt school's criticism of the hegemonic nature of the media, but take a more nuanced and active view of the audience (Abercrombie and Longhurst 1998). This approach does not ask what effect the media have on people, but rather how people use media. Hall posits that media messages are encoded from within the dominant frame or dominant ideology by individuals who are often reproducing messages associated with political or economic elites. These encoded messages are then decoded by the audience. This framework allows for the audience to be seen as more knowledgeable actors, and allows for the possibility of intervening variables (like class structures, power relations and political economy) that influence the relationship between the "text" and the audience. It also allows for a richer reading of public health campaign materials and how they are interpreted by their audiences.

### *Unintended Consequences of a Public Health Campaign*

A critical approach to commercial advertising and their social consequences has been in effect for over one hundred years and has transcended such disciplines as communications, media studies, sociology, psychology and women's studies (see Berger 1972; Ewen 1988; and Schudson 1984). However, this same critique has rarely been applied to health campaigns, even though they use many of the same techniques as consumer advertisements. Research on public health campaigns need to go beyond analyzing what is being said and how it is being said and must identify the long term social consequences on an individual and collective basis, especially the *unintended* consequences (Pollay 1991).

The classic sociological analysis of the concept of the unintended consequences of purposive social action was first developed by Robert K. Merton (1936). Based on writings and observations that stretches back centuries, Merton was the first to posit that actions of people—and especially of government—always have effects that are unanticipated or unintended. Some examples of prior research on the unintended consequences of social actions include the counter productivity of arresting street prostitutes who leave jail more violent than when they entered (Norton-Hawk 2001), the expansion of educational opportunities for a society that can lead to diminishing returns (Bourdon 1982), and how Marxist ideals of creating neighborhoods of mixed social compositions in East Germany did not lead to friendships across class (Volker and Flap 2001). Other examples include the backlash against Mumps, Measles and Rubela (MMR) vaccinations and their contested link to autistic spectrum disorders (Zetterstrom 2004), and the stigmatization of the disabled in public health campaigns to prevent injury that uses the fear of ending up in a wheelchair as its main message (Wang 1992).

*Public health and parenting advice*

Within sociology, the literature on families and parenting[5] has covered the changing nature of the American family and its power dynamics over time. One area within this literature that most directly pertains to this dissertation focuses on the role of professional expertise in shaping ideas about and approaches to raising children. Social scientists have examined extensively the changing influence over the last hundred years of outside authorities who told mothers what to do and how to do it (Hays 1996; Crane 2000). Child raising science drew “more and more on the judgments and studies of the experts, less and less on the experience of mothers” (Ehrenreich and English 1978: 184), a trend that public health campaigns have also followed.

Parenting advice presented by experts has changed over time, reflecting the social and scientific norms of the times (Stearns 2004, Hulbert 2002, Wrigley 1989). For example, the content of early to mid 20th century pediatric textbooks, a primary source of the scientific information dispensed by the baby experts has been found to emphasize culture over the biological nature of breastfeeding, with a focus on the clock and feeding schedules as the main theme of advice (Millard 1990). This study found that cultural themes such as factory model regimentation, the extension of professional advice to family matters, the subordination of lay women to professional expertise, mistrust of women’s bodily signals, mistrust of signals from infants, and a professional ideal of flexible advice coupled with rigid limits concerning schedules dominated the supposedly

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[5] Though most of the primary caregivers are mothers, I will use the terms mother and parent throughout this chapter.

objective medical information over the past 100 years. Another example of this approach from the second half of the twentieth century provided communication to parents via infant care manuals distributed by the government and popular magazines. Studies of these materials reveal an interaction between science and culture in theories of infant development and child rearing (Young 1990).

The *Back to Sleep* campaign to reduce the risk of Sudden Infant Death Syndrome follows a tradition of public health campaigns aimed at mothers to protect the lives of their babies. These include such topics as the development of Fetal Alcohol Syndrome and its connection to American views towards alcohol, motherhood, and responsibility (Armstrong 2004). Another example is early 20th century breastfeeding campaigns to combat the rise of bottle feeding, the marketing of infant formula, and contaminated milk in urban areas (Wolf 1999). There were also the campaigns for the 'domestic science' of housework and the germ-free home in the late 19th century that taught women how to keep a proper household (Tomes 1999). Research on these campaigns delved into the creation of the various public health campaigns by successfully presenting them as products of their time in history and how they related to the prevailing ideologies of patriarchy, urbanization, and technology.

Other studies of past public health campaigns have looked at the social and historical context to help explain how controversial campaigns were created. For instance, the first eugenics campaign in New York State to institutionalize "fertile, feeble-minded female paupers" to regulate their reproduction took place in the late nineteenth and early twentieth century (Rafter 1992). In her study, Rafter uses social problems theory to discover how the campaign constructed feeble-minded women as a eugenic threat and why it concentrated exclusively on women. In another example, Wolf (2003) looks at the conditions that surrounded the development of breastfeeding campaigns by the medical community during the early 20th and 21st centuries and found that in the case of infant feeding decisions, American women are thwarted in their ability to choose the healthy option by the demands of work outside the home and lack of societal support for new mothers. As in the 19th century, the societal definition of appropriate infant care is a more powerful influence of human behavior than health warnings. Wolf's study shows how historical factors influenced the creation of a public health campaign and how it is difficult to change behavior when there are structural barriers in the way.

Medically derived advice given to mothers about how to care for their infants continues to be a common theme in public health campaigns, but do women accept it? One answer can be found in a study of 185 low income, inner city women interviewed after they gave birth. This study showed that respondents received a median of 20 pieces of advice related to pregnancy health from a median of 5 members of their social networks and that both folk beliefs and information aligned with accepted medical views were communicated (St. Clair and Anderson 1989). The study concluded that for some low income, inner city women, social networks serve as important resources for health information; however, some of the advice may come into conflict with recommendations of health care providers, and suggests that health information be addressed not to the individual women but to their social network as well. In addition, the relationship between knowledge about health behaviors and better health outcomes for new mothers may not be causal. Another study of patient knowledge about different health behaviors that relate to low birth weight found that a majority of the women knew about beneficial health behavior items. The study found that overall knowledge concerning health advice behavior was greater than previously thought, but was not associated with a reduction in low birth weight (Muvla and Miller 1999). Advice about improving health outcomes therefore are also influenced by other factors beyond individual knowledge.

Scientific advice related specifically to the risk factors for Sudden Infant Death Syndrome is also subject to ideology, culture, and the social context. For instance, a review of studies about mother/child sleep sharing shows that infant sleep arrangements are not simple, but are influenced by family, social and ethnic influences. This calls for different definitions of the types of co-sleeping and bed-sharing, and challenges health advice that says to never sleep with your baby as simplistic and scientifically inaccurate (McKenna & McDade 2005). Another example of this type of study, a meta analysis that reviewed associations between infant sleeping positions and SIDS, compared findings with published recommendations in child care books. The study found that by 1970 there was a statistically significant increased risk of SIDS for front sleeping compared with back, and that sleeping on the front was recommended in books between 1943 and 1988 based on extrapolation from untested theory. The study concluded that advice to put infants to sleep on the front for nearly half a century was contrary to evidence available from 1970 and that a systematic review of preventable risk factors for SIDS from 1970 would have led to earlier recognition of the risks of sleeping on the front and might have prevented over 10,000 infant deaths in the UK and at least 50,000 in Europe, the US and Australia (Gilbert, Salanti, Harden, et al. 2005). Communicating this health campaign information about how to care for infants has historically gone through many channels:

from doctor to patient, from mother to mother, and within families. However, one of the most popular ways for doing this is through public health campaigns that use mass media to get their messages across.

### *SIDS as a social issue*

Published research about the possible medical causes of crib death and Sudden Infant Death Syndrome has increased steadily since the late 1960s (when it was officially termed SIDS) and it continues to be a topic of interest. The medical research has reflected trends in the suggested causes of SIDS over the years and will be discussed in more detail in Chapter Two. However, the overall scope of this dissertation fits with the body of literature that looks at the history and social significance of SIDS. Research that examined the medical history of crib death and SIDS shows how people described and interpreted the manifestations of the sudden death of infants in social rather than medical terms, each with social consequences for mothers of infants who were found dead (Savitt 1979, Russell Jones 1985, Limerick 1992). Eventually, SIDS was developed into a national medical research problem through groups of parents of victims that called attention to the social significance of SIDS and demanded more research be done (Johnson and Hufbauer 1982). In their study, Johnson and Hufbauer detail how a mysterious phenomenon that attracted little interest from researchers became transformed in the 1970s into a high priority medical research problem. Though SIDS became developed as an area for research funding, a comprehensive study published in 1986 examined the role played by targeted funding in advancing research of SIDS, and it revealed that federal funding played a lagging rather than a leading role and that the big biomedical discoveries were not funded by federal money (Hufbauer 1986). Another strand of research of SIDS as a social issue looks at how the mysterious nature of a SIDS diagnosis was intertwined with cases of parents murdering infants for such reasons as insurance money and a psychiatric condition known as Munchausen by Proxy, where parents intentionally cause harm to their children to get positive attention (Havill 2000, Firstman and Talan 1997). Finally, SIDS has been used for many studies of bereavement to show how parents cope with the sudden death of an infant across racial, ethnic, and class designations (Palmer 1996; Boyle, Vance, Najman, and Thearle 1996; Dent, Condon, Blair and Flemming 1996). SIDS has also been a significant topic in books and magazines that offer advice for how to care for infants.

## Gaps in the literature

Though there are extensive literatures on public health and parenting, the use of media to communicate health messages, risk societies, and unintended consequences of public health campaigns, there have been no published studies that have examined the social factors that determined how an ongoing public health campaign on SIDS was created, how it communicated its messages, how it was interpreted by its audience and identified the unintended consequences of the campaign. It is, in part, because of this absence in the literature that I designed my study to fill this gap between the social causes of media campaign creation, the social production of campaign materials, and the social consequences of the campaign. I have also conducted this research to further bridge the disciplines of sociology and public health in order to introduce concepts, theories, and methods to both fields to facilitate the connections already being forged between the social sciences and public health theory and practice.

In this dissertation, I hypothesize that when we view the *Back to Sleep* media campaign from 1994-2006 as a product of both the construction of SIDS as a social problem, and the medicalization of motherhood and infant care that there are unintended social consequences. Pointing out these unintended social consequences are not meant to imply that they outweigh the benefits of the *Back to Sleep* campaign, but will serve to provide a broader theoretical foundation in which to grasp how health messages resonate in society.

## Research Questions

This dissertation will answer the following questions using the methods described in the next section. Specifically, how are print and new media, particularly pamphlets and the internet, used to communicate new health messages to the public? How do the social context and values influence the creation of these messages? What are some of the unintended social consequences of a public health media campaign that result from the influence of prevailing norms and values? And finally, how do the unintended social consequences of the *Back to Sleep* campaign affect parents and caregivers, particularly African American mothers?

## Methodology: Multiple Dimensions of a Public Health Media Campaign

The research design of this study of the *Back to Sleep* campaign employed a total of three separate qualitative methods to examine the three phases of the campaign: how it was created, the messages that were produced, and how it was interpreted. By using these different methods to investigate my research topic, I was able to provide a layered analysis of the issues as well as triangulate findings. Using multiple qualitative methods was also useful in going between the macro and micro levels of analysis and allowed me to establish the larger social setting for these issues and present individual voices as well. I approached these data through the lens of grounded theory (Glaser and Strauss 1967, Strauss and Corbin 1990), which involved a process of data gathering, observation, and understanding the different players and their roles within the *Back to Sleep* campaign. I was then able to compare my different data sources in order to establish and identify different categories and their properties to develop theory. This was an on going process that involved data collection, note taking, coding, sorting, and writing. Through this process I was able to build an understanding of this research situation and develop emerging findings as viewed through the lens of the theoretical framework described above to help to answer my research questions. Multiple data sources are helpful when using grounded theory and this process was well suited for the research questions posed in this dissertation.

## Research Approach

### *Semi structured interviews*

Interviews were conducted with 13 key players involved with the creation of the *Back to Sleep* campaign and with SIDS professionals who have implemented the campaign—medical directors, counselors, information officers, program directors and coordinators. These professionals represent national, state and city service organizations—four from the national level, three from the state level, and six from the city of New York. All of the interviewees were women, who have from between five to thirty years experience in maternal and infant health, with a focus on SIDS. Two are

African American and eleven are white. They represent several agencies and groups, including the American Academy of Pediatrics, National Institute of Child Health and Human Development, the First Candle/SIDS Alliance, the New York City Department of Health, Bureau of Infant, Maternal and Reproductive Health, and the Association of SIDS and Infant Mortality Programs. The interviews consisted of questions that were written out, with probes indicated on the interview schedule where needed. Follow up questions were sometimes improvised based on how the respondent answered the questions (Rubin and Rubin 1995). Prior to conducting these interviews I received IRB approval from the CUNY Graduate Center, and all of the participants gave their informed consent. Interviews were semi-structured, ranged from one to two hours, were tape-recorded and transcribed. These transcriptions were then analyzed in the qualitative software package Atlas.ti 5.0, where thematic codes and concepts were developed and refined to construct theory.

### *Participant Observation of SIDS education and outreach in New York City*

From February 2005 to the winter of 2006 I worked as a consultant and health educator hired by the New York State Center for Sudden Infant Death. I attended over two dozen health fairs in communities and at Babies R Us stores where I distributed *Back to Sleep* materials and talked to people about SIDS risk reduction. I also made presentations to different audiences of medical care providers, peer counselors, WIC counselors, parent groups, day care providers, and community based organizations. Through these different events I spoke to hundreds of people, either individually or as part of a group in every borough of New York City. I also attended two national SIDS conferences, though not as a representative of the NYS Center for Sudden Infant Death. Throughout these activities I took field notes, which I subsequently compiled and analyzed in Atlas.ti as data to help answer the question of how public health campaign messages are communicated to its intended audience. I recognize that this close involvement of the researcher to the subjects raises ethical issues as well as issues related to reflexivity, and I carefully considered my role throughout the interpretive process (Denzin and Lincoln 2003). However, there were also benefits to conducting this type of research for this study. Getting at the reasons why and how parents interpret public health recommendations for their infants is informed by observing the actions and interactions that take place between the one communicating those recommendations and the audience. By listening to and seeing how SIDS risk reduction recommendations were received, I was able to discover a level of interpretation that would have been missed in more formal settings.

### *Qualitative content analysis*

Qualitative content analysis can be used for several purposes that apply to my study. These include revealing the focus of individual, group, institutional or societal attention; reflecting cultural patterns and beliefs; describing themes, trends, goals, or other characteristics in media discourse (Faircloth 1995). The overall analytic goal here was to see how the content of the messages has changed over the time period and what underlying values are being communicated. As with the interview data and participant field notes, all content analysis data (including visual images which were scanned and stored) were coded and analyzed with Atlas.ti 5.0.

### *Sources of Data: SIDS Pamphlets*

I conducted a content analysis of the national *Back to Sleep* campaign materials from 1994 to 2006 produced by the National Institute of Child Health and Human Development (NICHD), including pamphlets and internet websites. This process included noting what information these materials contained, the source of that information, how the materials were worded, to whom were the addressed, and how they were physically presented. Often this was a comparative process, where I was able to look at a sample of campaign materials produced by different sources, which allowed me to highlight the differences and similarities in these materials. I was then able to summarize these findings and present them as a table, which allowed for further analysis along similar categories, allowing me to connect the data to the context in which they were produced as viewed through the lens of my theoretical framework. I obtained this material from the NICHD offices in Washington DC and from the New York State Center for Sudden Infant Death on the SUNY Stony Brook campus. I also analyzed the *Back to Sleep* campaign materials (brochures and videotape produced for distribution) that have been created by the NICHD in 2000 specifically for African American outreach that I also obtained from the NICHD. I also analyzed earlier pamphlets, from around 1984 to 1992 that were produced by SIDS parent groups and state agencies that I retrieved from the office at SUNY Stony Brook.

### *Sources of data: popular magazines and newspapers*

Studies of the role of newspapers in presenting public health topics such as HIV/AIDS (Lupton 1996), Sexually Transmitted Diseases (Davidson and Wallack 2004), smoking (Menashe and Siegel 1998), and alcohol (Jones-Webb et al, 1997) have shown the ability of newspapers to establish the boundaries of new information for the public. Health information presented in the news media has been found to have an influence on public opinion (Klaidman 1990, Hertog and Fan 1995) and government policy (Nelkin 1987). A quantitative examination of magazine and newspaper articles that I conducted during the research period provides for a landscape view of development of SIDS as a public health issue. I obtained many of these articles electronically, using the Lexis/Nexis database and generally using the search terms "Sudden Infant Death" or "crib death" to retrieve national newspaper articles. I used the electronic version of the Reader's Guide to Periodic Literature to get magazine articles, or often abstracts. I then went to the New York Public Library to make photocopies of the full text of articles I was interested in examining in more detail. I also used the electronic Ethnic Newspapers database for a more focused search of the terms "SIDS" and "African Americans".

## Limitations of this study

There are two major limitations of this study. First, the small sample size and low variance of the interview subjects does not allow for this analysis to be applicable on a wide level. By limiting my sample to those who are in the 'front lines' of SIDS education and health campaign, I have not been able to capture the experiences of SIDS families, for instance, and others who may only have occasional experiences with SIDS risk reduction messages. This limits the external validity or generalizability of this study. Second, since this study investigates within the field of public health, an area that I am familiar with, but not a professional in, and there is the possibility that as an outsider, I may have misrepresented the way that this discipline addresses media campaigns and their audience. Though my intention was to bring a sociological perspective to the field of public health, these findings may not be applicable to those who practice public health interventions.

# CHAPTER 2

> The odd thing is, I'm more worried about SIDS now, at 11 weeks old, than I was when he was newborn. I think it's because all the scary literature says the "peak" for SIDS is between 2 and 4 months (just my son's age) and the uncertainty of what causes it. While there may be some risk factors, the fact is that autopsies of a lot of babies found NOTHING wrong. They were perfectly healthy, and full-term. They just died, for no reason. No wonder we are all panicking! My son was term, a big boy, and is very healthy, and we don't smoke but it is STILL no guarantee. I think my fears will lessen when he passes the 4 month window, and after a year I'll breathe a sigh of relief. I guess the anxiety is just a fact of life now.:(
>
> --Lenore, posted on a parenting website at 8:51 AM on 12/08/2004

As Lenore, the woman who posted the above comments on an electronic message board exemplifies, one certainty of motherhood[6] is that with the exhaustion from caring for an infant, there is worry for the baby's health and wellbeing. Most new mothers today cannot avoid hearing the terms Sudden Infant Death Syndrome, SIDS or crib death. SIDS is now a well-known and well-established member of the constellation of parental fears, though this was not always the case. Particularly in the last fifty years, the definition, diagnosis, and acceptance of these silent deaths of seemingly healthy infants has changed from being seen as an act of neglect to an accident to a crime to a medical mystery. In the past, medical professionals were unable to find any evidence of fatal disease or injury and attributed these deaths to undetermined causes, pneumonia, or accidental suffocation. The suddenness of these infant deaths coupled with the uncertainty of its origin occasionally caused parents to be stigmatized by the criminal justice system and members of the community (Bergman 1986). Because the causes of these deaths were unknown, there was the suspicion that it must be due to neglect or

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[6] Though most of the caregivers are mothers, I will use the terms mother and parent throughout this chapter.

abuse by the parents, especially if everything else had been ruled out. A well-known expert in the field warned that intentional suffocation could not be excluded at autopsy with certainty, further blurring the line between abuse and disease (Valdes-Dapena 1967). Criminal investigations were not uncommon in these cases, particularly when poverty and race were factored in. Parents were also left feeling guilty for what they could have done to prevent these deaths from occurring.

Today, SIDS is recognized as an official cause of infant death and as a major issue that concerns many professions including those in public health and medicine (see national and New York City rates below from 1996-2002 in Tables 1 and 2). The epidemiological data on SIDS is carefully monitored in every state and nationally, and has been acknowledged as one of the major causes of infant mortality in the United States. Indeed, SIDS is the single most common cause of death in the post neonatal period (i.e., in infants aged 1 month to 1 year) which accounts for 35-55% of deaths within the post neonatal period and comprises approximately 20-25% of deaths in those younger than 1 year (Carolan 2006). Approximately two thirds of SIDS deaths occur in infants aged 2-4 months, and population studies of SIDS in the United States have demonstrated consistently higher rates among African American infants and Native American infants compared to white, Hispanic, and Asian American infants (Carolan 2006).

| **Year** | **US (Rate)** | **US (Count)** |
|---|---|---|
| | *Rate per 100,000 live births* | |
| 1996 | 78.5 | 3,056 |
| 1997 | 77.2 | 2,996 |
| 1998 | 71.7 | 2,827 |
| 1999 | 66.8 | 2,643 |
| 2000 | 62.1 | 2,522 |
| 2001 | 55.5 | 2,236 |
| 2002 | 57.1 | 2,295 |

**Table 1: Infant deaths due to SIDS: US 1996-2002**
**Source:** National Center for Health Statistics, period linked birth/infant death data

| **Year** | **New York City (Rate)** | **New York City (Count)** |
|---|---|---|
| | Rate per 100,000 live births | |
| 1996 | 49.0 | 60 |
| 1997 | 41.4 | 49 |
| 1998 | 32.1 | 39 |
| 1999 | 33.3 | 40 |
| 2000 | 33.0 | 40 |
| 2001 | 16.7 | 20 |
| 2002 | 20.4 | 24 |

**Table 2: Infant deaths due to SIDS: New York City 1996-2002**
**Source:** National Center for Health Statistics, period linked birth/infant death data

SIDS is the basis of millions of dollars of research funded on the federal, state, and local level, and its ubiquity is reflected in nearly every book about infant and childcare. And though the sudden death of an infant is undeniably tragic, it has not always existed as a social problem or a matter of concern for public health. This transformation occurred through a series of events and actions taken by claims-makers who had an interest in having these deaths be taken seriously: physicians, medical researchers, and most importantly, parents of babies who died. How these deaths were viewed by the public and medical professionals over the past fifty years fluctuated according to the social context in which they occurred, who they happened to, and the values associated with child rearing at the time.

The development of the sudden death of infants into a public health problem also has a larger history which has to do with the changing nature of responsibility for infant care. As the medical establishment, particularly pediatricians and psychologists, exerted more authority over infant care in the 20th century (Hulbert 2002, Ehernreich and English 1979) there was a shift from mothers being responsible for these deaths to the medical and scientific communities being called to task to explain what was wrong. The sudden death of infants was renegotiated from an act of neglect, to an accident, to a crime, to a medical mystery, to a matter of public importance during the mid 20th century.

Using the theoretical framework of social problems construction (Spector and Kisuse 1977, Schneider 1985, Best 1995, Conrad 1997), this chapter looks at how this transformation occurred as well as what social forces were at play to create sudden infant death as a pressing public health problem,. Specifically, I examine how SIDS was identified as a product that has been produced or constructed through social activities, particularly through claims-making, and how they were ‘typifyed’, which is how they shaped our sense of just what the problem was, by two sets of claims-makers: parents of infants who died and medical researchers, particularly pathologists.

In this chapter I show how SIDS parents were successful in typifying these deaths as a risk that could affect any family and how they were able to help construct SIDS as a public health problem through the use of affect and strong emotional cues to create knowledge. Pathologists were also valuable claims makers in constructing SIDS as a public health problem in that they were able to typify these deaths as medical events and not accidents. Medical examiners (who are mainly pathologists) in particular contributed to the designation of SIDS as an official cause of death by the late 1960s, even though there were no known biological factors that could be identified. They succeeded in establishing SIDS as a ‘diagnosis of exclusion’, which is undesirable in the world of forensic pathology. The power of this diagnosis represented a triumph by the claims-makers who sought to bring the sudden death of infants into the light. By determining that a cause of death could be identified, though not understood, this designation allowed medical examiners to establish “forensic authority” (Timmermans 2006) and for parents to achieve recognition as a victim, and not a suspect.

This chapter also analyzes what this designation of SIDS as a public health problem meant to health educators and other professionals and how the parents of a baby who died were addressed before and after SIDS was acknowledged as a public health problem. I divide the process of this social construction of SIDS as a public health problem into two time periods: “before” from the mid 1940s (when the first article appears in the *Journal of American Public Health*) to the late 1970s (when federal funding is established) and “after” from the early 1980s (when most states had established SIDS education programs) to 1994 (when the *Back to Sleep* campaign for SIDS risk reduction information began). The data for this analysis are magazine and newspaper articles from 1945 to 1994 that were instrumental in constructing the messages around the issue of crib death/SIDS[7] as a public health problem, since the media played a significant role in the development of these issues. During the “after” period, the successful construction of SIDS as a public health problem led to the development and distribution of informational pamphlets for parents and caregivers by federal and state health agencies. I analyze a sample of these pamphlets produced from 1983 to 1992 to look at what was communicated overtly and what values were transmitted sub textually about SIDS as a public health problem. I also provide context for this “after” period with analysis of data from a sub-sample consisting of four interviews with SIDS health educators and professionals who were working before the *Back to Sleep* campaign began. The chapter ends with an analysis of interview data and media reports that describe the various claims and conflicts that culminated in the creation of the *Back to Sleep* campaign in 1994.

## Historical claims about sudden infant death

The history of medicine is tied to the search for answers to human pain and suffering--questioning, probing, and connecting parts of the body to each other and to the environment are patterns found in all early civilizations. These answers were placed in

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[7] The term crib death was used to identify the sudden death of infants regularly throughout the time period analyzed. After the official designation of Sudden Infant Death Syndrome (SIDS) as the name for this entity in 1969, there was an increase in the use of this appellation; however ‘crib death’ was a term still commonly used. Therefore both of these terms were used in the search of newspaper and magazine articles

the hands of the healers, who knew that some explanation for what was causing the pain was better than none. The explanations always referred to shared understandings of how the world worked, be it at the hands of the gods or Mother Earth, bad bile or blood, something in the air, or the work of invisible microbes. These various ways of looking at the world cloaks the same biological entity with different appearances: from unknown to known, from being caused from without to being caused from within, from the result of bad luck to the result of bad behavior. The rise of modernity and its accompanying norms and values presented a forum for explaining the cause of disease and death that focused on the social environment. Urbanization with its cramped living conditions, poor sanitation, and contamination; industrialization with its polluted air and dangerous working conditions were seen as part of the cause of disease and death and also as the frame to explain how it happened. By the late nineteenth century, the rise of allopathic medicine and expanding diagnostic categories provided a scientific basis for explanation, though this was by no means value-free. Science became a major player in the negotiation of a diagnosis.

Diagnosis has been identified as "politics of definitions" (Conrad and Schnieder 1992:22), whereby illness designations are created from social conflict. Phil Brown (1999) describes this process of the social construction of diagnosis by adding that for socially powerful groups and institutions, diagnosis "locates the parameters of normality and abnormality, demarcates professional and institutional boundaries of social control and treatment" (1999:35). The struggle to diagnose the cause of these sudden infant deaths over the past two centuries highlights the process of social construction by reflecting the prevailing norms and values. This was especially the case with two of the

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and the term "crib death/SIDS" will be used.

early explanations for the cause of the sudden death of infants, overlaying and the thymus theory.

### *Overlaying and Thymus Theory*

History is littered with tales of infants not surviving to their first birthday, of small headstones in cemeteries, of babies not given a name until it was sure that they would make it into childhood. In the literature on SIDS, the Bible is often referenced as evidence of the long history of the sudden infant deaths. In the story of King Solomon in the Old Testament (First Kings Chapter 3, Verse 19) describes the story of two women, most likely prostitutes, who were each sleeping in bed with their infants. One woman's child "died in the night because she overlaid it" and the grieving mother replaced her dead infant with the other woman's live one. Each claimed to be the living child's mother, and King Solomon's threat to cut the baby in two settled the dispute. This parable is often used as an example of Solomon's wisdom in resolving the argument, with little attention paid to the reason behind the baby's death. For centuries afterward, the cause of sudden infant deaths was blamed on the unfortunate, (but not always illegal) act of overlaying, or rolling over on a sleeping baby who shared the bed. This problem prompted the creation of a preventative device in Florence, Italy in the 17th century to protect infants. An *arcutio* was an arched cover made of wood and iron that was placed over babies during sleep to protect them from their mothers, but still allowed them to nurse during the night (Limerick 1992).

By the end of the 19th century, infants who died during sleep were scientifically associated with the ills of urban poverty. The first systematic epidemiological study of sudden death in infants in the industrial city of Dundee, Scotland was conducted by the local police-surgeon in 1892 (as cited in Guntheroth 1995). The study found that babies tended to die at night, during the winter and before the age of three months, and that the children from poor families were more likely to die. The study contended that overlaying was the principle cause due to the ignorance, carelessness, and drunkenness of the mothers, who lived in overcrowded conditions. The police-surgeon also suggested that the illegitimacy and life insurance on the infants should be taken into consideration (as cited in Bergman 1986). This study concluded with the recommendation that mothers be prosecuted for negligence. Overall, the diagnosis of overlaying as the cause of the sudden deaths of infants at this time was seen as an unavoidable part of life, especially for the poor.

The 19th century also saw the rise of pathological anatomy as a means to make sense of disease and to impose a framework in which to understand it. In 1842, an article was published in the *American Journal of Medical Science* on the abnormally large thymus gland in infants as a possible cause of sudden infant deaths (Guntheroth 1995). This theory, labeled *status thymicolymphaticus*, became the official cause of sudden death in infants until the early part of the 20th century. The actual cause of death was said to be due to an enlarged thymus -- a gland in the neck -- which obstructed airways for breathing. In the 1930s and 1940s the preventative measure for concerned parents made use of the most up to date technology of the time, which was to irradiate and shrink the thymus in children via X-ray. It took almost 100 years to prove to doctors that “normal” sized glands were actually based on autopsy specimens of infants who had died of malnutrition and who therefore had shrunken thymus glands. It did not take that long to discover that this cure caused thyroid cancer as some of those children got older (Golding, Limerick and Macfarlane 1985).

### *Now Known as Crib Death*

The eventual discounting of the thymus theory and the dismissal of deaths due to overlaying as a province of the poor left room for a new negotiation of the diagnosis of the sudden death of infants by the mid 1940s. Though these sudden infant deaths were often attributed to different causes, a common explanation during this time was that infants found dead in their beds suffered from accidental suffocation. This differed from the previous diagnosis of overlaying, as bed sharing was no longer a common practice in the United States. Indeed, by the middle of the 20th century, more babies, particularly those of the middle and upper classes, had rooms of their own. This change in the location of where infants sleep from sharing an adult bed to in a separate room is actually relatively recent in terms of human history and one particular to Western culture. Some have argued this shift has contributed to the higher SIDS rates in countries where parent-infant co sleeping is not the norm. James McKenna, a medical anthropologist who has extensively studied infant sleep under laboratory conditions (McKenna 1986, McKenna 1996) argues that the regulation of breathing and arousal patterns during sleep between mothers and newborns who share a bed is protective against SIDS for vulnerable infants. However, this theory and its encouragement of infant bed sharing has met with resistance due in part to the norms and values associated with independent sleeping for infants in Western cultures (Anders and Taylor 1994). A more detailed analysis of the bed sharing debate as it relates to SIDS risk reduction messages and values follows in Chapter 5.

The social shift from bed sharing to baby's own bed led to a new distinction in the accidental suffocation diagnosis. No longer were they said to have been overlayed by their mothers who they shared a bed with, but infants instead were said to have suffocated on the sheets and blankets in their cribs (Guntheroth 1995). Even the name that these deaths were given at this time--crib death—points to the space in which infants are put to sleep. Though the crib death diagnosis could leave the impression that the parents were neglectful, physicians generally considered these deaths to be accidents and did not follow up with an autopsy to determine the cause of death. However, the criminal justice system did get involved with many cases, leading the police to interrogate the parents as to the specifics of the baby's death, occasionally with arrests being made for infanticide (Bergman 1986). During this period, a crib death in the family was not only an individual tragedy, but one that carried with it the taint of neglect and crime.

One of the larger social forces during the mid 20th century period in the United States that influenced how crib deaths were diagnosed were shifts in how the medical establishment was organized. The profesionalization of medical education at this time meant that medical students were first instructed in classrooms, and then in teaching hospitals to learn how to become a physician (Starr 1987). Within this context, medical students did not encounter sudden infant deaths at all—it was not mentioned in their textbooks because it did not exist as a biomedical entity, and since these deaths occurred in the home and not in the hospital, medical students did not "see" these deaths happen. Also, as a result of increasing specialization of medicine in the United States, the only medical professionals who saw the victims of these sudden deaths were pathologists--physicians who are trained to identify the cause of disease in the body. However, as a result of the nature of crib death/SIDS and that it was only recognized upon death, autopsies were the only way that medicine would be able to diagnose this problem.

As the lone medical professionals investigating these deaths, there were several pathologists around the country who began to doubt that suffocation was the reason these babies died (Johnson and Hufbauer 1982). Since these deaths were relatively rare, only pathologists in large cities could have access to enough bodies to autopsy in order to make a significant study of the possible causes of death. One such study by a New York City medical examiner, Jacob Werne, and his pathologist wife, Irene Garrow appeared in an article in the *Journal of American Public Health* in 1947. They conducted autopsies on 167 infants and found that accidental suffocation was not the cause of death, and recommended that the American Public Health Association conduct more studies to investigate sudden death during infancy (Werne and Garrow 1947). This contributed to the development of the diagnosis of these infant deaths to be seen as a public health problem in need of a solution.

## From An Individual Issue to a Matter of Public Health: 1948-1969

By the late 1940s the United States was entering an era of population growth. During this time period, parenting magazines provided an arena for distributing and discussing advice on the latest (and presumably best) ways to raise children. Though most of the articles contained information from experts with a professional degree, occasionally there would be pieces written by parents that would express a different perspective. In the case of crib death/SIDS and the mystery behind its diagnosis, parenting magazines in this period before it became a public health problem offered a place for parents to make claims that would confront suffocation as the perceived cause of sudden infant deaths. An article that appeared in *Women's Home Companion* in February 1948 is the first to challenge the lack of biomedical information about these deaths. The article, "Death in the Bassinet", was written by an anonymous father of an infant who died. In it, the father claimed that when he questioned doctors about why his son died suddenly in his sleep, he was dismissed by them. The author also pointed out medical ignorance and apathy in this area. An editorial in the same issue of the magazine warned parents about the lack of research about the risks of suffocation, and readers were spurred to pressure the United States Public Health Service (USPHS) to act (Johnson and Hufbauer 1982).

The USPHS held a conference in 1949 that proposed that more investigation be done by experienced forensic pathologists in four sites around the country, to combat the belief in the "suffocation hypothesis" (Johnson and Hufbauer 1982). During this period from 1945-1960, the most prominent claims-makers for discrediting accidental suffocation were pathologists, with the support of government funding, who pushed for more scientifically rigorous investigations of the causes of sudden infant death (Guntheroth 1995). At this time, pathologists were the only medical professionals who had any interest in studying the causes of these sudden infant deaths, and they had produced the only modern scientific studies. In disproving the commonly held medical belief that these deaths were caused by suffocation, they also succeeded in legitimizing their field of study. This professional success was captured by changing the descriptions of these sudden infant deaths in the *Textbook of Pediatrics* by 1959--suffocation went from being listed as the first possible cause of death, to the declaration that death should not be attributed to suffocation at all, and that "the family should be made to understand that they were in no manner responsible for the death of their child" (as cited in Johnson and Hufbauer 1982).

Scientifically removing parents from blame by discrediting the suffocation hypothesis was one thing, but changing the perception of the public would be a more complicated undertaking. The publication of two articles in popular magazines in 1950: "Death in the Crib" and "When a Child Dies Unexpectedly" which appeared in *Time* and *The Child* magazines respectively, were part of an effort by the federal agency known as the Children's Bureau to reach audiences and to make them aware of research which questioned accidental suffocation as a cause of sudden infant deaths. By 1952, an article in *McCalls* magazine boldly announced in its title that "Babies Don't Smother", and tried to make the case for parents of infants who died suddenly in order to allow for an autopsy to be conducted (which was not the standard operating procedure at the time), so that research could be done to find the "real" cause of death, which could also remove feelings of guilt and responsibility from parents.

The push for forensic investigation of infant deaths during this time must also be seen within the context of the shift in the United States in the mid century of the official designators of the cause of death. The shift went from coroners—traditionally local elected officials who did not have medical backgrounds or training in death investigation—to medical examiners, who are physicians trained as forensic pathologists[8]. The embrace of a scientifically based conclusion on the cause of death from the more politically influenced decisions made by coroners predisposed how the

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[8] About half of the population in the US is still served by coroners in the beginning of the 21st century (Johnson-McGrath 1995).

sudden death of infants were categorized and classified across the United States (Timmermans 2006). This move towards a more objective, rational explanation for the cause of these deaths on the part of forensic pathologists in particular helped to remove the stigma from parents as being responsible for their baby's death, and move it into the realm of a pressing public health issue.

### *Enter the enigma*

By 1960, the United States was in the middle of a baby boom, and with an increase in the number of infants being born, more attention was being paid to their care and survival. As infant care guides gained popularity and science was successful in producing vaccines for deadly and debilitating childhood diseases like polio, there was a sense that uncertainty could be controlled, and that babies were safer than at any other time in history. Modern conveniences tucked into the typically portrayed suburban middle class home added to this feeling of neatness and order. So when old fashioned, unexplained infant deaths intruded on this perceived peace, there was an increase in the expectation for medical knowledge. The way that magazines and newspapers framed the issue of sudden infant death in this period reflect this growing need to diagnose its cause and explain the unknown and find out why medical science lacked the knowledge to protect their babies. And in keeping with the stereotype of the American family at the time, these stories overwhelmingly focused on the plight of middle class families.

In these articles, the discourse centers on *protecting* children, a task that appeared to be something that science could do, if only they put their attention on it. By posing the sudden death of infants as an uncertainty, there was less room for parents of infants that were found dead to be liable for putting their children at risk. One article in the *Saturday Evening Post* puts it succinctly: "…the parents are blameless. At present these mysterious deaths can be neither predicted nor prevented, and the medical profession is almost totally baffled." (Spencer 1966:82). After the guilt and suggestions of neglect that were associated with the accidental suffocation as the cause of these deaths, the move towards mystery could be considered in terms of humanizing the parents' despair.

In the magazine articles of this period, there are two intersecting themes identified that reflect the broader topic of sudden infant deaths as a mystery. The reliance on these medical professionals to solve the mystery that was plaguing parents is exemplified by the 1968 *Redbook* magazine article "What Doctors Know About Crib Death", where readers are brought up to date on what is fact and what is fiction, according to what physicians knew at the time. The other theme emphasizes the scope of the new research being done. Here, many theories are suggested as being "promising"—including hypersensitivity to cow's milk, bacterial or viral infections, and cardiac conditions. Newspapers in this period also typified the issue of crib deaths as being investigated by scientists who were on to several leads. A *New York Times* article from 1968 portrays the research of the time as taking a wide view: "Virus Suspected in 'Crib Deaths': Antibody Deficiency is Also Suggested by Research" (Brody 1968). This focus on reporting the latest medical findings underscores the hope and promise of babies being saved by the results of scientific discoveries.

### *Crib Death Parents: Looking for Answers*

Scientific study of sudden death for infants was meant to be reassuring to parents, a way to remove them from accusations of responsibility or blame. Though it was still seen as a mystery, the media typifyed these deaths as an agenda that was receiving some attention by the medical community, with hope for a way to prevent these deaths from occurring in the near future. But not all parents were comforted by this message. The search for answers for what caused these sudden infant deaths, and how they could possibly be prevented, was fueled by the parents of the babies who died. Unsatisfied with what modern medicine was doing, they organized to help each other.

In the 1960s, parents who lost children to crib death started to form organizations to help them deal with the tragedy. In particular, three families in three different states began support groups around the same time that grew to help parents cope with the loss and to minimize their feelings of guilt. Their claims located the problem in research that they felt remained unfocused and uncoordinated. The rising expectations of medicine, its attempt to dismiss the prevailing hypothesis and its inability to explain the causes of these deaths created two streams of social tension. First, the parents themselves were at a loss to understand how their children could have died so suddenly, and they knew that there was nothing that they could have done to prevent it from happening again. This lack of knowledge was unsettling and offered no comfort that subsequent babies would not die the same way. Second, the public's lack of knowledge about crib death led to discomfort in dealing with crib death parents. Was it a tragic accident or careless care giving? Accusations against parents, whether explicit or unsaid, fueled the desire to find the external cause of these deaths, one that the community could understand and that could help to make sense of this tragedy. The development of crib death parents as claims makers followed.

In October 1958, the death of Jedd and Louise Roe's six month old son Mark in Greenwich, Connecticut was the cause of despair and dismay within the white, upper middle class family. They were in despair that their seemingly healthy infant was found dead in his crib and dismayed that after an autopsy their doctor declared the cause of death as 'acute bronchial pneumonia', even though the doctor admitted that the evidence was not conclusive (Johnson and Hufbauer 1982). The family established the Mark Addison Roe foundation in 1963 to "promote and stimulate" research in the "diagnosis, treatment, and cure of sudden, unexpected death in infants" (Johnson and Hufbauer 1982). Bereaved parents of infants who died of crib death soon heard about the foundation and contacted them for information. Providing emotional support to parents from parents on a local level became a focus of the foundation. The first chapter was formed in Long Island in 1966, and other chapters opened across the United States. In 1967, the foundation changed its name to reflect their new focus and became the National Foundation for Sudden Infant Death (Bergman 1991).

In Baltimore, Maryland in 1963, the sudden death of two month old Suzanne Goldberg also sent her parents, Saul and Sylvia, searching for information about what happened. Dissatisfied with the response by the Mark Addison Roe Foundation about starting a chapter in Baltimore, they decided to start their own grass-roots foundation that would provide support, counseling and information to other parents and that would be an advocacy organization to prevent sudden infant death. In 1964 they created the Guild for Infant Survival, and began to raise money for research and lobby the state legislature for funds. Soon after, the Goldbergs realized that a national approach was needed for funding. They met with staff members of the National Institute of Child Health and

Development regularly and were sympathetically listened to, but no additional funding was forthcoming. By 1968, the Goldbergs decided to lobby Congress and by the next year they appeared at the hearings of a Senate subcommittee on Labor, Health, Education and Welfare (Bergman 1991). By the end of the 1960s, they increased the number of chapters of their organization in the United States and also in Europe and Canada.

In Seattle, around the same time the Guild for Infant Survival and the Roe Foundation were being established, another group of crib death parents were also advocating for change. Fred and Mary Dore's daughter died in 1961 and soon after they started their search for the cause of her death. After being told that research in Seattle was stalled due to a lack of funds to transport victims from the morgue to a medical facility to do autopsies, Fred Dore, a state senator, worked to enact a state law that would pay for the cost of transporting victims to an appropriate facility in order to conduct autopsies (Johnson and Hufbauer 1982). This was just one step in a larger plan to gather what was known about these sudden infant deaths and what could be done to prevent them. In 1963, Seattle was the location for a national conference to review recent research on the topic.

The Seattle conference become the genesis of a movement whose goal was not only to discover the cause and work to protect crib death, but to establish crib death as a legitimate medical entity, thereby shifting guilt and suspicion away from the parents and placing the burden of discovery on medical science. The conference ended with researchers split on a key point: some believed sudden infant death was caused by a specific disorder, while others thought the babies were dying coincidentally from a variety of hard-to-detect diseases (Bergman 1986). The different disciplines involved at the conference—pediatrics, pathology, epidemiology and virology--saw the unexplained deaths of babies from different angles. This was reflected in the fact that they didn't even call it the same thing. Pediatricians tended to use Sudden Death Syndrome or the traditional crib death, while some virologists used Sudden Unexpected Death, or SUD. In Britain, cot death was preferred (Golding, Limerick and Macfarlane 1985). A study by a prominent SIDS researcher, Abraham Bergman, who was affiliated with the parent group the National SIDS Foundation, found that death certificates listed pneumonia, interstitial pneumonitis, respiratory infection, acute necrotizing laryngitis, crib suffocation, aspiration of vomitus, suffocation under bed clothes, acute tracheobrochitis and pulmonary edema (Bergman 1986). Some coroners and medical examiners felt that these deaths were caused by another disease, like pneumonia, and preferred to use that term on the death certificate in the belief that it was more scientifically correct and that parents needed to be told something more definite.

The study also found that there were racial and social class differences in how different families were treated. Four times as many blacks as whites were told that their baby suffocated, and three times more blacks than whites were never told why their baby died (Bergman 1986). This report was used by Bergman and the National SIDS Foundation to present recommendations for changes to public policy to humanize the treatment of crib death parents. Bergman's efforts to scientifically demonstrate that parents were not to blame for these deaths made news in 1968 when he presented the results of a study he conducted to the American Academy of Pediatrics. The study was described in a headline in the *New York Times* as "Crib Deaths Linked to Normal Causes, Not Parental Neglect" (*New York Times* 1968).

### *Crib death parents as claims-makers: defining disease*

The conviction on the part of the parent groups and the core of crib death researchers was that this was an issue worthy of a proper name and one that deserved a lot more attention than it was getting at that time. In 1969, a second conference was held in the Seattle area to once again gather researchers together, and had as one of its goals to leave with a definition of sudden infant death that would allow medical examiners, pediatricians, and researchers throughout the world to be in synch (Firstman and Talan 1997). How the term was coined at the second international meeting in 1969 reflects the ordinariness and the potential for longstanding impact that comes from naming, as well as where this process occurs in time and space. In the opening minutes of the conference, pediatric pathologist Bruce Beckwith declared that “A good title for this entity should be short and euphonious, sufficiently descriptive to prevent confusion with other types of sudden death, and readily comprehensible to laypersons.” Sudden Death Syndrome, which some doctors had been using since 1963, was the first proposal. “Syndrome” signified the presence of a set of symptoms and characteristics, rather than a specific, identifiable disease process, though Beckwith noted that a name whose acronym was SDS might be a problem, since those initials “are at the present time popularly used for a militant student group.” He suggested the word infant be inserted. The term Sudden Infant Death Syndrome, or SIDS was proposed and agreed to. SIDS was defined as "the sudden death of an infant or young child, which is unexpected by history, and in which a thorough postmortem examination fails to demonstrate an adequate cause of death” (Firstman and Talan 1997).

This new definition would, it was hoped, give medical examiners, coroners, and hospital pathologists something uniform to write on death records, as well as something to tell parents when they found nothing else. A uniform diagnosis is also helpful from a public health perspective with surveillance and epidemiological studies. Now "SIDS" would be a way for doctors to rule out every possible medical explanation and still leave parents with the impression that their babies had died of *something*. At the end of the conference in 1969, pediatrician Abraham Bergman said that "…we can say that Sudden Infant Death Syndrome is a definable disease. It can no longer be called a mystery killer. It is a real disease every bit as much as cancer is a disease. We do not know the cause, but it can be readily diagnosed and the aura of mystery removed" (Bergman 1986:115). By giving this category of infant deaths an official name, SIDS claims makers appeared to take a step forward in dispelling the socially constructed mystery of its origin. The definition of SIDS actually produces a syndrome where none existed before, and firmly places the issue within the medical discourse. However, this definition of SIDS contained within it an admission of not knowing what the cause of death actually was. By declaring that a sudden death of an infant could be called SIDS as long as it was "unexpected" and that an autopsy (if one is completed) "fails to demonstrate an *adequate* cause of death " this diagnosis had uncertainty built into it. Perhaps these deaths could no longer be called a mystery, but they surely were still open to individual interpretation and negotiation.

Much of this negotiation happens among medical examiners. Sociologist Stefan Timmermans recently published an ethnographic account of how medical examiners explain suspicious deaths and how they wrest cultural authority in the practice of their profession (Timmermans 2006). He devotes one chapter to how medical examiners evaluate sudden infant deaths and finds that medical examiners constantly negotiate between scientific evidence and moral values when it comes to diagnosing a cause of death in these cases. In particular, Timmermans points out that the designation of SIDS as a cause of death represents the successful efforts of parent groups to leverage emotion and basic values associated with parental responsibility for caring for babies to construct medical knowledge. Indeed, he characterizes SIDS as a unique example of medical examiners "forensic authority":

> "…SIDS does not provide an answer as to the specific cause of death, but it officially validates parents as guiltless and tragic victims of an unpredictable and unpreventable event. The interpretive leap from evidence to final designation characterizes forensic authority: forensic pathologists turn lack of findings into a specific manner of death. From a professional perspective, SIDS is an amazing accomplishment of expert death brokering, as medical examiners' legitimacy depends on medico-legal proof and on a cautious engagement with socially contentious categories such as suicide and homicide." (Page 217)

By designating SIDS as an official cause of death, both medical examiners and SIDS parents were able to legitimize their claims and further establish SIDS as a public health problem.

Though claims-makers were successful in establishing SIDS as a public health problem for medical professionals, starting in the late 1960s crib death parents and researchers wanted to establish rhetoric about sudden infant death claims to help to motivate a higher *public* profile. This discourse would focus not on the individual trauma of SIDS, but on the social magnitude of these sudden infant deaths. The number of infants who died of crib death had always been difficult to estimate, because it was so frequently attributed to other causes. However as a few forensic pathologists began to do studies in cities across the United States in the 1960s, the death rate was estimated at three deaths per thousand live births (Valdes-Dapena 1967). This rate was thought by claims makers to insufficiently emphasize the significance of SIDS, and soon the estimated number of infant deaths per year began to be cited in magazine and newspaper articles—a number that ranged from 10,000 to 25,000 deaths a year. However, by the late 1960s, claims-makers contributed to the escalation of the SIDS rhetoric so that SIDS would sound more significant to all parents of infants. This rhetoric would emphasize the frequency of this problem so that the sense of risk was felt across the population as a whole. SIDS deaths began to be referred to as "the leading cause of death of infants from one month to one year" in the United States—a phrase that is still used to describe SIDS deaths today (Johnson and Hufbauer 1982).

## 1970s: The Legislative Era

For researchers and newly organized parent groups, the start of the 1970s began with hope of federal funding for research. Up to this point, claims-makers had been successful in constructing crib death/SIDS as a public health problem on several fronts: forensic pathologists had used their expertise in post mortem diagnosis to disprove suffocation was a cause of the sudden death of infants; support groups of 'crib death parents' were created and looked for ways to use these scientific studies to remove suspicion by authorities and their own guilt over possible negligence by framing these deaths as a 'mystery' killer that could strike any infant; researchers started to investigate possible causes of crib death; and researchers and parent groups met to agree on an acceptable and universal name and definition for these deaths.

Preventing SIDS deaths from ever occurring is a theme that begins to appear in the media of this decade. Claims-makers, particularly SIDS parent groups, were behind this push for SIDS prevention. Almost a quarter of the articles analyzed talk about reducing the risk of SIDS, or even of preventing it from ever occurring. References to a "welcome step to preventing crib death" (*Consumer Reports* 1973) and "Averting Crib Death" (*Science Digest* 1975) can be interpreted as an action that parents could take, as opposed to just waiting for crib death to occur. Prevention was not said to happen any time in the near future, however. When *Newsweek* in 1973 told readers "How to Stop Crib Death" the solution offered was not a magic pill, but more research. Researchers were still portrayed as working hard in the war against crib death/SIDS—the use of military analogies figures prominently in the discourse during this period of the Vietnam War. With rhetorical references to "battling" and "fighting" and the use of scientific "weapons", the reader is alerted to the seriousness of the scientific efforts.

How to deal with the aftermath of an infant death to crib death/SIDS are also developed as a theme in the media during this period, especially advice on bereavement. During the early 1970s, the topic of how to deal with death had become an issue that entered the zeitgeist, popularized by the publication of Elizabeth Kubler-Ross' bestselling book *On Death and Dying* in 1969. Based on studies of the terminally ill, Kubler-Ross proposed that there were five stages present in coping with death, from denial to acceptance. This model was frequently cited by professionals, and was often used in bereavement work to help people cope with death, and the field of thanatology, the study of dying, death and grief, became established as an inter-disciplinary academic area during the 1970s. SIDS, however, presented a unique challenge to the existing bereavement industry, since these infant deaths were sudden, unexpected and without warning.

SIDS parent groups stepped in to provide these services to their peers. Support was provided from parents who experienced the sudden death of an infant to other parents, and they were able to deal with their unique issue such as how to deal with suspicious family members, remembering the child that died, and dealing with the next pregnancy. The 1973 article "Somebody Help My Baby: Comforting Parents of Crib Death Victims and Fighting the Disease" in *Good Housekeeping* establishes parents as needing this type of counseling. This shift to the portrayal of crib death parents as "survivors" (as noted in a 1976 *Good Housekeeping* article) from the previous perception as potentially suspicious victims is in part a result of the efforts of the national parent groups to recognize SIDS as a legitimate medical entity.

The transformation of SIDS from a suspicious twist of fate to a legitimate medical concern was further solidified in the 1970s. The new definition established at the 1969 international conference became accepted as it was incorporated into "official" codes--by 1975 the National Center for Health Statistics introduced the code for SIDS into the Eighth Revision of the *International Classification of Diseases, Adapted for Use in the United States*. By 1976 investigative protocol for examining SIDS infants was developed by a group of pathologists, toxicologists, and other health professionals convened in New Mexico by the Maternal and Child Health program. The World Health Organization in 1979 recognized SIDS as an official cause of death (National SIDS/Infant Death Resource Center 1994).

### *Taking Claims to the Next Level*

In the early 1970s, The National Foundation for Sudden Infant Death Syndrome and the International Guild for Infant Survival were the two parent support groups that were the most determined to bring the claims of SIDS as a public health issue to the federal level and the accompanying appropriate financial support in two areas: funding for research for the prevention or cure of these infant deaths and for bereavement services and first responder awareness education.  Parent groups tried to urge Congress to recognize the need for this funding on the basis of the social significance of SIDS.

In January of 1972, the National Foundation for SIDS succeeded in persuading Senate subcommittee hearings to be held, led by Senator Walter Mondale.  Testimony was provided by members of the two major SIDS parent groups who talked about their personal experiences with their infants dying and with the ignorance and suspicion they received as a result of the public's misunderstandings about the cause of these deaths (Bergman 1996).  The Secretary for Health and Scientific Affairs at the Department for Health and Education Welfare and the President of the American Association of Pediatrics also testified, and they said that their policy of virtual silence on crib death was to "avoid alarming parents and making them anxious about a fatal disorder for which there was not yet a demonstrated means of prediction or prevention" (Lally 1977).

The reluctance to pursue scientific research on SIDS can be seen as a result of a vicious cycle, as Lally points out in his analysis of the social determinants of the allocation of resources in crib death vs. cancer (1977).  If physicians were reluctant to mention SIDS to parents because of a lack of scientific knowledge to prevent it, they were not helping the case by withholding information about it to the public, which could create popular concern, which could spur political interest, which would allocate the funds for medical research to find out the means of prediction or prevention. These Senate hearings, covered in newspapers like the *New York Times*, were successful in making the public and lawmakers aware of the scope of the issue and alerting them to the need for funding to study the problem further.

By January of 1974 success was theirs in the form of legislation to fund SIDS research on a national level, and the Sudden Infant Death Syndrome Act of 1974 (PL 93-270) was passed by the U.S. Congress. The law assigned responsibility to the National Institute of Child Health and Human Development to conduct SIDS research and the Maternal and Child Health Bureau was delegated the information and counseling component of the legislation. There would be a $6 million 3 year program which would develop public information and professional educational material related to Sudden Infant Death Syndrome and $12 million for direct Federal support for research into the cause of these deaths (*New York Times* 1974). The passage of this law represents a success for the claims-makers involved with establishing SIDS as a public health issue and also represents what Spector and Kitsuse identified as the second stage of the 4 stage natural history model of social problems—recognition of claims by governmental agencies that would make the social problem within an organization routine (Spector and Kitsuse 1977). This phase of SIDS research would occur as a result of this federal funding and would represent its establishment as a significant public health issue, not just a personal tragedy.

### *The apnea "breakthrough"*

With the availability of federal funding for research into the physiological causes of SIDS, new theories were promoted by scientists with research agendas. One of these agendas broke through in the early 1970s and was seen as a promising theory, particularly because it offered the possibility of identifying vulnerable infants and preventing their deaths. The theory was that SIDS was related to a pause in breathing during sleep, known as apnea. The study, titled “Prolonged Apnea and the Sudden Infant Death Syndrome: Clinical and Laboratory Observations” was published in 1972 in *Pediatrics* by Dr. Alfred Steinschneider. The article described five patients with abnormally prolonged periods of apnea, two of whom were siblings who eventually were said to have died of SIDS, and the paper provided support for the theory that prolonged apnea and SIDS are linked and was possibly hereditary. In his analysis of the scientific significance of papers on crib death from 1945-1980, Hufbauer (1986) ranked this apnea study as the field’s most prominent, and a breakthrough in SIDS research. It also left open the possibility for further clinical and physiological investigation (Hufbauer 1986). The apnea hypothesis also *created* biomedical knowledge about SIDS rather than revisit its unknown, mystery status.

The hypothesis stated that infants who experienced prolonged apnea spells were at risk for SIDS, and that their deaths could be prevented if they were wired to apnea monitors, which would alert caregivers that the infant had stopped breathing and would allow for resuscitation. During the mid to late 1970s, the NICHD supported the apnea hypothesis with generous support of research funds in efforts to locate the pathological abnormalities in SIDS victims, and to find the psychological indicators for identifying high risk infants, and to develop home monitors to warn parents of dangerous apnea episodes (Hufbauer 1986). Apnea monitors were prescribed for at risk infants and were used every time they slept. An alarm would sound whenever they stopped breathing, signaling a “near miss”, which was thought to precede death by SIDS.

By 1977, Dr. Steinschneider received a federal grant for $2.4 million to monitor over 4,000 infants born in the University Hospital in Maryland. His study looked to develop a profile of the typical SIDS victim, by monitoring them in the hospital and at home for their feeding habits, breathing and heart rates and crying patterns. The apnea hypothesis was also seen as a technological breakthrough, allowing for a modern machine to intervene in order to prevent SIDS from occurring. Ten percent of Steinschneider’s study participants were sent home with an apnea monitor in order for parents to observe and record their infant’s breathing during sleep. The alarm would sound, warning parents if the monitor determines that the infant has not taken a breath for a period of time, and parents were taught mouth to mouth resuscitation to revive their infants if needed. The reality of what this meant for a parent is highlighted in a statement by a nurse at another hospital that was conducting a similar study: “A parent can be no more that 10 seconds away from the baby 24 hours a day when it is on the monitor. They can’t shower, go to the mailbox, put out the garbage or care for other children unless someone else is around” (*New York Times* 1981). All of this effort was determined necessary according to Steinschneider, “if we’re really crazy lucky, at the end of five or ten years we may know if we’re headed in the right direction” (*Washington Post* 1977). This uncertainty did not stifle the market’s exploitation of the apnea hypothesis. During this period, the electronic baby-monitoring industry that manufactured and sold apnea baby monitors for $2,500 each to hospitals and parents was launched. By 1983, the infant monitor market reached $40 million in sales, and was considered to be a rapidly growing industry that was “good for stockholders” (*New York Times* 1983).

Though apnea research was well supported by the federal government and was seen as a positive direction for the future of SIDS prevention, there were many issues that were later revealed that shook the foundations of the scientific SIDS industry. In their book *The Death of Innocents: A True Story of Murder, Medicine and High Stake Science*, published in 1997, authors Richard Firstman and Jamie Talan uncover the unconventional methods that Steinschneider used to come to his conclusions, and chronicled the tragic misuse of the SIDS diagnosis. In his 1972 study, Steinschneider based his findings on his documentation of five patients with repeated apnea incidents, two of whom were siblings who eventually were said to have died of SIDS. These were the children of Waneta Hoyt, who also had three other children who died suddenly without explanation. At the time, all of these deaths were seen as suspicious, but Steinschneider’s findings legitimized them, and they were retrospectively said to have probably died of SIDS. It was not until 1995, almost 25 years later, Firstman and Talan explain, that Hoyt was convicted of murdering all of her children, including the siblings who were the basis of Steinschneider’s landmark study. The authors also reveal that Steinschneider ignored warnings from nurses that Hoyt may have been responsible for the deaths of her infants, and from other researchers who questioned his data. The book also documents the death of the three Van Der Sluys children in the late 1970s, who all died in their sleep, and who at the time were said to have died of SIDS. This diagnosis was based in part on Steinschneider’s hypothesis that SIDS was hereditary. Ten years after their deaths, after bodies were exhumed, it was revealed that their father murdered the children for insurance money. Though millions of dollars went to the study of the apnea hypothesis, subsequent studies failed to support these findings. The federal government also concluded there was no proof apnea monitors could prevent SIDS (Keens and Ward 1993). The desire for a biomedical explanation for SIDS superseded the truth, and left researchers and parents open to receive the next big thing.

By the late 1980s, the popular apnea theory was being discarded as yet another blind (though initially promising) alley in the history of biomedical SIDS research. Since its discovery, millions of dollars were spent on research and thousands of babies were fitted to apnea monitors, but there were no changes in the rates of SIDS deaths in the United States. According to the physician who was responsible for coming up with the term Sudden Infant Death Syndrome, Bruce Beckwith, “SIDS researchers are in shock from the loss of their favorite pet theory. The situation is verging on the chaotic. We’ve had lots of ideas but few hard facts” (*New York Times* 1989).

This chaotic situation was brought to a Congressional hearing in 1988 that was led by Senator Ernest Hollings, a Democrat from South Carolina, who had recently lost an infant granddaughter to SIDS. Here, a five year plan was laid out and $25 million was allocated for research in the most promising areas for study, which focused on the brain and brain stem. These theories made use of the latest computer imaging technology, and as with the apnea hypothesis, held the promise that the cause of SIDS could be found in the body and that the latest science would finally solve the mystery of these sudden infant deaths. The attention and funding for SIDS had reached a zenith, and what would follow would be a struggle for claims makers to maintain this level of interest and advocacy.

## SIDS as a Public Health Problem: The "After" Period

By the 1980s, SIDS had been established as an issue that was worthy of concern by the federal government representing its ascension to a legitimate social problem. The passage of the Sudden Infant Death Syndrome Act of 1973 authorized the Department of Health and Human Services to award grants and contracts to provide information and counseling to families affected by a SIDS death as well as to collect, analyze, develop, and disseminate information relating to SIDS to health professionals, public safety officials and the general public (National SIDS Resource Center 1994). By 1981, Congress passed the Maternal and Child Health Services Block Grant Act, which established federal-state partnerships for services that would improve the health of all mothers and children in the United States. State agencies received federal money to provide SIDS programs that would focus on providing "SIDS information and counseling to SIDS parents and families at the local level" (National SIDS Resource Center 1994:27). During this period in the 1980s, in addition to conducting information sessions, many state SIDS programs produced campaign materials to distribute to its target audience: parents, childcare providers and first responders, including police officers, EMTs, emergency room physicians, and coroners/medical examiners. These materials provide an insight into how SIDS was presented after it became established as a public health problem and how the interested claims-makers wished for it to be perceived.

### *Early SIDS pamphlets and their messages*

In my analysis of a sample of ten of these materials created from 1983 to 1994, there are several clear messages that are conveyed about SIDS and the official attitude towards it. This was a purposive sample of pamphlets that I was able to collect from the archives of the Association of SIDS and Infant Mortality Programs. My analysis focused on two questions: 1) What were the agencies that produced them offering to their audience, and 2) What do they say about SIDS? Though these materials came from a variety of agencies from different states and are meant for different audiences (See Table 3), there are consistent themes that resonate across the material.

| Pamphlet title | Agency | Date |
|---|---|---|
| "Sudden Infant Death Syndrome: What Every New Parent and Parents-To-Be Should Know" | Washington State Chapter, National SIDS Foundation | 1983 |
| "Sudden Infant Death Syndrome: What Childcare Providers Should Know" | Washington State Chapter, National SIDS Foundation | 1984 |
| "Sudden Infant Death Syndrome: What Childcare Providers and Other Caregivers Should Know" | New York State Center for Sudden Infant Death | 1987 |
| "Sudden Infant Death Syndrome: What Every Young Adult Should Know" | North Central Illinois SIDS Chapter, National SIDS Foundation | N/A |
| "Sudden Infant Death Syndrome: What Every Child Care Provider Should Know" | SIDS Resources, Inc., Jefferson City, MO | N/A |
| SIDS | Massachusetts Center for Sudden Infant Death Syndrome | N/A |
| Facts About Sudden Infant Death Syndrome | SIDS Resources Inc., St. Louis, MO | N/A |
| "Sudden Infant Death Syndrome: A Guide for Coroners" | The SIDS Northwest Regional Center, Seattle, WA | 1990 |
| Services Provided by the Program | Springfield (MA) Infant Death Support Program | 1992 |
| "Sudden Infant Death Syndrome: Trying to Understand the Mystery | US Department of Health and Human Services | 1994 |

**Table 3: SIDS Information pamphlets 1983-1994**

Overall, these materials appear to be offering one thing in common: to inform and educate various audiences about Sudden Infant Death Syndrome. The nature of this education includes information about the 'facts' about SIDS, the content of which is uniform across the sample. These facts are often presented as a way to dispel common, though incorrect beliefs, as one pamphlet puts it, "knowing the facts about SIDS can ease the feelings of frustration and guilt. There is hope that someday the cause and prevention will be found. In the meantime, families who lose an infant to SIDS must be treated with both knowledge and compassion" (SIDS Resources, Inc., no date). It is no surprise that several of the pamphlets were produced in conjunction with the 'crib death parent groups' that were instrumental in getting federal SIDS funding and recognition. Indeed, many of the messages in the pamphlets reflect the same agendas that these groups were advocating for years earlier: that the cause of SIDS is not due to suffocation, choking, or child abuse (which were previously indicated as possible causes), that SIDS is not contagious or hereditary, that SIDS occurs during sleep in normal, healthy babies, that death occurs rapidly and without warning, that SIDS occurs in babies up to one year of age, that SIDS can strike a family of any race, religion, ethnic or economic group, and that SIDS cannot be predicted or prevented. This information is meant to refute notions about SIDS that the parent or caregiver were in any way to blame for the death of the infant. The messages frame SIDS as a serious health issue that "remains as one of the last great unsolved childhood catastrophes" (SIDS Resources Inc., no date), a tragedy that parents and caregivers need to be aware of from an official source.

An analysis of the data from the interviews conducted with SIDS professionals also corroborates the bigger, moral value of these interventions:

> JA: It was mostly about legitimizing SIDS, making sure that people knew it wasn't the parent's fault, making sure that parents were understood, that SIDS was understood, and that they got humane care
>
> DH: A lot of the issues that were around at that time were issues left over from families being accused of having killed their baby. A lot of that misinformation is still around about SIDS, so a lot of the intervening and education with the hospitals and police and the people that work there, so that they wouldn't report the case to ACS, child services.
>
> MC: It was a big part of the counseling, [that] this is a natural cause…you were on firm footing to be able to say, you know, this just happened to you and we don't know why and you had nothing to do with it.

Several of the pamphlets also provide bereavement services to the parents of infants who die of SIDS in addition to general education. They provide 24 hour phone lines and availability for consultation to families and counseling through home visits and parent group meetings. They also provide education and training to those in the community who may interact with a parent of an infant who died of SIDS in order to sensitize them to the possible reactions that they may encounter, and to emphasize that these parents should not be seen as being responsible for their child's death. By convincing police officers, emergency medical technicians, and ER nurses and doctors that SIDS is a legitimate cause of death that has nothing to do with the parents, but is an unknown disease that the baby had, these pamphlets attempt to reverse the way parents had been treated in the past.

Providing bereavement services to the families of infants who died was the other main component of the federal funded state programs. This counseling was an off-shoot of the support group work that the SIDS parent groups had developed in the past, but now this outreach was in the hands of professionals, not parents. The shift of power away from parent groups, especially after their success with advocating for federal legislation was perceived as an affront:

> MC: parents really expected some of the programs to be, for funding to be awarded to parents' groups, but realistically they went to state health departments, to universities, to other institutions, and there was the beginning of a little bit of mistrust among parents because…it was like I've had the loss, I know what's going on, I can really, so there were shades of that AA kind of sponsorship thing that really drifted into the self-help movement, which through some absolute merit in that, you know, talking to people who have had a similar experience. But I think there was a little bit of annoyance that a lot of that money went to professionals.

Finally, these materials provide a unified message about SIDS: that no one is to blame for a SIDS death. This is true for the different audiences that are addressed: licensed child care providers, parents, babysitters, and coroners. This message is repeated throughout the materials, as is its corollary: that there is nothing that you can do to prevent SIDS from happening to a baby. The message is clear: there are no ways to prevent or to reduce the risk of SIDS, it can happen to anyone. Often mention was made of the unsuccessful scientific research that has been conducted to discover the causes of SIDS, and the hope that a cause will be found. The materials state that the only way to combat it is to let people know that it is real and that it exists, and that "the strongest weapons in waging the battle against ignorance and confusing or incorrect reports about SIDS are education and accurate, up to date information" (National SIDS Resource Center 1994).

The presentation of SIDS as an unpredictable and unpreventable disease that can strike any infant in these educational materials and interviews represents a shift in the locus of responsibility. Before SIDS was declared a public health problem, individuals, particularly mothers, were seen as being in some way responsible for their infants either through overlaying, excessive bedclothes, or lack of proper surveillance. With its establishment as a legitimate health issue, the burden was shifted to larger entities including the federal and state governments and the scientific and medical communities. SIDS was presented as an awful, unknown killer that left behind only victims. The villain was the unknown nature of SIDS itself, and no parent could be accused of doing the wrong thing because there was nothing that they could have done to prevent it from happening. Education and information were the only weapons that parents had, with the knowledge that there were caring people out there who would be sympathetic and supportive if SIDS crossed your baby's crib. The educational materials and professional outreach sent a sense of comfort home and discursively connected every parent together through the message that SIDS could happen to anyone, and that there is nothing that can be done to prevent it.

## Sleep Position Research and Campaigns: Maybe Something *Could* Be Done

The late 1980s saw two significant moments that established the period after it became a public health problem. The first was a change that occurred in 1989, when the National Institute of Child Health and Human Development (NICHD) amended the definition of SIDS to read "the sudden death of an infant under one year of age which remains unexplained after a thorough case investigation, including performance of a complete autopsy, *examination of the death scene*, and review of the clinical history" (emphasis added). After decades of claims-making and fights to get the sudden death of infants recognized as a public health issue, it was still seen as a diagnosis of exclusion, a mystery, and an unsatisfying example of the promise and peril of scientific discovery. Some felt that including the investigation of the death scene as part of the official definition for SIDS opened up private parenting practices, and gave opportunities for those who decided the official cause of death to make judgments that would influence the SIDS diagnosis. A thirty year veteran SIDS professional articulates this concern:

> MC: …there's a different level of visibility…where were these parents when that baby was dying, you know?...So it became, while people had always been saying it, so it was a mixture of events that I think led to this examining the scene, and then it gave people who were uneasy about certain diagnoses a forum to say, yeah, I think this scene doesn't look right to me.

This ambiguity over the diagnosis of SIDS in the late 1980s maintained the tendency to blame parents for the sudden death of their infants. So even though there had been success with the establishment of SIDS as a public health problem, there were still occasions for claims makers to be vigilant with maintaining this status. This conflict became evident as more and more evidence was indicating that sleep position contributed to the risk of SIDS, and that this simple, non technical change could have a significant impact on the death rates.

The second significant moment appeared by 1989, when a flurry of articles began to appear in newspapers about yet another scientific study that held promise for unraveling the mystery of SIDS. These reports were different from those that appeared in the previous three decades in two ways: 1) They were studies done outside of the United States, in Europe, Hong Kong, and Australia, and 2) Their findings were of a distinctly non-technical nature. With newspaper headlines such as "Sleep Position Linked to Crib Deaths" (*The Toronto Star* 1989), the results of two studies published in the *British Medical Journal* implicated the prone (stomach) sleeping position as being associated with a greater risk of SIDS. One study explained that the very low rate of SIDS in Hong Kong was due to the preference of Chinese parents to put babies to sleep in the supine position (on their backs), and a study in the Netherlands also found that SIDS is five times higher in infants that slept in the prone position. When these studies were published, there reasons *why* sleep position was shown to be so effective was not immediately known, further heightening the mysterious nature of SIDS. Indeed, a number of biological mechanisms were suggested for the correlation between sleep position and SIDS, including environmental temperature, risks of suffocation on soft bedding in the prone position, and an increase in arousal reflexes with babies placed in the supine position. After all of the biomedical research into the causes of sudden infant deaths, the millions of dollars of funding, and the abject failure of the apnea monitors, could something as simple and as un-technical as infant sleep position solve the mystery of SIDS?

Indeed, studies from the Netherlands, Australia, England, and other countries implicated the prone sleeping position as being associated with a greater risk of SIDS (DeJonge et al 1989, McGlashan 1989, Flemming et al. 1990, as cited in Guntheroth 1995). Public health campaigns that addressed the issue of supine sleeping and SIDS risk reduction were carried out in the United Kingdom, Holland, and New Zealand and five other countries. These campaigns were attributed with significantly reducing the number of SIDS deaths (Mitchell et al. 1991, Engelberts et al. 1991, Wigfield et al. 1992, as cited in Guntheroth 1995).

Actually, it appears that infant sleep position had been indicated as a risk factor for SIDS even further back than the above studies indicate[9]. A recent review of the

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[9] Looking back at the coverage of crib death in popular magazines over a forty year period, I was struck that there had been an early mention of infant's sleep position being linked to crib death/SIDS. This suggestion did not appear in a medical journal, but in the February 1948 issue of *Women's Home Companion* in the article "Death in the Bassinet". This article had been mentioned earlier in this chapter as

literature that examined associations between infant sleeping positions and SIDS, and compared findings with published recommendations in child care books. The analysis found that as early as 1970 there were studies that found that there was a statistically significant increased risk of SIDS for the prone position compared with the supine, and that sleeping in the prone position was recommended in books between 1943 and 1988 based on extrapolation from untested theory. The study concluded that advice to put infants to sleep on the front for nearly half a century was contrary to evidence available from 1970 and that a systematic review of preventable risk factors for SIDS from 1970 would have led to earlier recognition of the risks of sleeping on the front and might have prevented over 10,000 infant deaths in the UK and at least 50,000 in Europe, the US and Australia (Gilbert, Salanti, Harden, et al. 2005).

However, in the late 1980s, these findings did not seem to stir much activity among American SIDS researchers, even though these studies showed a correlation with sleep position and SIDS deaths, a feat that no previous SIDS theory of the past 30 years was able to do. The reason for this relative lack of interest is connected to the larger issues established by the claims-makers who were successful in establishing crib death/SIDS as an official diagnosis and public health problem. American SIDS researchers were initially skeptical of the validity and applicability of a health campaign for something as simple as back sleeping to reduce the risk of SIDS in the United States. Also the decision to recommend the supine position was in conflict with previous medical advice. For decades, pediatricians advised parents to put infants to sleep on their

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the first article that told a father's story of trying to investigate the medical cause of his infant's death. This article is credited with challenging the hypothesis that these infants suffocated in their beds. However, the article also mentions that the author was convinced that "his infant son had suffocated because, on the advice of a pediatrician, he [the infant] had been allowed to sleep on this stomach" (*Women's Home* stomachs. Parents were taught to avoid putting their children to sleep on their backs for fear that their children might choke on their vomit. Even SIDS professionals in the field had their doubts that a change in sleep position would be successful:

> JA: So but there was work going on in other countries, and recognition that infant sleep position seems to have an impact and when it was first heard, ASIP [Association of Sudden Infant Death Professionals], and at our conferences, everyone was a bit skeptical that how could something so simplistic as position change of an infant during sleep really reduce the SIDS rate, because we viewed it as so multifaceted…how could a simple procedure like turning your baby over, when that had never been part of infant care, it almost seemed unbelievable.

Despite these concerns, the advisory group of American Academy of Pediatrics (AAP) felt that they could not ignore the dramatic reduction in SIDS deaths in the countries that promoted back sleeping. On April 15, 1992 the AAP issued a statement recommending that "normal infants, when being put down for sleep, be positioned on their side or back" (Pediatrics, 1992). By 1994, this recommendation was expanded to a national public health campaign. The U.S. Public Health Service, in conjunction with SIDS Alliance, the Association of SIDS and Infant Mortality Programs, and the American Academy of Pediatrics launched the *Back to Sleep* media campaign[10].

The *Back to Sleep* campaign was a watershed moment on many levels. For parents in general, it represented a way to regain control over the unknown and frightening entity that was SIDS, for researchers it was a positive direction to focus future research on, and for SIDS parents it was another source of guilt over something that they possibly could have done to save their baby. The *Back to Sleep* campaign may have been a contentious issue for the parent advocacy groups and researchers, but for SIDS

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*Companion* 1947:114).

[10] The *Back To Sleep* media campaign also recommends avoiding soft bedding surfaces, tobacco smoke exposure, bed sharing, and overheating or over wrapping.

educators who had been in the field in the days when all they could provide parents with were general statements that there was nothing to be done to prevent SIDS and bereavement counseling, this was significant. Now they could present parents and caregivers with concrete advice and specific things to do. The following statement from SIDS professionals encapsulates their feelings:

> DH: And it was exciting, and I mean we wanted there to be some way to help parents, we didn’t want to have to say we don’t know, we wanted to be able to say something new to contribute to help these parents, you know, you want to be able to say there is something you can do.

*Back to Sleep* moved SIDS into the mainstream and into the cannon of literature on parenting advice. A more in depth discussion of how the *Back to Sleep* campaign used media to communicate its messages, how they were created, and how these messages have changed will be the focus of the next chapter.

## Conclusion

Claims makers were successful in moving crib death/SIDS from a personal, individual issue to a public health problem. SIDS officially shifted from being the cause of an accident or carelessness or murder to a scientifically investigated medical problem. The desire on the part of parents and medical researchers to define and diagnose the sudden death of infants has reflected changing standards of medical knowledge, and funding for SIDS research followed the creation of it as a social problem. SIDS was constructed as a mystery that science was working on to solve, which removed the responsibility from mothers to the state. This shift allowed for the first campaign materials to come out of this that supported the ‘no blame’ perspective. It also succeeded in the successful shift of SIDS as a public health problem and represented success for the claims makers in typifying these deaths. Finally, it served to medicalize infant deaths from sin to science. However, this victory was not easily relinquished once the issue of sleep position was found to significantly reduce the risk of SIDS with the development of the *Back to Sleep* campaign. After all of the effort to have SIDS be seen as a public health issue, not a personal one, and an issue that you could do nothing to prevent, the AAP recommendation and *Back to Sleep* represented a shift back to individual parental responsibility.

# CHAPTER 3

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> “Health officials want to change the way American babies sleep in the hope of saving thousands of them from sudden infant death syndrome. At least 2,000 infants' lives could be saved each year in this country if babies are always put to sleep on their backs or sides and not on their stomachs…That is the message the federal government and some private agencies hope to relay to parents, baby sitters and day-care workers in a national campaign to change the way baby sleeps…”
>
> *New York Times*, June 22, 1994

In June 1994, the U.S. Public Health Service, in conjunction with SIDS Alliance, the Association of SIDS and Infant Mortality Programs, and the American Academy of Pediatrics launched the *Back to Sleep* media campaign. This national public health campaign employed newspapers, television, and pamphlets to disseminate the recommendation that infants be placed on their backs or sides, not their stomachs when they are put down to sleep to reduce the risk of SIDS. Even though the *Back to Sleep* campaign represented a major turning point in the construction of SIDS as a significant public health problem, the years leading up to its implementation were fraught with conflict. As discussed in the previous chapter, several different American SIDS claims-makers were initially skeptical of the validity and applicability of a campaign to promote something as simple as back sleeping to reduce the risk of SIDS, even though campaigns were found to be successful in other countries. These claims makers--SIDS parent groups, SIDS professionals, the medical community (especially pediatricians) and the federal government --reacted differently to the news that a change in sleep position could reduce the risk of SIDS, and each had different ideas of how to proceed with informing the general public about it. This conflict was often played out in the media, with claims-makers using various outlets to negotiate for their particular perspective. From the time the reports of the first international studies found that there was a correlation between infant sleep position and SIDS in the early 1990s, the claims-makers sought to hold onto the ground that they had established over the past three decades: that there was nothing that could be done about SIDS, that no one was to blame for an infant's death, and that the medical community was doing all that it could to solve the mystery. Now there was a dilemma--something *could* possibly be done to prevent SIDS from occurring and something as non-technological, behaviorally based, and simple as changing sleep position.

This chapter will look at how scientific research about infant sleep position and its relation to reducing the risk of Sudden Infant Death Syndrome became established as a public health recommendation through the use of different forms of media and professional discourse. The concept of discourse in this chapter elucidates Foucauldian theories of how perspectives of biomedical risk are constructed through strategies, practices, and institutions, and I argue that it was through the use of various media that a new discourse of SIDS risk was brought into being via the *Back to Sleep* campaign. In the critical public health literature, it has been argued that risk strategies and discourses are means of ordering the social and material worlds through methods of rationalization and calculation in attempts to render disorder and uncertainty more controllable (Lupton 1995). In the case of the *Back to Sleep* campaign, this rationalization was accomplished through the media. Specifically, the media helped to re-establish the SIDS story from an unknown mystery that no one could do anything about to a public health intervention that offered specific risk reduction techniques.

Seale (2002) explains how the theories of how narratives used in health media are based on familiar storytelling concepts, characters, and plots. This narrative convention created by media producers rely on such stock devices as the hero and the villain, the struggle and the victory. Studies have shown that audiences are also aware of devices and often ‘fill in the gaps’ that are not shown in order to make sense of the story (Bell 1991, Fowler 1991, Kitzinger 2000).

> “The life of the media text depends on pre-existing frames, templates, stereotypes or common constructions between producers and audiences, which involve a process of active construction of meaning by audiences, though usually within the confines of dominant scripts. The prior knowledge of audiences bestows a degree of order and structure on media products that otherwise may appear fragmentary.” (Seale 2002:31)

Health communication campaigns then, as media products, also rely on these ‘standard story forms’, and I believe that they are often necessary components required for public health campaign construction. In the case of the *Back to Sleep* campaign, there was a need to create new claims around SIDS as a public health problem. This was particularly necessary in order to reconcile the issues that the claims makers had with this new knowledge about risk reduction as well as to maintain connections with their intended audiences. In this chapter I argue that after a period of deliberation, the *Back to Sleep* public health campaign claims-makers decided to target certain infant care behaviors by establishing new claims in various media so that the mystery of infants dying in their sleep could appear to be partially solved. How these risk-related discourses and strategies operated, negotiated and were taken up is the overall focus of this chapter.

I will first present the different positions established by the various SIDS claims-makers that responded to the initial AAP recommendation that infants be put to sleep on their backs or sides to reduce the risk of SIDS, and how these claims-makers attempted to negotiate the concept of SIDS risk reduction messages from 1992 to 1994. This analysis will use media reports as well as interview data with the campaign's creators to show how the *Back to Sleep* messages were created and how issues of morality and values were infused within them. Then I will trace how the series of arguments and assumptions that the different claims-makers held were able to come together to create the *Back to Sleep* campaign by establishing new claims. First I will look at how crib death/SIDS was covered in magazine articles from 1948 to 1989 and what the major themes of these articles were. Next I will specifically analyze how media coverage from 1992-1994 of the recognition of prone position as a major risk factor for SIDS continued these claims and established the basis for an 'advice shift' in infant sleep practices. Finally the similarities and the differences in the *Back to Sleep* messages themselves will be analyzed using a sample of campaign brochures (which are a form of media) that were produced by the four claims-makers.

## Announcing a policy change

### *Pediatricians take a position*

By the early 1990s there were indications that infant sleep position was a possible risk factor for SIDS. The results of a Dutch study was published in 1990 that showed a 40% drop in the SIDS rate after their public campaign against the prone sleeping position (as cited in Gunteroth 1995). In 1991, the British Department of Health and the government of New Zealand started nation-wide media campaigns against the use of the prone position for infants. Within one year, they were able to show a significant decrease in the use of the prone position and the incidence of SIDS (Gunteroth 1995). The reaction in the United States to these studies was surprisingly tepid, as discussed in the previous chapter, there were few reports of these findings in major American newspapers or magazines. The author of an article from an American newspaper in 1992 wondered why this was so, and asked one of the researchers who developed the successful back sleeping campaign in England why there was a lack of interest in their findings in the U.S.: "The British researcher said that the studies received wide publicity in Europe but little in the United States, where 'there was enormous resistance to the idea, especially from the medical profession'" (St. Louis Post Dispatch 1992). Why would there be an "enormous resistance" to the idea of changing infant sleep position from the medical community, a group that had presented themselves over the past 30 years as concerned about and dedicated towards finding a way to stop SIDS deaths? How could there not be an immediate reaction to published data that found that infants who slept on their backs had a significantly lower risk of dying of SIDS? Why did they not try to convince the public to put babies to sleep on their backs, which had significantly decreased the rates of SIDS in three different countries, particularly when no other intervention had been shown to contribute to any decrease in the past? In the media accounts at the time, it was suggested that the quality of the studies that were conducted and issues of their applicability in a country as large and diverse as the United States were to blame, I have found that this resistance from the medical community had to do with issues of power and jurisdiction.

Consider that pathology was the medical specialty that was involved with the construction of SIDS as a public health problem over the past few decades, and that pathologists were directly involved with SIDS moving from the realm of accident to that of a diagnosed entity. The power and "forensic authority" that they had established over the years was the ability to diagnose an infant death as SIDS, even without finding a definitive cause after conducting an autopsy. Though over the past 30 years other medical researchers were involved with trying to find the cause of SIDS in order to eventually find its cure, and after biological possibilities from apnea to viruses to milk allergies were published, there were many directions but no answers.

Pediatricians for the most part were strangely silent during the period that SIDS was being established as a public health problem. Though the mission of the profession (which was officially established by the creation by 60 physicians of the American Academy of Pediatrics in 1930) is stated to "obtain optimal physical, mental, and social health and well-being for all infants, children, adolescents, and young adults" (AAP website 2006), there was little that was done by pediatricians to address the problem of SIDS. Indeed, historically pediatricians were left without explanations for parents whose babies died of crib death/SIDS. Also, part of a pediatrician's alienation has to do with the nature of SIDS—it is not identified until after death occurs, placing it officially under the jurisdiction of pathologists. Finally, since claims-makers established SIDS as something that no one could do anything to prevent, pediatricians were left without any concrete advice to offer to parents to stop it from occurring.

Though the work of individual pediatricians is to treat their patients, advocacy and the establishment of proper policies and protocol are a major function of the American Academy of Pediatrics. The following description from the AAP website establishes this larger purpose:

> When it comes to keeping children healthy and safe, some of the greatest advocates are pediatricians. The American Academy of Pediatrics (AAP) and its members work everyday at the local level in hospitals, offices, and clinics and in state and federal government to protect the well being of children. Success is achieved through the efforts of dedicated staff, members, and chapters working with state and federal legislators and regulators. Lawmakers are responsible for creating the guidelines and systems under which America's children receive health care, but lawmakers are not necessarily experts in children's health. They welcome, and often seek out, advice from experts such as the AAP.(www.AAP.org)

One way that pediatrician's express their positions beyond working with legislators are to publish official policies. These Policy Statements are created by AAP committees and sections, who analyze research to come up with guidelines for how its members and the public are to care for children. This was the case with the new studies indicating sleep position as a risk factor for SIDS. Pediatricians, who had not made their voices heard up to this point, now took the opportunity to act by making a policy statement. In late 1991 the American Academy of Pediatrics brought together a task force consisting of 3 physicians to decide what the policy would be on infant sleep position and SIDS in light of the new research that had been published on the correlation between sleep position and SIDS. One of the members of the task force, Dr. Brooks stated in a newspaper interview that in coming up with a policy, they "went through a lot of deliberation…we didn't want to panic parents. This [sleep position and SIDS] is purely a statistical relationship - it doesn't mean that prone causes SIDS." (Boston Globe 1992). However, after deliberation and a review of the other studies, the task force decided to make a statement about how to reduce the risk of SIDS

On April 15, 1992 the American Academy of Pediatrics (AAP) issued a press release and conducted a press conference where they released their new policy on sleep position and SIDS to the media. During the press conference John Kattwinkel, another member of the task force, conceded that this policy was not easily reached and stated that "[p]ediatrics is an art not science." (NBC Nightly News 1992). At the press conference, Dr. Kattwinkel noted that the evidence for their recommendation is based on studies carried out in other countries where some conditions may be different (Boston Globe 1992). In a later interview, Dr. Brooks said that "some people felt they [the AAP] went too far with the recommendation while others felt they didn't go far enough" (Today Show 1993). Indeed, this new policy was not universally approved of by its members, many of whom felt that the prone position was the safest position for infants to sleep.

Although the AAP had never taken a formal position previously on the preferred sleeping position for infants, many pediatricians have for years advised parents to put infants to sleep on their stomachs to minimize the possibility that they would inhale vomit. Traditionally, when mothers and their infants share a sleep surface and they are nursing, the back position is the natural way for infants to fall asleep. Indeed, this practice has been cited as a reason why SIDS has never been a significant problem in cultures where bed sharing and nursing are the norms (McKenna 1996). However in Western cultures during the 20th century, two shifts in infant care practices--the increase of formula feeding and providing an infant with a separate sleep surface or room of their own--supported a change in the position infants were now "put" to sleep, as opposed to how they naturally fell asleep in the past. A meta-analysis of the recommendations for infant sleep position made in infant care texts found that from 1940 to the mid 1950s, child care texts favored the back or side positions and only one, in 1943, recommended the front position. However, from 1954 until 1988, a substantial proportion of texts consistently favored front sleeping (Gilbert, Salanti, Harden and See 2005). The sudden shift in favor of the prone position is best illustrated by 'Baby and Child Care' by Dr. Benjamin Spock, who recommended the supine position in his 1955 edition, and then switched to the front position in 1956. In his 1958 edition, he argued 'If he vomits, he's more likely to choke on the vomitus. Also, he tends to keep his head turned to the same side—usually toward the center of the room. This may flatten the side of his head. I think it's preferable to accustom babies to sleeping on their stomachs from the start, if they're willing.' (Spock 1958). In the 1960's pediatricians began recommending to parents that infants be placed face down for sleeping. Indeed, most pediatricians recommended that their patients sleep in the prone position, and by 1992, over 75% of infants slept this way (NICHD 2001). The prevailing medical explanation for the change is that around that time, doctors noted that premature babies seemed to breathe more easily when placed face down, so pediatricians in many countries extrapolated from those findings to advise the same for healthy full-term babies. However, there have never been any published studies that support this notion of babies in the supine position were more at risk of choking on their vomit. Indeed, when the AAP Task Force investigated these claims, they found that there were no studies "proving, or even strongly suggesting, that sleeping on the side or back is harmful to normal infants", while there were many suggesting a linkage between SIDS and the prone position (*Saint Louis Post Dispatch* 1992).

By June of 1992, the AAP released its full report in their journal *Pediatrics* that cited previously unpublished data on infants in the United States and increased risk for the prone sleep position. Not all pediatricians agreed with the official recommendation, and editorials and commentaries appeared in other journals that argued with the findings of these studies and the effectiveness of interventions and campaigns against the prone sleep position, and whether the AAP should have taken a stance on the subject (Guntheroth 1995). The theme of these critiques were that if medicine did not understand the mechanism of how sleep position acted as a risk factor for SIDS, then it should not be implemented. Despite these assessments, the recommendation was made as an official policy of the American Academy of Pediatrics. This established their authority as medical professionals and now it was up to the other claims-makers in the SIDS community to respond.

### *The SIDS Alliance reaction*

The SIDS Alliance was a national organization that focused on the support of SIDS families, education and research that was the latest incarnation of the National SIDS Foundation, an original parent advocacy group from the 1960s. The SIDS Alliance was established in 1987 to unite parents and friends of SIDS victims with medical, business and civic groups and one of their goals is to "improve community understanding and elevate Sudden Infant Death Syndrome to the level of societal concern appropriate to one of our nation's major causes of infant mortality." (SIDS Alliance 2000). When the AAP recommendation was released in 1992, it was vital for the SIDS Alliance, as the only major parent group still involved with advocacy for SIDS parents, to maintain the positions that they had established over the past three decades. This included protecting the parents of infants who died of SIDS from feelings of guilt and blame for their child's death. As one of the original claims-makers, the SIDS Alliance was in a delicate position: how to accept new evidence that might undermine their established discourse of "no one is to blame" for SIDS, and that "there is nothing that could be done to prevent SIDS" and yet respond to this breakthrough in order to maintain the level of concern that SIDS was a significant public health problem.

Parent groups like the SIDS Alliance felt that sleep position recommendations put the focus back on the individual parents for the responsibility for their infant's death. This represented a possible step back from the gains that were made in legitimizing SIDS as an unknown cause of death that could happen to anybody. The resistance by these groups is summarized by a professional who works for one of the major SIDS advocacy organizations:

> …[T]he issue in the U.S. was that what you're doing is increasing the guilt of a parent by telling them that they could have done something differently, and their baby died because they put their baby to sleep in the wrong position…They [the parents] were already blaming themselves. Now if you tell them that they could have done something differently, what does that do? (WCJ)

After taking these factors into consideration the SIDS Alliance issued a statement in one week after the AAP press release in April 1992 that appeared to counter their Policy by stating "American families need answers, not just interventions" and demanded studies about sleep position and SIDS be funded on American children (as cited in Gunteroth 1995). This position appeared to represent the interests of bereaved parents at the expense of living infants and their parents.

### *NICHD reaction*

The branch of the federal government that was the center for SIDS research and funding, the National Institute of Child Health and Human Development (NICHD), which is part of the National Institutes of Health (NIH), were also skeptical of the AAP recommendation. Dr. Marian Willinger, the head of the SIDS program at the NICHD responded the day after it was released, and as a guest on the Today Show on NBC she expressed disagreement with the AAP announcement. She stated that the "The NIH has been interested in sleep position in SIDS risk; but the statistical association in studies from other countries may not be applicable." She added that other countries have higher SIDS rates and that changing the sleeping position may or may not help. Willinger stated the AAP had a very difficult decision to make and that the United States needed to watch other countries for adverse effects before making blanket statements (Today Show 1992).

The official position of the NICHD was that they need to have a proper "research base" before they can issue statements that can effect the United States population. The NICHD felt that the research findings from other countries may not apply to the US population and said that more studies were needed. This position is articulated by an employee of the NICHD:

> [I]n '92 when AAP nationally released their policy, their recommendation about babies sleeping on their backs or sides. Now, the Institute here was just a little reluctant to have a full blown campaign. They wanted to make sure there was nothing different between those babies that are in New Zealand and Great Britain, and the United States, because the United States was supposed to be the big melting pot, so there might have been some difference. (AF)

It is interesting to note that though the population of the United States is among the world's most heterogeneous, that there was a significant scientific feeling that we are biologically unique from the rest of the world, and that the results of studies of infants from other countries would not apply to infants here. By relying on such a scientifically shaky and culturally chauvinistic position, the United States government seemed to be stalling for time before making a definitive statement about SIDS risk reduction. The NICHD's insistence on having sufficient evidence before they could make a statement about sleep position and SIDS also appeared to be the result of the federal government not wanting to make a mistake by making a recommendation that did not have the proper (according to their standards) scientific weight behind it. This decision was certainly safer for the organization, and reflected their values and norms. The decision to 'wait and see' about the relationship between sleep position and SIDS would take the burden off of the government to prove if it would work, and keep them blameless if it did not.

### *ASIP reaction*

The professional organization for SIDS professionals, Association of SIDS and Infant Mortality Programs (ASIP), had a different take when the AAP recommendation came out. They were concerned, like the SIDS Alliance, about not alienating the families of infants who died of SIDS by telling them that there was something that they could have done that might have been able to prevent the death from occurring. Since these professionals dealt with these parents on a one to one basis, they had to interpret the new recommendation in a very sensitive manner, and had to work to negotiate the information that came from the AAP. One prominent ASIP member who was working at the time of the AAP announcement recounts the delicate nature of the new health messages:

> [W]hen you have grieving families whose babies may have died [sleeping] on their stomachs, how do we talk to them in such a way that it does not compound their grief? You know, you don't say, "Well, if that baby had been on its back that baby would be alive today", and that's a knife in their heart. (MC)

The reaction from the members of ASIP to the AAP recommendation were also skeptical in that they wondered how, after all of these years of being told that SIDS was a complex syndrome that involved many possible mechanisms, could something as simple as changing the position a baby slept in have such a huge effect? The members of ASIP also straddled the line between advocates and professionals who kept on top of the latest scientific research in order to communicate it to their clients. Though in the past they primarily provided bereavement counseling and raising the awareness of SIDS among first responders like Emergency Medical Technicians, emergency room doctors and nurses, and police officers, they were intrigued by the possibility that there might be some good news to now deliver. ASIP's response to the AAP recommendation also tended to straddle the line between acceptance of a legitimate breakthrough to reduce the risk of SIDS and reluctance to undo all of the work that had been done with removing parental blame for a SIDS death.

Each of the claims makers had a particular perspective and way of interpreting the AAP recommendation and incorporating it into how they addressed the issue of SIDS. However, to reach some kind of consensus and to let the public know that there was something that could be done about SIDS would require accommodation. What was needed was to bring all of the players together in some way in order to advance this new public health message.

## Negotiating the *Back to Sleep* Message

A public health campaign to reduce the risk of SIDS in the Untied States may have appeared to be the next logical step in light of their success in other countries around the world and the recommendation of the American Academy of Pediatrics to change infant sleep position. However, there were several barriers in place that had less to do with whether or not it would work, but who would say it and in what way. The tension was also around how these recommendations would be presented: as SIDS prevention methods or as ways to reduce the risk of SIDS? A lot of the early language uses the phrase "prevention", especially from the federal government. This was a particularly prickly subject for the professionals working with bereaved parents. Their interpretation was that the supine position *reduced the risk* of SIDS, but could not be used as an assurance that it would *prevent* SIDS from ever occurring. Ultimately though, SIDS professionals wanted to have fewer grieving families to counsel, and were able to look upon the AAP recommendations as a piece of "good news" to finally talk about.

In January 1994, a meeting was convened by Marion Willinger and the NICHD to review all of the data from the United States and six other countries over the effectiveness of campaigns to avoid the prone position. By May of 1994, the journal *Pediatrics* reported that "the overwhelming opinion of the assembled experts was that the evidence justified greater effort to reach parents with the American Academy of Pediatrics' recommendation…" (Willinger et al 1994 as cited in Guntheroth 1995). Also involved in this 'meeting of the minds' were ASIP and the SIDS Alliance. The decision by the NICHD to bring together these different claims-makers in 1994 represented a way to present a united front and to show that something was being done about SIDS on a large scale. By 1994, the campaign was launched, which cited new research. According to a SIDS researcher at NICHD:

> So in the two years between the [AAP] statements coming out to the campaign being launched, there were more research studies done to make sure there were not differences, and there were no differences. There really was a reduction in SIDS with babies on their backs or sides, so that's when the campaign was launched. Actually got it through fairly quickly once they learned that this was definitely something we needed to do. So the campaign logo, everything was

> done really quickly just to launch this campaign in 1994 because they felt it was just really important information that parents needed because a lot of babies were sleeping on their stomachs at that time. (AF)

Collaborations with other claims-makers were an important step in agreeing on the messages of the *Back to Sleep* campaign. Though parent groups challenged *Back to Sleep* on ideological levels, and the government was not convinced of the scientific findings were robust enough to apply to the population of the United States. SIDS professionals were also skeptical that a change in sleep position could be the information that they were looking for. However, a decision was made to collaborate on a national public health campaign. The four claims-makers: ASIP, the AAP, the NICHD, and the SIDS Alliance appeared to be pleased with the idea of co-sponsoring the larger campaign, now known as *Back to Sleep*.

On June 21, 1994, a national campaign was announced by Surgeon General Jocelyn Elders. But how would the messages of this national campaign be presented that represented the interests of its four co-sponsors and also get the messages out to all parents? The media would be a significant factor in communicating this new position and help to establish a national response to SIDS as a public health issue.

## Communicating *Back to Sleep*: Building New Claims

How did the media represent the story of the *Back to Sleep* campaign? By 1994, claims-makers had successfully positioned SIDS as a public health problem worthy of resources from the federal government that corresponded with its established status as "the leading cause of death of infants from one month to one year of age in the United States". Though there was debate about accepting and recommending the change in sleep position, the decision to do so was made by the medical community who after years of unsuccessful attempts to define and prevent SIDS, was finally able to make a concrete statement to reduce the risk. As demonstrated in the previous chapter, the media was significant in constructing SIDS as a public health problem and generating awareness of SIDS as a specific and legitimate cause of death. Through the efforts of various claims-makers, including pathologists and SIDS parent groups, the classification of SIDS was determined to be a cause of death that socially absolves parents from involvement in their infant's death. When viewed historically, the media over this thirty year time period also established a larger story about SIDS.

### *Crib Death in the Media: Establishing a Public Health Problem*

The topic of infants dying in their sleep may not rate high on a list of cheery topics to read about but it but it has been a solid area of interest for magazines over a period of forty years. The representation of this topic in mainstream print media such as consumer magazines offer a means to examine how the issue was constructed as a social problem through public discourse. Social problems construction and the media have an interdependent relationship. Claims-makers often use media coverage as an integral part in establishing social problems such as urban crime (Fishman 1978), the crack epidemic (Reinarman and Levine 1995), and missing children (Best 1987). The media also constantly depend on social problems as the basis of stories that will interest and captivate their readers (Gitlin 1980, Tuchman 1978). This relationship is acknowledged by social constructionists, who often use media claims to identify, measure, and analyze how issues get transformed into social problems over a period of time. The numbers of articles that have been dedicated to the subject of crib death/SIDS in American popular magazines have fluctuated over this time period, starting with just one or two articles appearing a year between 1948 and 1968, with a spike in the number of magazine articles appearing in 1969 (when SIDS was officially designated), which had five. The period from 1973 to 1980 had at least four articles a year, and the period from 1983 to 1989 settled back to one or two articles a year (see Table 4).

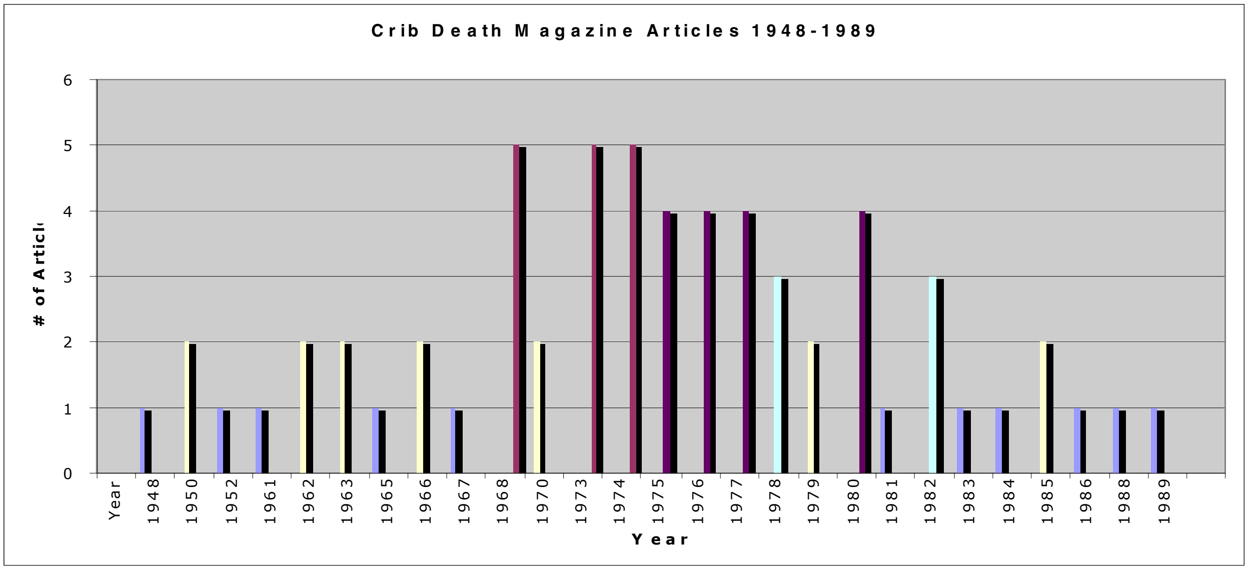

**Table 4: Crib Death Magazine Articles 1948-1989**

The way that magazines framed the issue of sudden infant death from 1945 to 1989 reflect a need to identify its cause as well as attempts to explain the unknown.

(n=16)

| Themes | % |
|---|---|
| Mystery/enigma/puzzle | 37 |
| Parent's personal story | 18 |
| Doctors trying to "solve" crib death and "search" for answers | 18 |
| New studies/new information | 18 |

**Table 5: Crib Death Magazine Article Themes 1948-1968**

(n=28)

| Themes | % |
|---|---|
| New studies | 32 |
| Risk reduction, “prevention”, “averting” | 21 |
| “Clues”, “some answers” | 17 |
| Mystery/enigma/puzzle | 10 |

**Table 6: Crib Death Magazine Article Themes 1970-1979**

For example, over a third of the articles that were analyzed from 1945 to 1968 frame these sudden infant deaths as an enigma, or mystery that needs to be solved (see Table 5). A theme that appeared in 18% of the articles over this time period focused on a parent’s personal experience with crib death. These articles worked to establish SIDS parents not being at fault for these deaths, and inevitably portrayed parents in a sympathetic light. The search for the cause of SIDS dominated the coverage in magazines during the 1970s, representing almost a third of all articles (see Table 6). Several articles during this time period indicated that there were ways to prevent or avert SIDS in the near future, a theme possibly spurred on by the availability of millions of dollars in federal funds for research in 1974. By the 1980s (see Table 7), magazine articles mainly focused on new studies that were being done to find out the cause of SIDS, followed by over 20% of the articles during this time period which gave readers an overview of SIDS as a public health problem. These magazine articles served to establish the positions of the different claims-makers who were invested in creating SIDS as a public health problem in the media over a 35 year period. These claims would later be challenged after the *Back to Sleep* campaign.

(n=14)

| Themes | % |
|---|---|
| New studies | 28 |
| Overview | 21 |
| Bereavement | 14 |

**Table 7: Crib Death Magazine Article Themes 1980-1989**

*Establishing New SIDS Claims*

The *Back to Sleep* was able to transform new scientific research findings into certain public health recommendations and bridge the gap between the different viewpoints of the claims-makers by creating new claims. Media presentations of the campaign after 1994 allowed the creators to rely on the audience's connection to the larger SIDS story and offered a way for parents to make sense of SIDS. *Back to Sleep* also successfully established the government (and the other sponsors) as 'doing something' about SIDS. The *Back to Sleep* campaign messages set boundaries of knowledge in the popular press about SIDS that influenced how the notion of SIDS was framed and thought of by its audience by establishing certain themes that would reappear and be built upon (See Table 8).

| **Previously Established SIDS Claims** | **New SIDS Claims** |
|---|---|
| •SIDS is recognized as a legitimate cause of death<br>•SIDS is not contagious, hereditary or caused by child abuse<br>•SIDS is a significant public health problem<br>•The cause of SIDS is still a mystery<br>•Researchers are working on finding the cause to one day prevent SIDS<br>•There is nothing that can currently be done to prevent SIDS<br>•SIDS is unpredictable and can happen to anyone<br>•Every baby is at equal risk for SIDS<br>•Parents of babies who die of SIDS need sympathy and support | •The latest medical evidence has discovered a breakthrough in mystery of SIDS<br>•These recommendations can reduce the risk of SIDS, but not prevent it<br>•There is new advice on a better, safer way to take care of infants when they sleep<br>•There is an easy change in behavior that parents can do to reduce the risk of SIDS<br>•This recommendation has been successfully tested in other countries<br>•Research is still being conducted to find the cause of SIDS<br>•Educate others about these changes in infant care practices |

**Table 8: Old and New SIDS Claims**

*The "breakthrough"*

The new SIDS claims built upon themes that audiences as a whole had been subject to and familiar with in past interactions with health issues and the media. The concept of a "medical/scientific breakthrough" was one that was constructed as part of the discourse, and a significant one considering that SIDS had been presented as a mystery in the past, and now the story that a mystery is on the brink of being solved suggests a common storytelling device. As the protagonists of this dramatic "breakthrough" story, medical researchers are familiar figures who have been presented as constantly coming up with new ways to improve the public's health. This theme built on previous work by SIDS claims-makers who had established in media stories that the medical and scientific community was working intensively on finding the cause of SIDS. This concept of the latest and best medical information bursting on to the scene is particularly common in the realm of infant care, where improvements on how to optimally feed, nurture, and put your baby to sleep are frequent stories for mothers and caregivers to be exposed to. It is familiar to this audience that infant care recommendations are constantly updated in the media, and the *Back to Sleep* campaign built upon this narrative concept.

### *Trust the source*

Where the information behind the *Back to Sleep* campaign's messages came from was another important piece needed for the new SIDS claims to develop. The familiar narrative theme in medical stories is that really good information comes from really trusted, solid sources who are conducting serious research for the public's benefit. The evidence that a change in sleep position could have an effect on the SIDS rates came from trusted, legitimate sources such as the professional group the American Academy of Pediatrics and the federal government's National Institute of Child Health and Human Development. This new claim established the evidence that this recommendation would work to reduce the risk of SIDS and that this was not simply a capricious decision made by these experts, rather the result of proven, quantifiable success in other countries. The notion that there was disagreement between these groups only a couple of years earlier had vanished, and the familiar narrative structure (particularly in public health campaigns) of being told what is best for your health from a solid, legitimate source was a comfortable stance to take. Plainly stated, the message was that government and doctors agree that this is the best thing to do for your baby, so it should be done. The simplicity and apparent agreement of these sources further established this particularly paternalistic theme.

### *Risk reduction, not prevention*

In spite of all of the media attention to the prevalence of SIDS in the United States, the reality is that most families will never encounter it. However, the risk of SIDS was established by claims-makers as universal, something that *could* affect every family, even though it actually only affected a small percentage of the population. The meta-narrative theme of risk reduction was framed such that it puts the power of reducing the risk of SIDS literally into parents' hands

Risk reduction is familiar theme to audiences of health media who are constantly told about how to reduce their risk of cancer or heart disease by eating right and exercising, or even how to reduce the risk of injury by wearing a seat belt.

This concept of risk reduction as it applies to SIDS reflects the concept of how risk is conceptualized in the neo-liberal state via health campaign as something that individuals should protect themselves from through constant self-examination and self-care (Lupton 1994). These risk reduction techniques are often focused on changes to individual behaviors rather than interventions on the structural level, and emphasize what "you" can do to improve your health, or in the case of Back to Sleep, what you can do to reduce the risk of an infant dying in its sleep. From the perspective of Foucault's theories of govermentality, in which the state shifts responsibility for health risks, the 'new' public health of the late 20th century sees SIDS and its individual risk reduction as a more appropriate focus for a public health campaign rather than similar issues with more complex intervention strategies such as low birth weight. By applying these risk reduction recommendations for SIDS to all parents, ‘the distinction between healthy and unhealthy populations totally dissolves since everything is potentially a source of “risk” and everyone can be seen to be “at risk” ’ (Peterson 1997:195). As a result, the narrative theme of risk reduction highlighted in the *Back to Sleep* campaign emphasizes the behavioral choices that the audience can make to minimizing risk of infant mortality through expert advice.

The preceding themes of the new SIDS claims could not exist in a vacuum. It needed the media to be established and communicated to the public through the conventions we are used to for learning about how to improve the health of the public.

## The Advice Shift

Newspapers and television programs often announce the results of the latest medical studies that proclaim a better way to be healthy, even if this advice may contradict what had been announced the week before. The public is often left to sort out the implications of these shifting pieces of information and how it may affect their health behaviors. The *Back to Sleep* campaign is a recent example of this ‘advice shift’—defined here as the transformative process that health recommendations go through from advising one perspective to another using the media as a mode for conversion. The health information presented in the *Back to Sleep* campaign not only represented a breakthrough in reducing the risk of SIDS, but was also a direct contradiction of the infant care advice advocated by pediatricians and practiced by most caregivers in the United States. The new claims that were established in the media helped to provide the groundwork for the communication of this advice shift. This section presents how articles in major newspapers from 1992 to 1994 helped to successfully communicate the new public health recommendations to reduce the risk of SIDS (see Table 9). Indeed, studies of how parents received the new infant sleep recommendations after the *Back to Sleep* campaign began in the United States have shown that parents reported that the impetus for changing position came from family or the media, rather than from health professionals (Gibson, Cullen et al 1995).

The majority of the articles (56%) mention the American Academy of Pediatrics official recommendation, and the same percentage of articles mentions the number of deaths that are attributed to Sudden Infant Death Syndrome in the United States.

| | N=41 |
|---|---|
| Article mentions “change in advice” | 48% |
| Article mentions “resistance to BTS”: | 41% |
| Article mentions “mystery”: | 43% |
| Article mentions “power of media message”: | 31% |
| Article mentions “BTS done in other countries”: | 48% |
| Article mentions “some babies should avoid BTS”: | 26% |
| Article mentions “anxiety”: | 29% |
| Article mentions “other recommendations” | 31% |

**Table 9: Descriptive Variables of Newspaper Articles, 1992-1994**

The mysterious nature of the cause(s) of Sudden Infant Death Syndrome (“a puzzling condition”) was mentioned in 43% of the articles sampled. Often the reference to the unknown nature of SIDS was also contained in the same article the mention that research on the success of back sleeping in reducing the risk of SIDS that has been done in other countries (48%), and that this research was the basis for the change in advice.

Almost half (48%) of all of the articles distinctly mentioned that the new recommendation for back sleeping was a change from what has been previously recommended. This was referred to as “an about face”, “an abrupt change of what generations of parents have been told”.

References to skepticism or concern with the back sleeping recommendation from parents or from professionals appeared in 41% of the articles. Doctors were very resistant because they said that kids may choke and that they weren't so convinced by the evidence--"It's hard to support something when we don't know if it's working or why it works." Over one quarter (26%) of the articles mentioned that some infants (i.e. born prematurely, suffering from reflux or colic) should avoid back sleeping altogether. Some of articles (29%) attempted to allay parental anxiety that this change in advice may cause by stating that the American Academy of Pediatrics did not want to "panic parents" and that the relationship between increased risk of SIDS and prone sleeping is "a purely statistical relationship--it doesn't mean that prone causes SIDS" and that infants older than 4 months may not need to change their sleep position. Less than a third (31%) of the articles mentioned the other recommendations to reduce the risk of SIDS that were also part of the campaigns in the other countries. They are the recommendations to not use soft bedding, not over wrapping the infant, and not smoking around the baby.

The power of messages in the media to change health behavior is mentioned in 31% of the articles. The campaign goal is seen as reversing a traditional practice of putting babies on their stomachs to sleep, and a need for an intensive campaign to overcome this "incorrect medical advice", which is a "dangerous tradition". The above findings point to several possible reasons why the advice shift presented in newspapers of the *Back to Sleep* campaign was successful in getting a majority of caregivers to go along with it.

### *Shift from parenting advice to public health recommendation.*

When the *Back to Sleep* campaign was launched in 1994, most parents in the United States put infants to sleep in the prone position reflecting the advice given to caregivers by pediatricians and nurses since the mid 1950s. This recommendation was made based on the assumption that infants who vomited would choke if they were on their backs, and that placing them on their fronts would prevent this from occurring. Recommending the prone position for infants represented a shift from previous medical advice, and even the popular Dr. Spock reversed his advice from supine to prone between the 1955 and 1956 editions of his bestselling infant care book. Though this advice of putting babies to sleep in the prone position was never based on any published studies of infants choking on vomit, and this position was the opposite of how infants who are nursed alongside their mothers naturally fall asleep, it quickly became the norm in most households in the United States. Though the advice of putting infants to sleep in the prone position began as medical advice, media accounts referred to it to a ‘motherly tradition’ and ‘common wisdom’. Now that this old medical advice was being disavowed, articles disseminating the advice shift claimed the source of this practice was from generations of caregivers, and not the doctors who had originally presented it.

Articles claimed that the “traditional motherly advice” that had been “culturally ingrained” was something that needed to be “reversed”. How to put a baby to sleep was portrayed as advice was similar to tips on how to burp and bathe a baby, and represented a way of handling a common concern for new parents. However, once the studies in other countries demonstrated that there was a correlation between this child care practice and the risk of SIDS, science trumped what was said to be common wisdom. In the United States, the influential American Academy of Pediatrics studied these results extensively before making their recommendation. The jurisdiction of infant sleep practices had now shifted from the province of "maternal advice" to medical knowledge. Though there were no conclusive scientific reasons to explain why the supine position was connected to a reduction in SIDS deaths, there was enough evidence to proclaim this finding to be a significant risk factor.

Pediatricians and nurses most likely had more trouble accepting this shift in behavior than parents. "The new advice flies in the face of what doctors have recommended for years and is contrary to the practices of most hospital nurseries", and "called into question the advice of many pediatricians in the United States". It also forced pediatricians to side with science instead of 'folk' knowledge. Eventually, many pediatricians became convinced by the weight of the scientific recommendation over common practice. The motivation to accept this new information was spurred on by the looming threat of the SIDS and the unequivocal decreasing rates of death in the foreign studies. The new framing of the information, from maternal common sense to scientific authority, provided the public with the needed weight to shift behavior.

### *Known vs. Unknown*

The mystery of crib death moved forward with official recognition as a cause of death and over thirty years of federally funded scientific studies. However this was not enough to answer the ultimate questions: what causes SIDS and how can it be prevented? Concern for solving this mystery spanned decades, with only one message to parents: there is nothing that you can do to prevent SIDS. The discovery of the prone position as a risk factor for SIDS along with the AAP recommendation and the *Back to Sleep* campaign represented a significant clue to help solve the “mystery” mentioned in almost half of the articles. It also provided a concrete step that anxious parents could perform in order to feel that they did all that they could to prevent the deadly event.

### *Belief in the power of the media*

Public health and mass media have had a long relationship, based on the idea that health messages are effectively communicated through public service announcements, posters, advertisements and news reports. The effectiveness of the mass media to actually effect behavior change has been difficult to nail down, especially in light of other persuasive forms of media that advocate for unhealthy behaviors. However, some public health practitioners are convinced that health messages presented in mass media have the ability to significantly change behaviors. Several of the articles in this study express the power of media to transform "conventional wisdom". In several articles a Seattle newspaper that announced the back sleeping risk reduction information from the international studies reported that SIDS cases dropped by 52% in eight months in the counties that had access to the newspaper article. The power of the media to deliver this message is also implied where reduction in SIDS rates were suggested to be a direct cause of change in sleep position and health officials urging parents to put babies to sleep in the supine position. One article states that "it would be a great mistake not to let the public know about this", which assumes that once people know the information, then they will do it—even if it refutes generations of motherly advice.

Overall, newspapers communicated the messages about the recommendation to change infant sleep position in a manner that presented the “news” angle of the story--a recently developed policy from the medical community on a vexing public health problem—as well as developing the new claims of SIDS by presenting the policy as a possible solution to a long running mystery. By emphasizing the potential life saving nature of the supine position as a public health recommendation, infant care practices that had been the province of motherly advice now became a mandate for proper parenting. The articles also continued the discourse of risk and SIDS that had been established years before, by presenting it as something that could happen to any baby, and that these were recommendations that needed to be followed by all parents. The presentation of this ‘advice shift’ in the media also continued to legitimize the claims-makers and allowed for them to use this new chapter in the SIDS story to continue their goals.

## Communicating the Campaign

The collaboration of the different partners was a key factor in getting the *Back to Sleep* message out to different constituencies: ASIP was able to reach their members of SIDS professionals, the SIDS Alliance had a national network of parents groups, and the AAP had thousands of pediatricians around the country.

> [O]nce the campaign was launched, the information spread quite rapidly, especially through the pediatricians and the health care professionals. That was how we started with the AAP members received information about it, we asked that they distribute the pamphlets and everything to their patients and even a couple years after the campaign there was a huge mailing to every licensed child care provider in the United States

> about *Back to Sleep*, so that information got out and there was a hospital mailing, all the hospitals in the US received the information, so I mean, it was just these national mailings to the major health care providers of these infants. (AF)

There were also collaborations that involved the government and private companies who were able to use their marketing techniques to get the message out. Initially, parents were reached through feature stories in magazines and on television, advice from pediatricians, brochures in medical offices and hospitals, publicity of a nationwide toll-free information/referral hotline, and a series of ads. Campaign materials were developed by both the National Institute of Child Health and Human Development (NICHD) and commercial public relations organizations. For example, the public relations firm Porter Novelli was hired as part of a public-private partnership to launch the initial radio, TV, and print campaign that propelled the issue onto the national agenda from 1995 to 1997. Another public relations firm contracted by the NICHD developed a strategy with Procter & Gamble's Pampers Parenting Institute to put *Back to Sleep* tabs on diapers. In 1997 the *Back to Sleep* message appeared on the backs of 3 million Gerber cereal boxes (Mann 2002). These corporations made good use of this information by appearing to be concerned about the well being of infants as the providers of this public service.

As for SIDS professionals, they relied on the media that was produced by their organization that was then used to communicate to parents. The wording of the recommendation of sleep position in 1994 was flexible enough to allow parents to adjust to this new information, and gave the SIDS professionals a way in:

> Well, we had the guidelines from the ASIP and we created a one-page flyer that had a little demonstration because at that time it was

> side or back, so it was more acceptable to people to hear that they could put their babies on their sides or back, side was more palatable. We even told them how to roll a towel to keep them on that side position, put the arm up, and they were pleased to hear that there was some finding that was to reduce the risk of SIDS. (EL)

The way the ASIP dealt with this conflict between new recommendations for risk reduction and the feelings of the population of new parents and SIDS parents that they served was resolved by carefully selecting the way that they talked about the messages. On one hand here was an official policy statement of concrete actions from a respected source, and on the other hand there were the claims that had been carefully established with the help of SIDS professionals over the past 20 years that said that there was nothing that a parent could do to prevent SIDS from happening. As a professional organization they were the bridge between the SIDS researchers and the public, so they were used to translating scientific findings into common language. This was fine when the scientific community really did not have any concrete findings to communicate, but with the AAP recommendation, there was a need to negotiate how these messages would be presented. When speaking to other professionals, ASIP members felt more comfortable using the language of the AAP in their education, the language of professionals, and when talking to different groups of parents, there was a reframing of these recommendations, according to those who were there at the time:

> I remember very clearly, I would describe *Back to Sleep* in one way to the professional community and a different way to new parents and bereaved parents. Not that I was withholding information, but the manner in which I presented it was really different. If it was a new parent who is saying, they're conscientious about it, they are saying "I heard about SIDS and this *Back to Sleep* stuff that's going on. What does it mean?", so you would approach it from like, yes these are good infant care practices, read over the information, search the media, and go talk to your pediatrician when you need to. With a bereaved parent you'd say it may reduce risk, but

it's not guarantee. (MC)

For SIDS professionals it was important to present this information in a way that did not just rest on the scientific findings and to tell people that this was a change in behavior that had to be done because those in power said that it should be. This is an issue that is found across all public health campaigns to promote health, as explained by a long time SIDS professional:

> Health education is a very hard sell because it is assumed that you have [health] until it is threatened or depleted. And even health educators-so we can't implement our own recommendations for ourselves. How can we ever expect our clients to implement them simply because we tell them about it? Simply because we share the information? The biggest obstacle is that information does not change behavior, and people share information, talk about information, process it, but it doesn't necessarily change their behavior, that there is a gap between receiving information and changing your behavior (JA).

One way that I found that SIDS professionals are able to combat this dilemma when it comes to communicating the messages of *Back to Sleep* was for them, it is important to let those that they address know that though this change in sleep position to reduce the risk of SIDS is a change in the way they may be used to caring for an infant, that their experience was still valuable. They find it important to let their audiences know that their ways are respected, and that this new information does not serve to disregard the ways that they had cared for infants in the past, but can allow for more infants to live, based on its success so far. This willingness to communicate the nuances of a public health campaign to their audiences and treat them as equals struck me as an important piece of communicating health messages. Though the media can reach a broad audience with its messages, the interpretive means of communicating that can happen on a smaller scale seems to be more effective in reaching an audience who may be more receptive of the information that they receive. Attempting to make a connection with the audience is a common way for SIDS professionals to try to get the *Back to Sleep* messages across, even though it is difficult for them:

> This stuff is thrown at them and it's assumed that by osmosis that they'll just get the message and we did something and people feel good about it. We threw some brochures at people, and I do that too. I don't have the time when I'm in the field at that sort of thing, to be able to do some of that, but I don't know, I hope that maybe if we do some education like take your time until you really connect with some of these young women. They have very complicated problems and many young women are feeling very alone (CR).

With SIDS risk reduction messages having gone beyond the traditional audience of SIDS parents and the *Back to Sleep* campaign positioned SIDS as something that everyone should be worried about, the problem was now: How do you frame this new message? The answer appeared to be by creating new claims based on familiar themes of larger SIDS story as it has been established by the media. Audiences, particularly parents of infants, are familiar with the story that there are 'always' changes in infant care advice, and that scientific advances ultimately provide their babies with greater safety and protection. In addition, *Back to Sleep* had something more than just the run of the mill infant care advice: it had the heft of being a public health recommendation, where there is little room for disagreement. Public health campaigns are usually presented as messages that 'tell you what to do', so in the case with *Back to Sleep*, audiences were familiar with the larger story of being told what to do to improve your (or your baby's) health. By presenting a united front from the different claims-makers in the BTS campaign, audiences were given the message that this recommendation was a sure thing that must be done to protect babies from SIDS. By relying on new claims, the media were able to communicate these messages to its audience in a way that they intuitively understood and hopefully would accept.

### How the claims-makers communicated their positions after *Back to Sleep*

Even though the *Back to Sleep* campaign was the official representation of the SIDS risk reduction messages, each of the claims-makers established their own campaign brochures that gave their own spin to the official messages. Brochures are a form of media that allow for an individual level of communication—often handed from one person to another or picked up by someone—that health educators have relied on for many years. Indeed, pamphlets are often noted as being one of the earliest forms of political communication that allowed for various groups to independently use media as a way to promote their cause that did not have to rely on the whims of those in power to communicate their messages. The concentration of written and often visual material in a small format allows the creators to give their own perspective on health information that can speak directly to the audience. Each of the claims-makers who sponsored the *Back to Sleep* campaign produced their own materials to communicate to different audiences their interpretation of the new SIDS messages (see Table 10).

### Table 10: Claims-makers "Back to Sleep" Pamphlets

| Pamphlet source | Title and audience | Visual Presentation | Recommendations |
|---|---|---|---|
| National Institute of Child Health and Human Development (NICHD) | “Safe Sleep for Your Baby: Reduce the Risk of SIDS”, general public | Blue eyed baby on cover, six other photos of multi-ethnic babies and families, photos illustrate risk recommendations, large type, “Frequently Asked Questions” section | • Presents the “Facts About SIDS” and how you can lower the risk of SIDS<br>• Explains risk factors and how to comply<br>• Addresses the advice shift and states that research shows that back sleeping safer<br>• Answers questions about risk of choking, bed-sharing, and flat head<br>• Provides toll free number, address and website |
| SIDS Alliance | “Facts about Sudden Infant Death Syndrome & Reducing the Risk of SIDS”, parents and caregivers | Four small photos on cover (pregnant woman on exam table and families with babies), six small photos inside, small type, little white space | • Providing the ‘latest medical evidence’ on reducing the risk of SIDS<br>• Paragraphs that explain other risk factors<br>• Mentions drop in SIDS rates since BTS<br>• Section that explains that following the recommendations will not prevent all SIDS deaths and that “things can go wrong when parents do everything right.”<br>• Describes what ‘risk factors’ are and how they are not causes of SIDS<br>• States that more children will die of SIDS in a year than all who die of many other conditions combined.<br>• States that SIDS is not contagious, caused by child abuse and no one’s fault<br>• Provides their own toll free hotline<br>• Ways for parents to get involved with the work of the SIDS Alliance |

| | | | |
|---|---|---|---|
| American Academy of Pediatrics (AAP) | "Questions and Answers for Professionals on Infant Sleeping Position and SIDS", health care professionals | *Back to Sleep* logo on cover, no photos, text presented in question and answer format | • Health care professionals urged to read the two articles from Pediatrics for "a review of the evidence that led to the [BTS] recommendation."<br>• Mentions decrease in SIDS rate since BTS<br>• Suggests some babies should sleep in prone position<br>• Parents should not keep checking on their baby after being laid down to sleep<br>• Avoid products to keep babies on side or back<br>• Mentions possibility of flat heads<br>• Addresses concern for choking in supine position<br>• Personnel in hospital nurseries should place babies in supine or side position<br>• Frequently refers to published studies |
| Association of SIDS and Infant Mortality Programs (ASIP) | "Infant Sleep Positioning and SIDS: Counseling Implications", professional caregivers | One page, double sided sheet on ASIP letterhead, simple format with no photos and academic style references | • Mentions decrease in SIDS rates since BTS as rationale<br>• Sleep position not a cause of SIDS<br>• Gives other risk reduction recommendations<br>• Offers counseling guidance suggestions: "It is anticipated that parents of newborns, child care providers, and families whose infant has died in any sleep position will require guidance as a result of the *Back to Sleep* campaign."<br>• Recommends additional studies to identify the basic mechanisms of SIDS |

**Table 11: Claims-makers "Back to Sleep" Pamphlets, continued**

Across the sample, there was uniformity in the larger messages that were communicated: placing a baby to sleep on its back during all sleep times, and using a firm mattress, removing objects from the crib, avoiding second hand smoke, and not overdressing a baby before sleep. Also, all of the materials acknowledged that their organization was one of the four groups that sponsored the *Back to Sleep* campaign. All of the materials provided ways to get more information, either through the *Back to Sleep* campaign offices (NICHD and AAP) or through the organizations themselves (SIDS Alliance and ASIP). As a way of justifying the rationale for communicating these new recommendations, all of the materials from the organizations mentioned the success of the *Back to Sleep* campaign by reporting the correlating decrease in SIDS rates since the campaign began.

Since each of the organizations addressed different audiences, there were also several differences across the materials. ASIP and AAP presented information to fellow professionals, and provides academic references on how the recommendations were reached. The NICHD pamphlet is targeted to a general audience, and provides short statements about SIDS and risk reduction techniques with photos to illustrate them. Interestingly, considering the debates prior to *Back to Sleep* about the validity of the research findings about sleep position and SIDS from different countries, the NICHD material does not use any scientific evidence or citations. It simply presents the “facts” about SIDS and risk reduction, relying on its position as a product of the federal government for authority. Also, the NICHD pamphlet and website represent the official center of the *Back to Sleep* campaign, and is considered the authoritative source of these recommendations.

The SIDS Alliance is addressing parents, but also its members which consist of 'SIDS parents', and dedicates space to explaining how infant sleep position does not prevent SIDS from occurring, and that since the cause of SIDS is still unknown, parents should not think that their child care practices may have caused their baby's death. This concern with how the parents whose babies died will feel in light of these risk-reduction messages is also addressed in the ASIP material, specifically ways in which professionals should counsel parents in order to alleviate feelings of guilt and culpability. Overall, each of the claims-makers were able to use the materials to communicate the new claims of SIDS risk reduction while also maintaining their particular positions as it relates to their constituents.

## Conclusion

In this chapter I argued that the establishment of the *Back to Sleep* campaign represented more than the sum of its parts---beyond the actual recommendations, it was a symbol sponsored by the federal government to show that 'something was being done' about SIDS, which had been established as a significant public health problem that every infant risked. The *Back to Sleep* media campaign promoted the U.S. government's concern about the issue which was significant considering that over the previous 30 years claims makers had succeeded in establishing the risk of SIDS from concerning a few thousand parents to the entire population.

In this chapter I also argued that by bringing the various claims-makers to the table and presenting a united front in the battle to prevent SIDS in the form of the *Back to Sleep* campaign, a necessary piece of public policy was created that continued to establish the significance of SIDS as a public health problem. Specifically, the way that this occurred was through the construction new SIDS claims. In using the media to communicate these messages, the *Back to Sleep* campaign was able to establish itself as a change in the way the SIDS story was being seen without losing the gains established by many of the claims-makers. Though there was conflict and uncertainty about what to do with the information about the correlation between sleep position and SIDS rates in the early 1990s, by 1994 a united front was presented that told the public the definitive way to care for infants to reduce the risk of these deaths.

Danger, rephrased as "risk" has become the mainstay of health campaign messages. Epidemiological and medical definitions of what behaviors are considered risky and how these behaviors in turn affect health status are subject to continual change (Lupton 1996). Not all of these changes occur as new information becomes available, and communicating risk factors to the public must take into consideration what effect the added information will have. This concern is especially pertinent when the focus of the public health campaign is to communicate changes in medical advice--often after a scientific discovery that reveals new, perhaps contradicting previous health advice. The potential effects of the new health information has been particularly true with the areas of women and infant's health: the 'discovery' of Fetal Alcohol Syndrome in the early 1970s changed the message of pregnant women's consumption of alcohol from allowing some to none (Golden 2006, Armstrong 2002); doctor's recommendations on the preference for formula or breast feeding has gone back and forth throughout the twentieth century (Wolf 2001). The strategy of public health organizations is to inform the population on the practices that will save lives. How these organizations go about this often involves using mass media to promote the message. Through the authority of the agency presenting the message, there is an understanding that the information is backed by the latest (and presumably the best) scientific information available, and that the behaviors suggested should be followed, even if they contradict previous practices.

As a public health campaign presented in the mass media, by 1994 *Back to Sleep* addressed all parents, not just the small group of families that were personally affected by SIDS. *Back to Sleep* represents a shift in the audience of the messages and brings the notion of risk of SIDS to every baby, and by informing every parent and caregiver, now an individual responsibility to protect your baby from SIDS. It also *created new knowledge* about SIDS by negotiating between the emotional and scientific positions that claims-makers were maintaining through the development of the new claims and provided a high profile platform for the four SIDS claims-makers.

# CHAPTER 4

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The beginning of the twenty first century was successful for the *Back to Sleep* campaign. By the year 2000, researchers analyzed the rates of SIDS and the prevalence of the supine sleep position since the American Academy of Pediatrics recommendation in 1992 and found that there was a dramatic reduction in the rates of SIDS deaths as well as an increase in the rates of babies who slept in the supine position in the Untied States. Articles appeared in professional journals such as *Pediatrics*, and announced that prone sleeping decreased more than 70 percent, and that SIDS deaths declined by more that 40 percent during the same time frame (Pediatrics 2000). The same article also concluded that "most researchers, policymakers and SIDS professionals agree that this significant decline occurred largely as a result of changing sleep position" (Pediatrics 2000:653). The popular magazine *Parents* announced in an article titled the "Ultimate SIDS Update" that "…the message that babies should sleep on their back to reduce the risk of SIDS has been hugely successful, due to the public-education *Back to Sleep* campaign" (Laliberte 1999:80). It appeared that the dissemination of the *Back To Sleep* information in all of its various forms was reaching parents and influencing which way their babies were being put down to sleep. But which babies?

Though the rates of SIDS deaths were also decreasing for African Americans, the incidence of SIDS was found to be more than twice as high among this group compared to whites, and up to three times as much for American Indians (Minino and Smith 2001). The rates of prone sleeping between 1994 and 1998 were also found to be different between blacks and whites, with 32% of black mothers placing their infants to sleep in the prone position as compared with 17% of non-black mothers (Willinger et al 2000). The interpretation of these statistics along with a shift in the nature of infant mortality research provided the basis for a change in the *Back to Sleep* and how SIDS would next be presented as a public health problem (see Table 11).

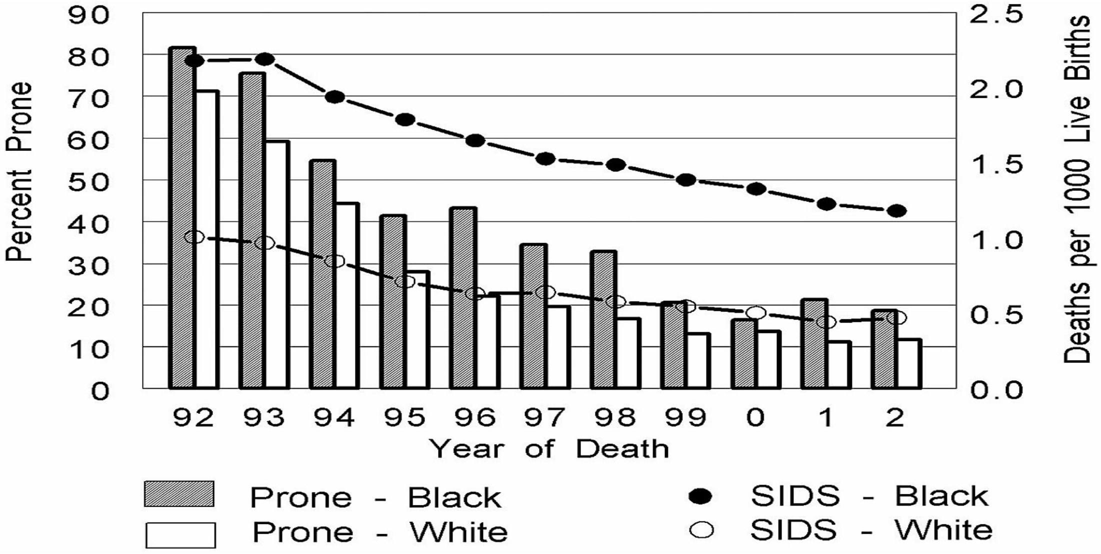

**Table 12: US SIDS Mortality rates and Prone Sleep Position Percentages by Race**
Source: Pediatrics 2005

Over the past three decades, claims-makers had established that the risk of SIDS can affect families of all races and income levels. The theme that "SIDS could happen to anybody" was important in the development of the SIDS social problem in order to ameliorate feelings of guilt from SIDS parents who feared there was something that they could have done to prevent their child's death. Careful considerations and negotiations were made by claims-makers in the *Back to Sleep* materials to continue the non-assignation of blame for SIDS through the development of new claims that focused on the latest scientific findings for risk reduction, particularly the supine sleep position. However, now that the *Back to Sleep* campaign appeared to be reducing the SIDS rates in the United States even without the discovery of its cause, SIDS was being featured more as a public health *success* rather than a public health *problem*. Though there was reason to celebrate this success, it was becoming more and more difficult for claims-makers to retain the level of interest in SIDS that it once had. How could the issue continue to generate the amount of public concern and funding needed to continue the work of SIDS professionals, educators, researchers, physicians, and the federal government? How would the SIDS story be re-framed in order to keep the momentum going in the post *Back to Sleep* era? By the late 1990s, all indicators were pointing to the burgeoning hot topic in public health: "racial disparities" as they related to infant mortality in general and SIDS rates specifically.

Throughout this chapter, race will be used to refer to white Americans ("whites") and African Americans ("blacks"), though there are problems with how a classification such as 'race' is defined, particularly with reports of infant mortality (Anderson and Moscou 1998). The decision to use the term in this chapter, rather than ethnicity, is in part to emphasize the health impact of racism and its health related consequences (Thomas 2001). Clearly there are concerns with defining race in this context, as it tends to reinforce the difficulty with classifying groups of people based on perceived categories. Indeed, the Institute of Medicine (Haynes and Smedley, eds., 1999) states that in all instances race is a social and cultural construct, specifically a "construct of human variability based on perceived differences in biology, physical appearance and behavior". The IOM states that the traditional conception of race rests on the false premise that natural distinctions grounded in significant biological and behavioral differences can be drawn between groups.

One of the many issues that this raises is sorting out the differences in cultures and practices as it relates to maternal health and infant care between those who are racially classified as black—from recent immigrants from the Caribbean and Africa who often carry over the "healthy immigrant effect" of better birth outcomes than whites in the same neighborhood (Newbold 2005) to seventh generation African Americans who have suffered from the cumulative stresses of marginalization throughout the life course that can have a effect on birth weight (Lu and Halfan 2003). By aggregating these populations, we lose the nuance and power of the category by treating a heterogeneous group as a homogenous one. However, the collection of demographic variables as it currently exists in the United States by the Centers for Disease Control and the National Center for Health Statistics tends to ignore these troublesome issues and continues to confound the constructs of 'race' and 'ethnicity', leaving critical social scientists to sift through the piles of information, looking for a way to make sense of it. In this chapter I will explore the way that 'race' developed as an epidemiological risk factor for SIDS and how race was construed *as a culture* in order to target a particular population to get the audience to comply with a public health message.

Specifically in this chapter I will be analyzing the construction, communication, and audience reaction to the "culturally competent" version of the *Back to Sleep* campaign that was launched in 2000 and that continues today. First I will examine how race became a risk factor for SIDS during the late 1990s by using accounts in the academic and mass media as well as using interviews to supplement this analysis. I will then look at how the culturally competent risk reduction messages were presented by analyzing the materials developed by the National Institute for Child Health and Human Development (NICHD) for African American SIDS outreach. Finally, I will examine how these messages have been interpreted by their intended audience based on analysis of my participant observation field notes and interviews. In doing so I offer an alternative understanding to the notion that African American mothers and caretakers are resistant to the messages of the *Back to Sleep* campaign by seeking to comprehend what the protective effects of culturally-based practices are.

## Constructing Race as a Risk Factor for SIDS

The disparities in the rate of SIDS deaths in the United States reflect the differences in overall mortality between blacks and whites, which are tied in with the history of urban public health. The early 20th century saw a dramatic overall reduction in infant mortality rates. During the same period, studies of the differences in health outcomes between the races in public health were focused on investigations of "the Negro Health Problem", as evidenced by a special issue of *American Journal of Public Health* in 1915. Articles in the journal attributed the poor state of the health of blacks in the United States to the 'unsanitary and overcrowded conditions' in which they lived, and their lack of desire to leave those conditions (as cited in Kreiger 2001). In her commentary, social epidemiologist Nancy Krieger argues that the belief in blacks' personal irresponsibility and innate physical and mental inferiority, which was the dominant scientific belief during the early 20th century to explain health differences, still informs the approach to public health issues and racial disparities today. However, the factors that contribute to these disparities are difficult to isolate, since they interact with each other and overlap. Some areas include environmental factors like stress and racism (Wang et al 2001, Mullings and Wali 2001) and socioeconomic status (Fang et al 1999), as well as individual risk factors such as smoking, drinking, and drug use, number of previous births, and genital infections (Starfield et al 1991, Chomitz et al 1995). It is probable that these stressors can have an effect on women throughout the life course--before conception as well as during pregnancy, which may contribute to poor outcomes for black babies. Indeed, Geronimus (1992) proposes a "weathering hypothesis" that posits that African American women's health begins to decline in early adulthood as a result of cumulative socioeconomic disadvantages in order to help explain the racial disparities in infant mortality. Today placing interventions on individual level health behaviors and conditions as approaches to reducing the disparities in infant mortality between the races fail to address these larger social structures. The “ecological perspective” on public health issues looks at public health issues like infant mortality as a social justice issue, not a personal one, particularly as it affects African Americans in the United States (Freudenberg 2002). Health disparities, in this light, are seen as a problem where equity and equal access go hand in hand with biological and lifestyle determinants. However, this perspective was not present in the development of race as an epidemiological risk factor for SIDS. The identification of race as an independent variable that affects which babies’ die of SIDS was constructed over a period of time during the 1990s and primarily focused on individual attributes.

The difference between ethnic groups in SIDS rates was also being investigated outside of the United States at this time. New Zealand had experienced a decline in SIDS rates after a public health campaign that promoted the supine sleep position. However, the Maori population continued to suffer from higher mortality rates than the Pakeha, or whites (Mitchell et. al. 1993). An anthropological analysis of infant caring practices and SIDS found that the advice to the Maori to place infants to sleep on their stomachs and to bottle feed instead of breastfeeding came from the Pakeha– and was seen as an "expansion of western values on indigenous people" (Gantley 1994). In contrast, the same study found that Banglideshi families in Wales had lower rates of SIDS than native whites. This was due to the practices of extended family living, children sleeping in the parents' rooms as opposed to practices in Welsh families whose households were smaller, with isolated infant sleep practices. Also, Bangladeshi mothers placed their babies to sleep on their backs while Welsh families placed their babies on their stomachs; Bangladeshi women rarely smoked, while smoking was more common among Welsh women (Gantley 1994). According to a literature review conducted by the National Center for Cultural Competency, this and other studies conducted in the United Kingdom suggested the importance of culture as the mediator for racial and ethnic differences in use of sleep position and child care practices. "Of importance is that these studies do not examine cultural differences in childcare practices as problems among diverse populations. This set of studies seeks to *understand the protective effects culturally-based practices can have on ameliorating the impact of other known risk factors for SIDS*" (NCCC 2001:7, emphasis added). Though "culture" itself is heterogeneous and can be found to contain risk factors across the spectrum, ethnicity and cultural practices for infant care clearly play a part in constructing the large web of reasons behind disparities in SIDS rates internationally, and significantly, these practices were not seen as barriers to risk reduction, but as potential benefits.

This approach to disparities was not evident in the United States. As discussed in the previous chapter, from the beginning of the *Back to Sleep* campaign, newspapers played an important role in communicating the latest messages about SIDS risk reduction. A search of a database of ethnic newspapers for the term "SIDS" from the early 1990s compared to the late 1990s shows how this issue of disparities was transformed and how it was framed as a public health issue for African American audiences. In 1992, a newspaper article titled "Sudden Infant Death Syndrome a Parents' Silent Agony" was typical of the type being written in all newspapers at the time; indeed the title could apply to any parent. The article stated that "SIDS occurs in all social, economic, ethnic and racial groups in the United States…other groups at increased risk are babies of American Indians, blacks and poor families. Although the previously mentioned groups have more of a chance of having a baby die of SIDS, most victim[s] of SIDS have few or none of the risk factors mentioned" (Hayes 1992). During this pre-*Back to Sleep* period, the unknown nature of the cause or cure for SIDS was stressed, which universalized the risk between *all* groups of infants.

After the *Back to Sleep* campaign had been established in 1994, headlines in ethnic newspapers reflected a change in tone. Article headlines ranged from the straightforward "African American Babies at Higher Death Risk: Risk Factor 2 ½ Times Greater for Infant Death Syndrome" (Tri State Defender 1998) to the more activist "Save Black Babies, Stop SIDS: Lack of Knowledge Kills Our Future" (Michigan Chronicle 1999). There was also the clearly plaintive "Why are Black Babies Dying in Their Cribs?" (The Jacksonville Free Press 1999) show a concern for the difference in SIDS rates between the races and what could be done about it. Though these articles raised the problem of the effects of Sudden Infant Death Syndrome on a population, what was not addressed were the reasons why the rates were so different. In part, this has to do with the larger and increasingly more complex issues that surround infant mortality.

In the United States differences between the death rates of white and black babies have existed since the days of slavery. However, a search of the academic research literature shows that scientific studies of the differences in infant mortality rates between blacks and whites only started to appear in 1985. This coincides with the release from U.S. Secretary of Health and Human Services Margaret Heckler of the *Report of the Secretary's Task Force on Black and Minority Health* in 1985. This document identified several modifiable risk factors associated with the six leading causes of "excess deaths", defined as the numbers of deaths in minority populations that were in excess of the adjusted number of deaths for whites from the same causes. Infant mortality was identified as one of these causes of excess deaths in the report (as cited in Kumanyika 2005). Here black race was presented as an independent risk factor to explain the causes for these excess deaths of infants.

The 1990s continued to bring an increase in studies and academic articles of what has become known as "the gap", and investigations looked for possible variables that contributed to higher infant death rates among black infants in the United States. This flurry of interest in researching the disparities between whites and African Americans in the infant mortality rates took place at a time when funding became increasingly available to study why it was occurring and what could be done to stop it. In 2000, the major public health document Healthy People 2010 announced one of its goals was to eliminate racial disparities in health, including maternal, infant and child health outcomes within the next ten years (U.S. Department of Health and Human Services 2000). Promoting the *Back to Sleep* campaign to reduce or eliminate SIDS was one of the objectives to reach the goal. In order to help to reach this goal, on November 22, 2000, the Minority Health and Health Disparities Research and Education Act was signed by President Clinton. This new law authorized millions of dollars to create new research on minority health and health disparities at the National Institutes of Health and other Federal agencies. This focus on the issue of the causes and possible cures for reducing these differences in health outcomes between blacks and whites was a major public health agenda, with many possibilities for funded research and interventions.

But how easy would it be to uncover the reason(s) behind the racial disparities in SIDS rates? By 1996, two years after the *Back to Sleep* campaign was launched, studies in medical journals such as the *Journal of the American Medical Association* and *Pediatrics* were framing the cause for the disparities in the SIDS rates as African American parents' failure to switch their infants' to back sleeping—especially if they were poor and there was the presence of infant's grandmother in the home (Brenner et al 1996). Later studies continued to frame the problem as one of 'non compliance' by concluding that "many inner-city parents of color prefer [the prone position] over supine" and that "more efforts are clearly needed to convince parents who disagree with and resist recommendations" (Johnson 1999:1210).

By the time a 2000 study of sleep position practices of parents of infants in Philadelphia was published, the image of the resistant African American, inner city mother was set. This study concluded that "an excessive number of African-American families and clinic families still choose a prone sleep position. Many who do so cite increased infant comfort, despite knowledge of the American Academy of Pediatrics recommendation" (Gibson et al 2000). African Americans' "lack of compliance" with SIDS risk reduction recommendations continued to be cited as attributing to the continued racial disparity in major studies that were published in influential journals (Hauck et al 2002, Pediatrics 2003).

These studies did not exist in a vacuum. The results were presented at SIDS and other organizational meetings across the country, and SIDS health professionals and educators took these research findings back to the states and cities that they served. An analysis of the interview data I collected shows that the "take home" message for the health professionals and educators who work in urban areas was that the presence and power of an elder in the family who was pro-prone sleeping was a barrier to following the *Back to Sleep* recommendations. One African-American SIDS professional in New York City described the nature of this resistance as she interpreted it from the research:

> …we kept ourselves informed of other articles that were coming out…and some of the researchers found that…African American families were somewhat reluctant to accept the guidelines, and the ones that were more reluctant were the African American families who had less than a high school education, who had previous children, other children before the back sleep was instituted, or who resided with an elder caregiver in the household. Even though they had accepted the guidelines when they were in the hospital, when they were re-interviewed at three months of age, they had reverted back to the belly sleeping, and they ascribe it to the fact that the elder in the family was extremely pro prone sleeping, belly sleeping, because this was what they were used to, and I suppose instead of fighting, you just give in because for generations 'this is what we've done and they were alive and their children and everybody else is alive, and so what's the big deal',…so we inferred then that our African American parents must be having the same problem with their grandmothers and godmothers and aunts, elders in the community… (EL)

The significance of these influencers in the African American communities was seen as being stronger than the doctors and nurses who informed mothers about *Back to Sleep*, a finding that should have come as no surprise. As discussed in the previous chapter, the recommendations of the *Back to Sleep* campaign in 1994 contradicted pediatric advice on infant sleep position of the past fifty years. The prone position was preferred by both whites and blacks alike because babies slept better and it removed the fear that they would choke on their vomit. The insistence of elder caretakers that the prone position was best for babies was based on years of experience and earned wisdom, which started as advice from pediatricians and nurses. Yet the solution to the disparities in SIDS rates was increasingly being framed as a failure on the part of black mothers to follow doctor's orders--individuals making bad, uninformed decisions. The larger issues that informed the reasons behind disparities in infant mortality were not mentioned in any of the SIDS literature as contributing to the problem. The focus was on the individual (black) mother who did not comply. If only the message of *Back to Sleep* could be properly delivered and received, it was thought, surely things would change.

### The Construction of 'Cultural Competency' as the campaign shifts focus

The disparity in the SIDS rates between whites and blacks was seen by claims-makers as troubling at all levels, in that the message of back sleeping had not been properly delivered—or received, or interpreted—by African Americans, the population who appeared to need it the most. The covert point expressed in the literature about SIDS disparities and *Back to Sleep* was that white parents got it, and Black parents did not. In this dichotomy, more African American parents were putting their babies at risk by not complying with the recommendations. The question for SIDS professionals on the local, state, and particularly federal level was: How to make *Back to Sleep* work for the group most at risk? In response, interventions developed by the federal government on how to get African American parents and caregivers to comply with the recommendations attempted to focus on the *culture* of African American infant care to close the gap between knowledge and behavior.

The culturally sensitive, also referred to as the ‘cultural competency’, approach to health education recognizes that ethnic communities have different languages and cultures that should be acknowledged. Ideally in this theoretical framework, messages in culturally competent health campaign materials should reflect the health beliefs and practices of the intended audience while “recognizing that some of those beliefs and practices may not be congruent with emerging knowledge of what supports healthy outcomes. Culturally competent health campaign supports and honors those practices and beliefs that are protective or benign, and respectfully helps identify and change those beliefs and practices that have a negative health impact” (National Center for Cultural Competence 2001). These culturally sensitive materials may focus on: beliefs, values, attitudes, cultural and spiritual traditions; literacy levels; format; and the types of pictures and symbols that will resonate with and reflect the culture of the target audience.

This task is daunting at best, in that the specifics of what a particular group will respond to that reflects cultural values and beliefs are difficult to identify, especially for a population broadly defined as “African Americans”. As a heterogeneous group that are clustered together on socially constructed designations based on phenotype, finding a culturally sensitive approach that would apply to the entire group would be destined to resonate with some, and fall flat with others. The difficulty of communicating SIDS risk reduction recommendations solely on the basis of racial or ethnic designation is further complicated by the beliefs and values inherent in infant care advice. As described above, SIDS health professionals based their interpretation of the higher SIDS rates among blacks on studies that showed that they resisted the new messages about infant sleep and relied on the advice of elders who insisted on the tradition of stomach sleep. This belief was seen as a barrier to SIDS risk reduction messages, but would there be an attempt to identify any protective cultural practices?

Research into the development of culturally competent materials to address SIDS risk reduction was investigated in a thorough literature review conducted in 2001 by the National Center for Cultural Competency, based at Georgetown University. This review found that there were many problems with existing studies on SIDS, race and ethnicity and how to approach the 'barriers' that African Americans had to the *Back to Sleep* messages. Ultimately, though the new version of the *Back to Sleep* campaign wished to be seen as culturally competent and sensitive to the needs of a particular community, there was practically no research to base this on. In summary the review found that:

> The current state of the data is woefully inadequate to support the design and evaluation of culturally competent approaches to addressing disparities in SIDS/ID. First, the review of the literature reveals that studies have used race and ethnicity as proxies for culture. Thus, what is reported about differences among populations does not yet provide direction for the nature of targeted, effective interventions. Second, without clear and consistent definitions of race and ethnicity, it is impossible to address the questions about the relative contributions of biological or genetic differences among populations as compared to behavioral differences, which may be mediated by culture. (National Center for Cultural Competence 2001:3)

The concerns raised by this review were significant and strongly worded. The problem with substituting race and ethnicity for culture is that any desire to truly get at the differences between infant care practices in order to reduce SIDS rates would be inaccurate at best. At worst, it would be a way to 'target' blacks and assign blame for the higher rates based solely on racial classification. The epidemiological studies that had been conducted through the 1990s on the differences among racial and ethnic groups in the use of sleep position and other child care practices to account for the continuing disparities in SIDS rates helped to identify groups who needed different approaches to education. They did not, however, help elucidate which culturally defined values, beliefs, and behaviors may contribute to the persistent use of prone sleep positions.

Despite the lack of appropriate data, in November 2000, the creators of the *Back to Sleep* campaign, led by the National Institute of Child Health and Development (NICHD), focused their efforts on a new initiative to reduce SIDS in African-American communities[11]. Efforts were made to align as much support as possible from traditional black organizations to take the SIDS cause on. Over the course of a year, materials were developed with the National Black Child Development Institute, National Association of Black Owned Broadcasters and historically Black organizations including the Congress of National Black Churches, National Coalition of 100 Black Women, National Medical Association, the sororities Alpha Kappa Alpha, Zeta Phi Beta, and Chi Eta Phi, and the National Association for the Advancement of Colored People.

The development of the materials that were to be used for the African American outreach for *Back to Sleep* involved the input of the different organizations to discover what would be read as being 'culturally appropriate'. However, it seems that that the focus was more on appropriately *targeting* blacks, rather than attempting to understand

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[11] There was also a culturally sensitive approach to American Indian SIDS outreach and education that is being developed by the NICHD. The disparity between whites and American Indians in SIDS rates is even greater than that between whites and blacks, and has not been adequately studied.

cultural practices. A SIDS health educator on the national level described the process:

> When we first started this thing on how we could get information out to African American communities, we needed to develop materials that were culturally appropriate. We had a meeting in 1999 with the National African American organizations, with African American communities across the country discussing what would be helpful and the kind of materials, what would they look like, what would they incorporate to get information to communities about SIDS…From that the groups and organizations helped us design the materials. We provided samples of designs and they picked out which ones were most effective, or that they thought that their membership or their communities would be most accepted, and we went forward with that. (AF)

The culturally competent approach to the *Back to Sleep* campaign focused on training and educating communities about "the fact that the responsibility for safeguarding the health and well-being of infants rests not only on parents but also on family members, loved ones, and all those who care for infants" (NICHD 2000). The campaign's message is "Babies Sleep Safest on their Backs", and promotes back sleeping as a community duty. The resource kit was distributed nationally for outreach efforts in presentations and workshops. Summits were held across the country to inform and train service organizations like sororities and the National Association for 100 Black Women to educate communities about the campaign. As for broadcast media, the cable channel Black Entertainment Television agreed to air public service announcements in between programs.

How would these media communicate the purported "culturally sensitive" approach to SDIS risk reduction? And understanding that 'culture' in this context was actually based on a substitution of race and racially targeted information posing as culture, what would the subtext of these materials say? In the following analysis of the *Back to Sleep* campaign materials that have been created specifically for African

American outreach, I looked at the brochures and videotape produced for distribution, described their contents, and identified how these materials attempted to communicate the SIDS risk reduction messages and what the “culturally competent” approaches were (See Table 12).

**Table 13: Culturally Competent "Back to Sleep" Materials**

| Resource Kit materials | Description | Culturally Competent Message/Theme |
|---|---|---|
| Parent Brochure: “Babies Sleep Safest on Their Backs” | Discusses SIDS risk factors and ways to help reduce the risk of SIDS. Written for a general audience, including parents, family members, child care providers | • Sepia colors<br>• Smiling African American woman holding AA baby, face to face on cover<br>• Last on list of *Facts about SIDS*: “African American babies are twice as likely to die of SIDS as white babies.<br>• Addresses fear of baby choking and “flat head” if placed on back<br>• Photos of AA baby on his back in crib, parents and grandparents with awake baby, father playing with baby on his back<br>• Photo and quote from AA U.S. Surgeon General Satcher |
| Refrigerator Magnet: “Reduce the Risk of Sudden Infant Death Syndrome (SIDS)” | Lists ways to reduce the risk of SIDS | • Sepia colors<br>• Back to Sleep logo<br>• Advises talking to childcare providers, grandparents and all caregivers about SIDS risk, but doesn’t explain them |
| Parent Video Tape: “Sudden Infant Death Syndrome: A Video on Helping to Reduce the Risk” | One minute video intended for a general audience | • AA woman walks into baby’s room singing a lullaby, holding a sleeping baby, puts her to sleep on her back and takes out toy<br>• Magically, toy talks to woman about staying in the crib, she addresses back sleeping, clearing out the crib, chocking fears, room temperature, well baby care doctor visits, breastfeeding, smoking and fear of SIDS striking (“it’s always in the back of my mind”)<br>• Shots of baby sleeping in crib on her back |
| Sample Bus Ad: “Babies Sleep | Smiling African American man and | • Smiling AA woman putting sleeping baby in an empty crib on his back as |

| | | |
|---|---|---|
| Safest on Their Backs" | woman putting a baby into a crib on its back | smiling AA man looks on<br>• Gives national toll-free number to call for more information |
| 15-minute, 30-minute, 60-minute community education training modules | Outline of presentation and handouts | • Important health issue for African American families<br>• SIDS can happen to any family no matter their race, ethnicity, income or where they live<br>• Many AA families have led the way in trying to find the cause of SIDS<br>• Addresses skepticism about changing practices from stomach to back sleeping, but emphasizes study results<br>• Addresses the issue of affording a safety approved crib, suggests creating safe sleep area in other locations (but not adult beds)<br>• Babies in AA community continue to die of SIDS more often than white babies<br>• Says no one is to blame for SIDS deaths, stresses community awareness and sharing information as a way to reduce risk for future generations |

**Table 14: Culturally Competent "Back to Sleep" Materials continued**

Overall, the materials presented raise more problems for caregivers than those that are addressed. Within these materials, race and ethnicity are treated as if they reflect some homogenous cultural aspect of populations. There was no acknowledgement of the enormous intra-group and cultural differences among various racial and ethnic populations and outcomes for infants, and the relationship between various aspects of culture within specific populations. What follows are the themes that were identified in the content analysis along with the supporting themes identified in the interviews I conducted:

### *Stating the Statistics*

In the materials, emphasis is placed on the disparities in the SIDS rates between African Americans and whites. The presentation of the rates of white SIDS deaths compared to black SIDS deaths appears as a stark and un-tethered statistic which was intended to point out the significance of the situation and to address the 'hard to reach' group of inner city African American mothers and caregivers so that they would understand the risk reduction messages of the campaign. However, according to the public health professionals that I interviewed, it is precisely this focus that may do more harm than good:

> "People don't want to be targeted, that's the problem.
> People are not so responsive to that, and I think one of the problems with it is because we are singling out disparities in every illness, at the same time people are sick of it…We [public health professionals] think we're alarmed and we think we ought to do something about it. The truth is the community thinks that we are picking on them." (LB)

SIDS professionals, who present risk reduction information and education in New York

City, said that African Americans that they address also see the term “disparities” as a racially loaded term.

> “…you use the word disparity, and it alarms
> people. So I think that somehow or other, in moving in the
> direction of dealing with disparities, we have also opened
> up another chapter in racial relations…” (JA)

This new chapter in racial relations could be titled “The Problem with Using Race as a Risk Factor”. There is a visceral reaction against pointing out differences in health outcomes according to race when there is nothing that can be done to modify it. Focusing on a particular population can cause the targeted group to feel blamed for the poor outcomes by just being a member of the group. It is logical, then, that the audience may have a negative reaction to pointing out the statistics behind disparities in SIDS rates. By isolating these numbers African Americans are placed at risk just by being born.

### *Privileged Information*

The power of the new risk reduction information is presented as the key factor to combat SIDS is present in all of the materials. Its power supposedly lies in this: the ability for the ‘correct’ information about back sleeping to be transmitted to its target audience, which leads to the proper behavior, and then this behavior will lead to reducing the risk of SIDS. However, the SIDS professionals in New York City, who are all aware of the research on the complex nature of the causes of infant mortality for African Americans, believe that there is more than information that is needed to reduce racial disparities. They argue that there is a complicated story behind these disparities, that there are reasons that have less to do with individual choice and more to do with the larger context in which women live their lives. A SIDS professional described the dilemma of trying to isolate these disparities in campaign materials without looking at the bigger picture:

> You are stuck in a very unfortunate place because white women do better than black women on every health indicator. And that is not fair, and it is not because of race. But it is because of race. It is not because you are limited because of race, but you are limited because of race. It is like circular. You don't get out of circle to make real change. (JA)

Seeing the culturally sensitive *Back to Sleep* materials from this perspective shows that what was intended as a simple communication of useful information is interpreted as "pointing a finger" at African Americans and identifying them as the cause of the problem. One possibility that there are negative reactions to this message goes back to the complex issues that influence the disparities with infant mortality, which include individual, community, and structural level issues like poverty, racism and social stress. Providing access to the risk reduction information may be a useful way for those who designed and implemented the campaign to feel that they were reaching African Americans, and making efforts to get them to get it. Yet the information itself is reified—it is privileged as possessing powers to transform the conditions that surround an individual whose baby might die of SIDS.

Reifying information is problematic in another way—when it is flat out rejected as being valid. This issue, as articulated by a New York City SIDS professional's interpretation of the audience response to the campaign, is less one of resistance than one of challenging the source of the "facts" being presented:

> "…this *Back to Sleep* campaign, we hear what you're saying, you are reaching African Americans…but my community doesn't agree with the message. So somewhere you're getting it across,

> but it's not being accepted. What are you going to do about that, because my community, I hear you, I hear you, I hear you, you're stuck on getting this message to African Americans, but are African Americans taking this message and agreeing with you and making these changes?" (LB)

### *Authority of the message giver*

Throughout the campaign materials there is an assumption that the newly discovered research on the risks of the prone sleep position is valid and better than what preceded it. As discussed in previous chapters, the discovery of this risk factor for SIDS was met with skepticism by SIDS researchers in the Untied States, in part because it challenged the prevailing information on infant sleep. Pediatricians and parents alike doubted the effectiveness of the shift from the prone to the supine position for infant sleep, indeed, the *Back to Sleep* campaign only came about after multiple attempts to convince the American Academy of Pediatrics and others that the switch was correlated with a decrease in SIDS deaths in other countries. In the materials for African American outreach, the validation of its messages presents a united front. There is no indication of uncertainty or for challenging the sources of the information. The recommendations are presented as the latest facts and are backed up by medical authority figures such as the Surgeon General, doctors, researchers, and the American Academy of Pediatrics.

Using these authority figures to justify the legitimacy of this new information provides a sense of consensus, with no room for questions. This model of those in power--as bestowed by the state, medical institutions, or the scientific community--setting the rules for the public to follow has a long history in public health. By creating new SIDS claims, the creators of the materials hope to convey this new information as an unchallengeable fact to be implemented immediately. However, this attempt to enforce these recommendations via the power of the message provider has been found to have the opposite effect with the exact audience that the *Back to Sleep* campaign wants to address. Focus group research conducted by the New York City Department of Health and Mental Hygiene in 2004 with young mothers, fathers and caregivers in Harlem and Brooklyn to investigate SIDS disparities discovered some surprising findings. They found that most of the SIDS prevention messages have reached their audience, but the message on sleep position has not been incorporated into behavioral change. Though parents and caregivers know that back sleeping was recommended by health professionals, they did not believe that this was the best way for their babies to sleep. This was due, in part, to a fundamental distrust of the message provider:

> Young parents and caregivers in all groups express skepticism about institutional forms of knowledge and *mandated* practices that seem to disregard their own parenting instincts, their own experiences of parenting, and the knowledge and experience of trusted advisors within their own family or community. As a result, the SIDS message for safe sleep is viewed by many as something distant and overly generalized, not necessarily applicable, disrespectful of their own knowledge and parenting skills – and, at worst, flatly incorrect or accusatory." (Bettegowda, Manzano, Boyd 2004, original italics)

The "institutional forms of knowledge" cited by the researchers are what the *Back to Sleep* materials are based on. Clearly the long held skepticism and mistrust among African Americans towards the medical establishment, medical professionals and their advice influences how they will process new recommendations for infant care. Patricia Hill Collins, in her study of Black feminist thought and the nature of black women's social knowledge (1990), illuminates the distrust of impersonal, "official" sources of health information. Collins argues that African American women have developed ways of knowing that considers the "dynamics of intersecting oppressions" which distinguishes knowledge from wisdom. The difference between the two has to do with lived experiences and the credibility and believability gained from these experiences, because "knowledge without wisdom is adequate for the powerful, but wisdom is essential for the survival of the subordinate" (1990:257). From this perspective, validation of a particular fact or knowledge claims is based on observed success with those actions, which begets wisdom. If the prone position is something that had been done for generations, and is something that women had seen as being a successful way to put a baby to sleep, it is logical that this would have precedence over the presentation of new information based on scientific studies. Here, instinct, experience, and advice from family members who have seen success are more legitimate sources of information than official entities.

Placed within this context, it makes sense for women to challenge the authority of the *Back to Sleep* message. But it also puts them in a position of being a non compliant "bad" mother for not following the new rules for infant sleep position. This major credibility gap between the authority behind the new recommendations and the authority of closer, trusted sources of infant care advice is not addressed in the culturally sensitive materials. This contradiction between the official sources of information and the more trusted sources puts mothers in the difficult position of having to choose between sources of infant care advice. At best this can lead to a sense of discomfort associated with the cognitive dissonance of receiving new information that conflicts the old (Festinger 1962) and at worse inaction when it comes to infant care. By presenting the supine position and the *Back to Sleep* campaign as the only acceptable source of information, these materials reinforce the stereotype of the mother who puts her child at risk, a deviant from the norms of protective motherhood.

### *Visualizing the middle class ideal*

The visuals used in this campaign show African American families, particularly mothers with infants. Other family members are also represented, emphasizing the multigenerational nature of infant care. Photos that illustrate the recommendations are clear, though they seem to represent an ideal situation, without the messiness of real life on display. The uses of these visuals in the campaign are to inform the targeted audience in how to behave to reduce the risk of SIDS. The uses of these visuals in the campaign are to inform the target audience how to behave to reduce the risk of SIDS. Unfortunately, the SIDS professionals who use these materials have encountered the opposite response from black audiences. As one white professional said:

> It was really meant to be culturally competent, and now suddenly that culturally competent, very refined, very specific message to reach a particular target audience is viewed as "Don't make it my problem because I am black". (JA)

Many SIDS professionals recognize that these "culturally competent" materials that were used to communicate the *Back to Sleep* campaign have been judged to isolate and target African Americans as somehow being responsible for the higher rates of SIDS rather than address particular risk factors behind these deaths. Often using these materials were found to have had a negative effect among African American audiences and I found that many of the SIDS professionals in New York City were reluctant to use them.

### *Putting the pieces together*

These culturally competent *Back to Sleep* campaign materials that were created to address the issue of disparities in SIDS rates between whites and blacks have several common threads. These materials use broad based information for producing and disseminating the newly culturally appropriate pamphlets, posters and presentations. However, the products are culturally sensitive only in a narrowly defined sense. These materials were seen as a way to reduce the disparities between blacks and whites in SIDS rates by giving blacks material that ‘speaks their language’, looks familiar, and resonates with culturally valued themes to get them to put their babies to sleep on their backs. In the materials, emphasis is placed on the disparities in the SIDS rates between African Americans and whites, offered in stark statistical terms. Though the presentation of the ‘facts’ of the differences between the SIDS rates appear to be objective, their presence alone emphasizes race as a risk factor. Since race is constructed as a risk factor, the latent values communicated are that African Americans are a *source* of problematic behavior based on ignorance of the latest studies and recommendations. In particular, the child care practices of prone sleeping are seen as a cultural risk factor for SIDS that exists within the community that may result in infant deaths. Overall, the presentation of the culturally sensitive material to address disparities in the rates of SIDS in the African American community are superficial and allow for the audience to have an unintended interpretation and mistrust of the materials.

Why would these carefully constructed messages backfire? When audiences are viewed as active, they interpret messages through intervening variables such as lived experience, community, social structure (Hall 1980). When viewed through this lens, then the “facts” about the difference between SIDS rates between blacks and whites serve to reinforce social inequalities that exist between the races in the United States. Also, no attempt is made to address the true issues of culture(s) within what is defined as the African American community. Simply adjusting the *Back to Sleep* materials to target this group does not address the larger issues behind the disparities in SIDS rates. These inequalities are beyond individual control, yet individual solutions are suggested for solving them.

Receiving medical advice or recommendations is a common occurrence for pregnant women and new mothers, and everyone seems to have an opinion about the safest way to behave and act for your baby's best outcome. However, we all process this information differently, depending on the mediating factors in our lives. Education, age, experience with infants, feelings of self efficacy, and social support are among the many things that can influence how mothers will process a particular recommendation for infant care. Also one's experience and history with following or rejecting health recommendations in the past would seem to play a part in how likely someone would be to follow new recommendations. Weighing the risks of health information is a constant and often unconscious calculation that is done on an everyday basis. So how is the infant care advice found in the *Back to Sleep* campaign interpreted on the micro level? The next section attempts to uncover the missing links between dissemination and audience interpretation.

## Agency, the active audience, and advice

In my experience with talking to African Americans about SIDS risk reduction, I found that there were common and inter-related themes that point to an active and responsive audience. What follows is an analysis of my field notes from talking to African American women and men, from teens to grandparents about SIDS risk reduction in New York City and how they interpreted these messages.

### *The "old fashioned" way*

Women have been caring for infants throughout history and have developed approaches that are successful in raising children through adulthood. These approaches are based on experience and empirical results that are passed down through generations and have traditionally been communicated through action, observation, and the spoken word. The written word, in the form of infant care books and pamphlets, is a recent addition to this core of communal knowledge. This way of communicating information about infant care has been influential for certain groups in American society, in particular white middle class women (Hays 1996). For the African American women I spoke to about SIDS risk reduction, the experiential mode of learning how to care for infants was more persuasive. When I would discuss how back sleeping was considered safer, women and men referred to mothers, grandmothers and ‘other mothers’ in the community (Collins 1990) and their experiences with always putting infants to sleep on their stomachs or on their sides. This knowledge was not easily dismissed by those to whom I spoke, even if they acknowledged that it was the “old fashioned” way of doing it. Disrupting what they saw as a successful way of putting infants to sleep, even if it contradicted the new information I was offering was not an easy option. The fear of a baby choking if it vomited was the primary reason why stomach sleeping was initially encouraged by pediatricians over fifty years ago, and this was often mentioned as a reason for continuing the practice.

A young woman said to me at a community health fair that she was scared not to put her kids on their stomachs to sleep, since this was what her mother and other women with whom she lived with told her to do. She did not want to challenge the older women in the house and their advice on infant care, and even though she listened to what I had to say, her allegiance was ultimately with those she trusted to care for her baby, and appeared to be afraid of what would happen to the baby if she was on her back. Here, the abstract risk of possible harm was outweighed by the real risks posed by challenging the women in the house who had more experience in caring for infants.

Continuing to do what had worked in the past was further strengthened by empirical evidence that stomach sleeping held no harm. Grandmothers and mothers of older children that I spoke to at community health fairs would constantly respond to my back sleeping information with some version of the statement “all my kids slept on their stomachs and they were fine”. I did speak with a few people who had experienced SIDS deaths, from a woman in her 70s that knew of two babies that died to a teenager who had a sister that died, for whom the concept of SIDS was more real. However, there was a certainty in seeing something work and the evidence of having babies who lived despite stomach sleeping is a fact that was not easily dismissed. In this case, the “old fashioned” way may be old, but it worked.

### *Passing it on*

Though there is a significant sense of history within families with the old fashioned way of putting babies to sleep on their stomachs, the information I was presenting about promoting back sleep and other SIDS risk reduction messages were very well received by the African Americans that I spoke with. In particular, pregnant women, their mothers and expectant fathers were open and attentive to what I had to say. These groups expressed interest to learn the new information about risk reduction and they were particularly aware that “they keep changing” what is recommended to care for infants. Women with their pregnant daughters who I spoke to would mention that they had put their kids to sleep on their stomachs, but were aware that this was the new way to do it. One grandmother-to-be told me that this was her first grandchild, and was eager to get as much information as she could about child safety. She was also setting up a room for the baby's nursery in her home and buying "two of everything" so the baby would have an easier transition from her daughter's home to hers. A young man who told me that "this is my first [baby]" took the materials I gave him and appeared to be trying to take it all in as his pregnant partner continued to shop.

From those who said that they "never knew" about the American Academy of Pediatrics recommendation for back sleeping to those who were familiar with it and had done it, there was a common theme of what to do with the informational pamphlets and materials—to pass it on to others who didn't know. Several people expressed the sentiment that this was important information that needs to be brought around and that "people need to know" about it. Often they would pick up extra pamphlets to give out and use them to physically pass the information along.

Those who needed to know included a woman taking a pamphlet because "My baby's father is stubborn. This will tell him."; an elderly woman who was going to bring the materials to other grandparents; a woman who was going to give the brochures to somebody she knew who had a baby; a grandmother who was bringing it to her family ("they are still having kids"); and a woman whose neighbor had a six week old and was "afraid to put her baby to sleep on the back". Here, the materials served as symbols to open up awareness and validity of this new information. There is also a personal connection from the message giver to the receiver in that the information is being passed on out of concern for the infant's safety.

### *Which culture?*

Though the materials I was distributing were not exclusively developed to be culturally sensitive, I encountered different cultural norms of infant care that presented a challenge to the idea what had been previously defined as culture. In particular, when speaking to women who were immigrants from the Caribbean and Africa, I was offering them little information that was new. These women had traditionally placed their babies to sleep on their backs and were already practicing the other risk reduction messages. Their infants did not sleep with many blankets or fluffy bedding, though they did often share a bed with their mothers. These mothers breastfed and did not have issues related to second hand smoke in the home.

Especially in urban areas where immigrants come from many different cultures with many different traditions to infant care, SIDS risk reduction messages may seen like much ado about nothing. According to a woman I spoke to from Barbados, "there are other issues" that caregivers of American infants should be concerned about more that stomach sleeping, including chemicals in food, lack of access to fresh produce, and drugs given to mothers during labor.

## Conclusion

Public health campaigns that are targeted to specific populations using a culturally sensitive approach appear to make efforts to address "hard to reach" audiences by presenting information in a way that can be clearly understood. All of this effort relies on information—the scientific evidence, the facts--and its ability to change behavior. However, without taking into consideration how issues of race, class, and family dynamics and culture intersect with risk reduction messages, those who choose to interpret them differently may be seen as deviant. Information alone fails to address the causes underlying the disparities in SIDS rates between blacks and whites. Campaign creators like the federal government must realize that by focusing on ways to get the information out, and not on other causes of SIDS in African American communities, that culturally sensitive approaches may raise more problems than they can solve.

In the interviews I conducted, I found that the SIDS professionals were very aware that with the issue of the disparities in SIDS rates between blacks and whites, that notions of risk are being twisted to fit the *Back to Sleep* campaign. Epidemiologically, risk is calculated on a group level, and the difference between the rates of SIDS deaths between the races applies to the entire population. However, the campaign is targeted towards individual level changes in behavior. Having placed the weight of millions on individual shoulders, it is not surprising that there is a resistance to what the culturally sensitive risk reduction messages asks of them. SIDS professionals also point to the use of the term disparities to apply to just about every chronic disease and condition, from cancer to obesity. They feel that African Americans have overdosed on hearing about disparities for so many different issues, that when SIDS is added to the list, there is a backlash from overloaded audiences. Pointing out disparities to those who are suffering from them does little to ameliorate the situation.

So in order to do their job and reduce SIDS rates, professionals have learned that there are different ways of communicating with African Americans that go beyond cultural sensitivity. Whether it is talking to grandmothers and valuing their wisdom and ability to keep families together, or using churches for their ability to be a trusted messenger to a community, or speaking to women in prisons or homeless shelters, it is, as one SIDS professional said,

> I think that is really the critical element to the education, is appreciating the audience, and giving credibility to the audience, and elevating the audience. (EL)

As of the end of 2005, there are still disparities in the rates of SIDS, and information alone is not going to work. Indeed, a recent study in the American Journal of Public Health that found that there was no evidence that the disparities in SIDS were reduced after the *Back to Sleep* campaign. Odds ratios for SIDS associated with lower social class *increased* between 1989–1991 and 1996–1998, and the race disparity in SIDS also increased after the *Back to Sleep* campaign. The study concluded that the introduction of "an inexpensive, easy, public health intervention has not reduced social inequalities in SIDS; in fact, the gap has widened. Although the risk of SIDS has been reduced for all social class groups, women who are more educated have experienced the greatest decline" (Picket et. al. 2005). Though this study did not take the culturally sensitive campaign into consideration, it shows the problem with using campaigns as a way of reducing disparities in SIDS rates.

Reducing the disparities between blacks and whites with infant mortality rates may be more than a campaign could ever do. The risk factors for infant mortality in the United States are complicated and difficult if not impossible to isolate. While individual level risk factors have a role, so do community level risk factors and what has been discussed in the public health and social science literature as *fundamental social causes of disease* (Link and Phelan 1995). This includes social and economic resources such as socio-economic status, knowledge, money, power, prestige and social connections. These resources determine the extent to which people are able to avoid risks to their health. This framework has two implications to my analysis of how the culturally competent *Back to Sleep* campaign was received. First, it suggests that the SIDS risk reduction recommendations that were contained in the *Back to Sleep* campaign were going to be more easily adopted by those who have more resources, and that those with fewer resources would inherently be less able to avoid the risks of SIDS. Second, by attempting to reduce the disparities in SIDS rates through a culturally sensitive campaign that was targeted on changing infant care behaviors, the social causes of the disparities are ignored. As Link and Phelan argue:

> "...some social conditions are fundamental causes of disease and as such cannot be effectively addressed by readjusting the individually-based mechanisms that appear to link them to disease in a given context. If we wish to alter the effects of these potent determinants of disease, we must do so by directly intervening in ways that change the social conditions themselves." (page 90)

By taking this perspective into consideration, campaigns that are designed to address disparities in health outcomes that do not address the larger social issues that contributed to the disparities in the first place will unlikely have a measurable outcome.

Indeed, the problem with media campaigns as they relate to race and with targeting a particular group is that they have the ability to alienate them because the campaign is sent out as a general message and it is interpreted as a personal one. According the above analysis, it appears that the more that campaigns attempt to 'target' it in its content, the more problems that are raised. The *Back to Sleep* campaign changed to address the hot topic of disparities, but by failing to take the context of the disparities into consideration, it fizzled. It also did not take into consideration the real issues with culture in African American communities and infant care advice. Not only the source of the information more trusted if it comes from a family member with experience, but there is profound distrust in the official means and media used to distribute health information. The challenge is not only with the source of information, but with identifying the validity of the information. As the above analysis shows, scientific research is not enough to determine precedence over lived experience.

SIDS also needs to be placed within the context of infant mortality and the disparities between whites and blacks. Research clearly shows that there are many issues at stake with examining racial disparities and infant mortality and the different causal factors that contribute to this, especially in urban areas. The assumption that information per se is a persuasive factor clearly falls short and makes the individual responsible for risk factors often beyond their control.

# CHAPTER 5

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On October 10, 2005 the American Academy of Pediatrics (AAP) released an update of its policy to reduce the risk of SIDS. Though most of the recommendations reaffirmed what had been declared before—babies should sleep on their backs on a firm uncluttered mattress, babies should not be overheated, and secondhand smoke should be avoided—some of the recommendations were new and contentious enough to stir debate. Among the controversial items were recommendations that parents not share a bed with an infant under any circumstances (though sharing a room with infants who slept in their own beds was acknowledged to be protective); pacifiers were recommended during bedtime for the first year (though not until after the first month); infants should be placed in the prone position while awake to prevent plagiocephaly, or "flat head syndrome"; and products marketed to prevent SIDS like breathing monitors and sleep positioners should be avoided. Though these new recommendations were meant to address some long simmering issues present since the *Back to Sleep* campaign began, they also signaled a turning point in the campaign's efficacy.

The detractors from these new recommendations appeared quickly after the American Academy of Pediatrics' announcement in 2005, indicating a dramatic switch from the welcoming response the *Back to Sleep* recommendations received eleven years earlier. Breastfeeding advocates like La Leche League International were concerned that the no bed-sharing and pro-pacifier suggestions would have a negative effect on infant nursing, and issued a press release to respond to the policy statement; members of the breastfeeding section of the AAP announced that they did not support the recommendations of the SIDS policy section; and the president of the Academy of Breastfeeding Medicine called them a "truly astounding triumph of ethnocentric assumptions over common sense and medical research" (LLLI 2005). SIDS professionals including nurses, doctors, and counselors debated the recommendations in person, in print, and on professional list-servs. Parents around the country bristled at the notion that their approach to infant care (particularly bed sharing) was being called dangerous and voiced their oppositions to the recommendations in the media.

Indeed, a lot had changed since the initial AAP SIDS risk reduction recommendations in 1992. Between 1983 and 1992, the average number of deaths diagnosed as SIDS per year reportedly ranged from 5,000 to 6,000. Since the late 1990s, the number of SIDS deaths has declined significantly—and in 2002 in the United States 2,295 infants died from SIDS (NCHS 2004). Another indication that much had changed is that SIDS does not receive the media attention that it once did. A survey I conducted of major newspapers around the country from 2001 to 2005 using the key words “SIDS” and “infant” found a total of 53 articles, significantly less than appeared during the same time period twenty years earlier. The topics of the articles often reflected some of the previously established narratives about SIDS: parents’ stories and offering support to one another; new research, specifically the newly discovered genetic links to SIDS; reports of the continuing disparities between African Americans and other groups in SIDS rates; and fundraising by SIDS support groups around the country. However, there were also new themes that appeared in the articles that challenged how SIDS was being framed, such as articles about mothers and fathers criminally charged with murdering their infants who were originally thought to have died of SIDS; the increase of infants with flat heads as a result of excessive back sleeping; the implication of bed-sharing as a possible risk for SIDS; and discussions of how the diagnosis of SIDS was changing due to the increase of declaring suffocation or 'unknown' as the cause of death.

This snapshot of how new SIDS risk reduction messages were received in late 2005 has all the makings of a *Back to Sleep* backlash. With the risk of SIDS becoming an even more remote possibility to an individual family, what significance does SIDS have as a public health problem today? Also, more than a decade after the *Back to Sleep* campaign began, what are its medical, social, and institutional by-products? Though viewed as a public health campaign success story, as a national public health policy, *Back to Sleep* has led to significant unintended consequences beyond its original scope and intent which need to be examined. As the sociologist Deborah Lupton has noted, "[l]ittle research has been undertaken into the practical and ethical consequences of health risk appraisals…" (Lupton 1995:82). Media critic Richard Pollay also reflects the need for investigating the effects of public health campaigns:

> "The seeds planted by campaigns may bear strange fruit….This issue of the by-products or unintended consequences of campaigns, however, is rarely researched and discussed, especially by professional persuaders and their associated technocrats, including applied academics." (Pollay 1991:190)

Sociologist Robert Merton described the concept of "unanticipated consequences of purposive social action" seventy years ago where he identified five sources (Merton 1936). He posited that government actions always resulted in these unintended effects, and were most often the result of the first two sources: ignorance and error. However the unintended consequences that I have identified of the *Back to Sleep* campaign have primarily been the result of Merton's third cause, the *imperious immediacy of interest*, which can override long term concerns. Merton describes immediacy of interest as:

> "…[I]nstances where the actor's paramount concern with the foreseen immediate consequences excludes the consideration of further or other consequences of the same act. The most prominent elements in such immediacy of interest may range from physiological needs to basic cultural values." (Merton 1936:901).

I argue that the desire on the part of the four claims-makers, particularly the federal government, to come up with a solution to the problem of SIDS as quickly as possible after studies in other countries showed a decrease in SIDS rates as the result of public health campaigns, long term effects were either ignored or not even considered. As discussed in Chapter 3, the *Back to Sleep* campaign was presented as a proactive step in the fight against SIDS, a pressing public health problem that could potentially happen to every infant. By dealing with these immediate consequences, the long term effects of the campaign were unintended.

This chapter looks at the unintended consequences of the *Back to Sleep* public health campaign and its messages of risk. Specifically, six unintended consequences and their implications are discussed: 1) the increase of "flat head syndrome" as a result of the *Back to Sleep* campaign and its effect on families; 2) the marketing of SIDS risk reduction products that sell (false) hope; 3) an increase in parental anxiety over the risk of SIDS; 4) the difference between how primarily white, middle class parents challenge the *Back to Sleep* recommendations and how African American parents who resist the campaign's messages are viewed by public health professional; 5) the conflict between parental values and public health recommendations with the co sleeping/bed sharing debate; and 6) recent diagnostic shifts from SIDS to suffocation as a cause of death, the diagnostic shift's resulting implications for bereavement, and a return to parental blame for the sudden death of infants.

## Medical Consequences Since *Back to Sleep*

### "HELP! MY BABY HAS A FLAT HEAD!"

This headline from an article in *People* Magazine on July 4, 2005 (three months before the AAP recommendations were released) exemplifies the public reaction to an unintended medical consequence of the *Back to Sleep* campaign—a consequence that could have been anticipated, but that nevertheless occurred. As a result of more babies being put to sleep on their backs to reduce the risk of SIDS, there has been an increase in "flat head syndrome" in some infants, which results from excessive back sleeping because their skull bones haven't fully hardened, and pressure from the mattress on the baby's skull can flatten it.

This condition, which is officially known as plagiocephaly, has increased five fold since the *Back to Sleep* campaign in 1994 (Meadows 2005), and though often considered to be harmless, the issue over possibly having a flat head for life has led concerned parents to go to doctors who will prescribe helmets (which cost up to $3000 and are not always covered by insurance as it is often considered a cosmetic procedure) to be worn by infants to reshape the head. The helmet must be worn for 23 hours a day, and must be constantly readjusted to re-shape the baby's head. Plagiocephaly has been said by plastic surgeons to have reached "epidemic proportions" (Lorsee, Corde, and Mason 2005) and they lay the blame for it solely on the *Back to Sleep* campaign. As far as the actual amount of babies affected, a recent cohort study in New Zealand found that the prevalence of plagiocephaly was almost 20% among infants at 4 months old

(Hutchenson et. al 2005).

Though flat head syndrome is not considered a risk that outweighs the benefit of the *Back to Sleep* campaign to reduce SIDS, the issue is brought up by the media and parents who are angry that they were not warned about it in the campaign's materials. As one SIDS professional who deals with these issues on the national level said about the media focus on flat heads:

> "Well, they're still sort of attacking us in terms of why didn't we push this since the beginning, or sort of saying something like is this something we've overlooked; they are trying to get at that angle. You know nasty reporters." (AF)

As a result of these types of complaints, the issue of flat head syndrome was addressed in the 2005 AAP recommendations. They now advocate for "tummy time"—placing the infant on its stomach when awake—and moving the infant's position in the crib each night. However the tummy time recommendation did not totally solve the problem of parent's perception. Since the *Back to Sleep* campaign successfully convinced its audience to avoid the prone position, some parents are afraid of putting their babies on their stomachs *at all*, even when their babies are awake. The following exchange between two mothers on an internet parenting discussion board exemplifies the concerns:

> Hey!
> I am listening to screaming as I type this!
> Ashlee is getting a VERY flat back of her head from being on her back ALL THE TIME!
> I try tummy time, but she absolutely hates it.
> So I always put her back to her back.
> WELL, this morning, I've just left her on her tummy, and I feel so bad cuz she is screaming and pi$$ed as heck!
> What do I do????? ~*~ Debbie ~*~
>
> The problem is that we are so conditioned to fear putting babies on their tummies that when the time comes to do it, the babies do not like it or they are scared. Maybe starting babies on their tummies earlier (although not to

> sleep) might help. Just an idea. --Diana

Failure to place an infant on their stomach when they are awake, along with the prolonged time infants are spending in car seats and infant swings have also led to delayed development of motor skills with some infants including holding the head up, crawling and pulling to stand (Davis, Moon, Sachs et. al. 1998). This developmental delay has also been attributed to parent's fear of putting their infants on their stomach when awake since the *Back to Sleep* campaign since these gross motor skills all require the use of core muscle strength that an infant develops while laying on their stomach (Meadows 2005). For some infants, these physical side effects can take years and thousands of dollars to undo. This unintended consequence of the *Back to Sleep* campaign demonstrates how the successful communication of the campaign's main messages over the years has transformed into a sense of fear among some parents. By focusing on the immediate issues of reducing the risk of SIDS, the claims-makers behind the *Back to Sleep* campaign were able to establish a public health problem but potentially create another one.

## Risk Reduction Products: Paying for Peace of Mind

Due to the uncertain cause of SIDS, there has been a history of attempts to reduce the risk of it occurring that have varied from harmless to life threatening, (as described in Chapter 2). Since 1994 when the *Back to Sleep* campaign and its risk reduction messages were developed, manufacturers have developed products related to the supine sleep position. These products are marketed to help to reduce the risk of SIDS and give parents a sense of security. However, many of the new consumer products that were created to protect infants and offer peace of mind to anxious parents either do not work or are not safe. This is another unintended consequence of the *Back to Sleep* campaign.

In March 2000, the Consumer Product Safety Commission (CPSC) went after manufacturers that made products that claimed to *prevent* SIDS. These products were advertised mainly on the internet, and included the Baby Safe mattress cover that claimed that they were "proven to 100% effective in preventing SIDS" and even that "your baby can sleep on his/her tummy" (thediaperlady.com). Other products include "breathable" mesh topped mattresses and mattress covers—one even came with an air pump—that promoted their safety and ability to remove the risk of infants who used them of dying of SIDS. The CPSC said that despite the claims, it was not aware of any evidence that babies can safely be placed to sleep on their stomachs on these products, or that using the products would reduce the risk of SIDS. There have been no deaths associated with these products and the CPSC was only moderately successful in preventing these products from being produced, though it requested that stores stop selling them (CPSC 2000). However, many of these products are still currently available for sale on the internet. The claims made by the products that babies were safe from harm when placed on their stomachs directly contradicted the prevailing public health advice about infant sleep position and reducing the risk of SIDS, and these claims led to the Food and Drug Administration to also investigate these products (CPSC 2000).

Since SIDS is still an entity with an unknown cause or causes and it still holds anxiety and uncertainty for parents and caregivers of infants, there continue to be products that are developed and sold that claim to help to reduce the risk of SIDS. Some of these products include: infant positioners, which are meant to keep infants on their backs in a crib when asleep, and a one piece wearable blanket that zips around an infant so that additional bedding is not needed. Also, even though the apnea theory was discounted as a possible cause of SIDS decades ago, there are now reconfigured apnea monitors on the market, which are designed to sound an alarm if it detects a stop in an infant's breathing. However, these monitors have been known to cause more anxiety than comfort to new parents as they tend to go off frequently. The impact of American Academy of Pediatrics 2005 recommendation not to purchase these products is not yet known, however, these products are currently available for sale at your local baby superstore.

Parents want to protect their infants from the risk of SIDS, but products that they buy cannot stop this from happening. The burden of responsibility for removing useless and potentially harmful products should not rest on the parents of infants, but be shared by the manufacturers and retailers. Retailers sell these products without guarantees to consumers that they are safe or effective, and there is no accountability on their part if the products are found to be hazardous. As new scientific findings indicate potential risks to infants, parents are left questioning what is safe and who they can trust. Risks already lurk just about everywhere for a new parent, and weighing the safety of the products that are meant to protect, comfort and soothe babies is enough to lose much more than sleep over.

## SIDS and Parental Anxiety

### *Bringing the inside out*

Studies of how people interpret health related messages in the context of their everyday lives show that they are able to "distinguish between the demands of institutional imperatives and how these should be applied to their private lives. This is particularly the case when researchers have been able to go beyond people's 'public' accounts of health, which tend to conform to official orthodoxies on the individual's responsibility for her or his health, to their 'private accounts'" (Lupton 1995:140). These studies find that people construct and enact lay health beliefs in a way that allows them to accept certain health recommendations and reject the ones that are too difficult to apply to their lives (Backett 1992, Lupton 1994b, MacInnes and Milburn 1994).

These flexible interpretations of public health recommendations in people's everyday lives in the studies cited above are based on personal health behaviors like exercise, diet, drinking, and smoking. Mothers are also constantly sorting through advice about how to care for their babies, discovering the ways that work for them. Today in the United States, mothers acquire information on raising children from a wide variety of sources—from books and magazines to nurses and doctors to family members, and digital divide be damned, increasingly from the web. Mothers also make selections among these sources and develop interpretations based on their social circumstances, and who they trust. Indeed, according to the research of sociologist Sharon Hays who analyzed different sources of mothering advice, almost all American mothers recognize, interpret, sort through, and respond to the ideology of 'intensive mothering' that focuses on providing the 'best' for children according to the prevailing experts of the time (Hays 1994). Hays states that mothers tend to 'filter the advice' that they receive from childrearing manuals and subject the advice to personal interpretation. This process usually takes place inside the home within family structures.

What the *Back to Sleep* campaign did was to bring the world of infant care sleep practices that were previously the province of inside the home to the outside world. As a public health campaign, *Back to Sleep* addresses all parents, not just the small group of families personally affected, bringing the risk of SIDS to every baby. By laying out the risk reduction methods for parents and caregivers and establishing concrete steps to do something about SIDS, there was less room for personal interpretation and selection on how to put infants to sleep. *Back to Sleep* brought about a different level of visibility to infant care sleep practices which were previously kept close, as information passed between women or interpreted from pediatricians or books and pamphlets. What *Back to Sleep* did was to open up the ways in which babies were cared for to the outside world, and placed a judgment value on them: the right way and the wrong way to put a baby to sleep--not what would be better or would be helpful, but what could reduce (or increase) the risk of the infant's death.

As discussed in a previous chapter, the media attention to this topic helped to establish SIDS as a significant public health problem that could possibly affect all infants. The increased visibility and judgment presented in the media that was associated with infant sleep practices changed child rearing from an 'inside' behavior to an 'outside' one as a result of the *Back to Sleep* campaign. This shift has been recognized by SIDS professionals:

> MC: With *Back to Sleep*…I think the spotlight was on it in a very different way than had been before. This has always been a part of maternal and child health, it's always been there in the teaching. All of a sudden it's a *Parents Magazine* thing, about here are all these things you can do to reduce risk, pay attention to bedding and pay attention to this and pay attention to that. Some of those were part of the common cultural norm. You sort of heard those things from your friends or your mother or all these sorts of things, but here it was articulated in more public venues, and a pamphlet, in *Parent's* articles, news reports. So I think, my hunch is that there were unintended consequences to taking this body of sort of quietly communicated cultural information and pulling it out and popping it out into different, there's a different level of visibility…

The unintended consequence of this increased pressure on parents to follow the recommendations and advice of experts has been noted by social scientists as an increasingly significant factor in modern life (Furedi 2002, Hays 1994, Stearns 2003). In recent books about this phenomenon, known as “paranoid parenting” or “anxious parenting”, as the dangers and risks to children get publicized in the quest to become social problems, parents are left feeling that they have to be on top of all the risk reduction recommendations that abound. By the beginning of the twenty first century, a sense of fatigue over these constant concerns began to take hold among social observers and parents themselves. The fear of SIDS is often mentioned as one of the issues that contributed to the rise of the ‘anxious parent’ in books that were published by sociologist Frank Furedi in 2002 and historian Peter Stearns in 2003 on the phenomena:

> Every parent is plagued by the media fueled fear that crib death, or SIDS might suddenly snatch their child away in the night. These apprehensions are regularly reinforced by new studies that claim to have discovered yet another cause of crib death. Small obscure studies contradicting previous findings are reported as serious news. The relentless publicity that surrounds crib death produces anxieties that are completely disproportionate to the scale of the problem…It almost seems that campaigns around SIDS guilt-trip parents. (From *Paranoid Parenting:* 12)
>
> Most important was the anxiety that the popularization of SIDS generated. Growing understanding that accidental deaths could occur, bolstered by reams of popular articles, left many parents nervously checking on their offspring frequently during the night—even though there was almost nothing they could do…Pediatricians eagerly distributed warnings, which further raised anxiety to potentially disproportionate levels. (From *Anxious Parents*: 33)

With the move from private to public, from inside to outside, from behaviors that are passed down and kept close from women to women to the surveillance of public health recommendations, there is an official designation of what is ‘right’ and what is the ‘wrong’ way to deal with an infant’s sleep habits. Though it comes from a supposedly objective scientific background, the transformation to public health recommendation is not value-free, and their creation now makes the discourse of infant care practices disciplining. *Back to Sleep* recommendations help to shape the broader norms of good parenting, with the lived experiences of the intended audience often dismissed, or not acknowledged at all. This tension between the nature of messages contained in public health recommendations and individual infant care practices is not only felt by parents, but also by those who create public health campaigns, as a coordinator for the federal *Back to Sleep* campaign told me in an interview:

> And that's probably why [parents] have this mistrust, you know? It's like you tell me this is good, you tell me this is bad and then you tell me it's good again, and it's so hard to keep up with it because you want people to trust you, you're trying to do something good, but it's hard because it just keeps changing and people are like "I don't trust this", you know? "They keep changing their minds; I don't know what's good." (AF)

This uncertainty and issues of trust do not show up in the *Back to Sleep* materials. Indeed, public health media campaigns of this nature are an instructive force by the state to normalize parenting practices, and as such present only the conclusions, not the process of decision making. The expectation is that the audience will follow the recommendations given without question or concern if they want to protect the health of their babies. Resistance to public health recommendations are often framed as deviant behavior (as in the case with African Americans and their 'failure to comply' with the *Back to Sleep* messages described in Chapter 4) and no room is left in the official discourse for challenging these recommendations by the audience.

However, with the rise of media technologies that allow for a more interactive public voice, particularly elements of the World Wide Web such as websites, email listservs, wikis (interactive websites) and individual web logs (blogs), there has been a new space opened for people to challenge many different forms of authority. This has been the case with infant care advice, where new media forms allow for a site of resistance to the prescribed recommendations and allow actors to present a challenge to the authority of public health recommendations by sharing these ‘inside’ practices and bringing them outside, but with a sense of agency, and on their own terms. For example, consider this posting that appeared on a parenting bulletin board:

> I am SO sick of being presented with official orders about how I should raise my child (it was even worse when I was pregnant). And when I try to find out why, what's the evidence, what's the incidence of negative outcomes, I usually just get a shocked, ‘You don't want to take chances with your baby, do you?’ I'm sick of the manipulative scare tactics being used to bludgeon parents into being obedient little sheep! Posted at 11:58AM on Oct 19th 2005

In addition to this general dissatisfaction with the increasing presence of child care recommendations, SIDS risk reduction is an increasingly popular area for people to challenge the public health establishment.

## The *Back to Sleep* Backlash

Though the *Back to Sleep* campaign has had an impact on how babies are put to sleep, there are parents who have resisted the message. The risk of SIDS on an individual level is small enough that one could never encounter its effects, allowing for personal experience of how babies sleep best to outweigh the latest advice from above. As *Back to Sleep* entered its second decade in the spotlight, there grew to be a sense of fatigue with the messages. The reasons for this have to do with the conditions in which the campaign was created: first, the risk of SIDS was always relatively low for the general population, and now it was even lower, making it harder to convince people that this was something that could affect them. Second, it was in the news less often, and when it was it was not portrayed in the way it had been. There was less focus on the distraught parents or the doctor's search for a cure, and more of a focus on the successes of the *Back to Sleep* campaign. Third, parents (particularly those in the upper and middle classes) began to react more vocally against being told what to do with their kids by 'experts', especially advice that seemed to be remote to their situations and that interfered with their own lives. Some parents found that putting baby to sleep in the prone position appeared to be more comfortable for their babies, and that the baby slept better and more soundly, other parents found that their infants 'preferred' the prone position, and struggled to get them to stay in the supine position. That parents were starting to challenge the recommendations of *Back to Sleep* have been acknowledged by SIDS professionals:

> LB: …it can get the parents going and then they are like, you know, I don't know anybody that ever had it [SIDS], I don't know anybody's family that ever had it, I've never heard of it and so it doesn't exist. People are concerned about tiring too, to the parent, if they feel that the kids aren't comfortable, and they don't want to be up all night, I mean who does.

Also, there was still the 'conventional wisdom' left over that babies should sleep in the prone position, which made it seem like an acceptable thing to do, since so many babies slept this way and nothing happened to them. The presence of this resistance was facilitated by the rise of the internet as a source for medical advice in the early 21st century, particularly bulletin boards and blogs where people could communicate to one another about these once private practices and seek out alternative sources of advice (Pitts 2004, Hardey 1999). This form of media also justified certain choices because there seemed to be others who were doing the same thing.

An article in the *New York Times* encapsulated this trend of parents' resistance to the messages of *Back to Sleep*. Published a week after the new AAP recommendations in October 2005, its title summed up the current ethos: "A Quiet Revolt Against the Rules of SIDS". The article talked about how parents were "mounting a minor mutiny against the medical establishment" by putting their babies to sleep on their stomachs because the babies slept better in that position. This practice, the article said, was done mostly in private or kept a secret from other parents for fear of disapproval, with confessions being posted anonymously on web sites. The reaction to this article prompted even more parental confessions of challenging official advice on parenting web sites:

> My wife and I are contemplating the whole "Back to Sleep" thing right now with our one week old. He sleeps so much better on his stomach, which we let him do when we're awake and in the room with him…We don't want to risk it, but it sure would nice if we could have something other than statistical significance as to why we shouldn't let the dear child sleep on his belly.
>
> Our baby (7 months old now) started sleeping through the night when she was 2 months old. We'd put her on her back, and she'd just slide over on her side. Once she learned how to roll over, it was all over. We're still kind of paranoid about it, after the 'shock and awe' Back to Sleep campaign, but she seems to have done fine.
>
> My doctor aunt told me that the conventional wisdom was now that it was ok for babies to sleep on their stomach. Do most parents take all risks that occur in the 1/1000-0.5/1000 range into account when ordering the lives of their children? Such as having a bucket anywhere on the premises? Or is it just the fashionable, "in-the-news" risks that we guard against?

Though by now smaller in number, SIDS parents also participated in these new media outlets, responding to the parents who are challenging the recommendations with the emotional appeals that they had been used so successfully in the past:

> Has anyone lost a child to SIDS? Do you know anyone who has? I do...not only do I know parents who have lost their babies to SIDS, but I lost my daughter. I once believed that things like SIDS only happen to other people. Well now that I

> am one of the "other people", I can tell you that I would recommend that you do EVERYTHNG in your power to decrease your risk factors…As a parent who has lost a child, I urge you all to do whatever you can to keep your babies alive. They have an entire life to sleep on their belly...place them on their backs until at least 6 months old. The rate of SIDS has dropped over the years because we have learned more about it as the years go on. Please don't let your children become a statistic! Posted on Nov 6th 2005 by Trisha

Overall, these responses indicate that parents negotiate how they interpret public health recommendations that pertain to the care of infants based on how much at risk they feel that they are in. Parents appear to be wary of the way that the SIDS risk reduction recommendations are meant to apply to everyone, particularly if they do not feel that the risks are significant enough to affect them. This backlash to the recommendations of the *Back to Sleep* campaign represent the growing awareness on the part of audiences to question the source of the information, and then to question the motives of the sources. I feel that this backlash is an unintended consequence of the campaign, one that was clearly not anticipated when the claims-makers got together to craft the original messages. This resistance also indicates a shift in the stages of SIDS as a public health problem, since its importance as an issue is being challanged by those that are meant to be persuaded. In addition, as the SIDS risk reduction messages continued to expand and incorporate critiques of different areas of infant care, parents continued to express their dissatisfaction.

### *Parenting choice or deviant behavior? Race and Resistance*

The resistance to infant care advice described above (which is seen as consisting of primarily white and middle class parents) has not been framed the same way as African American resistance to *Back to Sleep.* For white parents, choosing the prone position is seen more as a lifestyle or parenting choice that is being made by rational actors who are logically assessing the risks and making informed decisions as it applies to their infant's lives. However, as described in Chapter 4, inner city African Americans who put their babies to sleep on their stomachs are portrayed as non compliant care givers who cannot follow an important public health recommendation. As a result of African American's perceived resistance to *Back to Sleep*, there are special provisions made to target them through 'culturally sensitive' messages and outreach. There is no comparable concern for the increased resistance by the presumably white middle class parents who post on parenting message boards who are the subject of *New York Times* articles. This consequence of the *Back to Sleep* campaign in not unintended in the same way as the others mentioned, but instead tend to reflect the prevailing attitudes of the creators of public health campaigns and how they view issues of race, agency, and risk as it relates to infant mortality. Future campaigns may also veer in this direction by viewing resistance to pubic health campaign messages differently according to variables such as race and class.

## The Bed Sharing/Co-sleeping Debate

Sharing a bed with an infant is a common practice in many cultures around the world, and is a growing movement among parents in the United States (McKenna 1996). Commonly referred to as "co-sleeping" or "bed sharing", 13 percent of infants shared a bed with their parents for the entire night in 2000 compared with 5 percent in 1993, with nearly 50% of American infants spent at least some time sharing a bed with adults. A study (conducted by the NICHD) also found that African-American infants were four times more likely to bed-share than Caucasian infants and Asians almost three times more likely (Willinger et.al. 2004). However, in spite of its apparent ubiquity, the 2005 AAP recommendations designated bed- sharing a risk factor for SIDS for the first time. Previously, studies linking SIDS to bed-sharing had focused on the association between mothers who smoke and their infants' risk of SIDS, and the epidemiological evidence had never been conclusive enough to draw definitive correlations between an increased risk of SIDS and bed-sharing for non-smoking mothers (Blair, Fleming, Smith et. al. 1999). By 2005, the AAP, though acknowledging that adult/infant bed-sharing is a "highly controversial topic", stated that "…the task force concludes that the evidence is growing that bed sharing, as practiced in the United States and other Western countries, is more hazardous than the infant sleeping on a separate sleep surface, and, therefore, recommends that infants not bed share during sleep." (Pediatrics 2005:1252). This AAP statement was based on evidence from a multi-site study called the European Concerted Action on SIDS study that found that bed sharing with mothers who did not smoke was a significant risk factor among infants up to 8 weeks of age, and other studies that found that the risk of SIDS is higher when there were multiple bed sharers and when the bed sharer is overtired (Pediatrics 2005). As previously mentioned, this recommendation stirred up controversy among different groups who support bed sharing, and also fanned the flames over the concept of "the family bed", a practice which has divided parents and professionals for some time.

The arguments to support the practice of bed sharing rely on convenience for breastfeeding, comfort, bonding between a mother, father, and an infant and that it is the norm in many cultures around the world. This trend toward bed sharing in the Untied States appears to be supported by the increasing numbers of women who breastfeed, particularly women who work full time. Bed sharing allows for more bonding time as well as improved quality of sleep for these mothers. Those who support bed sharing also contend that it may *reduce* the chances of SIDS because of increased infant awakenings and less time spent in deep sleep (McKenna et al 1996). Other studies have shown that breast-feeding protects against SIDS, and bed sharing promotes breast-feeding (Chen and Rogan 2004). Organizations and others that promote bed sharing believe it can be safe with proper precautions.

Those in favor of bed sharing also noticed an inconsistency with the AAP recommendations: the combining of the risks of SIDS with the risks of suffocation. The AAP recommendations appear to suggest that bed sharing increased the possibility of SIDS, when they were really discussing the dangers of accidental injuries caused by an unsafe sleep environment. The implications of blurring of these two different causes of death will be discussed in more detail below, but it did not go unnoticed by parents who bed share as they reacted to the new policies in parenting web sites:

> I co-sleep with my babies and I can't imagine parenting an infant any other way. What is so ridiculous about telling parents not to co-sleep is that the studies that show it to be dangerous are referring to suffocation/asphyxia. THAT IS NOT SIDS. Sorry, this is so aggravating to me, it's like we're all considered idiots, why can't they just give recommendations on how to co-sleep safely. Japan has the lowest rates of SIDS in the world & they are a huge co-sleeping culture. Human babies, like all mammals are designed to be close to their mom, that's why they're helpless, in fact the most helpless of all mammals & yet they're supposed to be alone all night in our culture. Bizarre. Sometimes doctors over think and forget about common sense.

Those who oppose bed sharing are concerned about the safety of the infant as well as what is said to be the increased risk of SIDS, though they are often citing the risks of suffocation under the SIDS umbrella. The chief concerns of those who discourage the practice of bed sharing are: the type of bedding being used, the size of the adults (overweight and obesity are cited as risk factors), and the positioning of the baby, all of which could lead to suffocation if appropriate safeguards aren't put in place (Kemp, Unger, Wilkins et. al. 2000, Scheers, Rutherford, Kemp 2003). In 2002, the U.S. Consumer Product Safety Commission issued a warning against placing babies in adult beds, reporting that more than 100 deaths of children younger than 2 who died in adult beds from 1999 to 2001 (CPSC 2002). Typical of such cases are babies smothering from being rolled on by an adult, or suffocation from inappropriate bedding, such as pillows, comforters, soft mattresses or waterbeds. Other hazards include infants becoming stuck in headboard openings or entrapped or wedged between the mattress and the wall.

There is also opposition to bed sharing based on cultural taboos in the United States against parents sharing a bed with an infant. These norms reinforce notions of autonomy and independence of the individual (the infant), the practice of independent sleep spaces with the ideal of separate rooms for babies that perpetuates middle class affluence. There is also the idea of the parental bed as a place for intimate sexual contact, which is to be kept private. As a result of these cultural norms about infant sleep in the United States, parents who choose to share a bed with their infants are either seen as occupying a lunatic fringe or have been forced to engage in this practice in secret.

The unintended consequence of the AAP’s decision to include bed sharing as one of the risks for SIDS is that it has created a fundamental challenge to parental values when parents disagree with the child rearing practices being promoted, and those who choose not to go and heed the campaign’s advice risk being stigmatized. This has been recognized by SIDS professionals, who note:

> …most people don't want to tell you what their practices are. I think there are deeply entrenched beliefs that you know, babies are safer if you are right next to them. And the other thing is that [some] babies may not have cribs, or the apartment may not be large enough for a crib. Or there are several people in the bed, it is a family bed. And it isn't a matter of bonding, it's a matter necessity. So then what do you do? You have to try and teach, you have to be realistic, about how do you make the bed as safe as possible if it is the family bed and there is no choice. So we can have these guidelines, but it may not be implementable for a lot of people in their homes, or want them implimentable, you know? (JA)

Parents' bed-sharing with their infants can be seen as another example of the 'defiance' of expert advice. Similar to putting babies to sleep on their stomachs instead of on their backs, it is often done in secret and is frowned upon by society. This resistance to challenging of parental values has been expressed on parenting web sites, which offer the comfort of anonymity:

> What amazes me about this debate is that everyone thinks they are right for EVERYONE. We do not co-sleep but many friends (if not most) do, and whenever we talk about our sleeping arrangements it seems everyone feels like they have to justify themselves. I feel guilty, they feel guilty-it's like a huge guilt fest because everyone wants to do it right. Kinda depressing that no parent feels like they can make a decision without consulting an "expert". Posted at 1:52PM on Oct 31st 2005

The bed sharing debate touches upon many deeply held beliefs around the best way to care for an infant and represents a clash between these beliefs and the advice of 'experts'. This tension was noted by a New York City SIDS professional who saw that parents attach values to the practice of bed sharing:

> LB: the toughest one for us, I think, is this perception that the people in the focus groups had that babies are best cared for when the parents are attentive. When the parents are around, sharing the bed, the parents keep the babies close, and their perception is that bad things only happen to people who aren't good parents.

That's a tough one.

Though the discussion of bed sharing in relation to SIDS is the most recent, it is clearly an issue that will continue to cause friction between parents and professionals.

## Diagnostic shift

Though the cause of SIDS is still unknown, over the past 30 years there have been changes to what is diagnosed as a SIDS death. The diagnosis is still one of exclusion, and before the *Back to Sleep* campaign many infants that were found dead during sleep were signed out as a SIDS death. The cause of death during this time was usually made by coroners and medical examiners as a compassionate gesture meant to comfort the parents. As SIDS was being established as a public health problem, the main message in SIDS material and among professionals was that these deaths could not be prevented or predicted. Parents who were given a SIDS diagnosis as the cause of death for their babies could at least be comforted by the prevailing rhetoric that there was nothing that they could have done to prevent the death from occurring.

Since the *Back to Sleep* campaign began, this is done less frequently. Today the campaign provides concrete risk reduction measures to be followed and the consequences for parents whose babies die of SIDS today have shifted from "nothing they could have done" to something they failed to do. Also significantly in 1989 the official definition of SIDS was changed to "infant death that remains unexplained after the performance of an autopsy, an exploration of the medical history of the infant and family, and *an investigation of the scene and circumstances of the death*" (Willinger et al 1989, emphasis added). The addition of the death scene investigation to the cause of death had a profound change on the way that SIDS was diagnosed by scrutinizing private child care practices and presenting them to public authority figures to judge. With the campaign of SIDS risk reduction techniques such as the supine sleep position and removing excess bedding from the crib, if any of the identified risk factors are found present in the death scene investigation, a SIDS diagnosis was unlikely.

So what is the story behind the statistics that show a decrease in the SIDS rates since the *Back to Sleep* campaign—are they the result of fewer infants dying of SIDS or an increase in the sudden death of infants being diagnosed as something other than SIDS? The *Back to Sleep* campaign is often credited with contributing to the 50% decrease in the SIDS rates in the United States since 1996, since they occurred during the same time period. However, recent studies that delved more deeply into the details of these statistics tell another story. In an article published in *Pediatrics* in 2005, researchers examined changes in post neonatal mortality rates from 1992 to 2001 "to determine if the decline in SIDS was due in part to a shift in certification of deaths from SIDS to other causes of sudden unexpected infant death" (Malloy and MacDorman 2005). They looked at U.S. mortality data and reclassified all infant deaths according to the ninth and tenth editions of the International Classification of Diseases (ICD), which have different specific underlying causes of sudden infant deaths between editions. The authors looked for changes in the classification in these categories: SIDS, suffocation in bed, suffocation-other, aspiration, homicide, injury by undetermined intent, and other unknown or unspecified causes and adjusted the mortality rates for the differences between the two editions of the ICD. They found that between 1992 and 2001, all causes of post neonatal mortality dropped by 27%, and SIDS rates dropped by 55%.

However, between 1999 and 2001 they found no significant change in the overall rate of post neonatal mortality even though SIDS rates dropped 17% over the same period. The researchers found that increases in rates of mortality for “unknown” and “unspecified” and “suffocation” during this same time period (1999-2001) accounted for more than 90% of the decrease in SIDS rates. They concluded that since SIDS rates fell when the post neo natal mortality rate stayed the same suggested that a change in classification may be occurring, and that “the efficacy of the implementations of guidelines for the certification of deaths under the current definition of SIDS remains elusive” (Malloy and MacDorman 2005:1252). This study showed that a diagnostic shift away from SIDS as a cause of death to other, more specific causes was indeed occurring.

This diagnostic shift away from SIDS and its implications is another unintended consequence of the *Back to Sleep* campaign. Today, if there are other possible causes of infant death found in the investigation of the death scene, they are increasingly cited, when before the *Back do Sleep* campaign these same deaths would have been called SIDS. For instance, currently in New York City, infants found dead in an adult bed or in the presence of other risk factors are not classified as SIDS, but as “possible suffocation”. A maternal and infant health professional elaborated:

> JA: This just came out…guidelines for death certificates: “An infant co sleeping or bed-sharing with adults or siblings, the case should not be SIDS. If an infant dies while sleeping on soft, compressible bedding, it should not be SIDS. If an infant death during prone sleeping is anything other than a hard mattress designed for safety, this is not SIDS.” So do you see what is happening? What I conclude from this, or the way I see it anyway, is what we see as risk factors for unsafe sleep are becoming factors that determine the certification of the death. That is how the death is certified. The certification of death is now influenced by these factors that we know are risk factors for unsafe sleep.

The implications of this diagnostic shift are both epidemiological and social. Now with the increased investigation into the cause of these infant deaths, there inevitably is a change—a decrease—in the numbers of SIDS deaths. This diagnostic shift has been indicated as contributing to the decrease of SIDS since the *Back to Sleep* campaign (Sheehan, McGarvey, Devaney, et al. 2005). As a medical professional in New York City explained how the decrease occurred here:

> LB: I think that in 1990 there were 97 deaths that were classified as SIDS in New York City and now it's down to like 25, but how many of those are undetermined? Some of those are certainly undetermined, some of those are specific injuries, but I think we can feel comfortable that the ones that they are classifying as SIDS are real deaths and not a hodge-podge of deaths like they are around the country, where people really don't know what they have, because nobody's checked.

The diagnostic shift is similar to the time period before SIDS was constructed as a public health problem, where coroners and medical examiners either didn't believe in or were reluctant to classify an infant death as SIDS and suffocation was often given as the cause of death. One of the SIDS health professionals who worked in the area for thirty years noted this change during an interview:

> MC: [N]ow there are some who feel uncomfortable calling it SIDS if the baby was sleeping on its stomach.…15 years ago we would have said, "it doesn't matter how the baby was found, or who the baby was sleeping with, it's SIDS, and that means it is nobody's fault…Now, can't say that. Can't say it was the fault, but you can't say it's not anybody's fault. The message is out there. Don't co sleep and don't put your baby on the stomach."

The above quote also suggests one of the social implications of the diagnostic shift is that bed sharing has increasingly been implicated as a risk factor, if not for SIDS, then for "accidental suffocation" or "positional asphyxia", or even another cause of death

"SUDI", the Sudden Unexplained Death of an Infant. Moving away from a SIDS diagnosis to implicate infant care practices such as bed sharing also brings back the issue of individual responsibility for the sudden death of infants. Where SIDS has succeeded in removing the parent's guilt because SIDS can not be prevented, this trend towards these other, more specific classifications put it right back. Thus the unintended consequence of the diagnostic shift is that less attention is paid to SIDS, and more to "bed related" deaths of infants that revive many of the issues SIDS parents faced 30 years before have increased.

### *Changes in Bereavement and Blame*

As a result of the diagnostic shift away from calling certain deaths of infants SIDS, there has been a more emotional and personal unintended consequence: the way that a parent grieves for their baby. With the increase in causes of death that implicate bed sharing and other infant care practices, parents can be left with the feeling that there was something that they should have done to prevent the death. The parent or caregiver becomes the person who put the infant in a vulnerable position, for whatever reason, and therefore can be blamed for contributing to the death. This effect of "blaming the victim" occurs as a result of these new classifications when personal child rearing choices become the domain of public health campaigns. This change in parental blame and bereavement was articulated by a SIDS parent on a professional SIDS list serv[12]:

> Two SIDS parents recently contacted me with SUDI [Sudden Unexplained Death of an Infant] rulings that I feel sure would have been ruled SIDS 14 years ago…I know these SUDI rulings (in which it is often noted that "asphyxiation cannot be

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[12] This is another example of a form of electronic media where people are challenging the official word and where SIDS risk reduction recommendations are often debated and negotiated.

> ruled out") are causing lots of distress among the SIDS parents I've talked to, especially when there appears to be no evidence that the babies have suffocated...It really freaks me out to think that if [my son] had died during one of the many times I slept with him and if it were the year 2005 instead of the year 1991, then I would most likely have the words "possible asphyxiation" on his autopsy report. I hate to say it, but I fear I would have taken my own life if I'd seen those words because I was in such tremendous grief that I was already thinking of suicide even when everyone, including the medical examiner and the doctors and the police and my neighbors, were telling me that I was not to blame. SIDS parents always feel guilty even if there is nothing to feel guilty about, so you can imagine the daggers that strike their hearts if people are telling them they ARE to blame. I can't even imagine the agony of that.
>
> --Mother of Christian (3/8/91-5/9/91), who died of SIDS

The assignation of blame when it comes to an infant's death can be especially devastating when it comes from an official outside source. With the cause of death shifting from SIDS to possible asphyxiation, parents are not only left with feeling that there was something that they could have done to prevent the death from occurring, but that something *should* have been done to stop it from happening. Bereavement also shifts from the helpless feelings of "why me" to feelings of culpability and "why didn't I do something". There is also outside scrutiny of parenting practices that would allow for such an accident to happen. When the SIDS diagnosis was successfully constructed by claims makers in the late 1960s, particularly among parents of infants who died, it was to avoid these types of accusations from those outside of the family that parents were to blame. This helped many parents to deal with the death of their baby, and empowered them to marshal resources to support one another and to research the true cause of these deaths. Though many of the deaths that had been signed out as SIDS since that time may have actually been caused by suffocation, it was often seen by pathologists as a "diagnosis of compassion", often made specifically to help parents to deal with the tragedy of a sudden death (Timmermans 2006).

With the diagnostic shift from SIDS to accidental suffocation, the causes of death might be more specific for statistical recording purposes, but there is a trade off with how families handle their grief. A SIDS professional told me during an interview that the diagnostic shift has had this kind of an impact on how families deal with an infant death. Before this diagnostic shift, when the cause of death was SIDS, they might have come together to comfort each other. Now, they look to blame each other for the responsibility of the infant's death. In the example below, she described how one care giving decision led to tragedy:

> JA: I made a home visit not that long ago and the mother and the father asked the father's sister to take care of the baby for one night, and this was the one night the baby died. And they told the sister, the father's sister to put the baby in the crib on the back. And the father's sister let the baby sleep with her daughter, who was a teenager. Now OK, so the baby died. Now why did the baby die? I don't know. Was it related to overlaying and suffocation? I don't know…Was it because the baby wasn't on the back? I don't know…

Now that SIDS is no longer possible as a cause of death because the baby was found in the death scene investigation in an adult bed, there are changes in how the blame is assigned. In this case, the result was that blaming the person responsible led to a very different bereavement and mourning:

> JA: So this mother is living in a family where they won't talk to each other. Her baby is dead, the mother and father, their baby is dead. They blame the sister in law. The sister in law is now persona non grata, no one wants to deal with her, do you know?...So, in the end, they are all these other issues to deal with because a baby died. What are you going to say to that family? It is very complicated. You are dealing with loss, and you are dealing with loss with people who do feel responsible…

The process of grief over the death of an infant is often complicated and long lived.

However, the change in focus to diagnosing fewer deaths as SIDS and more as accidental suffocation or other designations is an unintended consequence of the *Back to Sleep* campaign and the way that SIDS has been constructed and reconstructed over time. This shift seems to bring the pendulum back to where it was when SIDS parents organized 40 years ago to alleviate feelings of responsibility and blame by constructing SIDS as a public health problem. Today, it appears that this most emotional unintended consequence resurrects issues that were thought to have been resolved, and leaves behind more questions than answers, all these years later.

## Conclusion

As the *Back to Sleep* campaign continues in its second decade, there is a need for a re- evaluation of the significant accomplishments that have been reached. Looking at the unintended consequences raises awareness of knowledge and the social factors that are involved with the campaign's construction. SIDS was constructed as a public health problem by claims makers who had their different interests served by establishing its risks for all parents. However, the success of *Back to Sleep* opened up the possibility that the knowledge that was created would be challenged and re-negotiated by claims makers. On one side, it seems that the AAP and the NICHD were satisfied with keeping the knowledge the same as it had been, but tensions arose from SIDS professionals and from the now general category of parents. The establishment of SIDS as a public health problem got all parents good and scared, and actually added to a growing sense of 'parental anxiety' that has emerged in the past few years. This tension would be broken in a way that was not intended: parents challenged the recommendations about SIDS because they did not feel that it applied to their lives.

From individual parents and how they relate to the diagnosis of SIDS today to the changes in the classification of SIDS and how these ‘new’ classifications (SUDI, etc.) are further extending the work of some of the original claims-makers. For SIDS professionals, they seem to still be negotiating SIDS recommendations and how they should be delivered. There seems to be a splintering of this group, and they are making their voices heard. This is the case with the bed sharing issue and how this has entered the SIDS debate in a way that it never had before. The new AAP policy from October 2005 brought SIDS back into the news and opened up new levels of debate about the nature of their recommendations for all parents. For parents, things have changed in that there is now resistance to *Back to Sleep* recommendations as well as using the media to challenge the official world of parenting advice. Also for parents, the changing nature of SIDS has brought up different issues of bereavement and blame that harkens back to the original concerns SIDS parents had over 40 years ago.

# CHAPTER 6

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The SIDS story documented in this dissertation has gone through dramatic conflicts and resolutions, impressive negotiations, reinvention and backlash, all underscored by the overwhelming emotion associated with the sudden death of an infant. Over the last sixty years, the explanation for the cause of these deaths has shifted according to the social context in which they took place, and various claims-makers have succeeded in making SIDS a significant public health problem. In addition, the *Back to Sleep* campaign to reduce the risk of SIDS is seen as one of the more successful public health campaigns in recent history, and it has contributed to the reported 50% decrease in SIDS rates over the past decade. However, with all of the significant steps made to move the social construction of SIDS forward since the middle of the 20th century, there was still on constant dilemma: no one knew what caused it. Hypotheses were tested, risk reduction factors were found, but SIDS was still centered on an unknown. The most recent chapter in the SIDS story was revealed in late October 2006 with the release of findings from studies of brain stems of infants who were diagnosed with SIDS. Drs. Kinney and Paterson, researchers from the Children's Hospital of Boston and the Harvard Medical School, released their findings that suggested that the babies who died of SIDS that they studied had defects in the brain's ability to produce serotonin, which is a neurotransmitter that significantly influences a baby's breathing and heart rate.

The results of these findings made the news, and many of the media accounts focused on the theme that the medical answer to the SIDS question had been finally found. The national newspaper *USA Today* presented a quote from Marion Willinger of the NICHD, one of the most significant SIDS claims-makers in its lead paragraph, who presented the by now familiar narrative:

> ’SIDS is no longer a mysterious entity,’ says Marian Willinger, a SIDS specialist at the National Institute of Child Health and Human Development, part of the National Institutes of Health in Bethesda, Md. The new findings add strong evidence to the theory that SIDS is caused by biological differences in the brain. This report should go a long way toward easing the guilt that some parents feel when a baby dies of SIDS, Willinger says. (*USA Today*, October 31, 2006)

This latest addition to the SIDS story revisits the themes of medical mystery, scientific breakthrough, and parental guilt. The serotonin study may or may not lead to the Holy Grail of the prevention of SIDS, but it certainly underscores how SIDS continues to develop as a public health problem into the 21st century.

The research for this dissertation revealed that over the past forty years, claims makers were successful in moving crib death/SIDS from a personal, individual issue to a public health problem. SIDS officially shifted from being the cause of an accident or carelessness or murder to a scientifically investigated medical issue. The desire on the part of parents and medical researchers to define and diagnose the sudden death of infants has reflected changing standards of medical knowledge, and funding for SIDS research followed the creation of it as a social problem. It was seen as a mystery that science was working on to solve, and removed the responsibility from mothers to the state. This shift allowed for the first campaign materials to come out of this that supported the ‘no blame’ perspective. Finally, the work of the claims-makers served to medicalize infant deaths from sin to science. However, this victory was not easily relinquished once the issue of sleep position was found to significantly reduce the risk of SIDS with the development of the *Back to Sleep* campaign. After all of the effort to have SIDS be seen as a public health issue, not a personal one, and an issue that you could do nothing to prevent, the *Back to Sleep* campaign represented a shift back to individual parental responsibility.

## Revisiting Theory

In this dissertation I presented three theoretical frameworks that I found to be useful in analyzing my data and answering my research questions. The theories of critical public health, medicalization and the social construction of illness, and social problems construction were used to understand what was "behind" the creation of a public health campaign like *Back to Sleep*. At the end of my analysis, I found that these theories were enlightening in allowing me to comprehend how a public health campaign gets created, who is responsible for its creation, and what the consequences of this creation are. By looking at the *Back to Sleep* campaign through the lens of these three theoretical frameworks, I was able to unpack the influence of claims-makers on the development of SIDS as a public health problem. The critical public health perspective allowed for me to see how the emotions associated with parenting, particularly the emotions of fear and guilt, were used to bring about action from the federal government to 'do something' about SIDS.

In particular, I found the model for social problems construction proposed by Hilgartner and Bosk (1998), which examines the 'rise and fall' of social problems through the lens of public arenas to be helpful in analyzing the SIDS story overall. This model stresses the 'arenas' where social problems definitions evolve, and examines the effect of those arenas on both the evolution of social problems and the actors who make claims about them. This model focuses on competition and assumes that public attention is a scarce resource, allocated through competition in a system of public arenas. I feel that my research contributes to the development of this model of how social problems are developed. From this perspective, overall public attention over SIDS and *Back to Sleep* campaign has waned over the years as the media arena displays less interest and the audience resists its messages. This has required that claims-makers re-establish the importance of SIDS as a public health problem, for example by connecting it to the problem of racial disparities and the creation of culturally competent campaign messages.

As the numbers of SIDS cases decreases, programs that were established over the past 30 years are not going away, but are re-branding themselves. One parent group (and one of the original claims-makers behind the creation of the *Back to Sleep* campaign) formerly the SIDS Alliance, is now called First Candle, which reflects its changing focus to the overall health of infants until their first birthday and deals with issues of miscarriage and still birth in addition to SIDS.

In addition, as the policy arena is showing less interest in SIDS as a public health problem, SIDS programs are aligning with the broader issue of infant mortality. Indeed, as a researcher from the NICHD said in response to the future of the *Back to Sleep* campaign:

> AF: "…until there is any indication that we know what the cause is and if any way to screen for SIDS, I don't think we can wrap it up. We might get a little closer as to risk reduction recommendations, it might be narrowed down a little bit more, and I think in the future of SIDS is going to be broader than just SIDS. It's going to be infant mortality and there's a lot more - - I mean if you look at the recommendations, it applies to more than just SIDS, to infant mortality in general"

The continuation of the *Back to Sleep* campaign and the increased focus on the causes of infant mortality in general represent a new possibility for SIDS as a public health problem. However, by focusing on the larger issue of infant mortality, claims-makers will need to move beyond individual level risk factors that have been the focus of the *Back to Sleep* campaign and focus more on the fundamental causes of infant mortality that require change on the community and policy levels.

## What could/should have been done differently with *Back to Sleep*?

The *Back to Sleep* campaign on many levels represents success in terms of a public health campaign that brought attention to a significant issue that had previously been dismissed as an accident or neglectful child care. It also successfully brought together different advocacy groups to change public policy and established federal funding that continues to today.

However, after looking back at the way that the campaign was constructed and after my analysis of how the campaign created its messages, I feel that there is one significant decision that could have been made differently. The *Back to Sleep* campaign focuses on several techniques to reduce the risk of Sudden Infant Death Syndrome. These include putting babies to sleep in the supine position, as well as removing extra soft bedding from their cribs and not overdressing the infant. Though these factors have been shown to increase the risk of SIDS, they are all individual actions for parents and caregivers to take, a focus of the campaign that should have been downplayed.

Putting responsibility on the individual parent for reducing the risk of SIDS, considering how claims-makers established SIDS over the years as something that “no one could do anything about" brought blame back to the parents. A mother could follow all of the risk reduction techniques and still have and baby die of SIDS. In these cases, blame and guilt go back to what "could have been done", as well as suspicion of child rearing techniques instead of the sympathy for the parent that is usually associated with a tragedy. As the diagnostic shift takes place away from SIDS and towards such causes of death as "suffocation", the increase in parental blame and difficulties with bereavement may increase.

Focusing on the individual risk factors in the *Back to Sleep* campaign should also have been avoided because of the nature of the 'causes' behind infant mortality in general do not end with individual level issues, but are multi-factorial, particularly for blacks and Native Americans in the United States. The disparities in infant mortality rates between races and ethnicities contribute to the United States as having one of the worst rates among developed countries, and focusing on individual risk factors does not go far enough and serves to blame the victim. When the *Back to Sleep* campaign began in 1994, the federal government did not put SIDS within the context of infant mortality and did not look at community and policy level influences on these rates. By connecting SIDS to larger social issues like maternal health, poverty, and social support, these same resources could have had a more long lasting effect on improving birth outcomes in the United States.

### How can public health campaigns be better designed to avoid unintended consequences?

This dissertation examined the unintended consequences of a public health campaign, and found that there were several that occurred as a result of the need to *do* *something* about SIDS as quickly as possible. Though it is impossible to anticipate all of the possible scenarios that result from any policy action, there may be ways for public health campaigns to be better designed to avoid unintended consequences.

Based on my research, I feel that when interventions and campaigns are designed, they need to consider how the messages will play out over time. Often campaigns are designed to address an immediate need, and do not take into consideration how the audience will react to prolonged exposure to the campaign's messages over the course of several years. In order to address this, campaign designers should assess what the *social landscape* is for their particular issue and how this may change. For example, questions that could be asked are: who are the claims-makers behind the discourse as it already exists, what is their motivation, and how are they presenting themselves in the media? The social landscape also involves looking at how this particular public health issue came to be seen as a problem. Looking back into the history of the issue may help to understand the current situation and how to construct appropriate messages.

Another consideration for how public health campaigns can be better designed to avoid unintended consequences would be to understand that the audience will have different reactions to the messages at different points in time, especially if the message stays the same. With the proliferation of health advice from many different media, we are all exposed to recommendations of what to do to improve our health or the health of our families. Interactive media allows for a new way for audiences to negotiate these health recommendations, and this ever increasing reality needs to be accounted for. I have found that unintended consequences arise from looking too narrowly at a health issue and by not anticipating alternative interpretations of the messages presented. The field of public health can benefit from a critical sociological perspective that can examine a health issue as it is mediated through issues of class, race, and gender. Integrating these perspectives still needs to be resolved, though there are many opportunities for collaboration as both disciplines continue to grow.

## Next Steps

After completing this research, I am encouraged to bring a sociological perspective to public health and health policy. I would like my future research to be able to communicate solutions to health issues in a way that empower those who receive its messages. How health information is created, communicated, and interpreted is my overall focus, and I believe that the audiences who receive this health information need to be aware of the larger social structures that created and shaped them. By exposing the way that health information comes into being and why it is being presented, I feel that audiences will have more power behind their individual and family's health decisions.

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