**Title**

Breathing Uneasy: Citizenship and Subjectivity in Pediatric Asthma Management

**Permalink**

https://escholarship.org/uc/item/3848f0zf

**Author**

Higashi, Robin Takeko

**Publication Date**

2010

Peer reviewed|Thesis/dissertation

# Breathing Uneasy:
# Citizenship and Subjectivity in Pediatric Asthma Management

by

Robin Takeko Higashi

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

Medical Anthropology

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

AND

UNIVERSITY OF CALIFORNIA, BERKELEY

[redacted]

# Acknowledgments

I could not have completed this dissertation or the graduate program without the support of several key people:

First, thank you to the members of my Dissertation Committee, Profs. Sharon R. Kaufman, Ian Whitmarsh, and Charles Briggs. Sharon, your encouragement and support for the kind of anthropological project I wanted to conduct was unsurpassed, and I am profoundly grateful to you for your belief in my talents. Ian, your warm demeanor arrived like a ray of sunshine on the Department; thank you for your astute feedback. Charles, your work continues to inspire how I view the world and the kind of contributions I wish to make; thank you for your nurturing influence on my thinking and being.

I'd also like to thank Prof. Dorothy Porter who, as Chair of my Qualifying Exams, made the four-hour ritual a positive and productive experience. Dorothy, your "Health and the Modern State" was my favorite graduate class, and your influence on my intellectual development is evident especially in the chapter on health citizenship.

I had the honor of working with two exceptional medical anthropologists earlier in the graduate program: Profs. Philippe Bourgois and Gay Becker. Philippe, your work inspired me to become a medical anthropologist many years ago; I am lucky to have learned about structural and symbolic violence from its preeminent scholar. Gay, your spirit lives on in the legacy of your work; I will continue to emulate the kind and sensitive ethnographer and person that you were.

Thank you to Prof. Rosemary Joyce for selflessly supporting me through the first year exam at Berkeley.

Thank you, Kimberly Bissell, for the reliable administrative support that allowed me to devote maximum thinking to the dissertation. Thanks also to Daniel Hayes.

I am grateful for the helpful feedback and moral support provided by many classmates, especially those in my dissertation writing class.

I owe a huge debt of gratitude to the staff at the Pediatric Asthma Clinic at San Francisco General Hospital, especially Dr. Shannon Thyne and Nan Madden. Thank you for giving me the opportunity to conduct this project in the midst of your clinic work and for responding so generously to all of my questions and requests. Special thanks to Stephanie, Silvia, Andrea, Alice, and Andy – Asthma Clinic is a special place not only because of the cutting-edge medical and social services that you provide, but because you are all such compassionate and trustworthy providers. Thanks also to the many other clinic staff members and students for assistance with patient referrals and recruitment.

Thank you to Gloria Thornton for allowing me to participate in the San Francisco Asthma Task Force and to share my findings with the many committed professionals in attendance.

I am deeply grateful to the many providers, children and families who agreed to speak with me individually, welcomed me into their homes, and allowed me to observe them in intimate clinical settings. While I have altered your names and personal details in order to preserve your anonymity, I hope you will find your voices and your experiences in this text.

This project was funded by the University of California President's Fellowship, the UC Berkeley Mentored Research Fellowship, the UCSF Health Services Research Fellowship, and the Fletcher-Jones Fellowship. The generous financial support of these organizations allowed me to focus my time and resources on completing this project.

Finally to my parents and my sisters, it is only because of your love and commitment to me that I have arrived at this moment. I share this achievement with you.

# Breathing Uneasy:

# Citizenship and Subjectivity in Pediatric Asthma Management

Robin Takeko Higashi

This dissertation answers the question: Given the availability of inexpensive and effective medications and services that make asthma a controllable disease, why do so many children continue to suffer from asthma? This is a timely and compelling question given that asthma is the second leading chronic disease among children, and costs the U.S. upwards of $20 billion a year. In this ethnography, children (ages 7-17) and caregivers from some of the poorest African-American and Latino communities in San Francisco describe the constant, ongoing array of daily life challenges that makes effective asthma management a frustrating and sometimes unattainable goal. These barriers to care take many forms: social and economic inequalities that produce instability and health hazards in the home environment; fear and the durable impact of negative experiences with health care providers and insurance workers; gaps between health insurance eligibility, enrollment, and long-term coverage; and the ambiguous and conflicting roles and expectations of children and caregivers in health maintenance tasks. Participant narratives illustrate how families negotiate these barriers, why they may choose not to, and why they sometimes fail. The dissertation also describes how the State's imbalance of health care provisions for children and adults has produced a unique situation in which children have the opportunity to act as the conduits to health citizenship for uninsured family members. And it shows how medical practitioners who are cognizant of these challenges sometimes find themselves in an uncomfortable position in which they must reconcile their professional and moral obligations.

Although the barriers to asthma management may seem daunting, this dissertation argues that suffering from asthma can be mitigated by practitioners who communicate empathy informed by an appreciation of the impact of poverty, immigration, and bureaucracies of power; it can be reduced by policymakers who recognize patterns of discrimination and the impact of denying health care to certain population groups; and it can inform health care consumers and advocates that the context of individual experience often limits the conditions of possibility for achieving better control of asthma symptoms.

Table of Contents

# List of Tables and Figures

Tables

Figures

# List of Photos

# Chapter 1: Introduction

This dissertation answers the question: Given the availability of effective and inexpensive medications and services, why do so many children continue to suffer from asthma? This is a compelling question given that asthma is the second most common childhood illness, affecting nearly 7 million children in the United States (Bloom, et al. 2009). According to the National Health Interview Survey (NHIS), the primary tracking system for asthma reporting, asthma prevalence in the U.S. doubled between 1982 and 1995.[1] While adults suffer from asthma as well, the disease disproportionately affects children and African-Americans, as well as other low-income minority populations.[2] Poorly controlled asthma results in a variety of symptoms that commonly include chronic cough, shortness of breath, and fatigue, but may also lead to respiratory arrest, organ failure, and death. Since its peak in the mid 1990s, asthma prevalence has continued to increase steadily, making it a compelling health problem in the United States today (American Lung Association, 2010). This dissertation offers ethnographic evidence of how families contend with the challenges of pediatric asthma management, and how they assess the problem of asthma in the context of their everyday lives.

---

[1] Note: NHIS data on asthma prevalence is based largely on self-reports. In 1997 NHIS changed its system of reporting from "period prevalence" (having asthma in the last 12 months) to prevalence based on having the disease at the time of the interview and experiencing an attack in the last year. Understanding this change in survey reporting is important when examining longitudinal statistics of asthma prevalence. Further information about changes in asthma reporting is beyond the scope of this dissertation, but is available at *http://www.nhlbi.nih.gov/guidelines/asthma/asthgdln.pdf.*

[2] Throughout this dissertation I use the terms "African-American" and "Black" interchangeably because participants in this study used both terms to describe their racial identity. Likewise I use the term "Latino" for non-White Hispanics as this was the self-descriptor used by the majority of participants of this ethnic group.

## Impact and Significance of Pediatric Asthma

Many years ago while working on a project on children with cancer, I overheard a physician tell a parent, “This is complicated stuff. It's not like asthma where you just suck on an inhaler and it's all better.” The steady increase of urban pediatric asthma prevalence in the 1990s and its disproportionate impact on poor African-American and Latinos, however, belies the argument that asthma is easily controlled. While the physician may have been trying to express compassion for the parent of the child with cancer, I realized that his remarks were far from accurate. Still, the notion that asthma is a “controllable” disease persists, and this misconception may be a factor in the blame and stigma sometimes directed toward parents of children with poorly controlled asthma.

Unlike some childhood diseases, such as autism or diabetes, pediatric asthma can be managed effectively with inexpensive medicines, and can be controlled with relatively simple treatment regimens. Despite the fact that the cause of asthma is yet unknown, the pathophysiology of asthma is well understood: airway inflammation and constriction creates respiratory distress characterized by diminished lung capacity and mucus buildup in the respiratory airways. Likewise, asthma management techniques are relatively straightforward and low-tech; steroidal inhalers reduce airway inflammation and broncho-dilators open constricting airways. Proper use of medications and the reduction of environmental asthma triggers has been shown to be effective in reducing the frequency and severity of symptoms for the vast majority of asthma sufferers. In sum, if prescribed medications and management techniques are followed, asthma can be almost entirely controlled such that patients experience symptoms far less frequently and far less severely.

As is often the case, however, many patients do not follow prescribed asthma management protocols. Poor asthma management results in increases in the frequency and severity of symptoms and a greater likelihood of asthma-related illnesses such as pneumonia. Asthma and asthma-related illnesses are the third leading cause of hospitalization among children under 15 (ALA 2010). While asthma mortality rates are much lower for children (ages 0-17) than for persons over age 65, asthma accounts for nearly 200 child deaths per year in the U.S. (ALA 2010).

Racial and economic disparities is asthma prevalence and severity have been well documented in the literature. African-Americans (12.8%) suffer from asthma at a significantly higher rate than Whites (7.9%) (Akinbami 2006: 9). Among Latinos, prevalence varies among ethnic groups and geographic regions of the U.S. for reasons that are not entirely clear. For example, Puerto Rican children have the highest asthma prevalence rates of any racial or ethnic group in the nation at 19.2%, while Mexican children have among the lowest rates at 6.4% (Akinbami 2006: 9). Asian children (4.9%) have the lowest asthma prevalence rate of any racial group, and Native Americans fall about midway between Blacks and Whites at 9.9% (Akinbami 2006: 9). In addition to disparities in overall asthma prevalence, Black children have higher rates of emergency department visits and hospitalizations, and asthma deaths among Black children are a staggering six times higher than Whites (Akinbami 2006: 8-9). While overall asthma death rates have declined since their peak in 1999, the rate among Black children remained unchanged, thereby increasing the disparity of asthma deaths between Black and White children.

The continually increasing prevalence of asthma has produced significant health and economic consequences. Poorly controlled asthma leads to more frequent use of costly emergency services and hospitalizations and reduces quality of life. Asthma costs the United States $20.7 billion dollars a year, $15.6 billion of which is a result of direct health care costs and $5.1 billion from indirect costs like loss of productivity when parents miss work (ALA 2010). Asthma is one of the leading causes of school absenteeism among children, and is the leading chronic condition leading to limitations in physical activity, making asthma a major co-morbidity factor for children with type II diabetes.

In sum, we know who asthma affects and who is at risk of developing asthma, we have the tools to diagnose and monitor asthma and asthma triggers, we know how asthma affects the body, and we know that inexpensive medications are highly effective in reducing asthma symptoms and severity. So why do so many children continue to suffer from asthma? Also, what accounts for the race- and class-based health disparities that put low-income urban African-Americans and Latino children at greater risk? The dissertation answers these questions using patient and caregiver perspectives, provider perspectives, historical and social analyses of poverty and race, analyses of federal, state, and city health policies, and a critique of children's subjectivity and cultural constructions of childhood. Viewed as a whole, these analyses and perspectives portray how cumulative and intricate barriers make asthma management far from simple and straightforward.

## Contributions of this Research

In this dissertation I argue that pediatric asthma management is difficult, if not impossible, for many low-income San Francisco families because of the cumulative impact of daily life challenges that are a product of poverty and immigration status, life experience, and organizations of power. I demonstrate how historical events that produced social and economic inequalities over the course of the 20th century today constitute durable and ongoing barriers to care for many families.

Some barriers are structural in nature. Racist housing and employment policies and practices, urban "renewal" projects, and increasingly concentrated neighborhoods of poverty and violence have spatially and socially segregated low-income communities in San Francisco. In addition, the State[3] has failed to act in a timely manner to reduce environmental toxins and improperly disposed hazardous waste, despite extensive documentation of the levels of toxins and their impact on residents' health. For example, the higher concentration of asthma, birth defects, infant mortality, and cardiovascular disease in Bayview Hunter's Point are widely attributed to the neighborhood's toxic

---

[3] Throughout this dissertation I use the term "State" to refer to the collective resources of the U.S. government at the federal, state, and/or local levels.

environmental conditions. Thus, I illustrate how, contrary to the American cultural values of rugged individualism and self-determination, poverty and poor health are not (purely) the result of individual behaviors. Children in low-income communities suffer from asthma because of the structural and historical conditions that have pre-disposed them to living in toxic environments and that continue to act as barriers to better asthma care.

Other barriers are rooted in and continue to impact individual experiences. For example, for some African-Americans, decisions about whether and when to seek medical care have been influenced by historical patterns of abuse by medical providers and institutions. These abuses do not solely reside in the past, however; fear and distrust are generationally and culturally reproduced and act as durable barriers to effective asthma management. Likewise, fear and mistrust constitute ongoing barriers for many Latino families whose individual experiences have been conditioned by hostile interactions with health providers, including both practitioners and health insurance workers. In addition, fear of deportation, which would produce family separation and economic instability, figures prominently into the medical decision-making processes for many immigrant families. Decisions that are reasonable and fitting in the context of individual experiences are often misunderstood by health providers as illogical or irresponsible. However, participant narratives demonstrate that barriers affecting individual experience can sometimes be bridged by sensitive providers who convey compassion and an openness to understanding the lived experiences of children and families.

This research builds on a number of themes relevant to medical anthropology. Chapter 2 contributes to ethnographies of structural and symbolic violence by illustrating the internal logic of why some low-income families do not seek or do not continue with clinical care for asthma symptoms. I argue that historical patterns of discrimination do not solely exist in the past; rather, fear and distrust of the State and of medical providers constitute durable ongoing barriers to asthma care.

In Chapter 3, I argue that asthma management is complicated by the ambiguous and conflicting roles and expectations of children in self-care tasks. That is, problems arise because children's subjectivity is conceived differently by providers, parents, and children themselves. For example, some providers feel that parents are primarily responsible for children's asthma care and other health guardianship tasks, whereas others feel that children must take greater ownership of their health and perform self-care tasks. I argue that these conflicting messages are communicated to children and caregivers and it sometimes produces a lack of consistency that reduces the quality of asthma management. Anthropological debates about children's agency and autonomy have produced compelling evidence that children's subjectivity is contextually defined, and that age is an inadequate predictor of children's roles and expectations. This research contributes to these debates by offering an explanation of why pediatric asthma management may be rendered ineffective given the lack of consistency in constructions of children's subjectivity.

In Chapter 5, I argue that the imbalance of health care between children and adults has produced a situation in which children may act as liaisons for parents to achieve health citizenship. That is, some parents who are ineligible for health insurance, unable to enroll, or otherwise unable to afford health services, may acquire health information and even medication and services through the relationship with their child's medical provider.  The extension of health citizenship to parents by children is a unique observation because it upends the traditional model of children as solely the recipients of care by adults. I argue that children's greater access to health citizenship, given expanded insurance eligibility for health services, is based on the cultural conception of children as innocent and unable to care for themselves, and thus especially deserving of the State's resources and protection. Thus, the State production of children's health citizenship, through greater access to care with public health insurance provisions, in turn creates an opportunity for adults to achieve health citizenship through their children.

In addition to contributing to debates in anthropology, I hope that this research will be of relevance to health practitioners, policymakers, and health consumers. In many ways, this research is not specifically about pediatric asthma. The narratives of patients, caregivers, and practitioners speak to broader concerns related to health care and health insurance, structures of power and bureaucracy, and understandings of poverty, race and immigration. They describe the “on the ground” experiences for children and families when public health policies fail to meet their needs, and they demonstrate how practitioners who are sympathetic to families' daily life challenges occupy an uncomfortable position as intermediaries between the State and individual health. I hope that by representing the thoughts and feelings of patients, caregivers, and practitioners, I have demonstrated not only why children continue to suffer from asthma, but also why it is imperative to understand the context of individual experiences as a basis for judging health behaviors.

## Overview of Asthma

In this next section I step back momentarily to provide an overview of asthma. This basic understanding of the disease is necessary in order to understand the physiological impact of the disease and the logistical challenges that make pediatric asthma management complicated and realistically unfeasible for many families.

### *Cause*

The exact cause of asthma is still a matter of scientists debate. Asthma incidence and morbidity have been linked by several studies to environmental factors such as cigarette smoke and outdoor pollutants (Gilmore, et al. 2006). However, evidence suggests that the cause is complex and multifaceted. Most scientists believe that genetic predisposition in combination with exposure to environmental triggers is the most likely explanation (Reed 2006). Some reports speculate that the disease currently known as asthma is actually a spectrum of conditions, and more research will yield evidence about a broad variety of causal explanations (Akinbami 2006). But for now, scientists do not know why some people get asthma and others don't, why asthma is more common in young boys than young girls but more common in adult women than adult men, and why some children's asthma worsens in adulthood while for others symptoms can completely disappear. The indefinite nature of the cause and progression of the disease may be a contributing factor to common misunderstandings about asthma.

### *Pathophysiology and Features of Asthma*

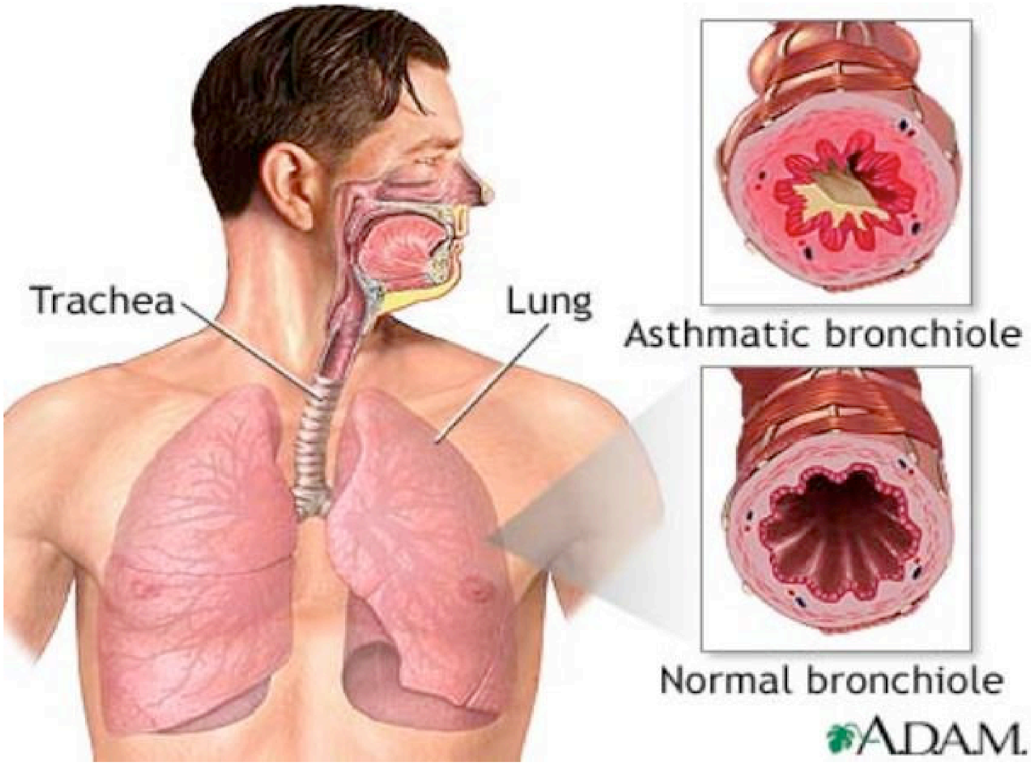
While the precise cause of asthma is yet unknown, the pathophysiology of asthma is well understood and the disease expresses fairly consistently among those who suffer from it. Biomedically speaking, asthma is a chronic illness that affects the respiratory pathways. There are three main physiological features of asthma: airway inflammation, airway congestion, and airway constriction. All three features causes the airways to be narrowed, reducing the volume of air passing through the lungs and making breathing difficult. Common symptoms include cough, wheezing, chest tightness, shortness of breath, fatigue, and asthma "attacks". Attacks are acute episodes of airway constriction that cause extreme difficulty in breathing, sometimes resulting in acute respiratory distress (very shallow breathing, intermittent breathing or person stops breathing for some time), organ damage (from lack of oxygen) or death. Asthma attacks and other symptoms can be triggered by environmental allergens (e.g. dust, pollen, pet dander), airway irritants (e.g. cigarette smoke, pollution), infections, exercise, and changes in temperature and climate. Sensitivity to environmental triggers varies so an important component of asthma management is the identification and reduction of those triggers specific to each individual.

Asthma attacks are the most visible feature of the disease and often incite emotional responses both from the person having the attack and from persons witnessing the attack. Several participants in this study indicated that fear of having an asthma attack or fear generated by witnessing an asthma attack motivated their decision to seek medical attention. In 2008 over 4 million children experienced an asthma attack in the U.S. (ALA 2010).

Mucus congestion produces the second most visible expression of asthma, characterized by wheezing and often “gurgly” sounds coming from the chest. It is possible that people without asthma can more easily relate to this symptom as it often sounds like a severe version of a chest cold in someone without asthma. While they may seem similar, however, the causes and treatment of mucus congestion in an asthmatic person often differs from that in a non-asthmatic person. The misunderstanding of this distinction, as participant narratives will show in Chapter 2, constitutes a major barrier to care. That is, persons who have undiagnosed asthma may dismiss symptoms of congestion because they seem similar to a non-asthmatic's cold symptoms. Many use over the counter cold medicines to try to alleviate symptoms such as cough or mucus. Cold medicines are generally ineffective in reducing symptoms in a person with asthma;

only asthma medications can  resolve the underlying cause of congestion and reduce the likelihood of recurrence.

**Figure 1**. Dissected View of Normal and Asthmatic Bronchiole



Source: *http://www.mdconsult.com/.../0/0/10041/19375_en.jpg*, accessed 4/1/10.

Chronic airway inflammation is the most common feature of asthma and may exist even if the person has no noticeable symptoms and feels mostly well. One of the medical providers in this study speculated that people with undiagnosed asthma may have even adapted to reduced lung capacity such that they may not realize that their lung function is compromised and that they could feel better. As an invisible feature of asthma, airway inflammation is poorly understood. Many people with chronic airway inflammation do not seek medical attention unless their symptoms become unmanageable or prevent them from doing routine tasks. Based on participant responses it seems that, even among persons who have been diagnosed with asthma, the invisibility of airway inflammation makes it difficult to appreciate the severity and consequences of the disease. Unlike asthma attacks, which provoke an immediate physical and emotional response, reduced lung function due to chronic airway inflammation does not evoke the same level of urgency and does not convey the importance of seeking medical attention.

### *Asthma Management*

Most primary and asthma specialty clinics utilize the diagnostic and management protocols established by the National Heart, Lung and Blood Institute (NHLBI, a division of the National Institute of Health). The use of evidence-based guidelines such as these promotes consistency across providers and institutions in the diagnosis and management of disease.

According to the NHLBI's 2007 “Guidelines for the Diagnosis and Management of Asthma” there are four essential components to effective asthma management. The first is assessment and monitoring, which utilizes objective reports such as pulmonary lung function tests, the physical examination, and an assessment of symptoms based on patient- and caregiver-reporting to establish an asthma diagnosis and classify the severity of symptoms. The second component is control of environmental factors and co-morbid conditions that contribute to asthma severity. Allergies provoke symptoms in over 60% of persons with asthma (ALA 2010) so the reduction of environmental triggers is an essential component to controlling asthma. While total environmental control cannot be achieved, the reduction of obvious exposure to known allergens is effective in reducing the frequency and severity of symptoms. As will be demonstrated in Chapter 3, however, the reduction of allergens is a never-ending task and can require an immense amount of time and energy. In addition, because patients (and their family members) are primarily responsible for this component of asthma management, they become easy targets for blame when asthma is poorly controlled. The third essential component of effective asthma management is education and the development of a partnership between providers and patients to participate in the treatment plan. And the fourth component is pharmacotherapy, i.e. medications to manage the severity and type of asthma symptoms. I will return to this four-step approach toward effective asthma care in Chapter 3, where I demonstrate why adherence to asthma management protocols is difficult for many families to achieve.

If followed, the NIHLBI's four component approach to asthma diagnosis and management is highly effective. However, as this dissertation demonstrates, many patients are unable to adhere to prescribed self-care regimens, and many providers and medical institutions are limited in their ability to provide all of the essential four components. In particular, most clinics do not provide comprehensive patient education about asthma and asthma management, including in-depth instruction of how to reduce triggers and use medications correctly. These components, which one physician described as “social, not medical”, are often neglected in clinical care by practitioners that focus on “objective measurements” like the physical examination and pharmacologic interventions. To be fair, medical practitioners such as doctors and nurses have rigid time constraints that prevent them from being able to adequately address the so-called social components of asthma management. Some practitioners have even remarked to me that they “weren't trained to” or “aren't paid to” do these tasks.

In sum, the logistical limitations of practitioners and facilities and attitudes about medical vs. non-medical tasks constitute a major obstacle to achieving the essential four components of asthma management. I will return to this point in the Conclusion, where I discuss how integrated models of care have already proven to reduce asthma suffering. And I argue that health care efficiency would be greatly improved by altering the organization of health care delivery to children and families.

## The Research Site: San Francisco, California

San Francisco, “the city by the Bay”, is one of the most ethnically diverse and politically progressive cities in the United States. It is the smallest of the three major cities in the San Francisco Bay Area, behind San Jose and Oakland. San Francisco's population of just over 800,000 (U.S. Census Bureau 2008b) resides within roughly seven miles by seven miles of the city's hilly terrain at the top of the Bay Area Peninsula. With the Pacific Ocean to the west, the Golden Gate Bridge and grassy headlands to the North, and the calm bay waters to the east, San Francisco offers spectacular views of nature for its urban dwelling residents.

**Photo 1**. San Francisco's Golden Gate Bridge, as seen from the Lands End Trail.

(photo by R. Higashi, 2008)

But despite its reputation for diversity and its celebration of human equality, San Francisco is also home to a large number of individuals and families living in abject

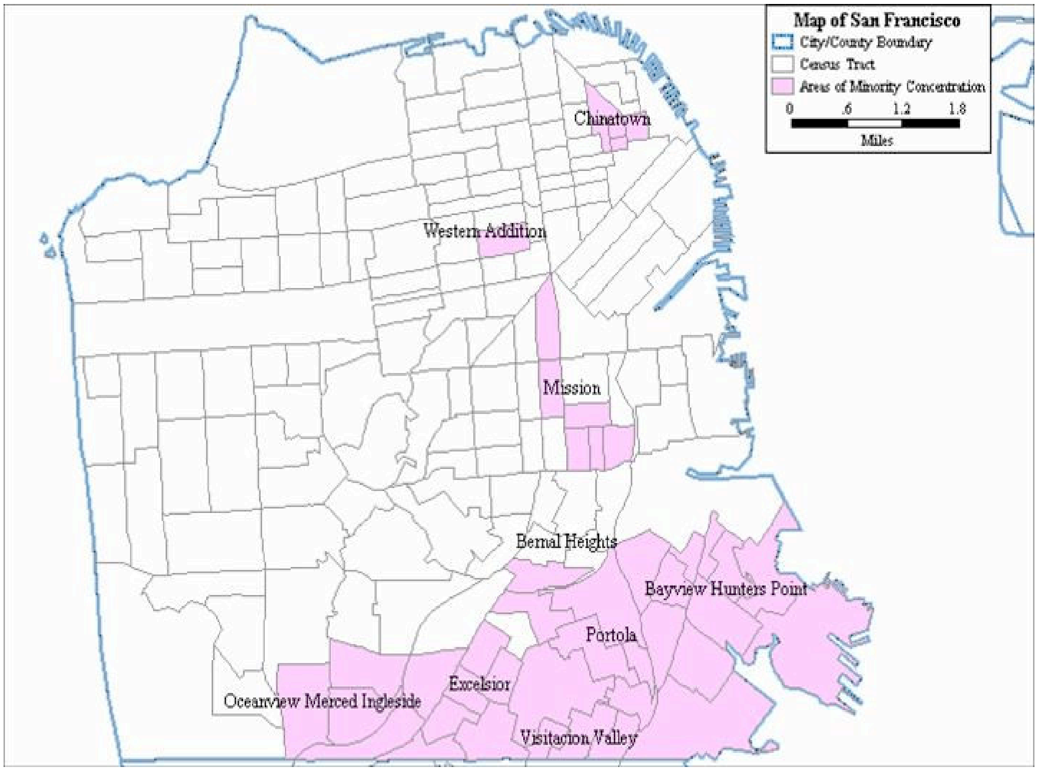
**Photo 2**. Part of San Francisco's Mission District, as seen from Bernal Hill with downtown in the background. The series of red brick buildings in front of the hill on the right is San Francisco General Hospital.

(photo by R. Higashi, 2009)

poverty. More importantly, because most of the poorest populations live in neighborhoods that are geographically and functionally segregated from the rest of the city, San Francisco's social and economic inequalities remain largely invisible and absent from the daily consciousness of many residents and visitors. While some neighborhoods showcase the city's ethnically diverse population living side by side, other neighborhoods represent the paragon of segregation, populated overwhelmingly by poor people of color. Non-residents generally do not step foot in or interact with residents in these segregated neighborhoods.

Figure 2 shows the areas of San Francisco with the highest proportion of minority residents. Latinos are the predominant ethnic group in the Mission, Bernal Heights, Excelsior and Visitation Valley; Blacks are the predominant group in Bayview/Hunter's Point, the Western Addition, and Ingleside; the city's poorest Asians are concentrated in

**Figure 2**. San Francisco's Areas of Minority Concentration



Source: www.sfgov.org/site/uploadedfiles/mocd/demoprofile.pdf, accessed 3/31/10.

Chinatown and in smaller neighborhoods across certain western areas of the city (not shown). These neighborhoods are also the most economically depressed in the city, with housing projects and substandard housing conditions that contribute to higher rates of asthma prevalence. For example, in Bayview / Hunter's Point, a neighborhood in which 52% of residents live in poverty (Palmer 2007 in Thyne, et al. 2007), the San Francisco Asthma Task Force reported pediatric asthma prevalence at an alarming 15.5%. In comparison, the national average for children ages 5-14 was 7.4% at the height of the "asthma epidemic" in 1999 (Thyne, et al. 2007). Perhaps most concerning, the hospitalization rates among San Francisco's Black residents was more than three times greater than the city's overall rates (Thyne, et al. 2007).

### *Asthma in San Francisco*

By the time asthma emerged in the early 1990s as a major health problem, San Francisco was already experiencing higher asthma rates than that of the U.S. as a whole, particularly in low-income neighborhoods. While the city overall boasts one of the most concentrated areas of wealth in the country, 13% of San Franciscans and more than 20% of San Francisco children under 18 were living in poverty in 1995 (Thyne, et al. 2007). However, there is no definitive explanation for why San Francisco's minority populations suffer from asthma at a greater rate than minorities in other areas. For example, Latino children in San Francisco suffer higher hospitalization rates compared with Latino children in other (non-urban) counties of California, and hospitalization rates among San

Francisco's Black residents was more than three times greater than the city's overall rates (Thyne, et al. 2007).

Despite the fact that scientists have yet to pinpoint the cause of asthma, many Bayview/Hunter's Point residents believe that the higher prevalence of the disease is related to environmental pollution. Numerous industrial and construction sites, two power plants, a sewage treatment facility, and the naval shipyard are all concentrated in the southeast corner of the city. Recalling Figure 2, this is also the area of the city with the highest minority concentration. In addition to higher asthma prevalence, infant mortality rates are disproportionately high in Bayview/Hunter Point, and both asthma and infant mortality are linked by the Environmental Protection Agency to particulate exposures. So while a direct causal relationship has not yet been established between the neighborhood's environmental pollutants and asthma, scientists have clearly demonstrated that asthma may be triggered and worsened by common conditions of urban poverty, including poorer housing conditions, air pollution, lack of ventilation, cigarette smoke, and other airborne allergens (Kattan, et al. 1997).

In addition to its diverse population, the city of San Francisco is an interesting study site because of its progressive health policies and services specifically aimed at alleviating health disparities among low-income and immigrant communities. San Francisco is home to a number of “free clinics” that provide medical services and medications at low or no cost, and that are funded primarily by charities and volunteer practitioners. In addition, health insurance programs in the State of California significantly extend federal and state funded coverage to a greater proportion of the population than is available in most other states. However, in Chapter 4 I describe how, despite the availability of such programs, certain challenges in accessing insurance have produce *de facto* barriers to care that account for the significant gap between health insurance eligibility and enrollment.

San Francisco General Hospital (also known as “SF General” or “the General”) is a large public hospital affiliated with the University of California – San Francisco's Medical Center and School of Medicine. Located at the southeast corner of the Mission,

**Photo 3**. San Francisco General Hospital

(photo by R. Higashi, 2008)

SF General is situated close to many of the poorest neighborhoods. Indeed, the vast majority of the hospital's patrons are low-income African-Americans, Latinos, and other immigrant groups, and most do not have employment-based or private health insurance. Much of the research for this project began at the General because of its proximity and service to residents of the city's poorest neighborhoods.

Another reason I chose the General is that it is home to one of the most comprehensive and effective asthma management programs in the country. In response to increasing pediatric asthma prevalence in the 1990s, professionals from local colleges, medical, government, and social service organizations collaborated to develop the San Francisco Asthma Task Force, dedicated to reducing the overall impact of asthma among San Francisco youth. This led to the creation of the "Yes We Can" Urban Asthma Partnership, and the implementation of a highly effective medical-social integrated model of intervention for "clinic-based, community-focused, team-oriented pediatric asthma management" (Thyne, et al. 2006: 668). The program provides services and support far beyond what is typical from most medical institutions or providers, including comprehensive education, home visits for environmental exposures, and ongoing clinic-initiated follow-up care.

Using this integrated model, the Pediatric Asthma Clinic at SF General achieved significant success toward its ultimate goal of reducing the impact of asthma. In its first two years the Clinic reported increases in prescriptions for controller medications[4]

---

[4] Steroidal inhalers, which are taken daily to reduce airway inflammation, are often referred to as "controller medications".

(conducive to better outpatient management), increased use of “action plans” (medication and asthma management instructions for families), increased use of special pillowcases and mattress covers (to contain allergens), and an overall decrease in reported asthma symptoms among pediatric patients at SF General (Thyne, et al. 2006). Despite its overall success, however, program evaluations identified that certain subpopulations did not improve significantly. Thus, evaluators were left with several questions: Why did the interventions succeed overall but fail among certain subgroups of patients? Why do Latino families report significant trouble with insurance barriers despite the availability of on-site eligibility workers? Why don't more African-American families seek treatment, and why do several not return to Asthma Clinic after the initial appointment? This dissertation answers these questions by providing both a macroscopic view of the structural barriers to care, as well as individual accounts that describe in detail the experience of asthma among low-income minority populations and why asthma is difficult, if not impossible, for many families to achieve.

## Study Design and Methods

Fieldwork for this project began at the Pediatric Asthma Clinic at SF General, where I observed clinic staff members during outpatient clinical appointments with children and their caregivers. I spoke with patients and caregivers briefly during their appointments, and with their permission, later contacted them for individual interviews with the child and caregiver. Because I was allowed to interact freely with staff and patients, I was able to observe interactions at all levels of formality, including doctor-patient interactions, casual staff conversations, and waiting room conversations. I interviewed each of the staff members at Asthma Clinic as well as other hospital staff including insurance eligibility workers, social service workers, and emergency and urgent care providers.

I then moved on from the General and conducted interviews with practitioners and administrators at several smaller community clinics and "free clinics" across the city.

**Photo 4**: A nurse examines a child with asthma

(photo courtesy of Asthma Clinic)

I was unfortunately unable to directly observe or interview patients at these other sites because separate IRB requirements at each institution would have delayed the timely completion of this dissertation. However, I was able to interview several children and families who attended other clinics through referrals provided to me by participants at Asthma Clinic. In total I interviewed 33 "families" (i.e. the child and at least one adult caregiver): 18 Latino, 12 Black, 1 Chinese, 1 Chinese-Vietnamese, and 1 Pakistani.[5] I also conducted lengthy interviews with over a dozen health practitioners (mainly physicians and nurse practitioners), and countless shorter and less formal conversations with other providers. I became an informal member of the San Francisco Asthma Task Force, attending quarterly conferences and networking with various asthma care professionals across the Bay Area. And I spoke with several health care professionals who attended my presentations at SF General and at Asthma Task Force meetings.

In addition to clinic-based observations and interviews, I also spent time in the local communities in order to witness daily life activities and solicit conversations about a variety of related topics, like housing, economic challenges, familial and social networks, schools, etc. I walked along neighborhood streets, talking with store owners, parents and children in recreational areas, and other individuals who seemed intrigued by my presence. I was often a conspicuous outsider as the only person not of that community's ethnic group. The total data collection period occurred primarily over a period of about 20 months, between August 2007 – March 2009. Several common themes

---

[5] These are the ethnic descriptors used by the participants.

emerged from the interviews and observations, and these became the primary topics of the chapters in this dissertation.

## Outline of Chapters

The chapters of this dissertation are organized by major themes in the types of barriers to effective asthma management. In each chapter, I situate participants in the context of their daily lives in order to convey the complexity of barriers they face and the logic of their decision-making process.[6] Each story is but one example of how poverty and immigration status, life experiences, and hierarchies of power and power relations make a patient's and family's behaviors reasonable and fitting, if ultimately ineffective in controlling children's asthma. My intention is not to document a series of miscues or failures by individual patients or providers. Rather, I wish to show how each challenge is negotiated (or not), and how a singular experience may impact subsequent decisions. Thus, I urge the reader to consider each story as part of a whole because it is often the *cumulative* effect of these barriers, rather than any one in particular, that ultimately answers my original research question: Given the availability of inexpensive and effective medications, why do so many children continue to suffer from asthma?

In Chapter 2, I illustrate how the social and economic segregation of San Francisco was produced by historical events that have continued to shape the daily life

---

[6] I have altered the names and personally identifying information of participants in order to preserve their anonymity.

conditions of residents today. This chapter contributes to ethnographies of structural and symbolic violence by demonstrating how decades of institutional and environmental racism have produced not only higher asthma prevalence, but a legacy of fear and distrust that constitutes durable ongoing barriers to asthma care. It is only by situating study participants in historical and social contexts that the insidiousness of segregation and discrimination is obviated in a city that is otherwise touted as a model of social progress. From this vantage point, the reader may understand the logic of caregivers' decisions about whether and when to seek clinical care for their children.

Chapter 3 describes how subjectivity in the clinical process of asthma care impacts the dynamic between children, caregivers and providers and affects the quality and effectiveness of treatment protocols. I explore how children's subjectivity as patients and minors is defined and contested in ambiguous and conflicting ways by providers, parents, and children themselves, both within and outside of clinical spaces. I also demonstrate how the social and economic inequalities outlined in Chapter 2 continue to create challenges for effective clinical care. This chapter builds upon existing ethnographies of children in clinical spaces by offering further evidence of how children exercise autonomy and how they understand their role in the triangulated relationship between themselves, caregivers, and providers.

Chapter 4 illustrates how health care eligibility does not necessarily result in effective, long-term health care enrollment and coverage for many children and families. Every single Latino family in this study, including both U.S. citizens and undocumented residents, reported negative experiences with enrolling in and maintaining their child's health insurance. And although they encountered problems with insurance far less frequently than Latinos, African-American families also experienced disruptions in health care coverage due to changing compositions of family units that impact requirements for health insurance such as guardianship, residence, and income verification. Insurance-related barriers constitute a significant barrier to asthma management, particularly given that asthma is a chronic disease that requires ongoing care. Enrollment difficulties and disruptions to ongoing coverage produce dire health consequences for many children with asthma and their families. This chapter contributes ethnographic evidence of how well-intended health policies may in fact negatively impact the communities that they are intended to serve.

In Chapter 5, I describe the imbalance of health care between children and adults, which I argue is based upon cultural constructions of children as especially vulnerable and worthy of the State's protection. This cultural bias eclipses the needs of other vulnerable communities who, as adults, are given far more limited assistance by the State. This imbalance of care, I argue, produces opportunities for unique forms of subjectivity and health citizenship. Participant narratives demonstrate how children sometimes act as the conduits for adult caregivers to achieve health citizenship, particularly in mixed-status immigrant families (i.e. families in which some members are U.S. citizens and some are not). That is, adult caregivers may acquire health information, advice, referrals, and even services and medications through their child's greater access to health services and insurance. Medical providers play a pivotal, if uncomfortable, role in the production of health citizenship. Their narratives illustrate conflicted emotions in negotiating their role as medical professionals and compassionate human beings.

In the concluding chapter, Chapter 6, I evaluate how the U.S. health care reforms of 2010 speak to the themes in this dissertation. I argue that a reorganization of health care that promotes integrated models of medical and social services would better increase quality and reduce health care inefficiency by streamlining the delivery of care, particularly for children and families who face significant challenges in achieving the basic necessities of living. Finally, I draw on the experiences of participants in this research to offer specific recommendations for improvements in clinical care that would better serve the needs of low-income populations by employing strategies that are more closely attuned to their needs.

The goal of this dissertation is to contribute to both the knowledge and practice of anthropologists, medical practitioners, and health policymakers. I am hopeful that by understanding the problem of pediatric asthma from multiple perspectives this dissertation will promote on-the-ground improvements and will inform a better approach to working with low-income and immigrant families that will ultimately reduce asthma suffering.

## Chapter 2: Segregation and Suffering

San Francisco is often touted as one of the most progressive, cosmopolitan cities in the world. Indeed, the city is home to innovative technologies, socially responsible businesses, and is a hotbed of community activism groups. Overall, the city is ethnically diverse: Whites comprise less than half the city's population (46%), 31% are Asian (including many new immigrant groups), 14% are Latino (the fastest growing minority group), 7% are Black (steadily decreasing in the last few decades), and 1% are Native American or Polynesian (U.S. Census 2008b). But while some neighborhoods are ethnically diverse, others are highly segregated by race and class. In such a small city – just 47 square miles – the rich and poor are separated in some instances by just 30 feet of asphalt from one side of a street to another.

This was the case in the neighborhood where I lived, Potrero Hill, where public housing projects and million dollar homes could be found within one block of each other. The visibility and proximity of wealth angered many of the poorer neighborhood residents with whom I spoke. One young man told me, “It's bad enough we gotta live here [in the projects]; why we gotta look at *that* all day [pointing to expensive houses], huh?! Drivin' their Beamers and big fancy cars...” Likewise, San Francisco tourists who stay in the the ritziest hotels and frequent the fancy shops at Union Square are warned by locals and by travel guides which areas to avoid because high-end real estate transforms abruptly into the drug- and crime-ridden Tenderloin area. It isn't hard to tell if one inadvertently traverses the boundary between rich and poor, however, as the sidewalks with red carpets are replaced by homeless people and urine stains, and the skin color of the passersby is noticeably non-White.

**Photo 5**: Potrero Housing Projects with Naval Shipyard in Background

(photo by R. Higashi, 2009)

For some people, the association of poverty and minority groups in segregated neighborhoods may seem like a natural and inevitable byproduct of urban life. But as I demonstrate in this chapter, the production of poverty in San Francisco was anything but natural. The structural conditions of oppression among low-income minorities today are the direct result of policies and practices that favored Whites over non-Whites and pre-determined the economic opportunities available to different racial groups. This situation is not unique to San Francisco. Several ethnographies and critiques of U.S. history have described the institutional production of social and economic segregation among various minority groups (Anderson 1990; Massey and Eggers 1990; Bourgois 1995; Cobb 1998; Baca 2005).

Despite these historical facts, however, many people today still believe that poverty constitutes a moral and individual failure (Wacquant 2008, 2009; Farmer 2006). In the United States, blaming the poor is rooted in the American values of rugged individualism and self-determination, including the belief that all individuals have the same degree of agency and opportunity to shape their environment. And yet, some studies have demonstrated that perceptions of individual accountability for poverty are attributed to poor Blacks more readily than to poor Whites (Hopkins 2009a, 2009b). In either case, but particularly with respect to race-based perceptions, moralizing judgments about the poor obscure the discriminatory events and conditions that produced poverty and social inequality historically, and that continue to shape socioeconomic mobility today.

The effects of structural violence, i.e. the macroscopic events and conditions that produce social and economic inequality, and subsequently disease, have been documented in several prominent ethnographies (Bourgois 1995; Farmer 2001; Briggs and Mantini-Briggs 2003; Wacquant 2008; Bourgois and Schonberg 2009). Documentaries such as “Unnatural Causes” (2008) and “Sicko” (2007) have shown how sickness is directly caused by, not just linked to, class difference because, for example, sickness is produced by greater exposure to environmental pollution, lack access to nutritious foods and safe areas of recreation, and greater exposure to stress and community violence. Equally devastating, however, is the accompanying effect of what Bourdieu (1990) called symbolic violence. In this case, the belief that poverty is an individual failing is a shared American value such that poor people themselves internalize blame for their condition and do not recognize poverty as structurally determined. Several poignant ethnographies have illustrated the production of social isolation and the destruction of individual will as a product of symbolic violence (Taussig 1986; Feldman 1991; Biehl 2009). The combination of structural and symbolic violence creates insurmountable conditions of oppression, and produces what Nancy Scheper-Hughes has referred to as “the violence of everyday life” (1992).

In this chapter, I hope to contribute to ethnographies of structural and symbolic violence by documenting how the historical and sociopolitical events that produced segregation in San Francisco have continued to affect low-income residents today. I argue that these events and experiences have not only produced poverty and illness, but that they constitute durable, ongoing barriers to asthma care for children and families. My goal in this chapter is to give voice to the people whose life experiences are often invisible or misunderstood, by their health providers and by the public at large, even as they live but a few blocks away. I hope to convey the logic of why some children and caregivers do not seek clinical treatment for asthma by situating families in the context of their daily life conditions. It is only through this lens that one can begin to understand why so many children continue to suffer from asthma.

## Migration and Institutional Racism

The history of San Francisco is often portrayed romantically, with emphasis on its unique social and economic fluidity and racial integration, as compared with other American cities of the 19th century. For example, unlike New York or Boston, San Francisco was not first settled under colonialism and controlled by Anglo Saxon Protestants before waves of new immigrants arrived from distant shores and competed for a place in the social and economic hierarchy. San Francisco emerged as an “instant city” (Berglund 2007) at least a century after most East Coast cities.

Before 1846, the area that is presently known as San Francisco was a Mexican pueblo known as Yerba Buena. The San Francisco Bay Area of today was mostly comprised of farm lands and was sparsely populated until the discovery of gold in 1848 at Sutter's Fort. This sparked an international migration that grew the population of San Francisco exponentially over the next three decades. In 1848, San Francisco's population was recorded as less than 1,000 people; four years later it was 30,000; and another eight years later it was nearly 60,000. By 1870 the population reached nearly

150,000, and by 1900, San Francisco became the largest city on the West Coast, with 342,782 people (Broussard 1993:11).

The early population of San Francisco was ethnically diverse, but mostly male. Whites and Latinos[7] who were living along the western frontier migrated in search of fortune shortly after gold was discovered. Chinese immigrants, who worked along the transcontinental railroad and on other labor projects, comprised nearly 8% of San Francisco residents by the 1870s (Berglund 2007). African-Americans comprised a smaller share of the population, arriving mostly from the mid-Atlantic states during the Reconstruction Era at the end of the Civil War. The large influx of migrants to the area displaced many of the Native American populations.

By 1850, half of the residents of San Francisco were born outside of the U.S., whereas only one in ten of the national population registered foreign places of birth (Berglund 2007: 4). In fact, according to Census figures for 1870, 1880, and 1890, San Francisco had a higher percentage of foreign-born residents than any other major American city, including New York, Boston, Chicago, Detroit, and Cleveland (Berglund 2007: 5). Early San Francisco provided ample opportunities for workers, businessmen, and politicians to earn a share of social and economic capital. Construction laborers and other blue-collar workers found lucrative opportunities in the

---

[7] By “Latinos” I am referring to predominantly Spanish-speaking people including both people who were born in Central or South America and migrated northward, as well as those who were born and already living in present-day California and the Southwest (also known as “Californios”). In the early to mid-19th century much of the present-day Western U.S. was ruled by the Spanish and then Mexican governments before the land was purchased as a U.S. territory under the 1848 Treaty of Guadalupe Hidalgo. Thus by “Latinos” I intend to convey an ethnic identity rather than nationality.

needs of a rapidly expanding metropolis, while owners of public gathering places like bars and hotels became some of the most well-recognized faces in town, profiting greatly from the growing numbers of residents and newcomers to the city (Berglund 2007).

**Photo 6:** “High and Dry” by Frank Marryat (1855)

Source: Bancroft Library, http://content.cdlib.org/ark:/13030/tf5g5010m2/?brand=calisphere, accessed 5/3/10.

San Francisco's emergence as an “instant city” allowed for greater social fluidity and economic mobility, at least in comparison with East Coast cities. Visitors, authors and artists have emphasized these qualities in romantic portrayals. For example, Englishman Frank Marryat produced a series of engravings based on his visit in the early 1850s. One such piece, entitled “High and Dry,” was described in this way:

> “In the far left of the foreground of this typical street scene stand two Chinese men, wearing straw hats, elbow-to-elbow with bearded Euro-Americans in their red miners' shirts. Close by, a dark-skinned man, possibly African American, stands with his arm raised. In the left corner, a man astride a horse, sporting a broad-brimmed hat, talks to another wearing a poncho, both likely Latin Americans. In the background... a bustling block, complete with some important early cultural frontiers – like the Eagle Saloon and Niantic Hotel – that San Franciscans of the early 1850s poured into when not congregating out on city streets.” (Berglund 2007:4).

While it is true that San Francisco's early character differed from other American cities because of its unique origin, some scholars have argued that San Francisco's history has been revised in a way that minimizes the racial and social tensions that existed from its outset and that escalated steadily (Broussard 1993). Others flatly dispute the idea that San Francisco today, that is, segregated and economically stratified, is radically different from its original character (Dawson and Brechin 1999). Certainly, evidence exists that historical events and patterns of urban organization produced White- and male-dominated hierarchies; these accounts refute claims of a utopian, egalitarian San Francisco.

For example, by the 1860s, industrial jobs had become the primary source of employment for nearly half the city's workforce. But the economic downturn during the 1870s brought out racial tensions that had been simmering as the city expanded in population and density. Competition for labor and increasing class conflict occurred as burgeoning elites maneuvered to control the political and economic sectors. Perhaps because they constituted the greatest minority group, the Chinese bore the brunt of racist sentiment during this time from the public as well as federal and local governments. In response to increasing complaints from American-born Whites about competition for jobs, the federal government passed the 1882 Chinese Exclusion Act, and subsequent extensions and renewals of the Act banned immigration of Chinese workers by 1902.

Likewise, the fate of African-Americans was pre-determined by labor policies and practices that effectively excluded them from higher wage jobs and better working conditions. For example, the Building Trades Council, arguably the most powerful labor union in the country at the time, operated in such a way that "undesirable workers such as Black and Asians would not easily obtain membership" (Broussard 1993:13). In addition, with Jim Crow laws that effectively excluded Black children from affordable nearby schools and barred them from using certain modes of local transportation, many Black children simply stayed home. As a result of increasing racial hostilities, the Black population of San Francisco had declined by the turn of the 20th century. Some Blacks relocated across the Bay to Oakland, a city whose Black population doubled between 1890-1900, and tripled between 1900-1910 (Broussard 1993: 21-22). Those who stayed in San Francisco organized into neighborhood communities and supported Black leaders to fight institutional racism. As these efforts achieved modest success during the early decades of the 20th century, the Black population of San Francisco rose slightly again.

The 1906 earthquake also affected racial tensions and the re-organization of the city after thousands of residents were displaced by the ensuing fires. When the American Red Cross set up “White only” tents, many Chinese and African-Americans fled the city and headed east across the Bay (Public Broadcasting System 2006). This massive influx of Chinese to the East Bay following the 1906 quake is credited with the establishment of Oakland's Chinatown.

The greatest wave of African-American migration occurred during World War II, when Southern Blacks, primarily from Louisiana and Texas, migrated to work in what later became known as the Hunter's Point Naval Shipyard. The shipyard, originally established in 1870, was acquired by the Navy 11 days before the Japanese attack at Pearl Harbor in 1941, and quickly became the site of major shipbuilding and Naval activities until it closed in 1974.

At about the same time, the Fillmore district had become the heart of Black San Francisco, known internationally as the “Harlem of the West” (Sumchai 2008). But by 1966, a citizen action committee called the San Francisco Planning and Urban Research Association declared, “If San Francisco decides to compete effectively with other cities for new 'clean' industries and new corporate power, its population will move closer to standard white Anglo-Saxon Protestant characteristics. Selection of a population's composition may be undemocratic. Influence on it, however, is legal and desirable for the health of the city" (Sumchai 2008). The "urban renewal", also known as "Negro removal", projects of the 1970s displaced over 10,000 Black San Franciscans from the Fillmore. Some moved into Bayview Hunter's Point, and some relocated across the Bay to Richmond and Oakland. Thus the neighborhood formerly known as the Fillmore (now known as Western Addition), the once thriving cultural hub of African-American culture, was "rid of its undesirable elements" (i.e. Black people) and was "re-peopled", according to city redevelopment agencies (Sumchai 2008).

**Photo 7**: Children in San Francisco's Fillmore District

Source: Photo by Gerald Ratto (1952), courtesy of *The New York Times*, http://www.nytimes.com/2009/12/06/arts/design/06sfculture.html, accessed 5/3/10.

At the same time, federal housing policies directly altered the racial composition and prosperity of San Francisco neighborhoods. The federal government set up neighborhood appraisal systems that explicitly tied mortgage eligibility to race. “Between 1934 and 1962, the federal government backed $120 billion of home loans. More than 98% went to whites. Of the 350,000 new homes built with federal support in northern California between 1946 and 1960, fewer than 100 went to African Americans.” (California Newsreel 2008). As a result of these home owner incentives almost exclusively available to Whites, many White families left the poorer neighborhoods of the city and moved into wealthier neighborhoods or into the suburbs. With fewer White residents, neighborhoods became more concentrated in racial minority composition. Commercial prosperity in these neighborhoods declined with the departure of Whites, making the areas with greater minority concentrations even more isolated and economically depressed. This is how the “ghetto” of Bayview Hunter's Point was created, and why Black San Franciscans are concentrated in low-income neighborhoods. Clearly, the conditions of poverty for many African-Americans were not the result of individual failing. They were the direct result of institutional racism – discriminatory labor and housing policies, and the  ensuing social and spatial segregation.

Latinos from Mexico and South American migrated into present-day San Francisco for the same reasons as African-Americans and Asian immigrants: primarily for employment opportunities, but also for family reunification (once the male workers had accrued enough income, women and children followed). It is also important to remember that a significant number of Latinos lived in present-day California and the Southwest before the land was purchased and officially became part of the United States. Thus, some Latinos were not “foreign-born”, but became foreigners when the border crossed through the lands that their families had occupied for centuries. With the creation of new national boundaries, movement across areas that were once familiar territories suddenly excluded resident Latinos. Furthermore, border crossings in search of economic opportunity have arguably been exacerbated by the North American Free Trade Agreement (NAFTA) in 1996, which resulted in greater profitability of corn production in the United States. Thus, Mexican farmers, who would have continued to produce corn in their native country, have been put out of work by large-scale U.S. agribusiness.

During the latter half of the 20th century Asian and Latino immigrant groups continued to migrate to San Francisco in search of greater income opportunities. Many immigrant families regularly send a significant share of their U.S. earnings to family members in their home country. In fact, in some countries, such as Mexico and the Philippines, remittances from the U.S. constitute a major source of capital for the local economy.

While the overall minority composition of the city steadily increased, the economic and spatial segregation of city residents became increasingly visible. The income and health disparities among San Francisco residents today are similar to those found in most other major American cities. In this sense, San Francisco is not unlike most East Coast cities were 150 years after their establishment.

In this section I have briefly described the social and political history of San Francisco in order to emphasize that, for many residents, poverty is not the result of individual failing; rather, it is the direct result of federal and local policies and practices that shaped the city's development and determined the economic fate of San Franciscans during the 19th and 20th centuries. Next, I use ethnographic excerpts to illustrate how these historical events have shaped the experiences of children and families living in the poorest neighborhoods of San Francisco today, and why so many continue to suffer from asthma.

## Environmental Racism

Where we live bears directly on our quality of health and access to health resources. People living in poorer neighborhoods suffer greater health risks for a number of reasons: exposure to toxic materials, lack of access to nutritious foods, exposure to violence, lack of safe recreational areas for exercise, easy access to tobacco, liquor, fast food, and drugs, and chronic anxiety and stress, which produces elevated stress hormones that lead to greater risk of chronic disease and lower life expectancy (California Newsreel 2008). Thus, the social and environmental features of economically depressed neighborhoods not only predispose residents to illness, they also limit the choices and individual behaviors that could potentially improve their health as well. In other words, the “self-care” tasks that are an essential part of asthma management (and other chronic illnesses) are more difficult for many poorer families to achieve given the conditions of their environment that have pre-determined their ability to care for themselves and pre-disposed them to acquiring certain illnesses.

San Francisco's Bayview Hunter's Point (BVHP) neighborhood, comprised primarily of African-Americans, and more recently, Latino, Asian and Polynesian immigrants, is infamously known as one of the most toxic residential environments in the

**Photo 8**: The Potrero Housing Project Overlooking an Area of Waste and Pollution

(photo by R. Higashi, 2009)

country. In the previous section I demonstrated how historical patterns of migration and institutional racism affected the settlement of low-income minorities in segregated San Francisco neighborhoods like BVHP. In this section I show how economic development and environmental racism have produced disproportionate rates of a number of diseases linked to environmental toxicity among BVHP residents, including: allergies and asthma, birth defects, premature infant deaths, cancers and immune system disorders (Sumchai 2008). In the late 1990s, for example, the San Francisco Asthma Task Force determined that the prevalence of asthma in BVHP was double that of the overall national prevalence, with 15.5% of children having been diagnosed with or treated for asthma (Thyne, et al. 2007). Moreover, since many children suffer from asthma that is undiagnosed, the actual prevalence of the disease is no doubt much higher.

Residents of BHP are highly cognizant of the environmental pollutants in their neighborhood, which is not surprising given the significant number and visibility of polluting sources. Bayview Hunter's Point is home to: 429 hazardous waste facilities (including those with radiological materials), one federal and two state Superfund sites, and the Southeast Wastewater Treatment Plant (Sumchai 2008). Before the Hunter's Point Naval Shipyard closed in 1974, it was the site of radiological defense research and hazardous materials from shipyard operations; after it closed, toxic materials were not disposed of properly by the Navy and the area became a popular dumping ground for additional toxic waste materials from small businesses that subsequently leased the land for this very purpose (Federation of American Scientists 1998).

Air monitoring studies have reported toxic level concentrations of over 200 toxic chemicals and materials monitored by the Environmental Protection Agency including sulfur dioxides, asbestos, ionizing radiation, PCBs (polychlorinated biphenyls) and the volatile organic compound benzene (Sumchai 2008). The oldest and highest polluting natural gas power plant in the State of California, the PG&E Plant, was closed only as recently as 2006 after years of legal and community activism. Many of the residents I spoke with recalled the 1998 explosion at the PG&E plant that galvanized support for BVHP residents by external legal and environmental advocacy groups who lobbied not only to shut down the plant but also to clean up various hazardous sites. Notwithstanding the thousands of citations for illegal dumping and improper waste disposal (Federation of American Scientists 1998), perhaps the most insidious crime is the lack of action taken by city, state, and federal officials in response to decades of documented research and reports of environmental toxicity that have resulted in "statistical concentrations" of greater infant mortality, birth defects, cancers, and asthma in the BVHP neighborhood.

In the mid 1990s, San Francisco legislators proposed the Bayview Hunter's Point Redevelopment Project, which many local residents criticized as yet another effort to "re-people" the neighborhood once the environment had finally been detoxified. The proposal was cited as yet another episode of "Negro removal" like the one that had occurred during the redevelopment of the Fillmore district during the 1970s. As was the case in the Fillmore, the BVHP Redevelopment Project was projected to displace thousands of African-Americans in the conversion of real estate to higher end markets. The massive exodus of African-Americans from San Francisco in the last 30 years is more than a pattern of gentrification, according to Dr. Ahimsa Sumchai, who led an appeal to the United Nations' Commission to End Racial Discrimination in 1996. Sumchai and the appellants have argued that historical events and the actions proposed by the Bayview Hunter's Point Redevelopment Project, if implemented, fulfill the UN criteria for genocide.[8]

Although plans for the clean-up of BVHP are already underway, current residents are still exposed to highly toxic pollutants on a daily basis. Many of the parents of asthmatic children directly cited the environmental pollutants and toxic materials as the cause of their child's asthma. I was at first surprised by the fact that many parents spoke of the widespread pollution without expressions of anger and resentment that I would expect from those living in a government-facilitated toxic dump site. I later learned that my impressions were consistent with neighborhood medical providers who also did not witness highly emotive reactions from parents in response to the environmental conditions that contribute to their child's suffering from asthma. Given the legacy of the U.S. government's production of toxic materials and failure to dispose of hazardous waste, it would be understandable that residents would feel abandoned and ignored by a government that directly and deliberately caused their suffering. Their calm demeanor in describing the situation felt to me like a resignation of will; their experience of asthma as

---

[8] The appellants contended that the government action proposed by the BVHP Redevelopment Project "parallels in anticipated outcome the genocidal campaigns waged by legitimate government entities to depopulate, disenfranchise, and displace ethnically distinct communities in Armenia, World War II Germany and Poland, Bosnia, Cambodia, Southern Sudan, Rwanda and in Darfur Province." In addition to the effects of the Redevelopment project, if implemented, Sumchai, et al. (2008) cited as existing evidence the systematic closure of public schools, stores and businesses, the unemployment rate of 40%, the elevated rate of children placed in foster care, the decline in the African-American population of 48% since 1970, and the substantiated incidence of police brutality.

an inevitable product of their environment constituted but one of centuries of injustices perpetrated upon them by their own government.

My assessment of this attitude of seeming resignation was validated by a doctor I interviewed in Bayview, herself African-American, who recounted a similar interaction with the mother of a new patient:

“I was asking them questions about school and what kind of sports the kid liked to play, just trying to make the kid feel at ease. And the mother tells me, 'Oh and don't forget to check him for asthma because we live near the shipyard,' and then she continues to talk about the kid's sports and stuff without missing a beat.” The doctor conveyed to me that this interaction was typical of the experiences she has encountered in her practice that remind her of her patients' inability to control most of their environment. Thus, she surmised, “they put effort into other things, like sports, which is psychologically adaptive in a healthy way, actually.” The doctor's comments underscore the importance of seeking and understanding the logic of parents' and children's feelings about asthma and the experiences underlying their attitudes and medical decisions.

Some BVHP residents have vocalized their outrage and participated in community action groups and environmental movements. However, among the community members that I interviewed, the vast majority conveyed disinterest in taking action because they believed that their efforts would be futile in effecting any meaningful change. “Ya, it's bad, but what am I gonna do about it? I mean, those guys [the neighborhood protesters] have those parades and all their signs and stuff but nothing ever changes. Why should I care? They [presumably, State officials] obviously don't!"

While some residents expressed hopelessness that the environmental toxicity proven to exist in their neighborhood would ever be cleaned up, other expressed hopelessness toward their own inability to change their surroundings. This was the case in this particularly memorable interview:

I met Gloria while she was waiting at the outpatient clinic along with her three kids, a 9 year old, a 4 year old, and a 1½ year old. Her two older children had already been diagnosed with severe, persistent asthma and her baby had been hospitalized three times in the past eight months for respiratory distress. I could scarcely imagine the stress felt by this single mother with three very sick children. I asked her why she thought her children had asthma.

"Well I already know it's the mold," she said. "They came and did some tests and they said it's toxic. They're tearing it down in four months."

"They're tearing the mold down in four months?" I asked, wondering why it would take so long to get rid of mold.

"No, they're tearing my house down in four months. They said it's condemned. It's all in the walls and stuff so they can't fix it."

"Wait," I said, as I tried to wrap my head around what she was saying. "You're saying they know the house has toxic mold but they won't clean it up for four months?"

"No, they're not gonna clean it up ever. They told me I gotta leave and they're gonna tear the place down. They put one of those red papers on my door."

"Oh, so the house is condemned?" (Upon review of this interview I notice that Gloria already stated that her house was condemned, but at the time I hadn't followed her first statement.)

**Photo 9:** Mold discovered during a routine home evaluation for asthma triggers

(photo courtesy of Asthma Clinic)

“Yeah.”

“So where are you living now?”

“In the house.”

“In the house that's condemned?”

“Yeah.”

[pause] I'm still trying to process what she's telling me.

“So, let me make sure I understand. Some officials or something said that your house has toxic mold...”

“Yeah.”

“...And they're going to tear your house down in four months.”

“Yeah.”

“...But you're still living there now?”

“Yeah,” she states, with a chuckle that I perceive as recognition of the seeming implausibility of the situation.

“...With your three kids?”

“Yeah.”

“Well...[pause] I'm sorry, I don't understand. Why are you living there if it's toxic and they're going to tear the house down?”

“"Cuz I don't got nowhere else to go.” Her tone is matter-of-fact, like it should be obvious to me even though I'm clearly not understanding.

[long pause; I'm having trouble fathoming the reality of what she's telling me]

“So...[pause] I'm sorry. This is...so you're saying that you don't have anywhere else to live besides the house that's toxic. Is that right?”

“Yeah. Because my mom used to live in Daly City, but she passed. I got a sister in Richmond but they got their own kids. Plus they [Gloria's kids] go to school here.”

“So are you allowed to live in that house that's condemned?”

“Technically no. I mean, it's not like they care, really. It's not like they gonn' come around and kick us out. But the sign on the door says 'no trespassing' and stuff and the guy said we had to move.”

“So are you still paying rent?”

“Nah, that's why we're living there,” again, she stats matter-of-factly.

“But you were paying rent before they declared it condemned, right?”

“Yeah, of course.”

“So...[pause]...I'm sorry, I don't mean to be rude, but... Can you help me understand why you wouldn't move to a different place that's not toxic, but that's an affordable rent?”

“It's OK,” she says, reassuringly. I am relieved that she senses that I am genuinely trying to understand and am not trying to blame her for being in this situation. “It's 'cuz they aint gonn' pay me back my deposit til after they tear it down.”

“You mean your security deposit?”

“Yeah.”

“They have your deposit but they won't give it to you for four months even though it's condemned?”

“Yeah.”

“Well...[pause]...Why? Why can't they give it to you?”

“I dunno. I just figured that's how it was, so when they paid me then we can use that on the next place. 'Cuz I don't got no money to pay rents *and* a deposit on a new place.” [her emphasis]

“Wow...[pause]. You know, I have no idea how this type of thing works. But I'd like to ask one of the nurses or the health workers because this just doesn't seem right to me. I mean, it's not fair because if it's condemned then it's unlivable and whatever contract you had as a tenant should be over. I mean, look, I really don't know, maybe it's some legal thing that's tying it up. But I think we should at least ask someone if there's something that can be done so you don't gotta keep living there and your kids getting sick, you know?”

"I guess...yeah." I wait for more of a response from Gloria, some kind of indication that either she's tried that or she knows it won't work or she thinks it's a good idea or something – some indication that she recognizes how incensed I am for her and encouraged by the possibility that someone might be able to intervene to help her. But she seems oddly passive so I wonder if I'm overstepping my bounds.

"Do you want me to ask the health workers about it?...[pause, no response]...I certainly won't mention it if you don't want me to. And I don't know for sure if they can help but I'd be happy to at least find out for you who could maybe help."

"OK, yeah. OK."

"OK? OK, I'll check with them now, OK? You'll probably have to talk with them yourself at some point about all the details but I'll ask."

"OK, thanks."

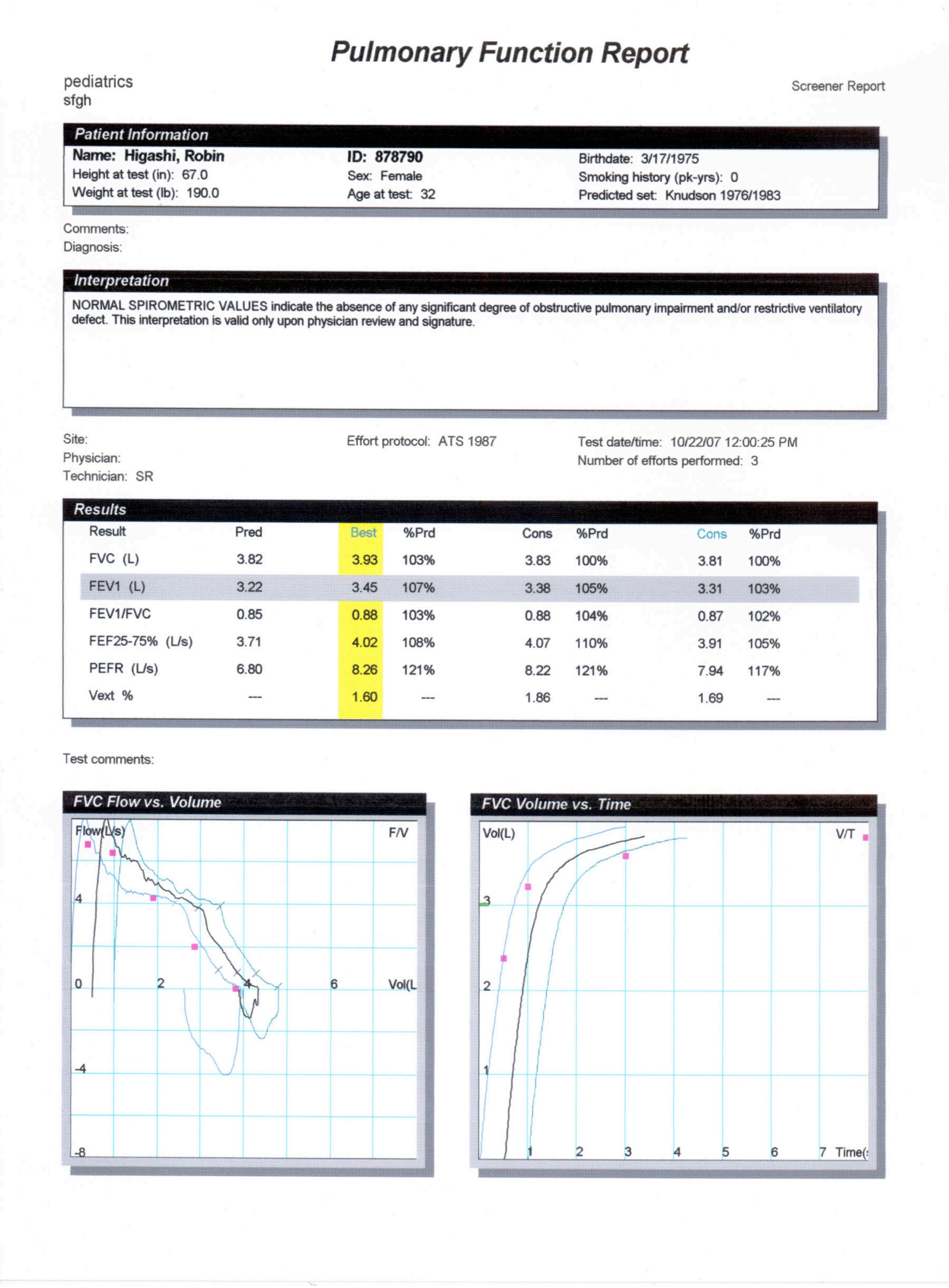
I remember this interview clearly for several reasons. First, I remember feeling stunned by what seemed like such an inhumane situation. Simultaneously, I remember feeling guilty and naive for being so incredulous. Especially given her matter-of-fact description of the situation, I realized that Gloria may not have seen the situation as the kind of injustice I felt it to be. I've often replayed the interaction with Gloria in my head, trying to interpret her body language, tone of voice, how she looked at me and what she said. Her lack of outward expression seemed to me to be a sign of utter physical and emotional exhaustion, and perhaps an unwillingness to expend any energy fighting a system that had treated her so inhumanely for so many years. I recalled how the Bayview doctor had characterized this coping mechanism with things beyond one's control as psychologically healthy. The memory of Gloria and her three sick children serves for me as a humble reminder to resist the temptation to judge a parent's decision-making as negligent or inappropriate when a child's asthma is so poorly controlled.

Another such reminder occurred as I observed a first-time clinic evaluation with a father and son:

Charlie was a tall, lean gentleman who appeared to be in his early 50s. Given his wrinkled appearance and the smell of cigarettes on his breath, however, I think he may have actually been in his 40s. Charlie greeted me with an easy-going smile and offered a handshake, which I remember clearly since many parents with sick children are understandably less cheerful during their child's visit with the doctor. As his son Jesse conducted the pulmonary function test, he chatted and asked me questions. Looking at my ID tag with the words “Doctoral Student” under my name, Charlie asked, “So you're studying to be a doctor?”

“Not quite. I'm a student in medical anthropology. It takes just as long as becoming a doctor, but I don't poke people with needles.” My experience is that most people (including a lot of my family members) don't really want an explanation about what medical anthropology really is, so I usually say something kind of humorous and dismissive and then explain more if they continue to ask questions. This approach seems to work, as Charlie laughs softly and moves on to the next topic.

**Figure 3**: Sample Pulmonary Function Report Following Spirometry Test



## Pulmonary Function Report

pediatrics
sfgh

Screener Report

**Patient Information**

**Name: Higashi, Robin**
Height at test (in): 67.0
Weight at test (lb): 190.0

**ID: 878790**
Sex: Female
Age at test: 32

Birthdate: 3/17/1975
Smoking history (pk-yrs): 0
Predicted set: Knudson 1976/1983

Comments:
Diagnosis:

**Interpretation**

NORMAL SPIROMETRIC VALUES indicate the absence of any significant degree of obstructive pulmonary impairment and/or restrictive ventilatory defect. This interpretation is valid only upon physician review and signature.

Site:
Physician:
Technician: SR

Effort protocol: ATS 1987

Test date/time: 10/22/07 12:00:25 PM
Number of efforts performed: 3

**Results**

| Result | Pred | Best | %Prd | Cons | %Prd | Cons | %Prd |
|---|---|---|---|---|---|---|---|
| FVC (L) | 3.82 | 3.93 | 103% | 3.83 | 100% | 3.81 | 100% |
| FEV1 (L) | 3.22 | 3.45 | 107% | 3.38 | 105% | 3.31 | 103% |
| FEV1/FVC | 0.85 | 0.88 | 103% | 0.88 | 104% | 0.87 | 102% |
| FEF25-75% (L/s) | 3.71 | 4.02 | 108% | 4.07 | 110% | 3.91 | 105% |
| PEFR (L/s) | 6.80 | 8.26 | 121% | 8.22 | 121% | 7.94 | 117% |
| Vext % | --- | 1.60 | --- | 1.86 | --- | 1.69 | --- |

Test comments:

**FVC Flow vs. Volume**

**FVC Volume vs. Time**

While Charlie continues to chat, I'm distracted by what I overhear in the nurse's conversation with his son, Jesse. I look over toward Jesse, hoping Charlie will stop chatting so he can also listen to what the nurse is saying. The nurse has just completed an initial pulmonary function test using a spirometer, an instrument that provides quantitative measurements of things like lung volume and peak flow strength. These numerical values will be used to assess and compare Jesse's progress on subsequent tests, which in turn will help his doctors determine how his medications and dosages are working to control his asthma. In addition, the spirometry test produces a spirograph, a

**Photo 10**: Child conducting spirometry test with health worker

(photo courtesy of Asthma Clinic)

graph that plots Jesse's values alongside what would be considered normal for a child of his age, size, and sex (see sample spirograph in Figure 4).

“Wow, your lungs are really sick, sweetheart,” the nurse tells Jesse as she reads over his spirometry report. “Do you feel worse today that you normally do or is today about the same as other days?”

“About the same,” Jesse says. He coughs, and it sounds horribly congested.

To this, the nurse says in a concerned voice, “Well, we gotta find a way to help you out because you're only 7 years old but you're breathing like a 70 year old man!”

I'm stunned by what I hear, as this is the worst I've heard a nurse say about a child's report. I look up at Charlie for his reaction. He makes a dismissive gesture with his hand and says nonchalantly, “Ah, he aint gonn live that long anyway.”

Just as I did with Gloria, I feel my eyes opening wide with surprise but am trying not to show it. In my head, I understand why Charlie would make this kind of statement. As residents of Bayview Hunter's Point, Jesse was born into an environment of toxic waste, drugs, violence, and gang activity. After the Naval Shipyard closed in 1974, escalating poverty and joblessness ushered in a new era of drugs and violence in the 1980s-1990s. For example, following a drive-by shooting that killed her 17-year old son in 2006, the mother of the slain boy reportedly said, “You don't have to be in a gang to be killed. All you have to do is live in this neighborhood and be a boy.” (McCormick 2008).

Given this reality, is not surprising in some sense that Charlie would not expect Jesse to live to age 70. Nevertheless, it was still heartbreaking to hear. Neither Jesse nor the nurse said anything in response to Charlie's comment, and they were ushered out to the exam room shortly thereafter. Later I spoke with the nurse about what Charlie said, and she was horrified. She hadn't heard Charlie's statement at the time, but she thanked me for sharing it with her so that she could follow up and talk with them.

Like the conversation with Gloria, this interaction has remained with me as a poignant illustration of the logical basis of decision-making as to why some families do

**Photo 11:** Bayview Street Corner. Compare this image with the romantic images of San Francisco's Golden Gate Bridge, or the wealthier neighborhoods and shopping districts that are commonly depicted in tourism publications.

(photo by R. Higashi, 2009)

not adhere to asthma management tasks or seek clinical asthma care. The potential of suffering long-term lung damage simply cannot compete with the more immediate, life-threatening demands of a daily life amid poverty and violence.

Not long after my interaction with Charlie, a similar incident drove home this message. I was interviewing a Bayview doctor who recalled her first lesson in learning the logic of parents' decision-making regarding asthma care. During an asthma follow-up appointment, the parent admitted that she wasn't very good about remembering to administer her son's asthma medication every night. The doctor sternly warned, “Well, the medicine can't do him any good if he doesn't take it.” Then the mother snapped back, “Look, I paid the rent, I fed him, he went to school, he didn't get shot...what more do you want from me?!”

So far I have demonstrated how poverty and segregation were produced in San Francisco, and how institutional and environmental racism have contributed to the higher prevalence of pediatric asthma in low-income San Francisco neighborhoods like Bayview Hunter's Point. It should be clear that residents of Bayview Hunter's Point did not choose to live in poverty, and they did not choose to live in a community with a higher prevalence of asthma (and other diseases). Their environment was pre-determined by the economic development and abandonment of the Naval Shipyard that left a legacy of massive toxicity and unparalleled rates of disease. Given these circumstances, it is easy to understand why parents of children with asthma feel helpless to reverse the impact of asthma as long as they continue to live in a toxic environment. Thus, the same structural conditions that produced higher pediatric asthma prevalence also constitute the ongoing barriers to better asthma management.

In the midst of their suffering, however, it is important to note that many parents also spoke about the positive impact of doctors who they felt genuinely and deeply cared for their needs. “She gets it. She knows it's not my fault,” one parent said of a trusted Bayview doctor, “She knows I'm trying my best and that's all I can do.” The mere acknowledgment by providers who recognized the sordid history of Bayview and its treatment of African-Americans was enough to communicate empathy and improve the likelihood of a caregiver to seek care. In a few memorable interviews, I remember caregivers speaking more articulately and emotionally about their appreciation of “good doctors” than about any other topic, positive or negative. Thus, while the impact of structural barriers on disease prevalence and disease management may seem insurmountable, it is important for health providers to keep in mind that sincerity and empathy have been shown to mitigate the experience of suffering.

## Fear and (Dis)trust

Early into this research I discovered that for many participants fear and distrust constituted the most significant barrier to medical care. The types of fear that participants described spanned a diverse array of situations, locations, and interactions. But the common thread among all of their accounts was the level of impact that such experiences had in subsequent decision-making about their child's asthma care. For some, a single negative experience was sufficient to impact all future decisions about when to seek care, from whom, what to share with the doctors during an appointment, and how much they would be willing to pay for medical services. In this section I use participant narratives to describe the different types of fear that participants encountered.

### *Fear of medical practitioners and institutions*

A significant number of participants reported fear of medical practitioners, hospitals, or of American medical institutions, broadly conceived. Some African-American participants cited the Tuskegee Syphilis Study directly by name and seemed well-informed of its details as a basis for distrusting medical institutions and practitioners.

"I know they did that Tuskegee thing...you know with the syphilis...And people died from that," one participant told me.

The Tuskegee Study of Untreated Syphilis in the Negro Male (also known as the Tuskegee Experiment) was a clinical study by the U.S. Department of Public Health conducted in Tuskegee, Alabama between 1932-1972. A total of 399 men, most of whom were illiterate sharecroppers, were enrolled as participants in a study to examine the long-term effects of untreated syphilis. Participants were deliberately and systematically deceived in order to continue the study long after penicillin had become standard treatment for syphilis by 1947. The African-American men who were enrolled in the study were not the only victims; many women and children became infected or were born with congenital abnormalities. The study was only stopped in 1972 because of a leak to the Associated Press.

Other participants, who were only vaguely aware of the Tuskegee Study or who didn't mention it at all, cited a more generalized mistrust of doctors based on stories they'd heard from older relatives and other members of the Black community.

A 12-year old African-American boy I interviewed told me, “I don't like going to the doctor.” When I asked why, he said, “My grandma says that people who go to the hospital all end up dead.”

I asked, “So what does your grandma think about your coming to Asthma Clinic?”

“She says I have to 'cuz I'm sick. But I can tell she's scared. She *never* goes to the doctor.” [original emphasis]

The broad distrust that this young boy learned from his grandmother is evidence of an important point that Harriet Washington describes in her book, *Medical Apartheid*:

> “It is a mistake to attribute African Americans' medical reluctance to simple fear generated by the Tuskegee Syphilis Study, because this study is not an aberration that single-handedly transformed African American perceptions of the health-care system. The study is part of a pattern of experimental abuse, and many African Americans understand it as such, because *a rich oral tradition has sustained remembrances of pain, abuse, and humiliation at the hands of physicians*.” (2006:179) [emphasis mine]

In a separate interview with a mother of an asthmatic child, I asked, “Why do you think some families don't bring their kids to the doctor if they're coughing really badly?”

“Maybe 'cuz they scared.”

“Scared of what?” I asked, hoping she would clarify, since participants expressed fear about a wide variety of things related to asthma care.

“The doctors,” she replied. “Even me, it took me a long time to bring [her son]. I don't trust them.”

“When you say 'them', you mean doctors?”

“Yeah.”

“Which doctors?” I asked.

Without hesitation, she said, “All of them, any of them. Even if they're Black.”

“So, even here [at the clinic where we were speaking], are you scared?”

“Well, they're nice. But I still don't *trust* them.” [original emphasis]

This generalized fear was evident in the comments made by two other African-American parents I interviewed. Although the Pediatric Asthma Clinic at San Francisco

General is known as the best asthma specialty care clinic in the city, one father said that he didn't like going there because of its very location within the confines of the hospital.

“'Cuz when you go [to the Pediatric Asthma Clinic at SF General], you see all these sick people...people getting wheeled around in chairs, with tubes in their nose and those IV things...The first time I went I thought, 'oh hell no!', and I actually turned around and took my daughter outta there.”

I had a similar feeling myself the first time I navigated my way through the front doors of the hospital, with the sound of an ambulance siren whirring in the background, past all the people waiting in the lobby with bandages and canes, past the flowers and stuffed animals and cards, up the elevator with dozens of doctors and nurses in lab coats, through the corridors with hospital beds (sometimes occupied by very frail individuals), past several glass doors with “ICU” (Intensive Care Unit) signs and machines beeping, until finally I reached the Asthma Clinic suite. It was easy to understand how, for someone not familiar with hospitals like me, this would have been an overwhelming and intimidating experience even before arriving at the doorstep of the clinic. And I can only imagine how, as a parent, it would be really scary to think about escorting my young child through the same sights and sounds en route to the doctor. For this reason, the father in the previous narrative decided to take his daughter to a small community clinic, not a clinic embedded within a large hospital and trauma center.

In another interview, a mother described an episode in which a community outreach health worker approached her in her Hunter's Point neighborhood.

"I was coming out of the grocery store and this woman asked me if I wanted information about some study, I forget what, but I don't think it was asthma."

"Do you remember what she said to you?" I asked.

"No, I think it was maybe some mental health service or something. I don't remember. But she had one of those clipboards and I just didn't trust her."

"Why do you think she was there?"

"I don't know. But she was White so she stuck out amongst all us Black folk so for me...I didn't like it."

In this instance, instead of the outreach effort being effective by sending health workers into low-income communities, it was perceived, at least by this mother, as potentially having disingenuous intentions. Thus, medical practitioners and other health providers should understand African-Americans' fear of doctors and medical institutions as a logical reaction to a pattern of historical events, of which the Tuskegee Syphilis Study was but one egregious example.

### *Fear of deportation or political persecution*

The persistent fear of deportation constitutes another significant source of fear for many immigrants caregivers, so much so that it may interfere with their ability to adhere to asthma management protocols. For example, Clara, the mother of an 8-year old asthmatic child, Mario, described this experience in which she felt such overwhelming anxiety and fear that she was unable to enroll Mario in the health insurance program for which he was eligible. I have paraphrased Clara's story here:

> When we [Clara, her husband, and Mario] first came to San Francisco, we just went to the free clinic down the street if we needed help with medicines or if someone was really sick. But after being seen there a couple of times, one of the nurses told us that Mario could actually get his own health insurance and he would be covered for many more services that the free clinic could not provide. They told us he had asthma but since they didn't have the right equipment to really measure it we should go to a specialist. But first we should get Mario's insurance from Healthy Kids so that we wouldn't have to pay so much for it. They gave me some papers that had information about the different kinds of insurances.
>
> I read through all the papers and it was so confusing I couldn't figure it out. So for awhile I just thought 'never mind', I'll just keep taking Mario to the free clinic. But when his asthma got worse, I knew I had to get him the insurance because he almost had to go to the hospital one time for not breathing well. My friend told me they have people at the insurance offices that speak Spanish, so I thought 'OK, I will go'.
>
> I found the address of the office on the papers they gave me so one afternoon I walked down there. It was a pretty far walk and I thought maybe I missed it. But then when I got to the right address I realized it was this big building; it had a huge U.S. flag and that seal, you know, and it said “United States, Department of...” something. It was a

big government building. I checked the address to make sure I had the right place, and it was. I didn't expect the insurance office to be in a big U.S. building so I got really scared. At first I went in but everywhere I looked there were more flags and a couple of police officers or something, like guards but all dressed in uniforms, just standing at different areas. I couldn't think any more about where I was going; I was just scared so I left.

In sum, just as the father in the previous section was afraid of attending the Pediatric Asthma Clinic because it was located within a hospital, the mother in this narrative was afraid of entering the Medi-Cal Office because it was located within a big government social service building. In both instances, the parents were forced to weigh their fear of placing themselves in a vulnerable position against the potential benefit of acquiring the services they needed to care for their child. The avoidance of U.S. officials and government offices is likely a contributing factor in the fact that over 40% of Mexican immigrants are chronically uninsured (Wallace, et al. 2003). Thus, some children and families rely on health services from neighborhood “free clinics” even though they may be eligible for insurance programs. Others may put off interacting with health officials until their child's symptoms are sufficiently concerning to tip the balance to overcome their fear of deportation.

Just as Harriet Washington emphasized the importance of understanding African-Americans' generalized fear of medical practitioners as a reaction to a pattern of historical abuses (i.e. not just a single event), it is important to remember that for many recent immigrants, fear is based on a pattern of abuses, threats, and the deportation of members of their community, handed down one generation to the next in precautionary tales. Thus, their fear is not an exaggeration or misinterpretation of facts; it is a reasonable and logical response given their own experience and the experiences of other members of their community.

### *Fear of Hostile Encounters*

Participants cited a number of reasons for deliberately not seeking care, delaying care, or not following through with asthma management tasks. As I reviewed my interview notes with both children and caregivers across a range of ages and ethnic groups, the most common theme uniting their accounts was the impact of a previous negative interaction with a health provider. By "health provider" I mean anyone with whom children and caregivers interact in the process of receiving health care; thus, physicians, nurses, ancillary clinic staff (e.g. phlebotomists, x-ray technicians, medical assistants), clinic receptionists or appointment staff, insurance workers (in person and on the phone), pharmacists, and phone representatives for medical billing issues may all play a role in shaping the participants' experience and impacting future decision-making. The impact of a negative experience was sometimes so significant that a single incident could effectively terminate the relationship with that person or institution, and deeply affect subsequent interactions with health providers overall.

For example, Rhonda, the parent of a child who had recently started as a patient at the Asthma Clinic said of her previous experiences: "I quit going there [another clinic] because the doctors weren't very nice. Until I found out about the nice doctors [at the clinic where she currently receives care] we just used emergency for everything.”

I asked, “What made the doctors not very nice?”

Rhonda replied, “They didn't listen to me. They were like, ‘let’s try him on this [medication].’ And I was trying to tell them that he’s been on that one but it didn't work so he needs to stay with this one because we know it works.”

“So they didn't want to prescribe the medicine you wanted?”

“No, they just kept saying ‘let’s just try it out and see’ and they ignored everything I said. But you know, I'm the one that sees him every day so I know what works!”

“I see,” I said. “So you felt like they weren’t listening to you.”

“Yeah! Plus, then when the medicine they gave me didn't work – just like I told them it wouldn't – they said it was our fault! Like maybe we weren't taking it the way we were supposed to so that's why it didn't work. That made me mad! 'Cuz it’s like – he's been diagnosed with asthma for, what, the past six years, and we’ve learned about it in these six years how to deal with it and how to keep it under control to the point where, if I go to the doctor for something I want them to understand that I know what I’m talking about!”

“Sure, I understand. That makes sense.”

“Because I’m the one that’s with him every day! So I know his symptoms and how he reacts to it and everything else.”

I notice that Rhonda has mentioned twice now the fact that she is with her son on an everyday basis, and that this is testimony to the level of her knowledge about her son's illness. In other words, Rhonda recognizes that her knowledge – the personal experience of witnessing her son's symptoms and how they have progressed and worsened over several years – is being minimized or outright disparaged by the doctor, who seems to feel confident that he knows better. As a medical anthropologist, I instantly recognize this as an example of how patient/caregiver experiences are often subverted to the realm of “belief” whereas practitioners believe that only biomedical expertise constitutes “knowledge” (Kleinman 1980; Good 1994; Estroff 1995).

“Geez, I'm sorry you had that experience,” I say, “But I'm glad you feel like the doctors here are listening to you. Having continuity of care is important for kids with asthma so I'm glad you found someone you trust.”

“Definitely! Because they ask me – and even my son – about what we think is working. And then it keeps working so we keep coming here.”

In a few instances, caregivers reported outwardly hostile encounters. One young mother described a number of difficulties she faced with her daughter's insurance coverage, which culminated in the following experience.

“I cannot understand all those papers they send,” Lidia said, bouncing her infant as she spoke of her older daughter's insurance enrollment. “There's so much information about what you have to do and what you can't do and I just get scared that we can't pay for it or we miss something we were supposed to do. So one time I asked [an insurance enrollment worker] about if I was doing this part right. And he told me something I didn't understand so I said, 'I'm sorry, but can you please say that again?' And you know what he said to me? He said, 'Are you deaf or are you illiterate?' Can you believe he said that? I was so stunned I just walked out and I went home and cried. Later I was mad but at first I just couldn't believe it. I just wanted to cry.”

Negative experiences such as these produce durable, long-lasting recollections that for many become generalized negative feelings about health providers and the overall health care process. Sometimes, I learned, positive experiences may help to keep negative experiences from affecting broader ranges of decision-making. For example, in the narrative above with Rhonda, the experience of finding a “nice” doctor at Asthma Clinic enabled her to put her past negative experience behind her. Rather than relying on the Emergency Department, as she once did when she did not have a trusting relationship with a regular provider, she began to see the “nice” doctor for ongoing outpatient services, which is more conducive to effective asthma control.

Other times, however, positive experiences were viewed as lucky exceptions that could not override persistent negative judgments. The grandfather of a young boy I spoke with said of his grandson's doctors, “Ya, they're OK. And [my grandson] thinks they're nice. But I still don't like doctors. I imagine I never will.”

### *Fear of Costs*

Though less commonly expressed, the fear of cost also ranked among the fears and concerns of some caregivers. Those whose children were already insured generally did not express fear of costs, although one mother did express that she lived in constant fear of receiving a large bill – for services that were not covered, for insurance problems she didn't know about, or for large hospital expenses if one of her children (not just the one with asthma) became very sick. Given that, under most insurance plans, outpatient visits and regular medications were very low- (or no-) cost, even for families living in poverty, the fear of cost seemed more related to unpredictable events or instances in which the insurance they counted on did not in fact cover their needs.

Interestingly, I asked each of the children I interviewed whether they ever thought about how much their medicines cost or about how much it costs to see a doctor. Not a single one said that s/he thought about costs at all. One even remarked, “You have to pay money to see the doctor?”

I also asked children, “Have you ever heard your mom (or whichever caregiver was present during the interview) talk about money for medicines or about the costs of staying healthy?” Again, none reported hearing their caregiver speak about paying for medicines or doctor's visits. However, two children recalled that their parents told them that they have to buy healthy foods in order to be healthy. One child told me that his mother said, “Money is not for candy because you can't grow big and strong if you eat candy.” His mother chuckled as she watched her child tell me this. “That's right,” she said, “I'm glad you were listening!”

The fact that none of the children in this study indicated knowing, or even hearing, about the costs of their asthma care surprised me pleasantly. Given that participants ranked among the poorest residents of the city, I had expected that some children would have been aware of the idea of health care costs, or perhaps would have overheard conversations about financial concerns by their parents or caregivers and absorbed some of this anxiety. Some studies have shown that sick children feel guilty about creating a financial burden on their parents, and that this emotional stress can exacerbate the physical stress that their bodies are already enduring (Bluebond-Langner 1978, 1995). Thus I was happy to know that this was not the case among the children I interviewed.

### *Fear of Death and Disease*

Sometimes the reason families delayed asthma care or were afraid to adhere to strict medication regimens had nothing to do with the providers or with navigating the process of care. A few participants were afraid of being told by a professional that their child had asthma (or some other disease), and were especially afraid of being told that their child might die of the condition. While it may seem obvious to medical providers that one's chance of dying is probably less if the disease is controlled with regular medical care, for many families the confirmation of hearing a doctor speak about the disease was more terrifying than having it but not knowing for sure. The irony, then, is that those who fear death and disease so much so that they decide not to seek care may actually be more at risk of death and disease because of their avoidance of care.

In another instance, I learned that a young boy's fear of death from asthma was part of a larger fear of death based his and his mother's previous experiences:

I asked 11-year old Darren, “When you have asthma, what does it feel like in your body?”

“Well sometimes I feel good but then at other times it feels horrible.”

I asked, “What does the 'horrible' part feel like?”

“It feels like I can’t breathe that well and stuff…And I might die in a few seconds.”

“Uh-huh. That must be scary.” Darren nods after my comment, but doesn't say much more. So I ask, “Can you tell me more about what it feels like when you’re scared?”

“Because when I was little there was this one time that I thought I was going to die from a fever and I got really, really scared. So nowadays I’m really, really scared of death.”

“So you were very sick when you were little?”

“Just this one time 'cuz I had a bad fever.”

“I see...So what made you think you were going to die?” I asked.

“'Cuz my mom said my fever was so high I had to get in the water [his mother put him in a cool bath] or I might die.”

“I see. So you still think of that?”

“Yes. I think about death a lot, like when family members are dead. And also what makes me think about death was that fever.”

“Did that happen recently?” I asked.

“No, it was a long time ago,” Darren's mother interjected.

“I see,” I said, turning to Darren, “but you remember that.”

“Yeah” he answered.

“So when you’re really sick with asthma do you think about that fever too?”

“I just get scared that I might die.”

“You think you might die from asthma?”

“Yeah.”

“Do you think about death at any other times?”

“Just when I’m having an asthma attack.”

Turning to his mother, I ask, “Do you also worry about Darren dying?”

She responds, “Sometimes. My aunt died of an asthma attack so I get scared whenever he feels like he can't breathe.”

“Oh, I'm sorry. I'm sorry to hear that,” I said. “Yeah, asthma attacks are definitely scary, and unfortunately sometimes people do die from them.” Darren and his mother say nothing, so I ask Darren, “Did you remember your aunt having asthma?”

“No, it was *my* aunt,” his mother replies. “She died like 30 years ago.”

I ask Darren, “Do you know anyone who died from asthma?”

“No,” he replies. “Just Aunt Rose [the mother's aunt], but I never met her.”

Darren's and his mother's fears about death from asthma were not typical of the other participants. Not all children with asthma have experienced an attack, and many (who have determined how to effectively control their symptoms) have not had an attack in several months or even years. While many children in this study did remark of being scared of asthma or being scared when they witnessed or experienced an asthma attack, Darren was the only child who explicitly stated that he was afraid of dying from it. Darren's and his mother's comments reminded me of the durability and significance of fearful experiences, and how children absorb their parents' fears when told as cautionary tales.

### *The Distrust of Difference*

Sometimes the racial background of the provider made a difference in caregivers' ability to trust them. For example, one doctor, who is White, recalled this incident:

“I gave the mother a scrip for this inhaler. But she told me, 'No, that's not the same thing as what my doctor in Mexico gave me. He gave me something that came in a box with blue writing...' blah blah blah. So I said, 'OK, why don't you bring me the box and let me see what I can do.' So the next day she brings me the box that the inhaler came in and it's the same thing – it's the exact same drug. So I tried to explain to her that the difference is just a brand name versus the generic. But we give the generic because the insurance only covers the generic. And I tried to reassure her that it's the same drug, it's just as safe, it's just as effective, but she said 'no.' She only wanted the exact same thing as what her Mexican doctor gave her. So I said OK, and I wrote the scrip for the brand name with no generic substitute. The next day she comes back again, and she says, 'This must not be the same thing as the one my doctor gave me either because it's really expensive.' So tried to explain to her that, as I mentioned, it's expensive because the insurance won't cover it, and also, the prices in Mexico are probably different. Anyway, she got pretty upset with me so I called on one of the nurses, who's Mexican, to come and talk with this mom. And [the Mexican-American nurse] told her it was the same thing.

She told her all the exact same things I said. The mom still didn't look completely convinced but she left and she didn't come back the next day so maybe it worked. But nothing I said could convince her.”

In another interview, a doctor serving predominantly Black patients described how being Black affects her patients' level of trust in her.

“I definitely get some patients who tell me up front that they don't go to any doctors but they'll come to me 'cuz I'm Black – which is kind of silly because in a lot of ways, we're very different, you know? Like, I didn't grow up not knowing where my next meal would come from, and they didn't go to an Ivy League school. But anyway, I get it. I'm Black and that matters to them, and actually it matters to me that I can be someone they'd trust. So even though other doctors deserve that kind of trust too, I can understand where they're coming from. Anyway, we just hired this guy on our team, this other doctor. And he's really good, really sweet, sharp, really good. And at first I just told my patients, you know, I'm gonna be on leave next time you come but Dr. Singer will take care of you. And then I'd get a call on my answering machine and the mom tells me, 'I saw Dr. Singer, but next time I'd like to see you.' So fine, I see her son again and I ask, 'Was everything OK with Dr. Singer?' And the mom says 'Yeah, but I don't want a White doctor.' So now, when I tell patients I'm referring them to Dr. Singer I tell them in advance, 'He's White, but he's really good. I trust him. He's a really good doctor.' And it cracked me up the first time I said that – he's White *but* he's good – because normally I think Black doctors have to prove they're good enough against White doctors. But here [in her Bayview practice, it's just the opposite.”

A few other caregivers conveyed similar experiences, of feeling more comfortable with a provider of their own racial or ethnic background. On the other hand, one commented on a notable exception:

“I looked up this one doctor in the insurance book because his name was Gonzalez and I wanted a Latino doctor. Well, I didn't like him at all. And my son didn't like him either. So we come here, and even though the doctors are White, they're much better. They're nicer and I like them better. And plus they speak Spanish so I can tell they're trying to reach out to us [“quieren acercarse a nosotros”]. And I see a lot of Latino families here so I know they take good care of people. So now I tell all my friends to come here.”

The different types of fear and distrust that I have described here are all conditioned by personal experiences, whether first-hand experiences or lessons handed down from caregivers and older family members. It is important to recognize that, while health providers may not be able to reverse the durable impact of negative experiences, it is clear that positive incidents can mitigate against them somewhat. Patients and caregivers described “nice” doctors as people who listened to their experiences, who accepted their feelings without judgment, and who praised and encouraged their efforts to keep their children healthy. Fear, like other barriers to care, must be understood in the context of the life experiences that shape caregivers' decision-making process about children's asthma care.

In this chapter I have documented the historical events and conditions that produced social and economic segregation in San Francisco, and I have argued that these very conditions serve as ongoing barriers to asthma care for children and families. It is essential that health providers recognize how structural and symbolic violence have conditioned the context of daily life for immigrants and low-income residents in order to understand the logic of their decision-making processes. Furthermore, the durable and broad impact of fear and negative experiences cannot be underestimated as significant barriers to care.

Although many of the barriers to care outlined in this chapter may seem insurmountable because they are deeply entrenched and systemically grounded, it is clear that families are receptive to providers who communicate empathy based on an informed appreciation for events and situations beyond their control. Thus, while I have utilized participants narratives here to illustrate why asthma management is so challenging for many families, I hope that I have also indicated how these challenges may be bridged given a better understanding of their decision-making logic as reasonable reactions to these historical events and life experiences.

These findings are also significant because they are not unique to the problem of pediatric asthma management. This research indicates that patients and families are receptive to providers who they feel are compassionate and understanding of the challenges of their daily lives. Furthermore, since studies have shown that patients and families who trust their provider are more likely to seek regular medical care, this trusting relationship would likely lead to improved overall primary care not just for the child with asthma but also for siblings and other family members.

In sum, this chapter contributes to ethnographies of structural and symbolic violence by illustrating how San Francisco's legacy of institutional and environmental racism have produced higher asthma prevalence and ongoing barriers to asthma care, particularly for residents of Bayview Hunter's Point. As subsequent chapters will show, these barriers are but a part of the overall picture that illustrates why so many children continue to suffer from asthma.

In the next chapter, I demonstrate how subjectivity in the clinical care process produces ambiguity and conflict in asthma management roles and techniques. The narratives in Chapter 3 also demonstrate how the structural barriers discussed in this chapter continue to play a role in negatively impacting many families' ability to adhere to asthma management protocols.

# Chapter 3: Subjectivity in Clinical Processes of Care

In the previous chapter I demonstrated how the structural violence of everyday life prevents some families from seeking or continuing clinical care for asthma. In this chapter, I show how these same structural conditions affect children and caregivers during the clinical care process. In other words, if a family were to push beyond the challenges discussed in Chapter 2, these are the next set of obstacles that they would face in seeking clinical care for relief of their child's asthma symptoms. Thus, the reader should think of Chapters 2 and 3 as a chronology of potential barriers in which any one may be sufficient to interfere with effective asthma management. Also, it is important to remember that for many parents it is the accumulation of frustrating experiences that reinforces and exacerbates negative feelings about medical providers and institutions. Thus, I extend my analysis of the impact of structural barriers to the context of the clinic to show how these conditions play an ongoing role in impeding effective asthma care.

This chapter also contributes to the emerging discourse on children's subjectivity in clinical settings. I use participant narratives to illustrate how children's role in asthma management is defined and contested by providers, parents, and sometimes by children themselves, both within and outside of clinical spaces. In the section on cultural constructions of childhood subjectivity, I offer a brief account of the historical trajectory of evolving notions of childhood and how they correlate with changes in beliefs about children's proper role in society. Likewise, in the context of this research, I argue that ambiguity and conflict over children's responsibilities for asthma management tasks today are produced by variations in the conceptualization of childhood by those involved in children's health care. For example, some people firmly believe that parents are responsible for the health and welfare of children; others feel strongly that children should take an active role in their health care starting at an early age and increasing in responsibility as the child matures. The participant narratives in this section illustrate how poorly-defined clinical roles and techniques produce ambiguity and conflict at each stage of the clinical evaluation process, ultimately reducing the quality of asthma care.

This chapter is structured as a chronology of the steps involved in clinical process of asthma care. As I walk the reader through each of the steps involved, participant narratives illustrate how the quality and efficiency of care is diminished by subjectivity in asthma management techniques and by conflicting messages about the roles and expectations of parents and children. The narratives also illustrate how the effects of structural violence continue to permeate the clinical care process. The harsh conditions of daily life often prevent families from achieving the level of consistency and attention that is vital for effective asthma management.

I want to emphasize that these accounts are not intended to chronicle specific errors or locate blame on any individual's actions. On the contrary, I hope to illustrate how well-intended individuals and practices can inadvertently result in inefficient or ineffective care. It is also important to remember that not all of the services and steps that I describe below are available at certain clinics. In other words, the problems that I document in these narratives exist even amid the best possible conditions for asthma care, especially for low-income minorities that have limited insurance coverage for specialty services. It is likely that further complications would exist among children who receive care only from primary care or “free” clinics, and from those that do not have integrated social and medical services.

## A Chronology of Care

### *Step 1: Decide to seek clinical care.*

As I discussed in Chapter 2, structural barriers often affect the decision about whether and when to seek clinical asthma care. Some families feel that having asthma is an inevitable byproduct of living in a toxic environment, and it is not worth seeking care if they cannot control their environment. Other families feel that the consequences of poorly controlled asthma are less concerning than the more immediate and basic struggles of daily life. Some caregivers admitted that they waited several weeks, if not months, after they first noticed the child's symptoms because they thought the symptoms might resolve by themselves. For many families, symptoms were tolerated unless they directly interfered with the ability to perform everyday tasks. I witnessed this scenario repeatedly among families whose first clinic visit was precipitated by the child's repeated absences from school or the parent's repeated absences from work in order to care for the child at home.

Sometimes concern over changes in their child's level of physical activity prompted caregivers to seek clinical care. For example, one father told me:

“He [his son] used to play basketball for hours. And really good, like better than the other kids. But now I see him stopping or he bends over and stuff because he's out of breath more. Like he doesn't cover the court as well. So I think maybe he has asthma or something because he can't play good.”

Children also complained about symptoms interfering with their physical activities. An 8-year old girl told me,

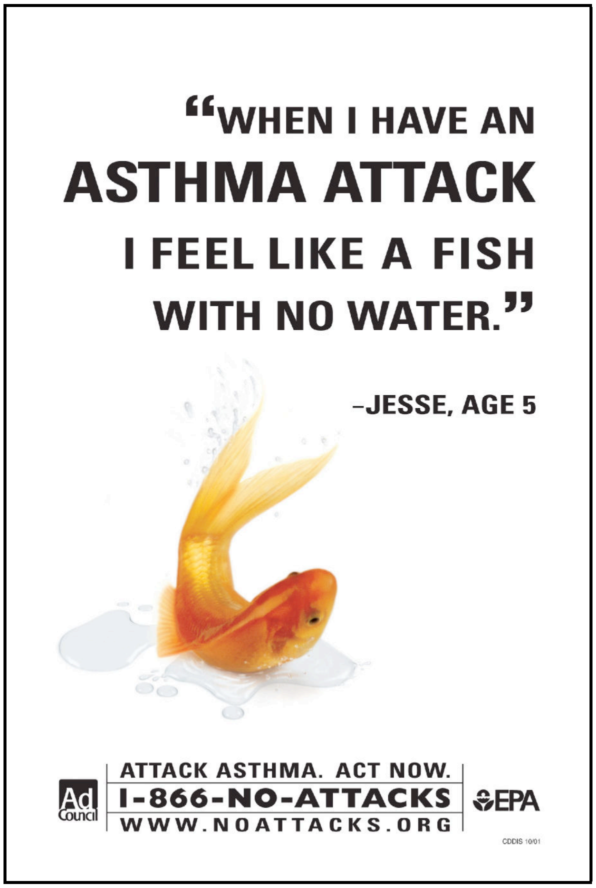
“When I don't have my inhaler I usually don't play at recess. Because I get embarrassed if I can't keep up with my friends. But if I can take the medicine before recess then I'm fine.”

A few caregivers dismissed the possibility that their child's symptoms were indicative of asthma because they equated the disease solely with attacks. As Tamika, the mother of a 7-year old girl, described in an interview with me:

“My daughter coughed a lot and so I thought she just had a bad cold or some virus that wasn't going away or something. I didn't think it was asthma because she never, like, stopped breathing. You know, because I saw those ads with the fish, you know what I'm talking about?”

“Yeah, I think so. You mean the ones that say that kids with asthma feel like a fish out of water?” I realize that that Tamika is referring to the Environmental Protection Agency's public service announcements that utilize the picture of a goldfish as a metaphor for children with asthma feeling like a fish out of water. In fact, for nearly a year during the time of this research, this message was posted on a large billboard in my neighborhood, also close to the area where Tamika resides.

**Photo 12**: EPA's “Fish Out of Water” Ad Campaign on Childhood Asthma



Source: Environmental Protection Agency, 2001

Tamika continues, “Yeah, that one. So I figured that since she never was like that, it wasn't asthma. She just had coughs and she was tired. But then when she said her chest hurt then I called the doctor.”

It is important to note here that the symptom of chest pain registered a more tangible, immediate cause for concern that ultimately prompted Tamika to seek clinical care. Her daughter's symptoms prior to that point, of chronic cough and fatigue, were not recognized as sufficiently worrisome to warrant clinical intervention. Tamika waited until she recognized a symptom that, to her, was indicative of a serious illness.

This pattern, in which a parent dismissed the possibility of a child suffering from asthma, occurred among several families because of similar misconceptions about the nature of asthma. During the sixteen months of fieldwork for this project, well over half of children and caregivers who I observed and interviewed described asthma as a disease characterized by acute, episodic attacks. This is a significant and highly consequential misconception. Asthma is in fact a *chronic* disease characterized primarily by chronic inflammation, often producing chronic cough, shortness of breath, and fatigue. Asthma “attacks” occur when the respiratory airways constrict, causing the person to feel like they cannot breathe. However, many patients with asthma never have asthma attacks, and among those who do, proper use of medications drastically reduce, if not completely eliminate, the occurrence.

The misconception of asthma as an acute and episodic disease is probably produced in part by the fact that attacks are the most visible feature of asthma. Inflammation and congestion in the lungs is not visually perceptible, and their manifestation as symptoms such as cough and fatigue may be confused with less serious ailments. The fact that Tamika noticed the “fish out of water” bulletin but deliberately dismissed asthma as the possible cause of her daughter's symptoms indicates a significant failure in the way that the campaign communicates information about childhood asthma. By focusing on the image of a suffocating child and the possibility of death, the fish out of water asthma campaign relies on scare tactics to motivate public behaviors. Unfortunately, this strategy also produced the misconceived equation of asthma solely with asthma attacks.

Structural barriers such as poverty and segregation also affect the phenomenological experience of illness. That is, the ways in which individuals experience sickness and suffering are inseparable from the social and physical contexts in which they occur (see Csordas 1994; Kleinman, Das, Lock, eds. 1997; Becker 2004b). Thus it is possible that the identification of asthma symptoms is complicated by the greater prevalence of violence in inner-city neighborhoods. Studies have shown that people who are regularly exposed to trauma and violence can become disconnected from their bodies as an adaptive mechanism to create distance and preserve emotional integrity amid physical distress (Steinberg 2008). In severe cases psychologists characterize this behavior as a dissociative or depersonalization disorder; in less severe forms, individuals under severe chronic stress may gradually become less attuned to the physical experience of their bodies.

Dr. Howard, a primary care physician in the Bayview neighborhood, speculates that children and caregivers may be less able to identify symptoms of asthma because of these dissociative tendencies. He described the following incident as typical of the types of situations that have led him to this opinion:

“A lot of times kids come into my office for some routine physical exam for school or for some totally unrelated problem, like a sprained ankle for example. And I walk in the room and before I even get to the problem they came in for I can hear the wheezing in their lungs – I mean without a stethoscope, I can just hear it. And they don't think anything of it. If I ask what brings them in, they say their ankle hurts. All they want is help with their ankle. But when I listen to their heart and lungs I hear major congestion, horrible congestion! And I'll ask them, 'how long have you had that cough?' And more often than not, they're like, 'I don't know.' And even if they stop and try to think about it, sometimes they have no idea how long it's been 'cuz it only occurred to them that they had a cough when I pointed it out in the first place.”

Another factor complicating asthma symptom identification, according to Dr. Howard, is the higher prevalence of asthma in inner-city neighborhoods.

“Everybody coughs,” he says. “So say you finally pick up on the fact that you have a cough [referring to his previous comment that most patients don't realize they have a cough at all]. You probably wouldn't think it's a problem if everyone else has got the same thing and they're still going about their regular routine.”

Indeed, studies have shown diminishing responses to otherwise errant behaviors when they occur commonly, especially among a discrete group of individuals. Psychologists call this the principle of normalization. Thus the higher prevalence of asthma and violence in inner-city neighborhoods supports Dr. Howard's contention that dissociative tendencies may reduce symptom identification, and may explain why some families do not seek clinical care for asthma symptoms.

In sum, in order to pass Step 1, children and caregivers must: recognize the child's symptoms, perceive the symptoms as problematic, feel that the symptoms will not resolve without medical intervention, and ultimately decide to seek clinical care. Note that this decision also requires that caregivers overcome the barriers discussed in Chapter 2, such as fear of medical institutions, fear of deportation, and hostile or degrading prior experiences with medical providers.

### *Step 2: Arrive for the appointment and wait to be seen by the practitioner.*

Step 2 in the chronology of care is not as easy as it may seem. Simply making an appointment and arriving at the scheduled time is difficult for participants whose employment situation is not stable and who rely on public transportation. For example, Ledia, the mother of 10-year old Michael, described why it was often difficult for her to keep her scheduled appointments:

"It's hard because I can't always come to the clinic. You have to make the appointment so many weeks in advance, and then by the time that comes I might have some work and I cannot take off." Ledia works several part-time jobs as a housekeeper and is an on-call employee for two different retail stores that rely on her to come in if their regular employees are unavailable. Thus Ledia must work whenever she has the opportunity to do so both because her income is unstable and because she will not be called upon by her employers for random jobs if they feel she is not likely to be available in the future.

"So if I'm stuck at work and if my mother is not available to take Michael to the appointment then I have to cancel it. And then we have to wait another few weeks and I hope I can make it then but I don't know. And maybe the doctors think I'm a bad mother because I keep missing Michael's appointments but I can't help it, you know?"

The fear of being perceived as a "bad mother" appeared in a handful of participant narratives. This underscores the fact that caregivers feel judged by medical providers as being neglectful or irresponsible if they do not adhere to prescribed asthma management regimens despite the fact that they are trying to do the best they can. Note that the "bad mother" comment will resurface as I continue along this chronology of care.

Several participants delayed calling for an urgent care appointment (i.e. not the follow-up ones that are scheduled far in advance, as Ledia spoke about in the above example) until they felt their child was critically ill because it required that they take off so much time from work. For example, one mother described how a ten minute appointment could take up to five hours of her time away from work:

1:00pm Claudia (mother) leaves work and walks to the bus stop.

1:08pm Claudia arrives at the bus stop and waits for the correct bus. Usually the wait is fifteen to twenty minutes, but sometimes she waits 40-45 minutes for the right bus to arrive.

1:32pm The bus arrives; Claudia rides toward her seven-year old daughter Mika's school.

1:47pm Claudia disembarks from the bus and walks to Mika's school.

1:53pm Claudia arrives at Mika's school. She must fill in a form to remove Mika from class early; then the administrator goes to Mika's classroom to get her.

2:09pm Claudia and Mika leave the school and walk back toward the bus stop.

2:17pm Claudia and Mika arrive at the bus stop and wait for correct bus to take them to the clinic.

2:33pm The bus arrives; Claudia and Mika ride toward the clinic.

2:41pm  Claudia and Mika disembark from the bus and walk to the clinic entrance.

2:53pm  Claudia and Mika arrive at the ground floor of the hospital building where Asthma Clinic is located. They wait for the elevator to take them up to the correct floor. This takes twelve minutes because the elevator stops at each floor where slow-moving family members, bustling doctors and staff members, janitors with big carts, and lab technicians with machines all squeeze in and out of the elevator at each stop. Then they walk through a maze of hallways until they arrive at the suite for Asthma Clinic. (Note: The first time I attended Asthma Clinic it took me about fifteen minutes from the moment I arrived at the hospital location to the moment I arrived at the clinic suite. Upon exiting the elevator, the room numbers are not clearly labeled at the top of each door frame, nor are they numerical in order; instead of Room 10, 11, 12, etc. the rooms are labeled in sections, like 6A12, 6D8, 6M25, etc. The signs are so confusing that I had to retrace my steps a few times. Even after I knew exactly where I was going it sometimes took ten minutes from the hospital entrance to the clinic door.)

3:05pm  Claudia and Mika arrive at the suite where Asthma Clinic is located to check in for their 3:00pm appointment. Claudia presents Mika's insurance papers and they take a seat in the waiting area. (Note: Most clinics have a policy that patients who are 15 minutes or more late must forfeit their appointment. This happened to a few participants, who described how a traffic accident or bus delay had made them more than 15 minutes late on occasion, despite having taken off of work far in advance of the appointment time. They were forced to pay the insurance co-pay for a missed appointment and schedule another appointment at a later time.)

3:52pm The staff nurse calls Mika and Claudia in to be seated in an exam room. She takes Mika's vitals and says that their nurse practitioner will be in to see them shortly.

4:13pm The nurse practitioner enters the room. She conducts a physical exam and asks about Mika's symptoms in order to assess the effectiveness of the current medication regimen. The nurse prescribes an additional medication for Mika's classic allergy symptoms that have caused her to be increasingly congested in the last few days. The nurse gives Claudia refills for her other medications and a note for Mika's school to verify her absence for the doctor's visit.

4:22pm The clinic appointment is over. Claudia and Mika exit the clinic, take the elevator down and walk toward to the bus stop.

4:34pm Claudia and Mika arrive at the bus stop and wait wait for the bus.

5:11pm The bus finally arrives; Claudia and Mika ride to the stop near their house.

5:28pm Claudia and Mika disembark from the bus and walk the rest of the way home.

5:45pm  Claudia and Mika arrive home. Claudia's work ends at 6:00pm so there is no chance that she could return to work in time. She has missed a full five hours of work for Mika's 10 minute appointment.

In order to appreciate the time and emotional energy required to conduct daily activities without access to a car, I spent several days relying purely on public transportation as I moved around the city. While this strategy does not truly replicate what participants go through on a daily, ongoing basis, I did encounter similar experiences as those described by participants: waiting 45 minutes for a bus to arrive, walking up and down San Francisco's sharply inclined streets (without cushy athletic footwear), not being able to escape exposure to second-hand smoke while waiting at bus stops, and not having convenient access to healthy foods in some neighborhoods.

In the above example Claudia and Mika were seen by the practitioners about an hour after their scheduled appointment time. Participants reported that they were usually called in to a room 20-40 minutes after their appointment time, but sometimes they sat another 15-20 minutes in the exam room before they were seen by a doctor. Thus, Claudia's wait time of an hour was fairly typical of most participants' experiences. However, some participants reported waiting much longer, between 2-3 hours, especially at certain community clinics and “free” clinics. In the waiting room at one community clinic, I noticed the following sign:

> Patients will be seen in order of medical necessity
> regardless of appointment time.

I polled the individuals in the waiting room of that clinic and determined that fewer than half had scheduled an appointment. One woman told me, “Why should I? They never see you at your appointment time anyway.” Many people told me they typically waited at least one to two hours to be seen; two people said they've waited over three hours in the past.

A couple of participants commented about how unfair it was that they are forced to wait for hours to see the doctor, but their appointment would be canceled if they are more than 15 minutes late. One participant, Shayna, angrily recalled an incident in which

**Photo 13:** Entrance area crowded with patients waiting in lines that snake around the room

(photo by R. Higashi, 2008)

her appointment was canceled when she and her daughter arrived 20 minutes late. They were delayed because of a problem with the school administrator who authorizes medical absences. Shayna recalled the episode this way:

> “The last two times I was there I waited for almost two hours for the doctor. And then this one time I was 20 minutes late and they said I had to reschedule. I told them, 'Fuck that! I waited 2 hours every time to see him and you guys can't wait 20 minutes for me?!' And I tried to tell them it wasn't even my fault that we were late because I gave the school the papers way before. And plus I covered my shift for the whole afternoon 'cuz usually we're here for hours, like I said. And after all that we still we got fucked. No fucking way I'm coming back. That's bullshit.”

I never found out whether Shayna followed up with her daughter's asthma care at a different clinic. She never to returned to the clinic where the incident occurred and she didn't return my phone calls. Not long after this interview I spoke with another woman, Camilla, who similarly recalled an experience in which her appointment was canceled because she arrived late. Camilla said that she was so “fed up” with the waiting and cancellations that she just relied on emergency care whenever her kids needed something. Thus it's entirely possible that for Shayna as well, the incident produced such antipathy, not only towards the clerk who canceled her appointment but perhaps more generally toward medical providers and institutions as a whole, that she decided not return to any outpatient clinic for her daughter's asthma treatment.

In sum, the process of arriving on time for scheduled appointments and waiting to be seen at outpatient clinics produces an immense burden upon families whose time and energies are already constrained by the realities of living in poverty. In order to accommodate the several hours that are required to attend a short outpatient appointment, caregivers must make arrangements in advance to take time off of work and possibly secure childcare for other children who may need to be picked up from school or looked after given the unpredictability of transportation and wait times. Sometimes arrangements can be made in advance, but others times they cannot. In addition to the short-term cost of forfeiting several hours worth of pay from missing work, some participants indicated that they delayed care because the repeated absences from work put them in an unfavorable position with their employer, who may, for example, offer other opportunities or increased pay to workers who do not miss work as often.

Thus, the time and economic forfeitures that are required for each clinical appointment constitute a significant deterrent to care. Urgent care appointments, in which the child is experiencing acute distress, may actually depend on when a family can afford to take the child to the doctor. In addition, regular outpatient appointments (which are essential for effective asthma management) are especially difficult because routine follow-up appointments are generally not perceived by family members as important medical events. Thus, caregivers would need to perceive the continuity of outpatient care as imperative to the child's well-being in order to justify the expenditure of time and endure the other negative consequences of accompanying the child to regular clinical appointments.

### *Step 3: The Pulmonary Function Test*

Most primary clinics do not have the spirometry technology that is used to quantify several measurements of a child's pulmonary functions like total lung volume and peak flow strength. Peak flow meters[9], which are much less expensive but less accurate, are typically used if spirometers are not available. At asthma specialty clinics like the one at San Francisco General, however, the spirometry readings are an essential part of asthma management because they allow the providers to quantitatively track the patient's physical progress along multiple indicators of lung health.

Most caregivers told me that they liked the pulmonary function tests because it provided them with a visual representation of their child's health. Particularly since asthma is relatively invisible because it affects the lungs and respiratory passages, parents liked seeing the concrete representation of their child's lung health on paper (see Figure 3 of sample spirometry report). In contrast, for example, caregivers usually rely on verbal representations of their child's health from the provider after the physical exam with the stethoscope (that allows doctors to listen to the child's heart and lungs) and endoscope (that examines the child's nasal passages and throat). Even though many of the values on the report (e.g. FVC, FEV1/FVC) are incomprehensible to an untrained observer, some providers felt that communicating the child's health to caregivers in numerical values helped providers to enlist greater participation and ownership of the child's illness and needs. Thus for both providers and parents, the pulmonary function report plays an

---

[9] Peak flow meters are small hand-held devices that are used to measure an individual's lung health. A patient blows forcefully (as forcefully as possible) into the mouthpiece and the device measures the strength of air flow.

important role in communicating a better understanding of asthma and in facilitating participation in follow-up and management tasks.

On the other hand, some parents seemed distressed by the quantified, visual representation of their child's illness. Dalia, who had accompanied her 9-year old son to his first appointment at Asthma Clinic, told me:

“They said his lungs are really sick, and his percentages are in like the 30s. I feel bad [“me da pena”] because I didn't come here earlier.”

Not realizing she was referring to the spirometry report, I asked, “What do you mean by his percentages?”

“You know that paper with the graph. The doctor showed it to me and I saw the numbers.”

“Oh you mean the spirometry report? I see.”

“Yeah, it said 30-something percent on a few of the places.”

It is important to note that, in this instance, Dalia did not know what the percentages actually measured because the values and labels on the report are listed in medical jargon. For example, as shown in Sample Pulmonary Function Report in Figure 3, the label “FVC” refers to forced vital capacity, which is equal to the inspiratory reserve volume plus the tidal volume plus the expiratory reserve volume. A lay translation might be “total lung capacity,” but the value is actually more nuanced for asthma monitoring.

However, Dalia wasn't aware that FVC meant total lung capacity, and she did not know what percentage range would be considered healthy or acceptable. All she knew was that on that specific indicator her son performed at 30-something percent of whatever it was measuring. And that made her feel bad.

I also witnessed seemingly indifferent reactions to the pulmonary function reports, but as I emphasized in Chapter 2, participants' attitudes and behaviors must be considered in the context of their experiential background. Earlier I described an incident involving Charlie, the father of a 7-year old African-American boy, Jesse. When the nurse said that Jesse's report showed that he was breathing like a 70-year old man, Charlie's quipped, “Ah, he aint gonna live that long.” Viewed within the context of socioeconomic patterns of discrimination and the violence of everyday life, it is easier to understand Charlie's dismissal of the possibility of his son living into old age. It is also worth nothing that the life expectancy of Black males, at 69.7 years, is significantly less than that of the overall population, at 77.7 years (Heron, et al. 2009: 7).

It is critical to bear in mind that the spirometry report (or the measurement from a peak flow meter if a spirometer is unavailable) is the only quantitative report that is available for asthma diagnosis and monitoring. Spirometers are not readily available at most primary care clinics and are not uniformly available even at asthma specialty clinics. In addition, the spirometer and peak flow meter are generally difficult or impossible to use with children younger than age 5 because they are unable to perform the breathing techniques that are necessary for their lung function to be measured accurately. In other words, for a vast number of asthma patients, only qualitative measurements are used for asthma diagnosis and monitoring. As I will describe in the ensuing steps of the clinical process of care, qualitative assessments of asthma are highly vulnerable to ambiguity and conflict. Unstable conditions of daily living make symptom reporting difficult and inaccurate, and the contested roles and expectations of children and caregivers further compound these inaccuracies and challenges. In sum, the subjectivity inherent in clinical assessments, I argue, inevitably and consistently reduces the quality and efficiency of asthma management techniques.

### *Step 4: The Intake Assessment*

The intake assessment consists of a series of standardized questions that are posed by the doctor or nurse practitioner primarily to the caregiver and sometimes to the child with asthma. In contrast with the pulmonary function test, the intake interview is highly subjective and, as I later determined, highly susceptible to inaccuracies that impact a patient's asthma diagnosis and treatment plan. As part of my study methodology, I initially observed patients and caregivers in clinical settings, and then asked for permission to interview them individually at a later date. Because of this, I had the unique opportunity to probe for more detailed answers to the questions originally posed during the intake interview. I compared the information I obtained during the interview with the responses that I had observed, and that the doctor recorded, during the clinical appointment. These comparisons yielded a number of patterns that revealed how the complexities of real life experiences are reduced, often inaccurately, in order to conform to the structure of the intake assessment. And because the intake assessment is such a critical component to determining the asthma diagnosis and treatment plan, the diagnosis and plan are often tailored inadequately to the child's actual experiences since they are based on truncated or contrived responses to the doctor's inquiry. In sum, I argue that the clinical process of care is one that attempts to generate standardized quantitative data from qualitative responses. The ensuing narratives show just how this occurs.

Again, I offer these narratives not to imply wrongdoing on the part of the participants, including practitioners, caregivers, and child. Rather, I offer them in order to

**Photo 14**: Intake Assessment

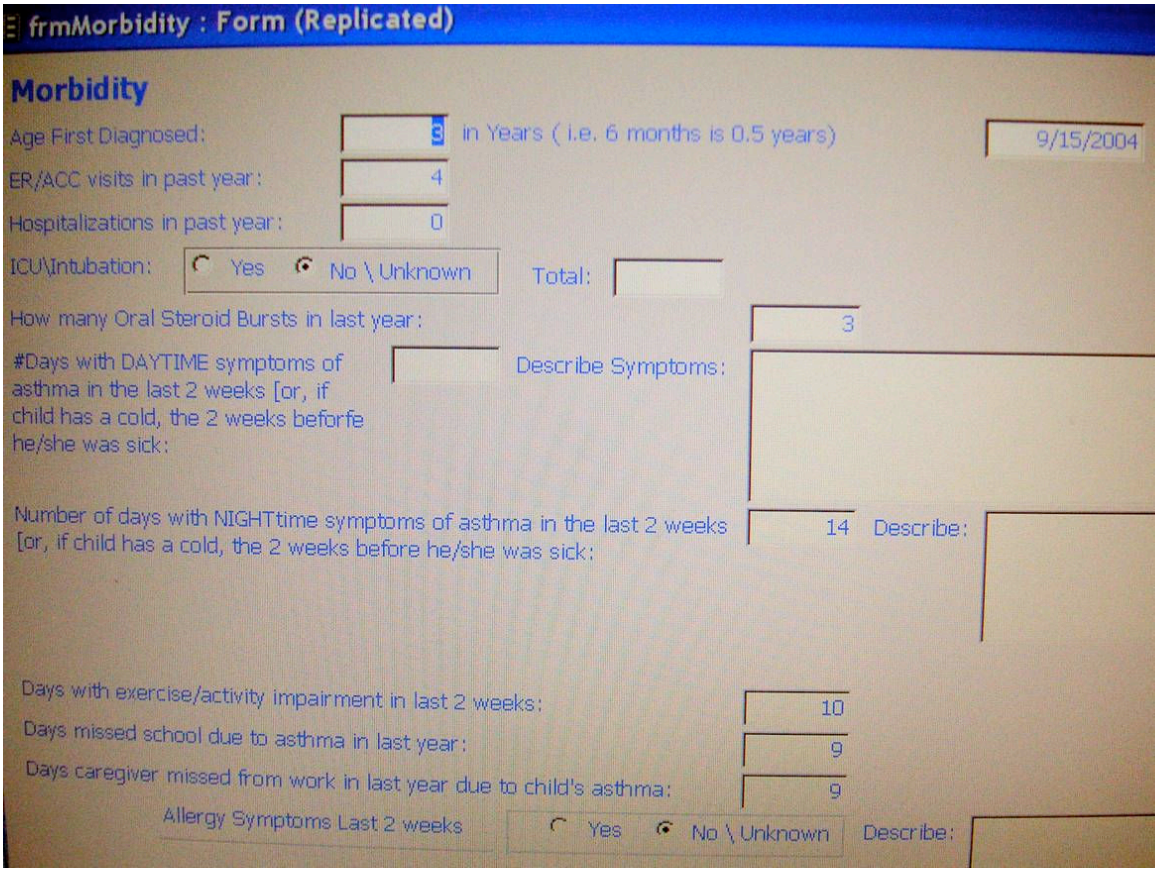
(photo courtesy of Asthma Clinic)

illustrate the extensive subjectivity that is inherent in the intake assessment component of the clinical evaluation. Furthermore, this chapter will demonstrate how good-faith efforts that have been implemented by providers in an effort to reduce inaccuracies and to improve quality and efficiency of care have in fact at times produced adverse consequences.

For example, in recent years some clinics have transitioned to electronic record-keeping instead of the more traditional method of practitioners using a pen and paper to record notes during the appointment. Thus, instead of the doctor writing down things like symptom frequency and intensity on paper, providers who use electronic records enter information directly on to a computer. The electronic method is generally viewed as favorable for a number of reasons: it reduces inaccuracies produced by illegible handwriting, it keeps records and information organized in a way that is consistent across various providers, and it ensures that new providers obtain the appropriate information that should be solicited from patients at each appointment.

Photo 15 is a closeup view of the computer screen during an intake interview. One can see the kinds of questions that the provider should ask, the order in which they should be asked, and the space provided for the patient's response. This is one of several pages of the total intake assessment. At first glance it is clear that the computerized assessment is likely to achieve more consistent “results” if any given provider at any given appointment must follow these prompts. Having numerical values in each of the spaces provides a seemingly quantitative evaluation of the patient's progress. Some questions also have a larger box that allows providers to describe symptoms or related information in free-form comments. Some, however, do not have an open comment box. In these instances I observed how providers reduced the ambiguity of the actual patient and caregiver responses in order to construct an appropriate numerical value out of the more complicated real-life scenario.

**Photo 15:** Closeup of Intake Assessment Form Filled Out on Computer



**Morbidity**

Age First Diagnosed: 3 in Years ( i.e. 6 months is 0.5 years)

9/15/2004

ER/ACC visits in past year: 4

Hospitalizations in past year: 0

ICU\Intubation: ○ Yes ● No \ Unknown Total:

How many Oral Steroid Bursts in last year: 3

#Days with DAYTIME symptoms of asthma in the last 2 weeks [or, if child has a cold, the 2 weeks beforfe he/she was sick: Describe Symptoms:

Number of days with NIGHTtime symptoms of asthma in the last 2 weeks [or, if child has a cold, the 2 weeks before he/she was sick: 14 Describe:

Days with exercise/activity impairment in last 2 weeks: 10

Days missed school due to asthma in last year: 9

Days caregiver missed from work in last year due to child's asthma: 9

Allergy Symptoms Last 2 weeks ○ Yes ● No \ Unknown Describe:

(photo courtesy of Asthma Clinic)

For example, the first question is “age first diagnosed,” and the prompt asks providers to list the response in years and months. Some families recalled exactly when their child was diagnosed. For example, a caregiver might say: “December of 2003. I remember because it was around Christmas time that year when my other daughter was 2.” In these cases a provider would able to record a highly accurate response to this question. More commonly, families did not recall precisely when their child was diagnosed. I often heard something like this: “Um, I think he was around 7 or 8 maybe.” In this type of situation, the provider usually wrote down one of the two numbers in response, so maybe “7” for this patient. This level of imprecision is irrelevant to the overall picture of how the patient's asthma will be treated. But it begins to establish how providers must create numerical certainty out of a vague response. Further, it is important to note that it would be impossible to record a vague response, like “7-8” because the computer program does not allow for a hyphen or more elaborate comment in this box. There are only two possible responses: one number (the year), or one number (year) then a dot and then another number (for months as a fraction of a year).

The response to the next question, “number of emergency room visits in past year,” will have a far more consequential impact on the overall assessment. That is, “2” ER visits portray a much different picture of the child's asthma control than “4” ER visits. Caregivers generally reported this number with a greater degree of certainty, possibly because a visit to the emergency room is a more memorable event. However, caregivers of children who visited the emergency room on multiple occasions, say more than three, were generally unable to report an exact number. Their responses were more often given, for example, as: “a lot” or “at least five but I'm not sure”.

Now turn your attention to the question in the middle of the screen that reads:

> “# of days with DAYTIME symptoms of asthma in the last 2 weeks [or, if child has a cold, the 2 weeks before he/she was sick]”.

This question produced highly inaccurate results as determined by the comparison between what the family reported during the clinical appointment and what I learned during my interview. There are a multitude of reasons why this question would solicit a response that does not accurately describe the child's actual experiences. First of all, the question asks the caregiver to recall any asthma symptom that the child experienced over the last two weeks. I thought to myself, when I go to the doctor they usually ask how long I've had the symptoms and I can barely recall when over the last few days the symptoms began, let alone a variety of symptoms over a two week period.

Second, the question asks the respondent to count only those symptoms that occurred during the daytime, and only if the child was not “sick”. Presumably “sick” refers to a bacterial or viral cold or something not related to asthma, but some asthma symptoms are very similar to ordinary cold symptoms, especially mucus congestion in the nose and lungs and fatigue. Third, what constitutes “daytime”? If a child goes to bed at 10pm but he typically coughs a lot between 8-10pm before he lies down, does that count as daytime or nighttime? Not once did I witness a caregiver asking for clarification about what constituted “sick” or “daytime” and not once did I witness the practitioner define these terms, leaving the meaning of the question open to interpretation by each respondent.

Not withstanding the above factors, the instability of families' home environments more often constituted the most significant factor that produced ambiguity and inaccuracy in responses. The vast majority of children I interviewed were looked after by multiple caregivers during a typical week. Most of the time the child's mother was the primary caregiver. Other caregivers typically included the child's father, step-parent, grandparent, aunt or uncle, older sibling, neighbor, babysitter, or friend of the family. However, during my interviews with the child and primary caregiver, I learned that most children spend a significant amount of time with caregivers who are not their primary. The following scenario based on one family's experience exemplifies this point:

6:30am Mother (primary caregiver) wakes child up, sometimes helps him take medicine, maybe eat breakfast. Step-father has already left the house.

7:00am Child walks to school with older sibling.

3:00pm School ends. Child and older sibling walk to their Aunt's house, where they play with their cousins.

6:30pm Child and sibling go home once mother returns.

7:00pm Step-father returns home. Sometimes mother or step-father remind child to take medicine.

9:00pm Kids go to bed.

Thus, the children in this family spend about 3 hours per day with their mother, about 2 hours per day with their step-father, and about 3.5 hours per day wit their Aunt. And of course, while this is the usual schedule, the actual time spent with each caregiver depends on a number of unpredictable factors, like whether a caregiver is delayed at work or by the bus, or needs to stop and run an errand on the way home, etc. So during the afternoon the children may stay longer with their Aunt, and then if their Aunt must tend to other tasks then their neighbor may fill in to take care of them at home until a parent returns. Thus, the mother would only know about the child's total daytime symptoms if the other caregivers carefully noticed and reported the symptoms and frequency to the mother, or if the child was able to self-report.

Furthermore, while the mother is usually the adult that accompanies the child to his asthma appointments, any one of the other caregivers may be enlisted to do this if the mother is unavailable for any reason. By now it should be clear that it would be virtually impossible for the one adult who accompanies the child to the clinic to answer the question" "How many days during the last two weeks has your child had asthma symptoms during the day?" And yet, I watched as caregiver responses were carefully translated into a number and a description of symptoms to fill in the box on the computer. It was only during my interviews with children and caregivers that I obtained more detailed information about their home environment, routines of daily life, relationships with family members and other caregivers, and typical activities and interactions, that I was able to understand the extent of the limitations and inaccuracies of the intake interview process. Thus, providers would generally be unaware of the extent of these inaccuracies.

The description above is typical in many ways of the experiences of other children and families. However, some children had far more unstable home environments that exacerbated the inability to accurately report on the child's condition. For example, in addition to having multiple caregivers, some children also reside at multiple residences. About one third of the children I interviewed lived at more than one address on a regular basis. This typically occurred among families with divorced parents, but a few children reported that their living arrangements had recently changed because of other events: a caregiver was incarcerated, children were removed from the custody of a caregiver because of drug or alcohol addiction, and in one case, a child had simply been abandoned. Sometimes these factors were noted during the intake assessment if the caregiver or child volunteered this information. More often, however, I learned about the family relationships and home environments because I had the added time to spend during my personal interviews with caregivers, and because I asked open-ended questions rather than needing to elicit specific responses for narrowly defined questions.

The fact that a significant number of children actually reside at multiple addresses is also significant because it increases their exposure to environmental allergens. As I will explain further below, the reduction of allergens and potential asthma triggers is a critical component of asthma management, but one that is often very difficult for caregivers to achieve. Furthermore, some caregivers expressed an unwillingness or an inability to ask other individuals, who they already relied upon for childcare, to do the extra tasks required for allergen reduction. For example, one mother said that she felt uncomfortable asking her elderly mother to dust the bedroom and wash her child's bed linens more often, even though these efforts had proven to be beneficial in reducing her daughter's symptoms. In another instance, a father shared his anger over the fact that his daughter was exposed to second-hand smoke whenever she stayed with her mother. The father said that he had repeatedly asked his ex-wife not to smoke around their daughter because smoke clearly irritated her airways and caused her symptoms to worsen. But despite several attempts in asking her to quit, he continues to smell smoke on his daughter's clothes when he picks her up, and he is resigned to the fact that he has little control over his ex-wife's behavior.

In sum, the intake interview process often fails to accurately capture important information about children's asthma symptoms. The systematized intake questions produce a neat but erroneous assessment of the child's actual needs and experiences. While the electronic format may impede the practitioner from entering more detailed information, I have also witnessed similar types of inaccuracies recorded on pen and paper. Thus, I argue that the procedural format of the intake interview, that attempts to translate complex human experiences into simple quantifiable responses, generates inaccurate profiles of patient health. And because the child's prescription medications and treatment plans are based heavily upon the information obtained during the intake assessment, I argue that these discrepancies should not be dismissed as incidental to the clinical care process.

## Constructions of Childhood Subjectivity

So far I have argued that the intake assessment process is highly susceptible to inaccuracies because complex human experiences are reduced to quantifiable data points that are more easily recorded in the medical record. But the intake assessment also yields imprecise representations of children's experience with asthma because cultural constructions of childhood impact the dynamic among provider, patient (child), and caregiver. By this I mean that the notion of childhood subjectivity may be conceived differently by these individuals, and these differences often produce conflict and ambiguity in how individuals conceptualize the appropriate roles and expectations for children with asthma. Further, notions of childhood subjectivity impact not only the clinical evaluation process, but also the ways in which children engage in asthma management tasks (or not) in their daily lives. Before I offer narrative examples of how children's subjectivity is enacted in the clinic, let me step back briefly to elaborate on the social and historical evolution of the notion of childhood.

The notion of childhood as a distinct phase of human development is relatively new in the history of human life. Historian Philippe Ariès, the father of childhood studies, argues that the modern notion of childhood as a distinct life stage emerged in Europe during Enlightenment Era of the 16th century (1962). Since this time, constructions of childhood have changed repeatedly over time, and have involved debates about children's physical and cognitive abilities, moral status, and role in society. For example, in medieval society, children were considered to be miniature adults, with the same needs and responsibilities as adults. Then in the 17th century the notion of childhood shifted to a view of children as innocent and vulnerable; during this time the Church was viewed as the primary protector of children against the moral corruptions of society. The notion of childhood innocence continued through the development of the modern welfare state in the 19th century, but the State emerged then as the primary protectorate of children's health and welfare; public health hygiene movements and disciplinary teachings were considered essential to assuring the quality of the population.

During much of the 20th century the notion of childhood was dominated by socialization theories in which children were viewed as receptacles of cultural transmissions and assimilated social values. Although they recognized certain unique elements of child development, socialization theories left children in a mostly passive role, with little independent thought or action outside of behaviors learned through observing and modeling adults. It was only in the latter third of the 20th century that socialization theory began to lose favor to the "new paradigm" of childhood studies, which is the dominant view held today. The new paradigm emphasizes children's role as products *and* agents of social processes. It also emphasizes the historical, social, and cultural variability of childhood around the world as opposed to any universal biological reality. Most importantly, the current construction of childhood emphasizes children’s engagement with political, economic, and social institutions, and children's ability to shape their environment (Stephens 1995).

Thus, in the context of the new paradigm, both of these statements would be true: Children are shaped by their environment – i.e. children's health is a product of factors such as their geographic location, economic status, and family relationships. And, children shape their environment – i.e. children's behaviors and thought processes play an active role in affecting their health status. I studied the comments of providers and caregivers in my observations and interviews, focusing on any judgments or assessments of children's role and expectations in asthma care. Some participants clearly expressed that, while they believed that parents are primarily responsible for children's overall health, children must also take responsibility for their illness by understanding how to care for themselves and by performing certain tasks on their own. For example, one parent stated:

> “I'm usually the one that takes her to the doctor when I think she is too sick, like when her cough is so bad or she can't breathe. But I expect her [the child with asthma] to tell me if, for example, she had to use her inhaler at school because I'm not there. Because she knows how to use her inhaler if she needs it. And sometimes she comes home and says, 'Mommy, I'm out of breath and my chest hurts.' And that's important because I need to know, and I told her that she needs to tell me. Because I can't be there all the time. She has to do some stuff by herself.”

This parent's comments are clearly aligned with the new paradigm construction of childhood in which children are both products and agents of their environment. The mother takes primary responsibility for ensuring her child's overall health, including taking her to the doctor when necessary. But she also believes it is her child's responsibility to take care of herself by self-administering her medications and by communicating how she is feeling physically.

Similarly, I recalled an interview with a doctor who asserted that children must be taught to participate in their own health care “from the very beginning”. As she put it, “My three year old nephew can practically program the VCR, OK? So yeah, I expect kids to take greater ownership of their illness and treatment. The expectations must fit the child's capabilities, but in general I think adults grossly underestimate what kids can do.”

In contrast, one provider said the following after seeing a 10-year old boy with poorly controlled symptoms: “That mother needs to do more because her kid is suffering! I don't know why she doesn't give him the medicine and make sure his symptoms are improving. She could have called me if she needed a refill!”

This provider's comments emphasized the negligence of the parent in meeting the child's needs. She did not comment on the 10-year old's role or responsibilities regarding asthma management tasks. This omission suggests that she did not hold the child accountable for participating in his asthma needs. When viewed alongside the historical paradigms of childhood subjectivity, the provider's comments are more aligned with the more outdated socialization theory of children as solely passive recipients of care rather than agents of self-determination.

I also observed how differences in the construction of childhood subjectivity were enacted during the intake assessment. For example, providers generally addressed all intake questions directly to the adult caregiver while the child sat passively next to the adult. That is, children were not solicited for their opinion or for information, and providers seemed comfortable recording the adult's responses with little or no input from the child. However, I witnessed a few occasions on which the child played a more active role in this dynamic, sometimes conflicting the information provided by the parent. When this occurred, the providers were confronted with the need to choose between the responses provided by the child versus the adult, or some midpoint in between. For example:

Nurse: [turning to child's father]: How many times has Brandon visited the emergency room in the last year?

Father: Just once, like in February or something.

The nurse begins to record "1", but Brandon, an 11-year old boy, interjects: Na-ah, pop. I went that time with mom, remember?

Father: When?

Brandon: I don't know. I couldn't breathe and we didn't have any more of that rescue medicine so mom took me to the emergency room.

Father: I don't remember that.

Brandon: I did!

Father: Are you sure that was this year? Or are you talking about a time a long time ago?

Brandon: No, it was this year, while I was still in 5th grade.

Father [shrugging his shoulders, he turns to the nurse]: I don't know. Once or twice I guess.

Nurse: OK.

I notice that the nurse records “1” for this question, thus disregarding the child's comment and recording the father's original response. Also, note here that the conflict in responses resulted from the fact that the child had multiple caregivers who may not have communicated these details to one another.

On the other hand, sometimes the practitioner recorded the child's response when it conflicted with the parent's, particularly if the child seemed especially articulate or willing to engage in the conversation. For example:

Doctor [turning to mother]: So you said almost every day of the last two weeks Michelle had asthma symptoms. What kind of symptoms?

Mother: Lots of coughing, sometimes wheezing. One time she coughed so hard she made herself throw up.

Michelle (10 years old): No, that was before. I didn't do that in a long time, mom.

Doctor [turning to Michelle]: So not in the last two weeks?

Michelle: No.

Doctor [still speaking to Michelle]: But do you still cough hard every day?

Michelle: Not every day. Some days I don't.

Doctor [at this point focuses her conversation on Michelle]: Is it like every other day?

Michelle: I don't know. I just cough when I have to cough.

Doctor: OK. Do you have any other symptoms? [Notice how the doctor backs off at this point of trying to nail down a specific number of days for the frequency of cough over the last two weeks. Instead, she asks about other symptoms, as perhaps this will indicate how often symptoms occur.]

Michelle: Sometimes I feel light-headed. Like after I run around a little.

Doctor: How often does that happen?

Michelle: Only when I run or something.

Doctor: So would you say once a week? Twice a week?

Michelle: Um, I don't know.

Doctor: Is it every day? Every other day?

Michelle pauses. Mother: Mija, answer the doctor!

Michelle: I don't know. Maybe every other day. [Notice how Michelle's responses, at one time voluntary, have become more restrained as the doctor pushes for a more quantifiable representation of her symptoms.]

Following this brief exchange, I watch as the doctor revises her earlier entry of the frequency of symptoms from 12 days in the last two weeks (because the mother originally said that Michelle coughed almost every day) to 10 days (perhaps because Michelle felt it was less than that). And she writes “cough, possible wheezing, light-headed during physical exertion” in the comments section to describe the patient's symptoms.

Thus, the dynamic between the practitioner, child and caregiver produces a situation in which ambiguous or conflicting information about the child's symptoms must be distilled into some numerical form that represents the child's actual experience. At one point, a doctor told me that she usually talks only to the parent because children are typically “poor historians.” I recalled that on previous clinical projects I have heard doctors use this term to describe older patients and low-literacy non-elderly adults. Thus, I wondered how individual practitioners judge the ability of patients and caregivers to report symptom history. After all, I witnessed how sometimes children contradicted their parents just to be antagonistic. For example, I watched a 13-year old girl continually interrupt her mother during the intake assessment. But when her mother left the room, she smirked at me and said in a cheeky voice, “I just do that to annoy her.”

Despite the frequency with which children interjected certain information, practitioners still spoke almost exclusively with the caregiver during the intake assessment. Likewise, children generally reported that their doctor didn't tell them anything about asthma. So I began asking children during separate interviews (not during the appointment), “What kinds of things do your doctors talk to you about?” The most common response was, “that I should eat vegetables (or “healthy foods”) and exercise”. When I narrowed my question to, “What kinds of things do the doctors at Asthma Clinic tell you to do?”, children most often shrugged their shoulders or said vaguely “that I should take my medicine”. The following interview with an 11-year old girl and her mother exemplifies this point.

Robin: What kind of things do the doctors at Asthma Clinic talk to you about? What kinds of things do they tell you to do?

Child: They tell me like lift up my shirt and breathe deep.

Robin: M-hm. What else?

Child: That I should eat healthy foods and exercise.

Robin: Good. What about how to take care of your asthma?

Child: Um, they don’t really talk to me much.

Robin: Do they tell you how to take your medicine?

Child: No.

Robin: No? They don't teach you how to take your medicine?

Child: No.

Robin: So do they mostly just talk to your mom? [Notice my erroneous assumption that the mother was the primary caregiver.]

Child: Either they talked to my uncle, because he’s the one that came with me last time, or we just figure it out at home.

Robin: Figure out how to take the medicines?

Child: Yeah.

Children's capacity for participating in health management tasks differed not only across individuals, but also sometimes across different moments of an individual child's life. One particular conversation with a nurse underscored this fact; she recalled the incident this way:

Julio is a 7-year old boy who has been treated for asthma for the past two years. His symptoms have at times been well controlled, but more recently they have been poorly controlled despite Julio's regular attendance to outpatient visits at the Asthma Clinic. On his latest appointment, however, Julio's tests revealed that his pulmonary functions were much improved, a drastic change from his test just three months ago. I asked Julio why he thought his asthma was much better. He shyly mumbled something about how he takes his medicines all by himself now. While I applauded the improvement, I was somewhat surprised by the sudden change and by Julio's response. So I called his mother at home, partly to report the good news of Julio's progress (since Julio had been brought to the appointment by a grandparent), but also to learn what she thought might account for the improvement so that I could make sure that we kept doing whatever it was that was working. Well, you'll never believe this. The mom told me that she was diagnosed with cancer a few weeks ago, and she has been very sick and unable to get out of bed sometimes. She said that Julio and his older sister simply began pitching in more with chores so that she would be able to rest more. And, she noted, Julio began to take greater initiative in performing the kinds of tasks he routinely did with his mom, like taking his medicines and brushing his teeth every morning and evening. And this kid is 7 years old! I thought, wow. All this time I didn't understand why his asthma was bad but it turns out all he needed was to take his medicine more regularly and it got better. And how ironic that it improved the most when his mom was so sick!

The narratives in this section illustrate children's variable subjectivity as active and passive participants in clinical processes of care. They demonstrate how differences in the perceived capacity of children to perform asthma management tasks affect the interpersonal dynamic of clinical interactions. And they expose inaccuracies in the information recorded by practitioners given the significant ambiguity and conflict inherent in the intake assessment process. I will return to the issue of childhood subjectivity in Chapter 5, where I argue that the cultural construction of children as vulnerable subjects has produced an imbalance of care between health services for children and adults that in turn produces new forms of childhood subjectivity.

Before I move on to the next section, I wish to clarify my recognition that the use of the terms “child” and “adult” in this chapter in some ways reproduces the false binary that I am troubling in this analysis. Anthropological literature has clearly demonstrated that the distinction between “child” and “adult” is a product of individual experiences and cultures that varies across global communities. For example, one of the patients in this study was a 16-year old emancipated minor who continues to receive care at the Pediatric Asthma Clinic. And the youngest primary caregiver, also the child's legal guardian although he looked no more than 16 years old, was the 20-year old older sibling of the patient. These factors underscore the need for human development to be conceived more broadly as a continuum of varying degrees of physical, cognitive, and emotional maturity, rather than an abrupt transformation at age 18. Bearing this in mind, I have nevertheless referred to all pediatric patients as “children” and all caregivers as “adults” for the purpose of this discussion.

### *Step 5: The Physical Examination*

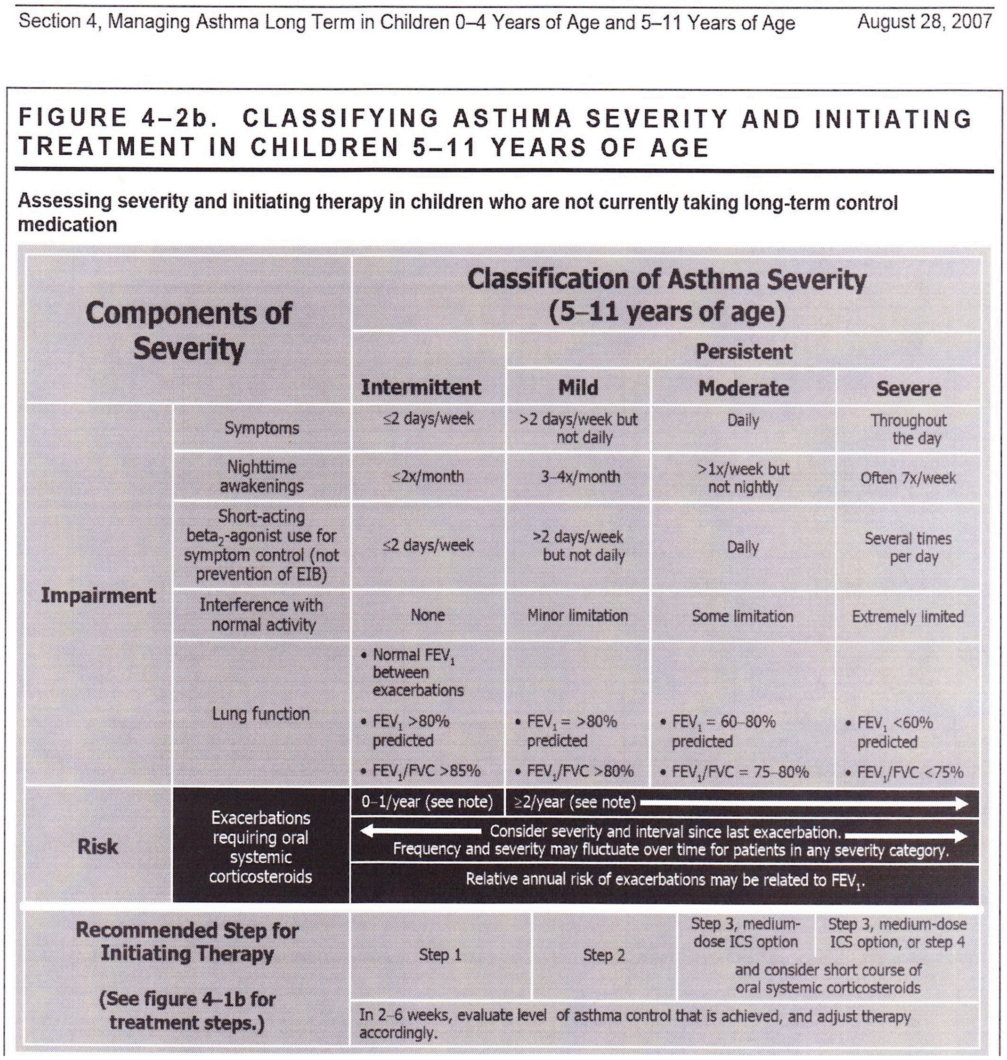
Unlike the intake assessment, in which children played a more passive role, children are physically and verbally engaged in the physical examination. Most children appeared relatively comfortable during the physical exam, and many anticipated the provider's requests to breathe deeply or hold still while they examined their nose and ears. All of the practitioners I observed exhibited a gentle, soothing demeanor while conducting the physical exam with children. Many also chatted informally with the child about school and sports, in stark contrast with the lack of engagement of children during the intake assessment. Most participants smiled and shared positive comments when I asked them whether they liked their doctor. Caregivers more often commented that they did not take their child to certain doctors for a variety of negative reasons, such as “he wasn't nice” or “she didn't listen” or “she put me down a lot”. A few parents took pride in the fact that they had spread the news about “nice” doctors or “mean” doctors to all of their friends and acquaintances, recommending which doctors they should see and which they should avoid. Thus both children and caregivers shared strong feelings about the perceived quality of a doctor and the nature of the rapport that encouraged or discouraged them from seeking care in the future.

While the intake assessment generally proved to be the most vulnerable to inaccuracy and ambiguity, the physical exam was not exempt from its own set of problems. Practitioners typically conducted the physical exam after the pulmonary function test (if a spirometer was available) and after the intake assessment. Sometimes a doctor conducted the physical exam after a nurse had conducted the intake assessment, so different practitioners performed different components of the clinical evaluation. Thus the person conducting the physical relied on the written (or computer-generated) record of the intake assessment, and the person conducting the assessment relied on the verbal characterization of the physical exam in order to produce an overall evaluation. Some providers admitted that they preferred to conduct both the intake assessment and physical exam in order to compare the results of both in greater detail, in a sense recognizing the potential impact of this exchange. However, the organization of the clinic and the availability of certain staff members sometimes did not allow for this to occur. Thus, an added level of ambiguity is produced in situations where multiple staff members are involved in piecing together various components of the overall evaluation.

### *Step 6: Putting It All Together*

So far I have described how the complexities of human experiences are reduced and translated into bite-sized, systematized, quantified information that purports to represent a patient's overall asthma control. With seemingly little regard for the ambiguity and inaccuracy inherent in each component of the clinical process, especially the intake assessment, practitioners generate a diagnosis and treatment plan based upon this (mis)information.

**Figure 4**. 2007 NHLBI Guidelines for Asthma Classification and Treatment of Children Ages 5-11



Section 4, Managing Asthma Long Term in Children 0–4 Years of Age and 5–11 Years of Age August 28, 2007

**FIGURE 4–2b. CLASSIFYING ASTHMA SEVERITY AND INITIATING TREATMENT IN CHILDREN 5–11 YEARS OF AGE**

**Assessing severity and initiating therapy in children who are not currently taking long-term control medication**

| **Components of Severity** | | **Classification of Asthma Severity (5–11 years of age)** | | | |
|---|---|---|---|---|---|
| | | | **Persistent** | | |
| | | **Intermittent** | **Mild** | **Moderate** | **Severe** |
| **Impairment** | Symptoms | ≤2 days/week | >2 days/week but not daily | Daily | Throughout the day |
| | Nighttime awakenings | ≤2x/month | 3–4x/month | >1x/week but not nightly | Often 7x/week |
| | Short-acting beta$_2$-agonist use for symptom control (not prevention of EIB) | ≤2 days/week | >2 days/week but not daily | Daily | Several times per day |
| | Interference with normal activity | None | Minor limitation | Some limitation | Extremely limited |
| | Lung function | • Normal FEV$_1$ between exacerbations<br>• FEV$_1$ >80% predicted<br>• FEV$_1$/FVC >85% | • FEV$_1$ = >80% predicted<br>• FEV$_1$/FVC >80% | • FEV$_1$ = 60–80% predicted<br>• FEV$_1$/FVC = 75–80% | • FEV$_1$ <60% predicted<br>• FEV$_1$/FVC <75% |
| **Risk** | Exacerbations requiring oral systemic corticosteroids | 0–1/year (see note) | ≥2/year (see note) → | | |
| | | ← Consider severity and interval since last exacerbation. → Frequency and severity may fluctuate over time for patients in any severity category. | | | |
| | | Relative annual risk of exacerbations may be related to FEV$_1$. | | | |
| **Recommended Step for Initiating Therapy**<br>**(See figure 4–1b for treatment steps.)** | | Step 1 | Step 2 | Step 3, medium-dose ICS option | Step 3, medium-dose ICS option, or step 4 |
| | | | | and consider short course of oral systemic corticosteroids | |
| | | In 2–6 weeks, evaluate level of asthma control that is achieved, and adjust therapy accordingly. | | | |

Source: http://www.nhlbi.nih.gov/guidelines/asthma/asthgdln.pdf, accessed 5/25/10.

Most clinics follow the NHLBI (National Heart, Lung and Blood Institute) guidelines that utilize information such as age, the frequency and severity of symptoms (as reported in the intake assessment) and the pulmonary function test (using the spirometer, if available, or a peak flow meter) to determine the diagnosis and treatment plan. The guidelines are organized as a grid of directives about how to assess asthma control and classify asthma severity and treatment. Thus the entire clinical evaluation is distilled down to a cell in a grid that determines the medications, dosage, frequency of medication use, and later, how to taper and adjust the treatment directives over time as symptoms improve. Figure 4 depicts one of these grids to illustrate this point.

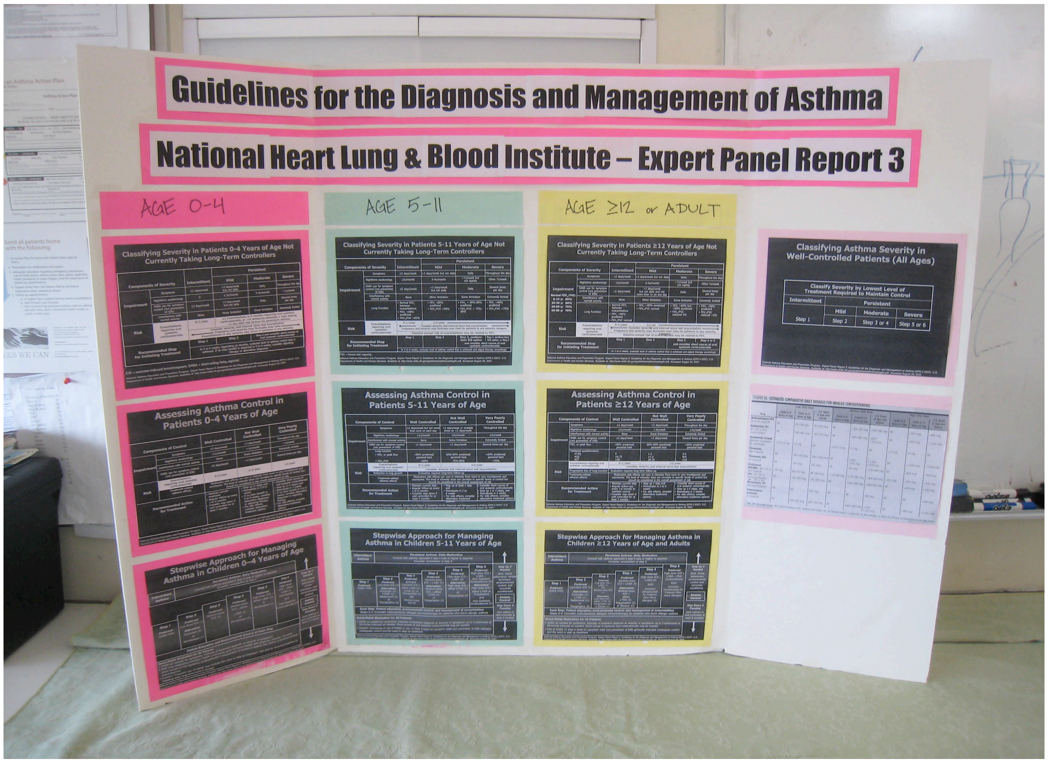
Asthma providers argue that use of the NHLBI guidelines improves consistency and efficacy in asthma diagnosis and treatment by reducing variances in the type of medications used, dosage, etc., especially since patients may be treated by a number of different providers over time. As one doctor told me:

> “Another thing that to me is very important is this sort of evidence-based and guidelines-based approach with which we handle all of our medical care. All of our providers are trained in providing state-of-the-art, the most up to date evidence-based approaches to treating asthma so we're not each providing our own type of care. Everyone is following the same guideline and it's very, very consistent.”

I would agree that by standardizing the way in which information is categorized and by linking it to a precise corresponding treatment plan, the NHLBI guidelines promote clearly-defined methods for identifying and executing asthma treatment. However, one cannot escape the fact that the information used to make these standardized determinations is based upon highly subjective and often inaccurate information. And for clinics that do not have spirometers, 100% of the information informing these decisions is derived from subjective characterizations of caregiver and patient reports that are classified according to the individual determinations of the provider that conducts the assessments.

If the prescribed treatment plan is ineffective in achieving the desired control of asthma symptoms, I would argue that the discrepancy between the information recorded by the provider and the actual experience of patients produces a significant disruption to the intended result. However, not a single provider indicated that the subjectivity inherent

**Photo 16**: NHLBI Guidelines at Asthma Clinic. This chart is displayed prominently in the staff work area so that providers may easily refer to them.



(photo courtesy of Asthma Clinic, 2008)

in the clinical process of care may be a factor in poorly controlled asthma in spite of the use of NHLBI guidelines. More often providers assumed that patients were not adhering to the prescribed treatment plan or were falsely reporting their actual usage.

It would be virtually impossible for any provider to record information about a patient's asthma symptoms in a way that accurately depicts actual experiences given the time constraints involved in clinical care. As I mentioned earlier, I was only able to determine the inconsistencies between the responses recorded during the appointment and the more elaborate description of the actual situation because I interviewed the caregiver and child for a longer period of time and I used open-ended questions that embraced the ambiguity of their responses. In sum, children continue to suffer from asthma because, despite the best intentions of providers and the best efforts of caregivers and children, asthma diagnosis and treatment remains a highly subjective endeavor.

### *Step 7: Adherence to the Prescribed Asthma Management Plan*

So far this chapter has illustrated how subjectivity inherent in the clinical care process reduces the effectiveness of asthma diagnosis and prescribed treatment plans. In addition to the difficulty that providers face in achieving an accurate clinical assessment, children and caregivers face a multitude of challenges that make adherence to treatment plans a difficult goal to achieve. In this section I describe how participants felt after their appointment and what kinds of barriers they faced in adhering to treatment regimens.

When I asked caregivers how they felt about their experience at the child's outpatient clinic appointment, most providers responded that they were happy with the care they received. Many participants cited the relationship with the doctor or nurse as the primary reason that they felt good about their child's care. Some participants felt dissatisfied with the experience, and these caregivers cited a variety of reasons. One parent felt that the appointment was confusing because the information conflicted with the things that she had recalled from previous appointments with other providers. A few caregivers felt skeptical about the doctor's recommendations because they conflicted with anecdotal accounts of how trusted family members and friends took care of their children's symptoms. As I mentioned in Chapter 2, negative attitudes toward practitioners, medications, services, and institutions are often reproduced in emotional accounts shared among family members. Accordingly, some participants felt torn between following the advice of family and friends and adhering to medical directives that conflicted with cultural, familial, or personal knowledge.

One parent felt that the appointment was a waste of time because the doctor did not prescribe any medication; instead, the doctor provided information about how to reduce environmental allergens and triggers and suggested that the mother administer Benadryl to alleviate the child's symptoms. This mother told me,

> "It was insulting. It felt like [the doctor] was telling me it was my fault because my house was dirty. Because she said that my son didn't have asthma, he just had allergies. But he's always sick and congested and my other son has asthma so I can't believe she didn't think he needed any medicine."

In a separate interview, I shared the above comment with a pediatrician (not the above patient's provider), and his comments echoed the mother's sentiment.

> "Sometimes I feel like if parents come here and don't walk out with a prescription they think we made a mistake or we don't really understand the problem. And in that case, if the child had allergies, what that doctor told the mother was absolutely correct. And these days there are a lot of remedies that are available over the counter so prescriptions are not always necessary to treat a child's symptoms. But I think a lot of parents, especially the ones in Bayview because I feel like they got it in their head that a lot of people have asthma, they feel like if it's not a prescription it's not worth taking."

Sometimes caregivers who are given anti-inflammatory "controller" medications for their child's asthma mistakenly believe that they are not working because their child does not experience an immediate tangible change in symptoms. Again, since inflammation of the respiratory passages is invisible, it is sometimes difficult for children and caregivers to appreciate the way that asthma affects the body and the ways that controller medications work to reduce chronic inflammation. In contrast, rescue medications like albuterol, which open constricted bronchioles, generate immediate physical relief, especially when taken during acute episodes with symptoms like chest pain or feeling short of breath. However, some caregivers do not seem to appreciate the necessity of reducing chronic inflammation as a preventive measure for controlling asthma. On several occasions I heard children say to their parents, “I don't like that one [pointing to the steroid inhaler] because it doesn't work.” Sometimes parents responded to this comment by saying something like, “It's working, you just can't feel it,” but other times the parent indicated that they didn't want to force their child to take a medicine if it wasn't working. Thus, both children and caregivers are vulnerable to misconceptions about the purpose of asthma medications despite the fact that practitioners (should) have explained the necessity of taking them as directed.

Other times children and caregivers did not adhere to medication regimens because they mistakenly believed that medications were not necessary if the child's symptoms disappeared. While some children have mild or intermittent asthma that does not require daily medications, most children with asthma are prescribed a daily controller medication that is used to keep irritable airways from becoming inflamed or constricted. A child with well-controlled asthma may not suffer from acute symptoms like asthma attacks, but it would still be important that the child continue to take his controller medications (if they were so prescribed). Finally, some studies have shown that fear of “steroid” medications may be a factor in lack of adherence to controller medications (Gillissen and Lecheler 2003; Yoon, et al. 2003; Orrell-Valente, et al. 2007). In sum, any one of these factors may generate skepticism or distrust that results in poor adherence to asthma treatment regimens.

Reduction of environmental triggers is an important component of asthma management, particularly for children whose allergy tests have demonstrated severe histamine responses to commonly encountered environmental allergens (e.g. grass, dust mites, pet dander). While the reduction of known triggers is proven to reduce asthma symptoms, modification of the child's environment is very time-consuming, sometimes costly, and often impractical endeavor in reality. For example, if the child is allergic to dust, caregivers must vacuum or clean the home more frequently, bed linens must be changed at least weekly, and home furnishings must be modified to reduce known triggers (e.g. curtains, rugs and carpets, comforters, stuffed animals and other trinkets are known to retain high quantities of dust). While some children may be able to help with

**Photo 17:** Allergy Skin Test. The provider places a tiny dab of various solvents on the child's forearm or back. Each number corresponds to a common environmental allergen (e.g. grass, dust, mold, pollen, pet dander, etc.). Histamine responses, characterized by redness, inflammation, heat, and itching, are recorded according to severity, and this helps to inform recommendations for environmental trigger reduction as part of the overall effort to control asthma.

(photo courtesy of Asthma Clinic)

these tasks, others are limited in their ability to help because they cannot reach high places, cannot handle certain cleaners, or cannot operate certain devices (like a washing machine).

In addition, trigger reduction may involve added costs (e.g. air purifiers, special covers for pillows and mattresses, traps for mice or cockroaches, etc.) that are

**Photo 17**: Stuffed Animals Collecting Dust

The Asthma Clinic recommended that children should keep just one or two cherished stuff animals in their room, rather than having dozens sitting out and collecting dust, as shown in this picture. Thus, while adults are challenged by the time and economic burden of allergen reduction, children face the emotional challenge of parting with blankets (of certain fabrics), stuffed animals and comfort items.

(photo courtesy of Asthma Clinic)

unaffordable for some families. For children with dust allergies, recommendations include the removal of carpets, curtains, certain comforters, and stuffed animals, all of which are known to collect greater amounts of dust. Or, if these items are not removed, they must be washed frequently (in a washing machine, not by hand) in order to cleanse them of the allergen trigger. Note that many low-income families do not have a personal washer and dryer at home, so these tasks would need to be accomplished at a neighborhood laundromat. Furthermore, since many families do not own a car, items would need to be carried, sometimes over several blocks, to and from the laundromat. Clearly, the time and monetary commitment of reducing environmental allergens creates an immense burden upon families who already experience challenges in daily life.

The determination of asthma triggers in the home environment is generally a task that is left to families. However, at the Pediatric Asthma Clinic at San Francisco General Hospital, home evaluations may be performed by Community Health Workers who have been trained to provide these types of public health services. If parents agree to a home evaluation, the health worker arrives at the child's home at a designated time to conduct a detailed assessment of the home environment. The purpose of the home evaluation is to locate and evaluate potential triggers and to recommend changes that may reduce the potency of allergens. Families who have taken advantage of this service offered by Asthma Clinic have uniformly expressed how grateful they were for the expertise and sensitivity that the health workers conveyed.

On the other hand, a few families expressed discomfort toward the idea of allowing the health worker into their home and declined the home evaluation service. As I probed for more information about this during individual interviews, caregivers who had refused home visits told me that they had done so because they were afraid that the health worker might judge them for not keeping their house clean and blame them for their child's poorly control asthma or think they were a “bad mother”. One parent expressed fear that the health worker might report them to the landlord or immigration authorities because they were undocumented residents and living “off-lease” (i.e. not registered tenants) in a house shared by several families. However, one Community Health Worker stated that there have been a few occasions in which a family initially declined the offer for a home visit but later changed their mind and consented to the home evaluation. This underscores the fact that a trusting relationship between the provider and family is likely to effectuate better continuity of care, a factor that is critical to effective asthma management.

In addition to conducting home evaluations, the Community Health Workers are available by phone and highly responsive to families' requests. They also perform follow-up calls to caregivers to inquire about the child's progress and to determine whether the medications need to be refilled. As one of the workers put it, “my job is to troubleshoot any problem the family may experience that prevents them from being able to care for their child.”

This approach to asthma care, that incorporates both clinical and social support services, is highly effective in reducing the impact of several barriers to care that typically remain unaddressed in more typical clinical arrangement. For example, since implementing this integrated socio-medical approach, the Pediatric Asthma Clinic at San Francisco General has reported tremendous success in reducing children's suffering from asthma: between 2002 and 2005 hospitalization rates decreased (from 18% to 14%), prescriptions for spacers[10] increased (from 47% to 75%), prescriptions for inhaled corticosteroids (“controller medications”) increased (from 44% to 56%) and patients who were seen in the emergency room for asthma symptoms were referred to Asthma Clinic for comprehensive care (Thyne, et al. 2007). And yet, some children continue to suffer from asthma despite the best-possible circumstances of this comprehensive approach that includes all four key components of asthma management as recommended by the NHLBI (assessment and monitoring, control of environmental factors, education and partnership between providers and caregivers, and pharmacotherapy). This chapter has shown how failures in asthma management are rooted in the inherent subjectivity and ambiguity at each step of the clinical evaluation that limits the ability of practitioners to achieve a more accurate picture of children's lived experiences.

## Good-Faith Efforts Gone Bad

---

[10] Spacers have been shown to enhance the delivery of inhaled medications deeper into the lungs, especially among younger children who are less able to inhale deeply. The NHLBI has developed specific recommendations for the use of spacers in young children.

In this final section I describe several interventions that practitioners have employed in a good-faith effort to improve the quality of asthma care, and why these efforts did not yield the expected result.

### *1. "Spacers are for Babies"*

As I noted in the previous section, the use of spacers greatly enhances the delivery of inhaled medications deep into the lungs, particularly among young children. The NHLBI recommends use of a spacer with a face mask for infants and preschool children, a spacer with mouthpiece for children aged 4 to 6 years, and a breath-activated inhaler for children ages 6 and up (see Photos 19-21). However, during my fieldwork I noticed that practitioners frequently provided spacers with mouthpieces for children past age 6, and breath-activated devices were generally reserved for children closer to age 9-10.

Although most children demonstrated the correct technique for using their spacer, I quickly learned that many children did not use the spacer outside of the doctor's office; rather, they used only the breath-activated inhaler portion of the device.[11]

I asked a 7-year old girl why she didn't like to use her spacer. She immediately quipped, "Spacers are for babies!" Several other children felt negatively about using

---

[11] The spacer and mouthpiece are manually attached to the inhaler piece so it is easy for almost any child to remove the spacer and use just the inhaler portion of the device.

**Photo 19**: Infant with Spacer and Face Mask
Source: www.american-allergy-supply.com/dn3000/dn3000.htm, accessed 5/25/10.

**Photo 20:** Child (age 4-6) with Spacer and Mouthpiece
Source: www.health.com/.../0,,20287392,00.html, accessed 5/25/10.

**Photo 21**: Breath-activated Inhaler (age 7 and up)
Source: loveisedward.blogspot.com/2008_12_01_archive.html, accessed 5/25/10.

spacers and preferred to use only the inhaler, whether or not they could sufficiently deliver the medication deep into the lungs for effective treatment. Some children commented that they did not use their spacer because they felt embarrassed about how it looked. One child complained that his spacer was too bulky, so he didn't use it because "it takes up too much room in my backpack." Another child said he didn't like how it "looks like a hospital." Presumably, he means that the spacer looks more like a medical device, and thus it was more stigmatizing to use in public than the breath-activated inhaler that several children thought was "cool."

For example, I asked an 11-year old girl what she thought about using her breath-activated inhaler. She said,

"Inhalers are cool. I think they're like smoking. I like to go like this [she pretends to puff on the inhaler like a cigarette, then she exhales through pursed lips as a smoker might do]."

Somewhat shocked, I asked, "So smoking is cool?"

"Kind of," she said. "The other kids at school think so. They like to try it."

"So you let other kids at school borrow your inhaler?"

"Yeah! They love it. They're jealous that they don't have one."

"Really?" I say, trying to hide my surprise.

“Yeah. Ever since I got my inhaler everyone wants to use it at recess.”

“So how many people do you share it with?”

“Well I used to share it a lot. But then I was running out of the medicine and my mom was like, 'Are you OK?' because I usually don't use that much. So now I tell my friends they can play with it but not to push on the medicine or actually use it.”

This narrative exemplifies how children sometimes play an active role in enacting certain health behaviors. In this instance, the pre-teenager recognized the wrongdoing in lending her inhaler to her friends, but she was motivated by the attention and used her inhaler inappropriately as an instrument of popularity among her peers.

### *2. Personal Peak Flow Meters*

In this second example of a good-faith effort gone bad, the doctors at a primary care clinic decided to devote some of their budget toward purchasing peak flow meters to give to their patients with asthma for personal, at home use. They had hoped that the visual and quantitative representation of their lung function would improve the chances that children would monitor their progress at home and that they would be more likely to take their medications in order to try to increase their measurements. Unfortunately, as this doctor described, the kids didn't use them, and more often than not, they lost them. She said, “We spent all that money on getting those peak flow meters. And they aren't cheap, let me tell you! And then the kids never used them! So that idea was money down the drain...”

### *3. Labeling Medications*

The same doctor and her colleagues thought up another intervention that they thought might improve patients' adherence to treatment regimens and ensure that children were taking their medication as prescribed. She asked her staff to put labels on each device (i.e. not the packaging that a medication came in, but on the actual device that children brought to their appointments). As she described her plan I thought yes, that's a great idea. I had frequently observed both children and caregivers unable to repeat back the medications and dosing instructions not two minutes after the provider had explained them. Many patients and caregivers also confused the two types of medications typically prescribed to asthma sufferers – the controller and the rescue medication. Improper use of either medication could in fact exacerbate the problem, so ensuring that they are being taken correctly was a major follow-up point among the Community Health Workers who contacted the caregivers a week or two after the appointment. While the doctor (and I) thought the labels were certain to improve proper medication usage, they turned out to be quite ineffectual.

Puzzled by the failure of a seemingly logical intervention, I asked, “Did you write the directions on the labels in plain English, not medicalized language, like 'once every morning and once every evening' instead of 'bid'?”

“Yeah, of course. We put the stickers right on the medicine and the spacer and it said like 'Rescue medicine, 2 puffs every 20 minutes when needed' and 'Control medicine, 2 puffs every morning and night'. But it didn't work.”

“Hmm. So why do you think it didn't work?”

“Well, I think it would only work if the kid (a) remembered to actually take his medicine every day, (b) he knows where he put it last, (c) he picks it up and actually reads the label, and (d) he understands those directions. And I guess those things never really lined up right.”

Some time after the interview above I spoke with a nurse at a different clinic about what she did to ensure that children and caregivers understood the correct dosage and timing for each medication. She replied,

> “I realized that whenever I asked, 'Do you understand?', they said 'Yes'. All the time. 'Do you understand?' 'Yes.' But then when I asked them to repeat it back to me a lot of the time they couldn't. And I had just then explained it to them! You definitely can't ask a yes or no question like 'Do you understand?' You have to get them to say it in their words. So I explained the medicines again and asked them to say it back to me again. And sometimes it took two or three times for them to get it right. And if I asked them again after a few minutes they forgot. So I've learned to ask them to tell me about their medications and dosages at a lot of different times during the appointment so that I make sure they remember.”

“Does that seem to work, then?” I asked, wondering if this might come across as patronizing.

“Yeah. A lot of times they think it's funny that I'm quizzing them.”

“Well that's good. At least they know it's all in good faith.”

These cases exemplify the “toolbox” approach that providers must employ in order to figure out which tools and techniques work best for which patients.

### *4. “Put it on your refrigerator so your parents will see it every day.”*

Finally, I offer a statement that I heard from a nurse who was trying to encourage the child to take greater initiative in adhering to asthma self-care regimens. I heard her say to the child, “Put it on your refrigerator so your parents will see it every day.” The 'it' in this case is the Action Plan. It's a sheet of paper that clearly spells out information such as what medications to use, how much, when to take them, what kind of symptoms would require a trip to the emergency room, when should they call the office for advice, etc.. But a closer examination reveals several assumptions built into the nurse's statement that may actually correspond to the patient's experience. First, the nurse says 'put it on your refrigerator.' During the course of several interviews I learned that many children do not eat fresh foods that come out of the refrigerator. Children often ate cereal or snack foods at home, and frequently ate from fast food establishments. Thus items posted on the refrigerator may not be seen on a regular basis.

Secondly, the nurse says 'so your parents will see it'. While some children had a mother and father in a more traditional nuclear family arrangement, many children did not. At least half of children lived in a home situation with one steady caregiver, usually the mother, and other caregivers who may have been present for more abbreviated periods of time (e.g. mom's husband before the divorce, mom's boyfriends, mom's grandmother before she died, mom's sister before she found her own apartment, etc.). Thus the characterization of 'parents' would not accurately describe most children's kinship arrangement. Similarly, the comment that the parents would 'see it every day' presumes that the child resides at a singular residence. As I mentioned earlier in this chapter, many children spent a significant amount of time, including sleeping, at more than one residence.

In this chapter I argue that asthma management is difficult for many families to achieve because of the high level of subjectivity inherent in the clinical process of care and because the ongoing effects of structural barriers create added challenges for low-income minorities. Narratives illustrate how, at each step in the clinical evaluation process, the complexities of human experience are distilled into neat numerical representations that are translated into standardized information about the asthma diagnosis and treatment plan. And yet, these standardized representations are highly vulnerable to inaccuracies. Ambiguity and conflict are produced by the interpersonal dynamic between providers, children, and their caregivers, but inconsistencies are quickly resolved when providers designate a discrete numerical value to stand for the muddled but more detailed portrayal of the child's actual experiences. Thus, returning to the original research question, “Why do so many children continue to suffer from asthma?”, the narratives in Chapters 2 and 3 offer countless examples of how historical, economic, social organizations of power have predisposed children from low-income families to greater vulnerability and futility in overcoming these barriers to care.

In the next chapter I address one of the most significant barriers to asthma care, as determined by both practitioners and families: health insurance. I argue that enrollment requirements in the health insurance process generate *de facto* barriers to care despite the *de jure* vulnerability of all children in California regardless of citizenship status. In light of the barriers already discussed in Chapter 2 and 3, the reader should appreciate the magnitude of barriers at every stage that ultimately precludes families from achieving greater control of children's asthma symptoms.

## Chapter 4: Health Care Eligibility vs. Enrollment

This chapter documents how problems with health care enrollment constitute a major barrier to asthma management for many low-income families, but particularly for Latinos and other immigrant groups. According to the California Health Interview Survey (CHIS)[12] of 2005, Latino (68%) and Asian / Pacific Islander (28%) children were far more likely than Black (8%) and White (4%) children to remain uninsured despite being *eligible* for public health insurance programs (Brown, et al. 2007). The prevalence of children's health insurance problems is significant because California offers better health care coverage for children than most areas of the country (see DeLeon 1992 in Marrow 2009; Frates, et al. 2003). Thus, if problems exist even amid California's progressive health care policies, it is certain that low-income and undocumented children in other states face far greater difficulties in accessing health care. This chapter outlines how the organization of power in healthcare bureaucracies produces a gap between children's eligibility and enrollment in public insurance programs such as Medi-Cal, Healthy Families, and Healthy Kids. I argue that the maze of bureaucratic enrollment requirements serve as a *de facto* barriers to care for some eligible applicants who are deprived of accessing the very health insurance provisions that are intended to serve them and for which they have *de jure* eligibility.

---

[12] The California Health Interview Survey (also known as CHIS) is the nation's largest health survey. Conducted by the state every two years using extensive questionnaires and surveys of household units, it provides detailed information about the health status of the population.

Several quantitative studies have published variances in the rates of health insurance coverage. For example, the report entitled “The State of Health Insurance in California” (Brown, et al. 2007) based on the 2005 CHIS findings, provides dozens of figures on health insurance statistics by age, race/ethnicity, income, geographic region, and type (employment-based, Medicaid, etc.). These quantitative reports clearly indicate which populations are lacking in utilization or eligibility for health insurance and health services. However, quantitative evidence is limited in its ability to convey the “on the ground” experiences of individuals, including how they negotiate barriers to health care, how they experience chronic and acute illnesses, and how they assess the value of health and health insurance. Qualitative methodologies are essential for capturing these details, and especially for conveying information in the words of individuals themselves. Thus, while a survey might ask respondents to choose from a list of potential reasons for being uninsured, open-ended conversations like my “interviews” with the participants in this study, allow individuals to speak about topics of their choosing, to elaborate on their feelings and details of their experiences, and to dictate the length and tone of the conversation. Because participants are not restricted to answering specific questions, their narratives contribute intimate details of their actions, feelings and  experiences that are often invisible to providers and policymakers. In sum, this ethnographic contribution, in combination with the statistical reports, paints a more vivid picture of how bureaucratic organizations of power effectively exclude certain individuals from accessing the information and health services that they need.

This chapter also contributes to anthropological works on poverty and immigration by illustrating how the failure of enrolling children in health insurance is not the product of individual failing; rather, these narratives clearly demonstrate parents' extensive and ongoing efforts to provide better care for their children in the face of fear and humiliation. In addition, this research conveys the emotional burden of caring for a sick child for families living an economically and politically precarious existence.

I begin this chapter with a description of current federal and state health care provisions as a context for the types of health care coverage available to participants during the time of this study. It is important to understand these coverage options in order to comprehend why certain individuals are not eligible for certain provisions. In addition, the reader should recognize that, while these descriptions of the various eligibility options and provisions may seem tedious and complicated, the information is actually presented here in a more concise and clarified form than is generally provided to health consumers. Thus, keep in mind that this slew of health insurance information is at least as challenging for the reader as it is for the parents in these narratives who, generally speaking, have far less health literacy and social capital in navigating the American health care system.

## History of Health and Welfare Programs in U.S.

On March 23, 2010, after over a year of debates on health care in America, President Obama signed the Patient Protection and Affordable Care Act of 2010. As he articulated many times, the President's commitment to reform despite the hostility of the bipartisan Washington climate is based on his belief that the current health care system is financially unsustainable for the U.S. economy, and that it does not meet the health needs of the population. As a testament to the national division over health care reform, universal care or the “public option” did not pass the debates in Congress and the House of Representatives despite the fact that universal health insurance was part of then Senator Obama's 2008 presidential campaign. In Chapter 6, the concluding chapter, I speculate as to how elements of the new health care legislation may in fact impact the population given the “on the ground” experiences that have been articulated by participants in this study.

In this chapter, however, I discuss the health care provisions and limitations that were in effect during the period of this investigation, roughly June 2006 – April 2008. As such, it serves as a kind of case study to illustrate how these health policies positively and negatively impact children and their families. Although this research could easily be used in the service of certain health care reform arguments, my goal in this chapter is to document the feelings and actions of participants within the existing health care system. I will focus my analysis on the successes and failures of currently available health care options, and how individuals and families respond to challenges in meeting their health needs.

The challenge of providing for the health and welfare of the population is not a new topic of concern. Medical historian Dorothy Porter (1999) traces shifts in the State's investment in public health, from concerns over epidemic diseases in medieval times, to population health as an instrument of economic expansion and prosperity during the Industrial Revolution, to the creation of the modern welfare state in the early twentieth century as a mechanism to reduce social and economic inequalities.

The modern welfare state in the United States began with President Franklin Delano Roosevelt's second New Deal. The 1935 Social Security Act created social insurance programs  like Social Security and Unemployment Insurance, and public assistance programs like the Aid to Dependent Children and Old Age Assistance. Prior to 1935, some commercial life insurance companies offered worker's compensation insurance, but very little private health insurance was available (Madison 2005). The welfare programs that sustained the population during the Great Depression were expanded in 1965 under President Lyndon Johnson's Great Society, when Medicare and Medicaid were enacted as Social Security amendments. However, studies demonstrate that (for reasons too numerous to discuss here) race- and class-based disparities in health continue to exist despite significant legislative efforts to reduce poverty and sickness.

Between 1935 and 1972, both legal and illegal immigrants were eligible for social insurance and public assistance programs (Fox 2009). Furthermore, federal confidentiality laws prevented welfare officials from cooperating with immigration officials. However, 1972 marked a change in policies toward undocumented immigrants' eligibility for federal and state welfare programs. In 1972 Congress amended the Social Security Act, adding a requirement that excluded persons not residing lawfully in the U.S. (Fox 2009). Within the next five years, restrictive changes in federal policies would bar illegal immigrants from accessing Social Security, Medicaid, Aid to Families with

Dependent Children, and food stamps (Fox 2009). In addition, reporting undocumented immigrants became permitted or required by various policy changes from 1972 onward (Fox 2009). Some mixed citizenship-status families, in which some members are eligible for welfare benefits, did not utilize public assistance because verification of status often required an interview with immigration officials (Marrow 2009). Thus, the *de facto* exclusion of certain *eligible* members based on fear of deportation existed at least 30 years before I had observed the same pattern under present-day policies during my research.

Like anti-immigrant policies, attitudes about immigrants being a "drain" on the public welfare system are not new. Xenophobic attitudes and accusations of immigrants as "dirty" and "uncivilized" have been applied to immigrants of a broad range of ethnicities across U.S. history and geographic spaces. Anti-immigrant sentiments tend to swell during economically depressed periods in particular, and often coincide with calls for greater restrictions not only regarding access to public welfare benefits but to stricter immigration laws as well.[13] Restrictive policies reflect a widespread public belief that welfare assistance programs will become a magnet for immigrants to cross the border illegally. However, studies have shown that illegal immigrants do *not* migrate to access free health care or welfare assistance programs (Yang and Wallace 2007; Berk, et al. 2000; see also Castañeda 2009). As Table 1 illustrates, employment and family reunification are cited as the primary reasons for immigration (Yang and Wallace 2007:

---

[13] On April 23, 2010, the State of Arizona passed Senate Bill 1070, the "Support Our Law Enforcement and Safe Neighborhoods Act", the broadest and strictest anti-immigration act to date. Opponents of the bill argue that it violates the civil rights of legal citizens. The Act is scheduled to go into effect on July 28, 2010, past the date of this publication; at the time of this writing, vehement opposition and support of the law have rejuvenated debates about immigration, discrimination, and the economy.

2). Furthermore, numerous studies have shown that the economic contributions of undocumented immigrants far outpace the costs to State resources such as emergency medical care (Nadadur 2009; Romano 2009; Porter 2006; Smith and Edmonston, eds. 1997). In sum, the public perception that immigrants exploit the State's resources is inconsistent with the facts (Pine 2008; Berk, et. al. 2000; Quill, et al. 1999).

**Table 1:** Main Reason for Immigrating Among Undocumented Latino Adults, 1996-97

| | Employment | Education | Family Reunification | Social Services |
|---|---|---|---|---|
| El Paso | 26.6 | 20.7 | 49.1 | 0.0 |
| Houston | 56.8 | 2.6 | 33.6 | 0.0 |
| Los Angeles | 56.2 | 4.1 | 33.0 | 0.6 |
| Fresno | 62.6 | 3.2 | 30.3 | 0.4 |

Source: Berk, et al. 2000.

## Current Health Care Coverage Options

The United States greatly expanded its social welfare programs for U.S. citizens over the course of the 20th century. However, these programs have been unsuccessful in reducing widespread and increasing race- and class-based health disparities. In fact, scholars from a variety of disciplines have argued that health disparities in the U.S. are *produced* by the inadequacies of the health care system. Thus, in order to understand the production of health disparities and to contextualize participants' remarks about barriers to care, I will first provide a basic overview of current U.S. health care provisions.

The United States, unlike every other industrially developed nation in the world, does not offer universal health insurance to its citizens. Instead, the U.S. health care system is comprised of a combination of public and private insurance programs and the health care “safety net”. The safety net, which I will discuss below, is comprised of a loosely organized system of charity organizations that provide free or extremely low cost health care to the uninsured.

According to the U.S. Census Bureau, in 2007 approximately 15% of Americans, numbering over 45+ million, do not have any health insurance (U.S. Census Bureau 2008a). While the majority of Americans (nearly 60%) still obtain health care coverage through an employer, the proportion of individuals receiving coverage through an employer has been steadily decreasing over the last two decades (U.S. Census Bureau 2008a). The uninsured population is comprised almost entirely of middle- and low-income families who are overrepresented in temporary, part-time, or low-wage jobs and are therefore not eligible for employment-based coverage. Not surprisingly, as employment-based coverage has become increasingly unavailable, the proportion of the population receiving health insurance from public assistance programs has steadily increased.

The consequences of inadequate health care coverage, including higher rates of mortality and morbidity, have been well-documented (Hadley 2003; Becker 2004a). The over-representation of ethnic minorities among the uninsured reflects deeply entrenched patterns of racism and structural inequality in the health care system. In 2007, 33% of Latinos, 20% of Blacks, 32% of Native Americans, and 17% of Asians were uninsured, compared to 11% of Whites (U.S. Census Bureau 2008a). These figures do not include non-U.S. citizens, so the number of persons living in the U.S. without health care coverage is far greater. Passel and Cohn (2009) estimate that undocumented immigrants now constitute 4.0% of the total population living in the U.S. (approximately 11.9 million). Because of restrictive policies that make them ineligible for publicly funded health care coverage, most undocumented immigrants rely on the health care safety net for health services.

Rather than elaborate on the health care system's private and employment-based options, I will confine subsequent discussions of health insurance to publicly funded programs only. All participants in this study were either covered by one of the following programs or were completely uninsured.

### *Public Health Insurance*

Public health insurance programs, of which Medicare and Medicaid are the largest, are provided by the State for select communities under strict eligibility guidelines. For example, Medicare is a federally administered program that provides health insurance primarily to persons over age 65 and to persons with disabilities.

Medicaid is a system of federal and state programs that provide health insurance primarily to low-income communities. Other public health insurance programs include the Veterans Health Administration, Military Health System, and the Indian Health Service. In addition, the State Children's Health Insurance Program (SCHIP), enacted in 1997, greatly expanded health insurance coverage for low-income children and families across the country. Since its inception SCHIP has greatly reduced the number of uninsured children nationwide and its success has prompted more recent proposals for its expansion (Paddock 2007).

Most of the children and caregivers in this study qualified under the income requirements for publicly funded health insurance programs like Medicaid and SCHIP. The majority of children in this study were enrolled in some Medicaid and/or SCHIP-funded health care program. In contrast, only about two-thirds of adult caregiver participants were enrolled in some Medicaid-funded program; others utilized the health care safety net or were completely uninsured. In the next chapter I will discuss the implications of this imbalance in health care coverage for children and adults, and I argue that this dynamic has produced new forms of health citizenship and child subjectivity.

### *Medicaid / Medi-Cal*

Medicaid was created in 1965 as part of the social welfare programs of President Lyndon B. Johnson's Great Society. It is funded jointly by the federal and state governments, and is administered at the state level. Medicaid is primarily intended to cover low-income children and families who are not eligible or cannot afford other health insurance provisions. However, despite the availability of Medicaid programs, the percentage of U.S. residents who lack any form of health insurance has been increasing since 1994 (Fronstin 2007). This is partly due to the fact that the number of physicians accepting Medicaid has decreased steadily due to lower reimbursement rates (Cunningham and May 2006). Data from the Robert Wood Johnson Foundation (2007) shows that many of the uninsured are non-elderly ethnic minorities with limited education who do not have employment-based coverage and are not eligible for Medicaid or Medicare under age and income requirements.

The Medicaid program in the State of California is known as Medi-Cal. In 2008, Medi-Cal provided health care coverage for more than six million low-income children and families in California, as well as elderly, blind, and disabled individuals (California Health Care Foundation 2010). The vast majority of pediatric patients served by San Francisco General Hospital, where much of this research was conducted, are covered by programs funded through Medi-Cal.

### *SCHIP / Healthy Families*

The State Children's Health Insurance Program (SCHIP), created in 1997, was the largest expansion of health insurance for children since Medicaid began in the 1960s. It is intended to provide health care coverage for children in families who do not meet Medicaid eligibility requirements but cannot afford to buy private insurance. On February 4, 2009 President Obama signed the Children's Health Insurance Program Re-authorization Act to continue and expand health care for children after the original SCHIP provisions had been reduced under the George W. Bush administration. Individual states have significant flexibility to design their own eligibility requirements, benefits, and payments for SCHIP programs within a broad range of federal guidelines because governance of funding falls to state administrators. In California, for example, the California Health Care Foundation (CHCF), an independent philanthropic organization, plays a major role monitoring health care finance and delivery (CHCF 2008).

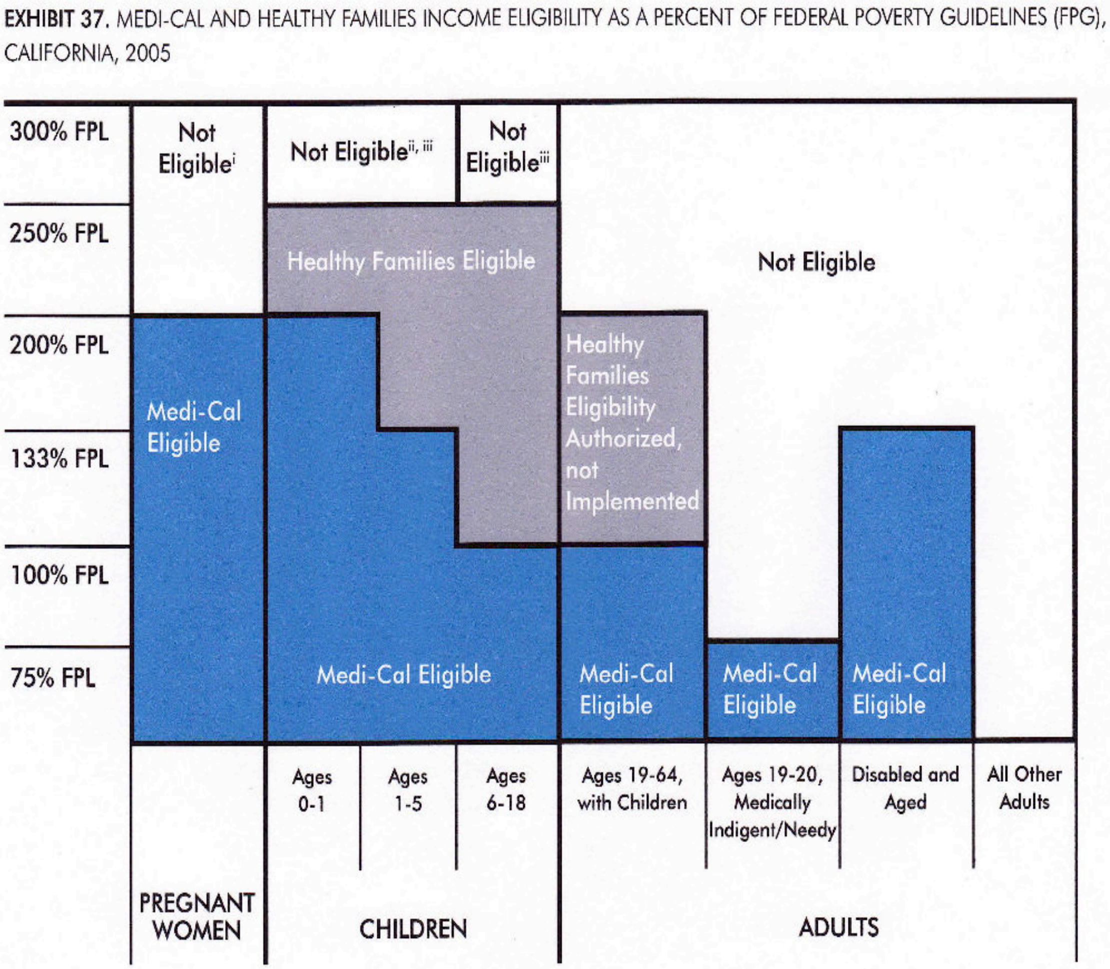
SCHIP is the primary source of funding for the Healthy Families Program in the State of California. Healthy Families provides health insurance for children under age 19 from families whose income is between 0-250% of the federal poverty guidelines (FPG). [14] As Figure 5 illustrates, the eligibility requirements for Medi-Cal and Healthy Families are overlapping in some areas, but together provide a kind of patchwork quilt that covers most low-income families (Brown, et al. 2007). California has the largest SCHIP enrollment of any state in the country, receiving roughly 16% of all federal SCHIP funds (CHCF 2008). And due to the recent economic downturn, the Healthy Families Program has experienced record-high monthly enrollment. Medi-Cal and Healthy Families more

---

[14] See Appendix 1 for enumeration of the 2009 federal poverty guidelines (FPG).

than offset children's loss of employment-based insurance between 2001-05 (Brown, et al. 2007). Thus, these programs are essential for ensuring health care coverage for

**Figure 5.** Medi-Cal and Healthy Families Eligibility by Income, 2005



Source: Brown, E. Richard, et al. 2007.

children and families, particularly given the instability of parents' employment-based coverage.

In sum, while thousands of children currently benefit from state- and federally-funded health insurance programs, my research clearly demonstrates that problems continue to exist for many children and families in the process of meeting eligibility and enrollment requirements. According to CHIS 2004 data, 71% of the 763,000 uninsured children in California were eligible for either Medi-Cal, Healthy Families or the Healthy Kids programs in their county of residence (Brown, et al. 2007). Clearly, the gap between health insurance eligibility and enrollment accounts for a significant share of the health care burden.

### *Health Care for Undocumented Immigrants*

The precise options for health care services and insurance coverage for undocumented immigrants in the United States varies because states are given some flexibility to determine eligibility guidelines for enrollment in programs administered at the state level. However, with few exceptions, undocumented immigrants are ineligible for all of the above-mentioned publicly funded programs including Medicare, Medicaid and SCHIP because of restrictive federal policies. As a result, most undocumented immigrants rely what is commonly referred to as the “health care safety net”. The safety net is a euphemistic term that describes the loosely-based system of community clinics and “free clinics” that do not require documentation for basic medical services that are provided at little or no charge to health care consumers. The safety net clinics are generally funded by charities, private, or non-profit organizations, and are staffed by medical providers who either volunteer or are paid nominal wages by the sponsoring organization. Fear of deportation is a major deterrent for many undocumented immigrants to access formal avenues for health care. I will return to this point in the specific context of participants' decision-making and feelings about health maintenance.

### *Healthy Kids*

Undocumented immigrants in San Francisco and in most areas of California, however, do have a few formal options outside of the health care safety net. Consistent with its progressive political character, San Francisco is home to several innovative programs aimed at providing health care services to the uninsured, including those without citizenship documentation. Of these, most of the children who participated in this study were enrolled in the “San Francisco Healthy Kids” program. Healthy Kids is a county-administered program that provides subsidized health care to children under age 19 from household incomes of up to 300% FPG who are not otherwise eligible for coverage through Medi-Cal and Healthy Families. Unlike its federal and state counterparts, Healthy Kids is able to provide coverage for undocumented immigrants because it is funded by a combination of public and private sources, the largest of which is the California Endowment.

Healthy Kids programs are currently established in 14 of 58 counties in California, including most of Southern California where the greatest number of uninsured children live, and San Francisco, where this study took place. Among the remaining, mostly rural, California counties Healthy Kids programs are either in the planning or development stages. In January 2007, Healthy Kids programs covered over 86,000 children in California (Brown, et al. 2007), providing comprehensive medical, dental and vision services. By extending the income eligibility guidelines to 300% FPG and by providing coverage to children regardless of U.S. citizenship status, it is clear that the Healthy Kids programs have greatly improved the health of children in California who would otherwise be excluded from accessing affordable health services. However, as the ensuing narratives will attest, many who meet the eligibility requirements of Healthy Kids are still unable to actually enroll in the program because of certain documentation requirements such as proof of residency and income. In other words, the State's *de jure* commitment to providing access to all children has the *de facto* effect of continuing to exclude certain populations. This is a significant finding because, as some participants describe, it has the effect of absolving the State of accusations of neglect toward the uninsured while simultaneously deepening the blame directed at individuals.

Health care options for undocumented adults are far more limited than they are for children. At the time that I conducted this research, the “Healthy San Francisco” ordinance (similar to Healthy Kids but for adults ages 18-65) had only recently gone into effect, in April 2007. Whereas nearly all undocumented children in this study were enrolled in San Francisco Healthy Kids, not one of the adult caregivers I interviewed was enrolled in Healthy San Francisco. The dynamic of unequal access to care between children and adults that I observed during my research may be mitigated somewhat by this more recent initiative to extend health services to undocumented adults. Apart from Healthy San Francisco, undocumented adults are somewhat protected by the Sanctuary Ordinance of 1989, which generally prohibits medical providers from asking or collecting information on citizenship status.[15] However, this “don't ask, don't tell for doctors” policy, as one study participant called it, does little to assuage the fears of many undocumented immigrants from seeking care except in cases of medical emergency. The consequences of disparate health care coverage for children and adults is the subject of the next chapter, where I show how children with insurance may sometimes act as liaisons between the State and their uninsured parents.

The maze of health care coverage options are confusing to even the most educated and experienced health care consumer. The less educated and non-English speaking consumers, like the participants in this study, often felt paralyzed by the overwhelming nature of the eligibility and enrollment process. Health care organizations provide “consumer advocates” to assist potential enrollees with the process, but as I will demonstrate, participants report numerous and severely negative experiences that have deterred them from seeking assistance from such persons. Participants describe how a

---

[15] The ordinance prohibits: (a) the asking or collection of any information on legal status other than that required by state/federal statute, court decision, or regulation, or by federal, state, or local public assistance criteria; and (b) the cooperation of public service providers with federal immigration officials regarding any persons not under investigation or convicted of felonies. (City and County of San Francisco, 1989 in Fox 2009)

singular experience of degradation and fear can easily sour their opinion of the sincerity of health care programs and program officers in meeting the needs of consumers.

## Eligibility vs. Enrollment

The experiences among participants in this study are consistent with the 2005 CHIS findings that Latino (68%) and Asians (28%) children are far more likely than Black (8%) and White (4%) children to remain uninsured despite being *eligible* for public health insurance (Brown, et al. 2007). All eighteen of the Latino families that I interviewed experienced at least one problem with health insurance, compared to only one of the twelve African-American families in this study. Two of the three Asian and Middle Eastern immigrant families in this study also reported problems in accessing coverage. In addition, Latinos more often encounter problems with meeting enrollment requirements and are uninsured for longer periods of time, whereas African-Americans more often experience temporary gaps in coverage due to changes in their home and family circumstances, often as a result of incarceration, abandonment, and relocation.

Medical providers are not experts in health care coverage and policies, and many are not fully aware of the challenges faced by their patients. One provider, in a moment of particular frustration, blurted out, “what's so hard about this anyway?” For some, the mere *availability* of health care coverage may be perceived as an effective solution to meeting the health needs of the uninsured. Upon closer examination, however, it is easy to understand why the availability of health insurance in theory does not easily translate into effective coverage in practice. Failure to provide documentation for changes in eligibility requirements, including residence and income, sometimes resulted in gaps in health care coverage. Other times, changes in the program's policies created confusion and resulted in a general avoidance of the complicated paperwork required to sustain coverage. For some, the continual investment of efforts to retain coverage was not worth the confusion and humiliation; many simply gave up (see Becker 2004a). For others, budgetary enrollment caps forced families to endure periods of uninsurance while remaining on a wait-list for effective enrollment once qualified. In sum, seven out of every ten children who were uninsured at the time of the 2005 CHIS interview were eligible for, but not enrolled in, Medi-Cal, Healthy Families, or Healthy Kids (Brown, et al. 2007).

The gap between the *de jure* eligibility for health insurance and *de facto* exclusion from effective coverage is an important and theoretically rich site for examining differences in expectations of self-care, decision-making, and the importance of health amid the challenges of everyday life. In this section I use participant narratives to illustrate why people who are eligible for health insurance are sometimes unable to obtain it.

### *Documentation of Residence*

Enrollment in Medi-Cal, Healthy Families, and Healthy Kids requires documentation of residence in order to benefit from funding designated for residents of the specified region (e.g. State of California, City/County of San Francisco). The requirement for proof of residence, however, effectively excludes some individuals from enrollment, as in the following two examples.

Adriana is a mother of two children living in San Francisco. Adriana and her husband Carlos, both born in Mexico, crossed the border illegally twelve years ago when Adriana was five months pregnant so that their children could be born in the United States. Adriana and Carlos made their way up to San Francisco to meet Carlos' brother, Julio, who promised that work and housing would be available for their family. When they arrived, Adriana and Carlos moved in to the living room of a one-bedroom apartment shared by Carlos, Carlos' wife, and their three children. Right away, Carlos left with his brother Julio each morning to find work in temporary construction jobs. Through Julio's existing social networks, Adriana learned where to buy groceries, where to find second-hand clothing, where to do laundry, which buses took you to places too far to walk, and how to make each dollar stretch as far as it possibly could.

Shortly after they arrived, Adriana gave birth to their daughter Cristina. Not having received adequate prenatal care, Cristina was born prematurely and was frequently sick. After trying several home remedies with limited success, Adriana took Cristina to the nearby community clinics at her neighbor's suggestion. Her neighbor assured her that the clinic would be safe for people who are undocumented ("la gente que no tiene papeles") and indeed, Adriana was relieved to meet the caring, Spanish-speaking doctors who took good care of Cristina. By the time she was two years old, doctors diagnosed Cristina with reactive airway disease, a common precursor for asthma in children too young to perform lung function tests. Staff members at the community clinic provided Adriana with information about how to enroll Cristina in "Healthy Kids", a health insurance program that would allow Cristina to receive ongoing care from a regular primary physician at San Francisco General Hospital and would expand coverage and services that the clinic could not provide.

Adriana took a bus to the General and eventually navigated her way to the insurance enrollment office. She waited in line for about twenty minutes, and when it was her turn, she asked the Spanish-speaking enrollment officer how to obtain health insurance for her two year old daughter. The officer promptly passed Adriana an enormous stack of paperwork, then abruptly called on the next of several people standing in line behind her. Adriana said, "Excuse me, but how do I....", but before she could even finish her question, the enrollment officer said, "Just read the papers! You do know how to read, don't you?" Adriana walked out of the General feeling confused, belittled, and vulnerable.

That evening, Adriana felt overwhelmed as she read through the papers. She recounted the interaction with the enrollment officer to her husband Carlos, describing how it left her feeling fearful and degraded. But he insisted that she return to the General the next day to try again, reminding her that Cristina's audible wheezing had become progressively worse. So Adriana returned to the General, this time meeting with a different Spanish-speaking eligibility worker. Although the worker reviewed the information more rapidly than Adriana could really follow, the officer's more positive demeanor was encouraging. Adriana understood that she needed to return the completed forms along with several documents, including proof of residence and income. She returned home feeling more hopeful that Cristina would soon be enrolled and could get better.

In order to establish documentation of residence, Adriana was instructed to provide either a utility bill or a copy of the lease contract with her or Carlos' name on it. Adriana and Carlos did not have any utility bills in their name: their cell phone account did not qualify as documentation of residence, they did not have a home telephone, they did not have a television or internet provider, and their gas and electric bill was paid by the landlord. So Adriana asked Carlos' brother Julio for a copy of the lease, to which she would add their names. Julio hesitated. The terms of the lease specified that Julio, his wife and their children were the only tenants residing at the address. And Julio recalled that his landlord had specifically warned him that the lease did not permit Julio to share the residence with any other individuals, or else he would either increase the rent or evict them from the apartment. Thus, Julio was already putting his family at risk by allowing Adriana, Carlos, and Cristina to live "off-lease" in his home. But without the lease, Adriana wondered, how would she be able to provide documentation of residence?

Adriana's predicament was shared by other participants I interviewed. I learned that this type of communal housing arrangement was in fact commonplace within the

Latino community, particularly among undocumented immigrants like Adriana and Carlos who did not have any form of identification or did not wish to provide their name on any official documents. In Adriana's case, nine persons were living in the one-bedroom, one-bathroom apartment. In another case, I interviewed a single mother of two children who lived with her children in one bedroom of a three-bedroom house. As she described it, her aunt and uncle occupied the second bedroom, and a non-relative family of five occupied the third bedroom. All ten of them shared the kitchen, living room, and bathroom.

Although space was limited and shared accommodations were primarily a product of economic necessity, communal housing residents such as Adriana did not feel entirely negatively about the situation. Some emphasized the tremendous economic, social and logistical support that such an arrangement offered. Some children enjoyed having other children to play with at home. Thus, it seemed that, although they acknowledged that they had few alternatives given their economic and citizenship status, communal housing residents were generally pleased with the housing arrangement and grateful for the support it provided.

Documentation of residence is a significant barrier to care for the multitude of “off-lease” residents. Other families face difficulties with documentation of residence because of unstable housing arrangements, e.g. moving frequently for proximity to work, threats of eviction, or increased rents that are unaffordable. While some participants faced insurmountable barriers to enrollment documentation, others were able to obtain documentation of residence but with great difficulty, as in the following example:

Twelve year old Gabriel, a U.S. citizen, is enrolled in Medi-Cal. He lives with his mom, dad, brother, and sister in a two bedroom apartment in San Francisco. Although Gabriel takes his asthma medications regularly, he continues to suffer from poor symptom control. A subsequent allergy test reveals that Gabriel is severely allergic to mold, and the doctors suggest that his mother Daniela conduct a thorough evaluation of the house. Daniela spends hours each week cleaning the mold in the bathrooms and closets, but despite her meticulous efforts, Gabriel's symptoms persist. Then one weekend, Gabriel's father examines an area of the bathroom where the mold consistently appears, and he discovers that the inner layers of the walls are in fact covered with black mold. Gabriel's parents, both undocumented, do not feel comfortable asking the landlord to fix the mold problem because they fear he might increase their rent, evict them, or report them to immigration authorities. So instead, Gabriel and his family move to a different apartment in the city where they hope that the building will not have structural mold damage. Daniela promptly submits a change of residence form to update Gabriel's Medi-Cal insurance. The new apartment is not available until a few weeks after they move out of the old apartment so the family lives temporarily with Daniela's sister. During the interim period, Daniela takes Gabriel to their regular doctor when he comes down with a cold. Shortly thereafter, the family moves into the new apartment and Gabriel's asthma symptoms improve dramatically. Gabriel's parents breathe a sigh of relief.

Two months later, Daniela receives a bill from Medi-Cal at the new address. The bill of $240 is for the outpatient appointment with Gabriel's regular primary care doctor during the time that they were living with Daniela's sister. Daniela is confused. Remembering her last interaction with the eligibility worker at General, who she describes as “not helpful and mean”, Daniela asks her neighbors about alternative Medi-Cal enrollment offices where she might speak to someone about the bill. One neighbor says she's heard of a place on Kennedy Street. So Daniela walks down Kennedy until she finds the Medi-Cal office that her friend described. But as she gazes up at the top of the building, she sees an American flag and the sign “Social Security Administration”. Daniela is torn. She cannot afford to pay the $240 bill, but as an undocumented resident she is afraid to step into a U.S. government building or to speak with government officers for fear she will be deported. So reluctantly, with the bill in hand, Daniela takes a bus to the General where she hopes that a more friendly eligibility worker will speak with her.

Daniela arrives at the General and waits the usual 20-30 minutes in line. The anxiety makes her stomach do cartwheels as she approaches the front of the line and it's her turn. Daniela tells the eligibility worker, “I don't know why I received this bill because I turned in the change of address form as soon as my family moved.”

The worker doesn't look up. “What's the name of the patient?”

“Martinez. Gabriel Martinez.”

“Date of birth?”

“The 23rd of September, 1995.”

“So what's the problem?”

“My son got a cold and we saw the same doctor here but then I got this bill and it's supposed to be covered by Medi-Cal.”

The eligibility worker types away at her computer, still not looking up and not looking at the bill that Daniela offered. “It says here that the coverage at the new address began on April 1. But this bill is for March 25. You weren't covered on March 25.”

Daniela's heart sinks. “Well, we had to move out of our old apartment by March 1 because the house was making my son sick. So we stayed with my sister until we could move into the new place on April 1.”

“Exactly. You have no proof of residence for March 25. You have to be a resident of California in order to receive Medi-Cal benefits.”

“But we *were* living in California! In San Francisco! Just not in our own apartment.”

“There's no proof of that. The proof of residence at Fourth Street started April 1. And the residence at Eighteenth St. ended March 1. I'm sorry, but you weren't covered when your son came in on March 25.” The worker passes the bill back to Daniela.

Daniela felt like she'd been hit over the head. She had been so diligent about submitting the change of residence form right away and they were so happy to move out of the moldy apartment so that Gabriel could sleep through the night without coughing and play during the day without gasping for air. It didn't occur to her that Gabriel's Medi-Cal eligibility would be terminated during the gap in residence contracts. “So I have to pay this?” Daniela asked incredulously, picking up the bill again?

“Yup,” said the worker. “Payment is due by June 25. You better make sure you pay on time or they charge a late fee.” Daniela was silent. “Next in line!”

These narratives illustrate the confusion, frustration, and failure that some families encounter in the health care enrollment and coverage process. In Daniela's case, she had succeeded in fulfilling the requirements for the initial enrollment, only to face an unexpected bill for services because she neglected to follow the specific details of the eligibility guidelines during her housing transition. Some might feel that this is just, that it was Daniela's error that produced this unfortunate result. But blaming Daniela fails to acknowledge the structural context that has produced the challenging situation in which the family now lives: migrating from abject poverty in Mexico to seek a better life for their children; living in a toxic home environment because they lack the economic means and experience to find safer housing; poorer health that is exacerbated by substandard housing; and citizenship and cultural barriers that make negotiating the health care system a difficult and often degrading process.

### *Documentation of Income*

Another requirement for enrollment in Medi-Cal and Healthy Families is documentation of income. As Figure 5 demonstrated earlier in this chapter, eligibility for the various programs is determined by the level of family income relative to the federal poverty guidelines. But despite the fact that many families qualify under the income eligibility guidelines, establishing proof of income can be very difficult or impossible given the parent's type and source of employment.

Some low-income adults work in jobs for which income documentation is available. However, for most of the participants in this study, their total income is derived from a combination of part-time and/or temporary jobs, many of which pay in cash and do not provide proof of employment. Some of the adult caregivers in this study had completed high school; many others did not. Some worked regular hours at established businesses, e.g. as fast food employees, janitorial workers, dish washers, or cashiers. Many other participants worked irregular hours in non-stable work situations and therefore had variable income. Men typically worked in construction or transportation of goods, whereas women typically worked as house cleaners, childcare workers, and cashiers. The majority of these workers did not have access to documentation of income. The following participant's narrative exemplifies the employment and income circumstances for many parents.

Santiago has been living in California for the last six years with his wife and son. Each morning Santiago leaves the house shortly after day break and walks down to

Chavez Street. There, he joins dozens of other young men like him who all line up along the curb and wait for someone to solicit them for work. On this day, a old truck pauses along Chavez Street and the driver waves his hand showing four fingers. Right away four men from the front of the line, including Santiago, hurry over and cram into the cab of the truck. Even though Santiago doesn't know the driver or the nature of the job, he doesn't hesitate to snap up the opportunity for work.

The driver of the truck, who's dressed a little bit better than the immigrants on Chavez Street, tells the men in Spanish, “I'm Mario. I know a guy who needs help redoing his basement. I told him we'll come do it today.”

When they arrive at the house in an upper class neighborhood of San Francisco, a tall White man, whom Santiago presumes is the owner of the house, comes out and shakes hands with Mario.

“Hey, Mario. Good to see you again. Hi guys, I'm Dave,” he says, smiling at everyone. “Let me show you around back and you can see what I need help with.” Santiago's English is limited, but he is receptive to Dave's friendly demeanor. He smiles back and follows Dave and the others around to the back of the house.

“Like I told Mario, I need to redo all the walls down here cuz I'm gonna make it my office. The guy I bought the house from just used this as a garage and it's got lead paint all over down here. Also I want to make this side here a door going out to the yard and maybe lay some stones down like a path. You think you can do all that?”

Mario replies, “No problem. So the walls, the door, and outside.” Mario and the workers are undeterred by the presence of lead even though they will breathe in the particulate when they reconstruct the walls. The potential long-term damage from lead exposure concerns them far less than the immediate daily need for income.

Dave continues, “Yeah, and maybe something with the floor later. I haven't decided yet. But I want to do the walls first cuz of the lead. I don't want my kids to come down here til it's all cleaned up.”

“No problem,” Mario repeats, “no problem.”

“Great. I'm gonna be upstairs for awhile and then I gotta head out this afternoon, but my wife will be home later. Can I get you guys something to drink?”

“Nah, we OK,” says Mario. Santiago and the others nod to Dave, who disappears upstairs. Switching to Spanish, Mario turns to Santiago and the other three guys and explains what Dave said and how he'd like them to go about the job. He tells them that he worked for Dave's friend last year, and the friend introduced Mario to Dave after Dave bought the house and needed some work done on it. Mario says, “I worked out a deal with Dave for this. I'll give you guys $10/hour up front and if it's good I'll give you more when it's done.” The men all seem pleased with the arrangement and quickly get to work with the supplies that Mario unloads from the back of his truck. Santiago is happy to have landed a job that will take at least a couple of weeks.

When the job is done, Mario thanks the men for their work and promises to call them again if he gets another job. He writes down their names and cell phone numbers, and gives Santiago a ride home. The next day, Santiago is up at daybreak as usual, and returns to Chavez Street. After awhile he's picked up for a job that ends up taking only a couple of hours. He returns promptly to Chavez street but he isn't picked up again for more work that day. This goes on for several weeks, until finally one day, Santiago gets a call from Mario. Like the job at Dave's house, this job offers several weeks of work for Santiago. They go to another house, but this time Mario is greeted by a White man who is

**Photo 22:** Immigrant laborers waiting along Chavez Street. Only a handful remain because at 4:00pm, at the time of this photo, few people are still seeking day laborers.

(photo by R. Higashi, 2009)

also dressed in construction-type clothes and who speaks limited Spanish. Mario gives Santiago instructions for several hours worth of work, and then leaves Santiago at the site. In subsequent days Santiago meets other workers who come to do specialized electrical and plumbing work. He isn't sure whether they were hired by Mario or the White man or someone else. He just does his job, contacts Mario and is paid when it's done, and then goes back to Chavez Street again the following day.

Santiago's income from these types of construction jobs, along with his wife's income from working at the bodega down the street, is sufficient to pay for his family's daily living expenses. But Santiago and his wife are both paid in cash and are unable to provide the documentation of income that is required to enroll their son in Medi-Cal. Thus, despite the fact that his son is eligible for coverage given that the family's typical earnings fall within the eligibility guidelines, Santiago is effectively barred from enrolling his son in health care coverage because they cannot provide documentation of family income.

These narratives are based upon the experiences related to me by participants and by my observations in neighborhood communities. I did not speak with the eligibility workers to determine the accuracy of participants' statements. Rather, I am focusing on the experiences of participants, including what they did and how they felt during the process of trying to enroll their children in health insurance programs. I must also note here that my request to interview an insurance eligibility worker was denied on two separate occasions. The first insurance worker refused the interview because he said he did not have time to meet with me. Unclear as to whether he might be available at a later time, I left my business card and made it clear that I was available to speak with him at any time of his choosing. When I returned some weeks later to ask again if we could meet, the eligibility worker told me not to come again; he said that his supervisor told him that he was not allowed to do any non-work-related business during work hours, so he did not have to talk with me. (Note that as a matter of conducting research with human subjects I could not have coerced the worker into participating in an interview regardless of his supervisor's comments.) Not wanting to cause further disruption to anyone at this office, I later approached a different eligibility worker at a different office, but I was also refused an interview. Had I been able to interview an eligibility worker, I would have liked to clarify whether there was any means by which a person in the above-described situation could still enroll. That is, was there any provision that would take into consideration the inability of potential enrollees to provide the appropriate documentation? And if so, why wasn't this information provided to the adult participants in this study?

These narratives also reveal an important characteristic of daily life among low-income workers. Despite their limited income, each of the adult participants I interviewed owned a cell phone. It may seem to be a frivolous commodity for individuals with such limited income, but the reason for owning a cell phone is in fact one of economic necessity. By having a cell phone, day laborers like Santiago are able to stay in contact with people like Mario who can contact them at a moment's notice for available work opportunities. The cell phone is thus an essential means for low-income residents to secure income. In addition, cell phones enable supervisors and workers, like Mario and Santiago, to communicate about work progress and equipment needs, much like how an office phone might be used among white-collar employees.

Separately, I have also witnessed how immigrants use their cell phone to obtain certain commodities, such as furniture or food. Many San Francisco residents discard of used household items by placing them on the sidewalks outside of their apartment with a sign indicating “free”. While some items are smaller and may be carried home by passing pedestrians, others like furniture items require a vehicle and more than one person to move them. On one occasion I overheard a woman on her cell phone in Spanish describe her location and ask the person to “come quickly with a truck”. She sat on the couch alongside the road until, shortly thereafter, two men pulled up and she helped them put the couch in the back of their truck and drive off. In sum, having a cell phone enables low-income residents to contact one another quickly to secure valuable goods and services.

Regarding other opportunities for income, I asked Santiago whether he had tried to find work through one of the more formal channels, such as the employment offices run by non-profit organizations in support of undocumented residents. Santiago told me that he had never been to those offices, but he had heard from other workers that they are worthless (“no vale nada”). He said he earned more from the jobs he got along Chavez Street and especially through supervisors like Mario who trusted him and would call anytime something was available.

### *Documentation of Assets*

In addition to residence and income, documentation of assets is required to establish whether an applicant for Medi-Cal or Healthy Families qualifies under the federal poverty guidelines. Documentation may be fulfilled by providing last year's tax information or at least three months of financial statements. While some participants were able to submit tax forms, the very idea of low-income residents providing documentation of assets seemed ridiculous to more than one participant in this study. One young mother, recalling the list of application requirements, said, “Documentation of residence – OK. Documentation of income – OK. Documentation of assets – ha! That's an easy one – none! You talkin' bout poh' folk! What assets?! I live in the projects!”

Other participants were unable to provide documentation of assets because they did not pay taxes and they did not have any bank account or membership in financial institutions. Here again, Latinos encountered problems with this eligibility requirement more often than American-Americans. Some participants reported that they were unable to meet basic banking requirements and felt adversely toward what they perceived as unmanageable financial costs, including minimum balance requirements and banking fees. In families for which monthly income minimally exceeds monthly expenditures, having money tied up in banking institutions is simply unaffordable. Thus, much like health care coverage, eligibility for basic banking accounts may be effectively prohibited if enrollment and account maintenance requirements cannot be met. My conversation with a financial adviser at a leading San Francisco bank illustrates this point. I called to speak with a personal banking representative in order to determine how feasible it might be for an undocumented resident to open an account.

“Hi, my name is Robin. I wanted to get some basic information about opening a checking account. Is a social security number required?”

“No,” she replied, “you just need two forms of identification.”

“What counts as identification?”

“A driver's license or passport plus any other identification that has both the person's name and date, like an ID card from an employer, a school ID, or a credit card within the expiration date.”

Noting that undocumented residents are unlikely to have any of these forms of identification, I asked, “Well, say I was an illegal immigrant. Could I use my passport from outside the U.S.?”

“Yeah, but your other ID still has to have your name and date, so like the ID from your school or employer.”

I was intrigued by her assumption that illegal immigrants could provide school or employee IDs. “So you're saying that you have some illegal immigrants with accounts at your bank?”

“No, I didn't say that,” she replied immediately. “But if the person comes in for an appointment we will answer any questions and help them figure out how to get an account.”

“OK,” I said, feeling like the banker was intentionally providing vague responses. “What are the other requirements?”

“Well, for our basic account you have to have a $300 minimum average balance. I mean, you could withdraw the $300 but then at the end of the month it has to have an average balance of $300 or they charge you a fee. We offer another checking account that's free if you meet one of these three requirements: either a $1000 minimum balance, a direct deposit from your employer, or an automatic monthly transfer from your savings account into your checking account. But if you want an account that accrues interest, the average minimum balance is $3500. But the benefit of these accounts is that you get a free set of checks when you open the account and there's no fee to cash checks at the bank. I know a lot of people go to those other check cashing places but they charge you a huge fee for each check so you're losing money every time you do that. But for account holders here there's no charge. And for a person like you described, with no VISA or U.S. passport, we would evaluate each person's situation individually to determine the best possible account that works with their situation.”

I ended the conversation despite feeling unclear about whether an undocumented resident really could obtain a personal bank account. But clearly, all low-income families would have some difficulty with banking requirements such as minimum balances and fees.

Thus, having a bank account or other means of providing the financial documentation required for enrollment in Medi-Cal and Healthy Families is beyond the reach of some applicants. The vast majority of the undocumented Latino adults I spoke were members of the so-called "underground economy". That is, all of their income and expenditures are conducted in cash only, they generally do not pay taxes, and they regularly wire money to family members in their home country. The utilization of the underground economy as a survival tactic has been well-documented in the literature about the Latino working poor (Zlolniski and Palerm 1996; Walter, et al. 2002; Takei, et al. 2009;). Here, my research demonstrates how it also constitutes a barrier to effectively enrolling in health care coverage.

Despite the challenges posed by a cash-only existence, I have also noticed that many businesses located in the Mission, a predominantly Latino neighborhood of San Francisco, recognize the significant presence of cash-paying patrons. For example, at one wireless phone company there is an ATM-like terminal in which cell phone account holders are able to pay their monthly service charges with in-person cash payments. In other words, in order to divert the significant number of patrons who pay in cash in person each month, the company has established a streamlined process by which the line for customer service agents will not be clogged by those who are simply making cash payments. Other businesses, such as gas stations and service industries, offer a reduced price for payment in cash rather than by check or credit card. It is important to recognize that businesses such as these profit as collaborative members of the underground economy.

It is also important to remember that low-income families like those in this study do not have access to the types of resources that most middle and upper class individuals rely upon for problem solving to greatly facilitate daily life activities. The significance of these time-saving technologies is difficult to appreciate without following individuals, as I did, through their routines of daily life. As I witnessed how participants accomplish seemingly basic tasks and negotiate challenges I had not anticipated, I began to appreciate the vast differences in our daily existence. For example, none of the families I interviewed own a computer so caregivers could not “look it up on the web” when they didn't understand things, like “what is asthma?”, and “how do I find a doctor?”. Every question must be answered on paper or by phone. This is difficult given that many businesses rely on web-based consumer information. Phone numbers often reach automated responses and the caller must navigate through a maze of menu options before possibly speaking with a live person. After being on hold for an indefinite time period, some participants were forced to hang up before their question was answered, were given misinformation, or were treated rudely perhaps because of their pronounced Spanish accent. Other questions, such as “what do I do if I have a problem with toxic mold?”, “where is the housing advocacy group?”, “how do I get there?” and “how much will it cost?”, involve time-consuming and intimidating processes so caregivers often do not act unless the problem escalates to a point of dire necessity.

Many participants did not “keep a calendar” to record future doctor appointments; some kept hand-written reminders on the refrigerator, and some said “I just go when they call to remind me”. None of the families in this study owned a car, and many did not have access to a washer and dryer at home. Without these amenities everything takes longer and is more difficult to accomplish: groceries must be carried by hand so you can only buy a few items each time, which means you shop almost daily; laundry must be carried to a laundromat where you wait while the load washes and dries so that no one steals your clothes. Reliance on public transportation creates unpredictable arrival times, which at times caused families to miss appointments at the clinic, as described in Chapter 3. At some clinics, patients who are more than fifteen minutes late forfeit their appointment, and patients who forfeit more than two appointments may be dropped as regular patients (see also Horton 2006). In sum, the structural conditions of living in poverty produce a confluence of factors that make daily living a constant, ongoing challenge. Providers who do not recognize the lived reality of these families' lives may think that caregivers lack an appreciation of the seriousness of their child's disease, or are irresponsible and lazy. While the vast majority of the providers I interviewed in this study exhibited compassion and sensitivity toward their patients, they were not except from finding fault in certain caregivers when children presented with poorly controlled asthma.

This chapter documents how the organization of power in healthcare bureaucracy results in the *de facto* exclusion of low-income immigrant children despite their *de jure* eligibility for health insurance. It further demonstrates how barriers in health care coverage negatively impact the health of children and produce adverse feelings among caregivers toward health care authorities. Every single Latino family that participated in this study had at least one negative experience with their child's health insurance, including problems with enrollment, inconsistencies with billing and payments, and being treated rudely by insurance eligibility workers. While African-American families in this study did not describe difficult encounters with enrollment as often as Latinos did, some reported difficulty with ensuring continuity of coverage given changes in family and home circumstances.

Low-income minority populations generally lack the power and cultural capital to negotiate an insurance bureaucracy that is already stacked against them. For those who had the experience of receiving large bills for services they thought were covered, the confusion and frustration was so overwhelming that the process of resolving these problems simply “wasn't worth it”. Consequently, some families put off dealing with billing and eligibility problems or simply gave up on trying to enroll their child in health care coverage (see Becker 2004a; Abraham 1994). Disruptions in health care coverage typically result in poorer medication adherence, fewer visits to physicians for ongoing primary care, and greater use of emergency services. Several participants in this study indicated that the reliance on emergency services spared them from feeling antagonized and ineffectual in trying to maintain insurance enrollment. In sum, the current inadequacies in health insurance directly result in poorer health among low-income families, higher costs for hospitals that provide emergency care, and adversarial relationships between insurance officers, health consumers, and providers.

## Chapter 5: The Imbalance of Care and the Production of Health Citizenship

In this chapter I argue that the imbalance of health care between children and adults is based upon the notion that children are a privileged population group. I demonstrate how cultural constructions of children as innocent and more deserving of the State's protection are reflected both in the State's greater allocation of resources to children's health care and in the language used to justify health policy decisions. I then argue that this imbalance of care has produced new forms of health citizenship: children have become the conduits to a form of health citizenship for their adult caregivers who have fewer options for attaining health citizenship on their own. That is, given the State's greater allocation of resources to children, some parents may seek health information, institutional support, and even medication and treatment for themselves through their child’s greater access to care. The narratives in this chapter illustrate how health citizenship is acquired and utilized, particularly for families in which some members have health care coverage and others do not.

The narratives in this chapter also exemplify the dual role of children as both the recipients and facilitators of State health benefits. Thus, I critique the construction of children as innocent and passive beneficiaries and I describe the positive and negative consequences that are produced by children's status as a privileged population group. Additionally, I evaluate how medical providers feel about the impact of the imbalance of care between children and adults, which often produces conflicting professional and moral responsibilities. Their comments reveal an uncomfortable existence within the triangulation[16] of children, caregivers and the State.

### What is health citizenship?

In its most common usage, “citizenship” refers to a person's national affiliation; persons are endowed with certain rights, privileges, and duties as a citizen of that country. However, citizenship may also be conceived more broadly as a form of ideological and actionable membership in a group that imparts certain rights, privileges, and duties. For example, Aihwa Ong's notion of “flexible citizenship” describes how the economic and political process of globalization affects culture, individual agency, and family life among Chinese transnationals (1999, 2003). Adriana Petryna (2002) shows how Chernobyl victims establish “biological citizenship” by claiming benefits from the State through their illness status. And Cybelle Fox's “social citizenship” concept examines the role of race and immigration in the extension of the American welfare state to Mexicans, European immigrants, and American Blacks during the first half of the twentieth century (2009). In my research, I use “health citizenship” to demonstrate how children are culturally and politically conceived as citizens worthy of the State's protection. At the same time, certain groups of adults, especially undocumented immigrants, are excluded from citizenship protections and privileges socially, if not politically. This moral division of persons into citizenship categories is similar to Briggs'

---

[16] The term triangulation is borrowed from legal scholar Mary Ann Mason's (1994) discussion of the competing and often conflicting interests of children, parents, and the State that are at the crux of legal disputes involving children.

(2003) distinction between sanitary citizens and unsanitary subjects as justification of the Venezuelan government's non-response to the cholera epidemic among poor indigenous populations. Similarly, I am arguing that decisions about the State's unequal provision of health services are skewed by cultural constructions of all children as more deserving, and adults as less deserving, of State resources.

Ideological discussions of citizenship often critique notions of individual agency and responsibility in relation to the State. For example, children today are portrayed as lacking in individual agency and thus in need of the State's protection, whereas adults are portrayed as universally capable of achieving good health and held to that moral responsibility. Structural inequalities like poverty and race discrimination that render some adults more vulnerable and needy are recognized far less than cultural constructions of children as supremely vulnerable subjects. However, distinctions in the subjectivity of adults versus children and attitudes about the individual's role versus the State's role in promoting population health have changed over time. It is important to remember that, while it may seem that children are “naturally” innocent and vulnerable, this present-day construction of childhood subjectivity is relatively new in the history of human life. As I discussed in Chapter 3, constructions of childhood have changed repeatedly over time. The qualities and characteristics ascribed to children are temporally-defined representations of social, political, and cultural beliefs.

Likewise, the State's social and political treatment of certain adult subpopulations has changed over time. Historically, the State acted as the principal guardian of the health of the population as an essential component of ensuring its political stability and economic development. In fact, the State had greater incentive to care for working (male) adults, who were the more economically productive members of society, than for women, children, or elderly persons. By the early 20th century, however, the establishment of the modern welfare state marked the State's greater investment in efforts to alleviate increasing social and economic inequalities. Then, with the rise of privatized market-driven health insurance in the mid- to late-20th century, the responsibility for good health shifted starkly to the individual. Public guardianship of health was replaced by neoliberal attitudes that emphasize the individual's moral responsibility to achieve good health; likewise individuals in poor health came to be perceived as morally deficient. For example, smoking, obesity, and addiction are today generally conceived as individual moral failings, and this masks the structural inequalities that produce ill health. Thus, present-day evaluations of the poor and sick as morally deficient are a relatively new phenomenon in the history of public health. Previously, the prevalence of poverty and sickness was a reflection of the State's negligence, not the individual's. Gay Becker's study of health care safety net consumers (2004a) exemplifies this point, arguing that the emphasis on individual responsibility, productivity, and autonomy as American values serves to further marginalize those who are poor and sick.

In my research, I demonstrate that this moral imperative for healthy self-governance does not apply to children the way it applies to most adults. I am not arguing that children should be equally accountable as adults for all health management tasks. I am, however, calling attention to the fact that there is a conceptual bias that exempts children from ultimately being responsible for their health, and an abrupt shift in expectations for self-care among adults. This begs the question, then, at what age, or by what other marker, does an individual change from being a child, exempt from self-care accountability, to an adult, whose poorly managed health is conceived as an individual failing? While U.S. health policy tends to distinguish between "deserving" and "undeserving" categories of adults, I am arguing that U.S. policy also constructs children as categorically more deserving than their adult counterparts. A closer examination of the daily lives of participants in this study clearly demonstrates that the actual vulnerability and ability for self-care is not solely a product of whether an individual is greater than or less than 18 years of age. The categorical treatment of individuals as "children" or "adults" reduces the complexities of their daily living conditions that are far more indicative of who is really vulnerable and in need of protection than are the cultural and ideological constructions of these groups.

Certain policy provisions must, I realize, designate an age for inclusion or exclusion of insurance benefits. For example, children under 19 years of age are eligible for Medi-Cal, Healthy Families, or Healthy Kids, as is described in Chapter 4. However, I argue that a greater emphasis should be placed on determining the extent to which individuals – both children and adults – are capable of performing self-care tasks *given the resources available to them*. In other words, the determination of an individuals' capacity for self-care must be based on a realistic assessment of his or her ability to access health services and health insurance, rather than being based on assumptions of age-related abilities. This assessment of an individual's health citizenship status is a greater predictor, I argue, of his/her capacity for self-care and potential for achieving good health. For example, I have witnessed that many teenagers with health insurance are more capable of achieving good health and performing self-care tasks than, for example, an undocumented adult without insurance or an adult who is a U.S. citizen but does not qualify for Medicaid and is unable to afford care. In sum, whereas children's health citizenship is pre-determined by their age and status as a privileged population group, adults may resort to employing creative strategies to attain health citizenship if they are unable to access the same privileges and provisions that the State provides to children.

In this next section I document the imbalance of care between children and adults that is produced by differences in State health insurance provisions. It is this imbalance of care that produces the opportunity for some adults to achieve health citizenship using the resources that are provided to their children, as are illustrated in the ensuing narratives. The chapter concludes with an assessment of the positive and negatives consequences of the imbalance of care and the production of new forms of health citizenship, including how this impacts children with asthma, their caregivers, medical providers, and the State.

## The Imbalance of Care

Racial and ethnic disparities in health care coverage have been documented extensively in the literature. Among non-elderly adults,[17] for example, Whites are more

---

[17] I am focusing on non-elderly adults (ages 19-64) because the vast majority of elderly adults (ages 65 and older) receive health care coverage through Medicaid. For example, in 2005 only 2% of the elderly (age 65 and over) lacked health insurance coverage for even part of the year (Brown et al 2007).

likely to receive coverage through an employer, and only 13% are uninsured. In contrast, 32% of Latinos, 21% of African-Americans, and 28% of non-elderly Native Americans are uninsured (Thomas and James 2009). Numerous studies have also demonstrated the significant health impact of being uninsured, including lack of preventive care and ultimately poorer health outcomes. Disparities in health and health care coverage reflect the over-representation of minorities living in poverty and working in low-wage jobs, as evidenced by the fact that two-thirds (66%) of the uninsured are full-time workers (Brown, et al. 2007:12). As a researcher at San Francisco General, a hospital that predominantly serves poor African-Americans and Latinos, I witnessed the faces of the individuals behind these statistics on a daily basis.

While acknowledging race- and class-based health disparities, however, this chapter focuses on the differences in health and health care coverage between children and non-elderly adults (hereafter "adults"). It is this dynamic, this imbalance of care, that has produced the unique forms of health citizenship and childhood subjectivity documented here. As a starting point, then, it is important to appreciate the significance of age-based disparities in health care coverage.

Between 2001 and 2003, California expanded its efforts to enroll children in Medi-Cal and Healthy Families. Enrollment increases were so significant, in fact, that they more than off-set the large numbers of children who lost coverage from a parent's employment-based insurance during the economic downturn. As a result of these efforts, children's public insurance enrollment increased steadily to nearly one in three (30.9%) in

2005, and the rate of uninsured children dropped to less than 11% (see Table 2). In contrast, adults' coverage through public programs and the rate of uninsured adults did not change significantly between 2001-2005, at about 9% and 25%, respectively. In other words, the gap between children's and adults' health care coverage has increased due to the State's greater focus on children.

**Table 2**. Adults' and Children's Health Insurance Coverage in California, 2001-2005

| | Uninsured All or Part Year | | | Medi-Cal or Healthy Families All Year | | |
|---|---|---|---|---|---|---|
| | 2001 | 2003 | 2005 | 2001 | 2003 | 2005 |
| Ages 0-18 | 14.8% | 11.3% | 10.7% | 24.2% | 29.2% | 30.9% |
| Ages 19-64 | 25.4% | 25.7% | 24.8% | 8.6% | 9.0% | 8.7% |

Source: Brown, et al. 2007:9.

It is important to remember that these statistics are intended to convey the rates of coverage for children and adults during the time of this study, roughly June 2006 – April 2008. California's escalating budget crisis has resulted in drastic changes to health care programs like Healthy Families, and I will discuss these changes along with the potential impact of federal health reform in the concluding chapter.

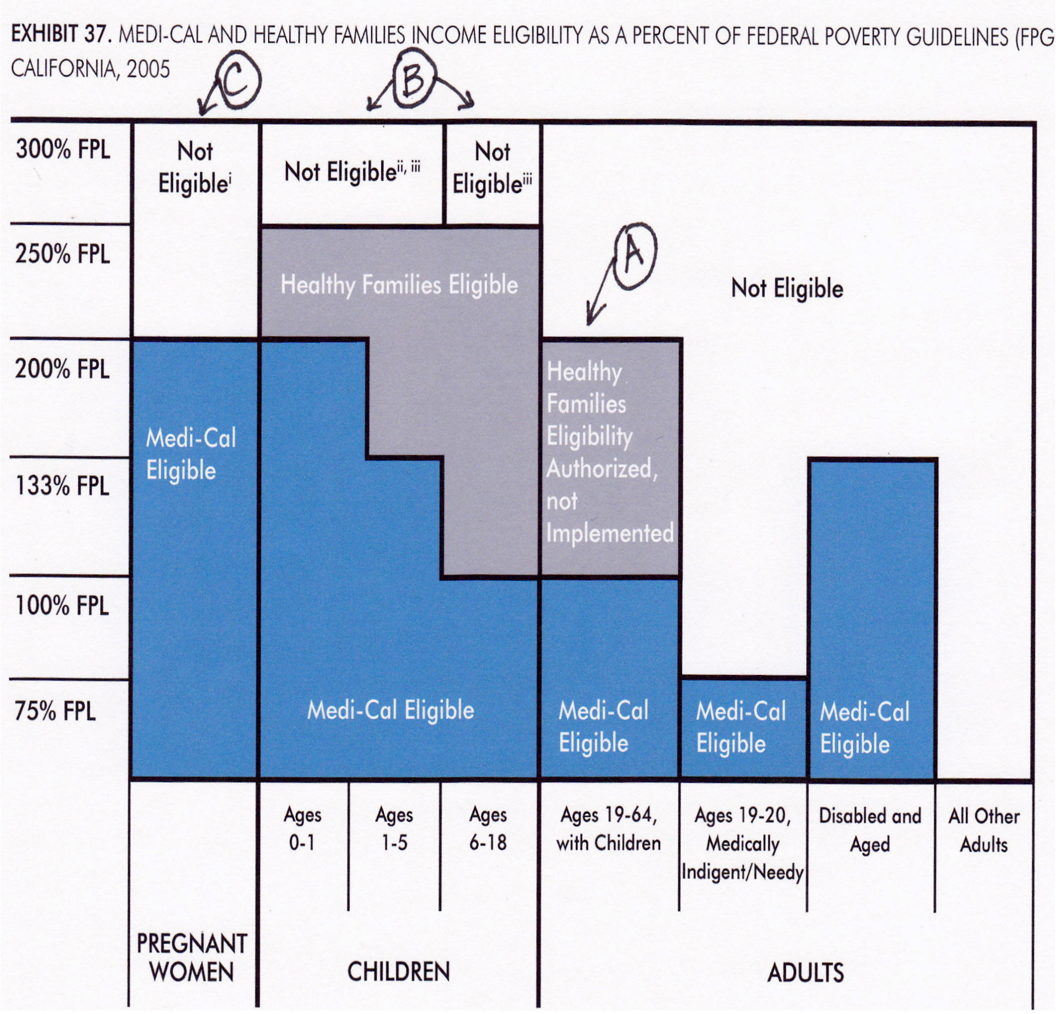
The impact of disparities in health care coverage between children and adults is somewhat comparable to that between racial groups. Children, like Whites, are far more likely than adults to have a usual source of care, such as a primary care provider, community clinic, or hospital (Brown, et al. 2007). Having a usual source of care is important for continuity of care, especially in managing a chronic illness such as asthma, and it results in better quality care and patient health. Likewise, adults, like people of color, are less likely to have a usual source of care and receive preventive services, and more likely to have poorer health outcomes given their ongoing lack of primary care. According to the 2005 California Health Interview Survey, uninsurance tends to be a long-term condition rather than a problem due to gaps in employment-based coverage for both children and adults. However, children were much more likely than adults to be uninsured for shorter periods of time. Children (31%) were twice as likely as adults (16%) to be uninsured for less than six months, and over half of adults (51.8%) had either been uninsured for more than three years or never had coverage (Brown, et al. 2007).

### *Delineations of Coverage between Children and Adults*

One in five children (21.4%) enrolled in Medi-Cal or Healthy Families has parents who are both uninsured (Brown, et al. 2007). So why, one may ask, are adults covered at a lesser rate than children? Perhaps the most obvious answer is that income eligibility guidelines vary, and the income limit for children is higher than that for adults, as shown in Figure 6, below (also listed as Figure 5 in Chapter 4).

Children ages 0-18 are eligible for coverage through Medi-Cal, Healthy Families, or Healthy Kids up to a family income of 300% FPG, whereas adults ages 19-64 (except for disabled) are eligible only up to 100% FPG. So for example, if a family of two parents and two children applies for health care coverage and their total income is 220% FPG, the two children would be eligible for care under Medi-Cal or Healthy Families, but neither adult would be eligible for any public insurance program.

**Figure 6.** Medi-Cal and Healthy Families Eligibility by Income, 2005

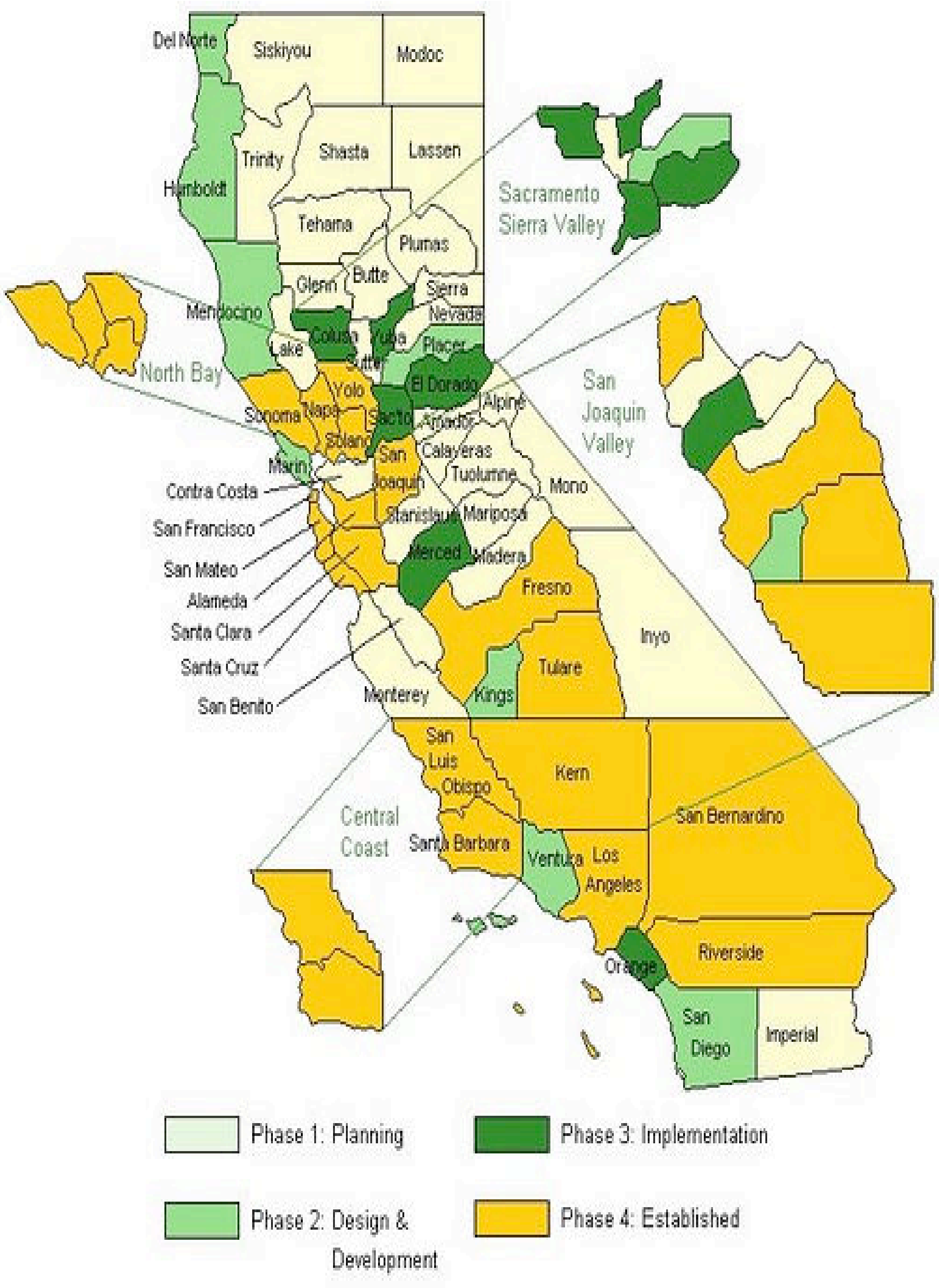


Source: Brown, et al. 2007.

There are several other important differences in eligibility that are worth noting in Figure 6, and that further the gap between children's and adults' health care coverage. First, note the area I labeled “A”, the gray-shaded area for adults that reads “Healthy Families Eligibility Authorized, not Implemented.” At the time this research ended in 2008, the 2005 proposal for increasing adult coverage (i.e. this gray area) still had not been implemented. Thus, only the blue shaded areas indicate the conditions for eligibility that were actually in effect for adults during this study.

Second, note the areas I labeled “B”, the white cells at the top of the chart for children labeled “Not Eligible”, with certain footnotes. These footnotes detail exceptions for *increased* coverage for children. The most important note is that health care coverage *is* available for children between 250-300% FPG (i.e. all of “B”) through the county-based private-public health care partnership program called Healthy Kids, which I discussed in Chapter 4. Healthy Kids extends the coverage of all children to 300% FPG *and regardless of citizenship status*. At the time of the chart's publication in July 2007, only 14 of California's 58 counties had established Healthy Kids programs, which is perhaps why the chart has footnoted this area. However, my research site in the City and County of San Francisco is among the 14 counties that does have an established Healthy Kids program, as are the most populous counties in Southern California and the greater Bay Area (see Figure 7, below). As such, all of the children who participated in this study, and the majority of children in the State of California, are eligible for coverage up to 300% FPG regardless of citizenship status, while only U.S. citizen adults are eligible

**Figure 7.** Expansion of Healthy Kids Program by County as of 2005



Source: Institute for Health Policy Solutions – California, 2005.

and only up to 100% FPG. In sum, differences in income eligibility and citizenship requirements produce a significant imbalance of care between children and adults.

In addition to Healthy Kids, there is also a lesser-known exception for *increased* coverage for children ages 0-5 from family incomes between 250-300% FPG (i.e. the left arrow cell of “B”). This footnoted exception states: “Children up to two years old with household incomes under 300% FPL with mothers in the Access for Infants and Mothers (AIM) program are automatically enrolled in the Healthy Families programs.” In other words, among the counties that have not yet implemented Healthy Kids, children ages 0-5 at this higher income eligibility level are automatically covered by Healthy Families while their mothers (U.S. citizens only) are covered by the federal social security program AIM. Similarly, the footnote for the area I labeled “C”, representing pregnant women between 200-300% FPG, states: “Pregnant women with household incomes up to 300% FPL are, however, eligible for the Access for Infants and Mothers Program.” Thus, in effect, pregnant women and all children in California are eligible for some form of public insurance up to 300% FPG, whereas adults ages 19-64 must be U.S. citizens under 100% FPG to qualify for public insurance.

As Figure 6 demonstrates, pregnant women, like children, are another privileged group that receives greater provisions for health care coverage. This fact only strengthens my argument that children are the privileged group *par excellence* because women are only covered during their pregnancy. In other words, an adult woman who is not pregnant falls under the adult eligibility guidelines (U.S. citizens under 100% FPG). Then when she is pregnant, and the State has a vested interest in her unborn child, she is eligible for an expanded range of public health care programs. After she bears her child, the woman's insurance eligibility is reduced again to the level of other adults. Clearly, women's temporary elevation to increased levels of health care coverage is solely related to the State's interest in protecting children. The most notable distinction in the value of pregnant women versus children, however, is that undocumented pregnant women are not eligible for health coverage, while Healthy Kids provides coverage to all children regardless of citizenship status.

### *Children as a Privileged Population Group*

In the section above I illustrated how the State has delineated health insurance coverage for different population groups based on income eligibility and citizenship status. In this section, I argue that these disparities in coverage are based upon cultural constructions of children as a privileged population group.

One of the primary arguments underlying the greater allocation of resources to children is that investment in primary care and preventive medicine is more cost-effective than treatment of disease. This is in fact the guiding principle behind the state-funded “First 5 California” program by the California Children and Families Commission. There are other widely-cited economic benefits to providing for the primary health needs of children. When children are sick, parents stay home from work to care for them, families go bankrupt from medical bills, and children fall behind in school. I am not disputing the economic or developmental benefits of investing in children's health, nor am I arguing that the State should disinvest in children. Rather, I am arguing that, aside from the economic and developmental benefits cited above, greater health provisions for children are based on deeply entrenched cultural beliefs in the innocence and vulnerability of children over other needy population groups.

For example, politicians are keenly aware of the political capital inherent in children's moral status. They recognize the public's willingness to prioritize investment in children's health given the cultural notion that children are innocent and deserving of the State's protection. Similarly, persons who support or reject the State's greater investment in children are themselves subject to moral scrutiny. For example, in a *New York Times* article entitled “Defying Slump, 13 States Insure More Children” (Sack 2009), Health and Human Services Secretary Kathleen Sebelius said that the Obama administration was “very pleased that even in what are some of the worst budget times in a very long time, children's health insurance continues to be an absolute top priority.” This is a significant statement given, for example, the large numbers of baby-boomer era adults that will soon qualify for Medicare, or the increasing numbers of non-Medicare eligible adults who are being dropped from employment-based insurance but who don't qualify for Medicaid. And yet, the Obama administration's re-authorization of the Children's Health Insurance Program (CHIP) in 2008 received very little legislative and public opposition, in stark contrast with other measures that have been criticized vociferously by Republican opponents as wasteful government spending.

The same *New York Times* article also mentions that some states have capped enrollment in CHIP-funded programs, citing state budget shortfalls that would increase the fiscal burden of the state despite the federal expansion of funding. This was the case in California, where Governor Arnold Schwarzenegger instituted an enrollment freeze on Healthy Kids and threatened to eliminate the Healthy Families program altogether. After a prolonged and costly battle between the Governor and the California legislature, children's Healthy Families coverage program was not eliminated, but an enrollment cap on Healthy Kids was instituted as compromise. Ginny S. Puddlefoot, the Deputy Director that administers California's CHIP program, is quoted as saying, “It's heartbreaking...For those of us involved with children's health care, this is just something we never imagined we would see.” In other words, the failure to expand health care for children is unthinkable even amid California's worst ever budget crisis. Also noteworthy, the expansion for Healthy Families coverage for adults that was approved back in 2005 has never been implemented and has been tabled in order to preserve coverage for children.

The imbalance of care that leaves so many adult caregivers uninsured produces serious health and economic consequences. Uninsured adults are 20-50% more likely to die than those who are insured; they are more likely to be diagnosed with diseases, like cancer, at a more advanced stage; they are more likely to die while in the hospital; and they are more likely to report being disabled by their health problem or suffer long-term disability (Hadley 2003).

When the State highlights the needs of children based on their supreme vulnerability and moral superiority, it makes invisible other needy population groups and implicitly declares them less worthy of State resources. Thus, the purpose of this analysis of the imbalance of care between children and adults is not to disparage the State's investment in children's health. Rather, it is to call attention to the consequences of under-investing in other population groups such as low-income adults and undocumented immigrants. The vulnerability of these other population groups often goes unnoticed or is perhaps eclipsed by the more powerful cultural construction of adults as capable of self-determination regardless of economic or social status. However, as the following narratives demonstrate, the actual vulnerability and moral status of children and adults varies greatly depending on individual circumstances.

## The Production of Health Citizenship among Adults

Earlier I stated that the imbalance of care between children and adults produces a situation in which children are positioned as the conduits to a form of health citizenship for their parents. By this I mean that, through their child's access to affordable health services, adult caregivers are able to interact with medical providers, obtain information, advice, referrals, and sometimes even receive medical treatment. The causes and effects of the imbalance of care illustrate the co-productive relationship between individuals and the State. By bestowing and excluding health-related rights and privileges to certain individuals, the State produces citizens and non-citizens. And in response to the State's production of citizens and non-citizens, disenfranchised individuals adapt and thereby produce new forms of health citizenship that enable them to access the rights and privileges that would otherwise remain out of reach.

Adults who are the primary caregivers of a child would benefit the most from the opportunity to establish health citizenship through the provision of healthcare to their children because of the frequency of interaction with the child's medical providers. Adults who are not the primary caregiver of a child would generally not interact with medical practitioners apart from their own needs and thus would not have the same opportunity to achieve health citizenship in this way. Even if there were occasions on which a non-caregiver adult accompanied a child to a clinical appointment, the infrequency of this interaction would not promote the same level of rapport as that between regular caregivers and their children’s providers. The rapport and regularity of interaction with the child's primary medical provider are key elements of what I argue produces parents’ access to health citizenship.

The benefit to caregivers who interact with their child's medical provider may be subtle but significant. During observations of clinical interactions at Asthma Clinic, I often witnessed the child's caregiver asking the provider a health-related question that was unrelated to asthma or an asthma-related illness, and sometimes on behalf of another family member who was not the patient. For example:

Teresa, a 10 year old, and her mother Lupita arrive at Asthma Clinic for a routine follow-up appointment. Lupita tells the nurse that Teresa still coughs a lot during the night, but has not had to use her rescue inhaler for several weeks. The nurse reviews Teresa's pulmonary function tests, asks about the frequency and severity of other asthma symptoms that had been problematic in the past, and reviews Teresa's asthma medications and dosages. During the physical exam, the nurse examines Teresa's nose, throat and ears, and listens to her heart and lungs. Teresa's little brother, 5- year old Manuel, fidgets on his mother's lap. Lupita interjects, “Doctor, could you take a look at his leg? He fell and got this cut a week ago but it's not healing and he says it hurts a lot.”

“Sure, I'll take a look,” says the nurse practitioner, who many patients refer to as their “doctor.” Nancy has been Teresa's “doctor” since her first appointment at Asthma Clinic three years ago, and has grown quite fond of Teresa and her mother. She's happy to spend the extra minute on what seems like a minor request. She picks up Manuel and puts him on the examining table next to Teresa and takes a look at his leg. “Looks like it's a little infected but I think it's OK. Make sure you wash the area with soap and water when you take a bath. These things just take time to heal, but if the redness or the pain get worse I'd take him to see his primary care doctor because he may need an antibiotic.”

“OK.  Thank you, doctor,” Lupita says. Reassured that the cut is not a serious problem, Lupita feels more comfortable letting her young son ride out the healing process knowing that his pain is normal.

“In the meantime, let me see if I can grab you a couple of samples of neosporin.” Nancy leaves the room to write up Teresa's asthma prescriptions, and hands Lupita a small handful of tiny neosporin packets for Manuel's leg. Even though Lupita could have bought a tube of neosporin at the drugstore for a couple of dollars, Nancy knows that the samples will save Lupita a special trip to the store for now and she will appreciate not having to buy the over-the-counter medicine if she can avoid it.

In theory, the providers at Asthma Clinic are paid to address the child's asthma specifically, and routine medical issues should be directed to the child's primary care provider. And clearly, the needs of other family members should be directed to that individual's own medical provider. In practice, however, these “off-the-books” accommodations occurred fairly often. While the quick medical assessment of Manuel's cut and the provision of sample over-the counter medicines does not seem to constitute a significant breach of medical protocol, it demonstrates how a singular appointment for a singular medical problem (Teresa's asthma) may sometimes result in added benefits for other family members. In this case, not only did Lupita receive medicine for Manuel, she obtained both the emotional reassurance and the convenience of not having to take her son to a separate doctor's appointment. This simple transaction helped Lupita in ways that may seem to be insignificant to an outside observer but that are in fact significant for Lupita. She saved money on not buying a topical ointment from the drugstore, she saved money by not having to pay another insurance co-pay for taking Manuel to his doctor, and she saved money and credibility from her employer by not having to take time off of work again to take her child to the doctor. For a family living in poverty, these monetary savings are not looked upon lightly.

Perhaps even more importantly than the monetary savings, the interaction exemplifies and reinforces the positive ongoing relationship with the family's doctor, who Lupita feels is caring and sensitive to her family's daily life challenges. Lupita hasn't specifically talked with Nancy about these challenges, but she feels that Nancy already understands given the emotional and material support that she regularly provides.

Judging both by my clinical observations and by the comments of caregiver participants, the trust between provider and family members is key to the dynamic that produces opportunities for health citizenship. This next example also demonstrates how the trusted relationship between the child's asthma provider and the child's caregivers can produce better overall health not just for the child with asthma but for other family members as well.

Carmela and Francisco have three children. Their youngest, Oscar, was recently treated at the Emergency Department for severe wheezing and shortness of breath. Oscar has been a regular patient at Asthma Clinic for over a year, but his symptoms appear to be worsening. When Oscar was first diagnosed his family was reluctant to consent to a home visit by the Community Health Worker, even though Oscar's doctor indicated that a home evaluation could greatly assist her in determining how to best manage Oscar's asthma symptoms. Carmela felt uncomfortable about allowing a health worker into her home; she was afraid that the health worker would think that Carmela did not do a good job taking care of her family and keeping her house clean, and that she might even report Carmela to authorities if she thought Oscar was sick because of something Carmela did or did not do to take care of him. Thus, Carmela declined the Asthma Clinic's offer for a home evaluation and told the nurse she would just like Oscar to be treated at the clinic.

Over the course of the year, Oscar's doctor monitored his lung function and tried to control his symptoms with medications. Still, Oscar was frequently sick and Carmela often brought him to urgent care and the Asthma Clinic. Carmela began to appreciate that Oscar's doctor was really sensitive to the challenges of providing for a sick child. She didn't feel that the doctors were judging her as a “bad mother”; rather, she felt that the doctor was genuinely concerned about Oscar's health and was worried that he wasn't getting better even after many months of treatment. So when the doctor suggested again that Carmela allow a health worker to evaluate her home, Carmela agreed. Whereas a year ago she was reluctant to consent to what felt like an invasion of her privacy, Carmela trusted that the doctors were just trying to help Oscar. Based upon their interactions at the Clinic over the past year, Carmela felt more certain that the doctors were not interested either in judging the orderliness of her home or in reporting her to immigration authorities.

During the home evaluation the health workers determined that Carmela's house was damaged in several places by mold. Carmela said she cleans those areas often but she cannot afford to replace the shower walls where there seemed to be mold within the structures.  The health worker gave Carmela information about mold toxicity and connected her with a community housing advocate in order to facilitate communication with the landlord. After some negotiation by the housing advocate, which largely spared

Carmela from having to deal directly with the landlord, they made an arrangement to replace the toxic mold structures while raising their rent by just $15/month.

Shortly after the mold was eradicated from her building, Oscar's asthma symptoms greatly improved. In addition, Carmela noticed that her older two children, who had not been diagnosed with asthma, did not cough at night as they used to before the renovation. Carmela said she hadn't realized how much all of her family members were affected until they all experienced better health. All three of her children played more vigorously and missed school much less due to illness. Even her husband Francisco reported feeling stronger and did not tire as quickly at work.

In this case, one's child’s access to medical services produced better health outcomes for an entire family. Even though Carmela and Francisco did not themselves have health insurance, they benefited from the information, referrals, and services that were all acquired through one son's membership in Healthy Kids. In sum, seven year old Oscar indirectly provided health benefits to his older siblings and adult parents, none of whom would have been able to access similar services if not for Oscar's access to insurance and services.

Generally speaking, the increased access to health information and services via the child serves other family members positively. But I also witnessed how this benefit can sometimes be used in a way that is detrimental to those involved. For example:

Veronica's daughter Diana, age 12, is a patient at Asthma Clinic. Although she used to suffer from frequent asthma attacks and relied heavily on her rescue medication, Diana's symptoms have greatly improved recently and she seldom experiences attacks. As part of her assessment of the effectiveness of Diana's current asthma management regimen, the nurse quizzes Diana about when she uses certain medications and how much. Diana responds appropriately, indicating that she is using the correct medications at the correct dosages.

The nurse turns to Veronica and says, “Great. I'm going to write you a refill for Diana's controller medicine and then let's check back in about six months.”

Veronica nods, then tells the doctor, “I think we also need a refill for the rescue medicine since we won't see you for six months.”

Although Diana is not likely to need much of the rescue inhaler based on her current experience of asthma symptoms, the nurse feels it's reasonable to make sure that she has enough of the rescue medicine just in case Diana's asthma worsens suddenly. Also, since Diana has shown that she knows how to use her asthma medications, the nurse doesn't mind giving Diana's mother the extra refills in case the need arises.

A few days after this clinical appointment I interviewed Diana and Veronica at a separate location. During the course of our conversation, Veronica admitted to me that she gives Diana's rescue medications to her husband, who frequently coughs and is short of breath. She said, “My husband works in construction and sometimes it’s bad in his chest and he coughs a lot. That medicine [albuterol] helps Diana breathe, so if his chest hurts I let him use it and he feels better."

While I was not as much surprised to learn that this family was using the child's medication "off-label" (i.e. not as prescribed), I was more surprised by Veronica's candor in admitting this to me. The fact that she was not overly concerned about sharing this information to me suggests that she may not believe that this is an unreasonable or especially harmful act. It is possible that she felt comfortable in being open with me since I told her I was a researcher, not a doctor, and was not going to report her actions to her doctors. But I also suspect that she was simply not embarrassed by admitting that she is doing what she feels is best to provide for the health needs of all of her family members. This may be particularly likely since the doctor made it clear that Diana's asthma was mostly under control such that she did not need to use the rescue inhaler daily. Thus, Veronica may have felt that she would not be hurting Diana (or her husband) by giving her husband the less frequently needed medication.

However, the off-label use of asthma medications is problematic for several reasons. For one, the child's prescription will run out more quickly if it used by other persons. In Diana's case this could be especially detrimental to her health if her asthma worsens and she must use the rescue medication more regularly but it is not available to be refilled. Insurance companies do not allow refills to be purchased in advance of the amount that would be required by the prescribed dosage. Secondly, the medications may have detrimental effects on Veronica's husband's health, especially if he does not have asthma. While not common, some people experience serious side effects to medications like albuterol. And the use of steroidal medications on a person who does not have an underlying inflammatory condition is likely to produce damage over time. Third, it is possible that that Veronica's husband suffers from a greater medical condition that is being overlooked, or possibly even worsened, by trying to reduce his cough symptoms with Diana's asthma medications. Veronica recalled how the nurse emphasized that she should *not* give Diana cough syrup, but rather she should increase the dosage of her asthma medications if Diana's cough becomes worse. Veronica may have deduced from this that the asthma medications are more potent than cough syrup for any individual, and if so, she failed to recognize the fact that treating a cough in an asthmatic child is entirely different from treating a cough in a non-asthmatic individual.

It is certainly understandable that, given her husband's lack of insurance and exposure to environmental hazards at work, Veronica did what she felt was reasonable for her family. Her husband's cough, shortness of breath and feelings of chest tightness seemed similar to Diana's asthma symptoms. And Veronica has witnessed how the asthma medications work effectively to improve Diana's symptoms. She told me, "I don't do it [share the child's medication] a lot but my husband, he has to work, and when he has a cough really bad he doesn't sleep good at night." Veronica's comments reveal that she is trying to achieve a positive outcome for her husband and child even though she knows she should not use her child's medications off-label. But Veronica does not seem to recognize the potential negative consequences this may have for her husband's health.

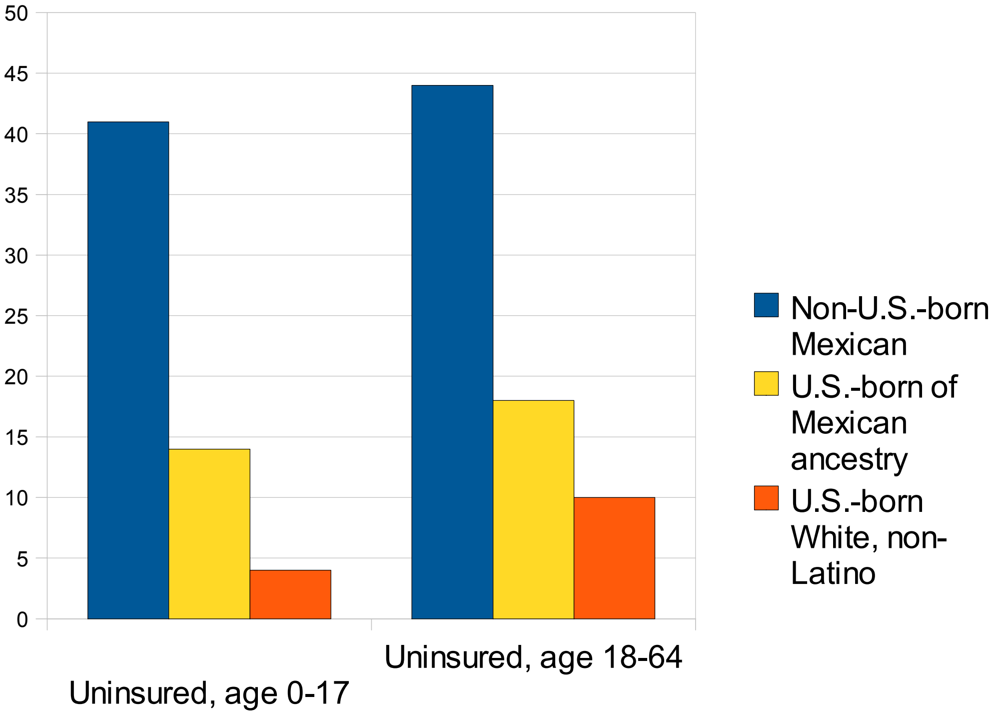
Given that many low-income families live in housing conditions with greater environmental toxins and asthma triggers, it was not uncommon among study participants for multiple family members within a household to suffer from asthma or asthma-like symptoms. Some family members, usually those who are under the regular care of a physician, have been diagnosed with asthma, whereas other family members may also have asthma that has not been diagnosed. Or, the latter may be suffering from a different illness that can exhibit asthma-like symptoms. For example, asthma symptoms such as cough, chest pain and chest tightness, shortness of breath, and fatigue are common to a number of serious illnesses such as congestive heart failure, tuberculosis, emphysema and cancer. Caregivers may also experience asthma-like symptoms as a result of poor working conditions, such as poor ventilation, chronic exposure to hazardous materials and chemicals (particularly given the number of men working in construction), and proximity to known toxic generators (e.g. the power plant in Hunter's Point).

Perhaps because of the greater prevalence of asthma among low-income urban communities, many are familiar with the commonality of asthma diagnoses among family and friends, and may think first of asthma as the likely cause of these symptoms. Or perhaps because asthma medications are highly effective, inexpensive, and reduce symptoms quickly (among asthmatics), individuals with asthma-like symptoms are likely to try asthma medications when over the counter remedies are not successful. In other words, asthma medications may be used as a kind of secondary line of home remedies before families decide to see a doctor. For example, one mother admitted that she gave her asthmatic daughter's asthma medications to her son, who had not been diagnosed with asthma. When her son's cough did not improve after several months of using her daughter's asthma medications off-label, she finally decided to take her son to the clinic, where he was then hospitalized for a severe case of pneumonia. She expressed deep regret in the fact that her son suffered because she had not taken him to the doctor sooner, but she did not mention the off-label usage of her daughter's medications as specifically regrettable.

This pattern, in which parents may acquire the means to health citizenship through their child's greater access to care, occurred more frequently among Latino participants than among participants of other ethnic/racial groups. As the narratives of Chapter 4 demonstrated, Latinos of all ages experience a variety of problems in accessing health care in comparison with African-Americans and Whites. However, these problems are not entirely explainable by differences in U.S. citizenship, as studies show that even U.S.-born Mexican populations encounter greater problems in accessing care (Wallace, et al. 2003). For example, as Figure 8 shows below, U.S. born parents of Mexican ancestry are three times more likely to be uninsured than their U.S.-born children; and Mexican immigrant parents, some of whom are documented and some undocumented, are four times more likely to be uninsured than their U.S.-born children. The fact that even U.S. born Latinos encounter greater problems with insurance access suggests that the impact of fear, degradation, language and cultural barriers have a greater cumulative effect on Latino families' ability to access health citizenship. As a result of these barriers, the rates of reported diagnosed asthma among Mexican immigrants and U.S.-born persons of

Mexican ancestry are likely to be far lower than the actual prevalence of asthma among the population at large.

**Figure 8.** Percentage Uninsured at Any Time in 2001, Non-U.S.- and U.S.-born Latinos and Whites



Source: Wallace, et. al. 2003.

Figure 8 compares the percentage non-U.S.-born Mexicans, U.S.-born persons of Mexican ancestry, and U.S.-born non-Latino Whites who were uninsured at any time during 2001. Clearly, a much higher proportion of non-U.S.-born Mexicans of all ages are uninsured than U.S.-born Mexicans and Whites. In addition, note the significant difference in uninsured rates by age. Children are uninsured at lesser rates than their adult counterparts in each population category.

While many African-American families, as U.S. citizens, are eligible for federally funded programs like Medicaid, their access to health citizenship is more often impeded by factors such as changing composition of family units and changes in income. For example, I learned during an interview with Shayna, a sixteen year old African-American girl, that she had recently been declared an Emancipated Minor by the State after years of custody battles between her mother, grandmother, and Child Protective Services. Prior to being emancipated, Shayna's mother lived cyclically between drug treatment centers, hospitals, jails, and the street. Despite the fact that she was mostly absent from her daughter's life, Shayna's mother was listed as the parent on her Medicaid account for a long time. Then for a few years Shayna's grandmother was appointed as her legal guardian, but when her grandmother became disabled, Shayna became a ward of the State. Each time her legal custodianship changed, Shayna's Medicaid was disrupted, then updated, then disrupted again. While she was able to enlist the help of social service workers, Shayna was forced to perform a number of tasks on her own to facilitate these administrative changes. During periods of disruption, Shayna described how she feared she might die from an asthma attack because she sometimes was unable to refill her rescue inhaler medication. In sum, the instability of family dynamics and her home environment disrupted Shayna's ability to exercise the rights and privileges of health citizenship afforded by Medicaid.

Thus, it is important to remember that enrollment in insurance programs like Medicaid does not mean that one has attained health citizenship. Preserving health citizenship is an ongoing process, as many participants described, because of the endless tasks required to manage the application of insurance coverage. For example, Abraham's ethnography entitled "Mama Might Be Better Off Dead" (1994), chronicles an African-American family's experience in negotiating the Medicaid system. It shows how family members spend extraordinary amounts of time and emotional energy to constantly produce certain documents, follow-up with medical or insurance personnel regarding billing problems, determine which medical decisions are covered and what health and cost consequences would be produced by these decisions, etc. The situation is ultimately so overwhelming and time-consuming that the family wonders whether they should abandon their efforts to negotiate the insurance bureaucracy and instead concentrate on spending time with Mama before she dies.

The longer-term perspective provided in Abraham's account is important to consider relative to the specific accounts I have provided of participants' experiences in this study. That is, in order to adequately appreciate the depth of frustration, humiliation, and incomprehension of participants, the reader should multiply each narrative excerpt by the number of incidents that each family continues to experience on an ongoing basis. While certain barriers may not seem insurmountable from an outsider's perspective, the individualized narratives do not adequately capture the continual struggle in which each singular episode is embedded. Thus, rather than conceiving of "barriers to health" as distinct factors, like "cost barriers", or distinct concepts, like "language barriers", it is essential to remember that the individual's actual experience is far more complicated. These so-called barriers to care cannot be added up to tally the level of difficulty in surmounting them. Rather, they are inseparable from the myriad of challenges that produce and are produced by the conditions of everyday life among low-income African-Americans and Latinos.

## The Practitioner's Role

My interviews with medical providers, primarily nurse practitioners and physicians, revealed mixed emotional reactions about their role as facilitators of health citizenship for non-patient relatives (hereafter “relatives”). Phrased more in their words, they were sometimes uncomfortable in acting as intermediaries between their patient (the child) and the patient's other family members. All of the practitioners acknowledged that they were at times confronted with the opportunity to provide general health information, personal medical advice, or even medication or treatment to relatives during the child's medical appointment. Their experiences highlight the ambiguous role of providers as sometimes direct and sometimes indirect participants in extending health citizenship to patient relatives. It is as if there is a continuum of behaviors and attitudes between what is perceived as clearly acceptable to what is clearly unacceptable for a provider's role, and different providers assess the appropriateness of behaviors in different ways. Providers' feelings and experiences illustrate how they grapple constantly with how to negotiate their personal and professional boundaries in their role as a provider.

For most providers, the emotional conflict over their role as intermediaries stems from a keen recognition of the ongoing life challenges of their patients and families. Providers at the clinics that serve the lowest-income residents of San Francisco witness daily the health effects of poverty and discrimination. While few medical providers have first-hand experience of living in poverty, their sensitivity toward patients reflects their awareness of race- and class-based health disparities. In other words, providers' second-hand understanding of their patients' daily life challenges creates a situation in which they witness suffering but are generally unable to change it. Accordingly, many practitioners talked about “feeling bad” when they witnessed a relative's obvious needs for medical attention. One of the doctors described her feelings in this way:

> “It's awful when you see the parent so sick and you know they need help but you can't help them. I mean, actually, I don't know if it's fair to say that I *can't* help. I suppose it depends on what you mean by 'can't'. Technically I *can* help because I'm a doctor. But I *can't* help because they're not my patient. Most of the time I really want to help, and sometimes I kinda do. But it's always a tough thing because I question whether I'm blurring the line in violating my role as a physician. It's tricky. I wouldn't feel comfortable fully *treating* someone that wasn't my patient, but sometimes I feel like it's OK for me to take a quick look just so they know whether they should seek medical care on their own. But then other times I think that's wrong, that's too much. So I just give them the sheet [of information] and tell them to ask at the free clinic. And then I feel like crap, like I'm giving them the run around. But that's my issue. They don't ever say or make me feel like they expect me to help them. I just feel like I'm guilty for not doing more. For me it's a conflict between my moral and professional obligations. And it's tough.”

This provider felt complicit in the family's suffering by not acting when, as she said, she is physically and intellectually capable of meeting perhaps a simple medical need. Perhaps as a younger physician she expresses a more idealistic view of wanting to "help" in any way possible. Or perhaps her feelings are simply indicative of a more sensitive personality. After all, providers who choose to work with low-income populations tend to do so because of their awareness of health disparities and their commitment to working with underserved populations.

Another provider, a non-clinician health worker, seemed to embrace the opportunity to facilitate access to health citizenship:

> "I really like my job. I know we do a lot of good for these kids and they're getting top notch care even though they're poor. Because poor people usually get bottom of the line care. But here I know they're lucky, and they get better most of the time. But what's hard is seeing their parents sometimes who are in really bad shape. I'm glad the kids are good, and they're [the parents are] glad their kids come here, but it's sad that most places can't do more. Even for the kids – the parents are always telling me how grateful they are for Asthma Clinic because they didn't like their other clinics. They [the patients and caregivers] know us and they trust us, so a lot of times they call me up and ask me whatever. They're like, 'where do I go if I need blah blah blah', or 'do you think I should take my husband to emergency if he's...whatever'. So I know they trust me. And how could I say 'no'? That would just make things hard with their kid next time. So ya, I do all this stuff that's not really my job, but I guess it's OK because that trust is really important."

In response, I asked: "When you say it's not really your job, what do you mean? What would you say is your job?" She replied,

> "Well, for example, it's not on my job description to tell parents where to go for x, y, and z or to help them figure out their bills and stuff. But it *is* my job to help them, to make sure they get what they need. I think my job is kind of a problem-solver. I just do whatever I can to make sure

> that parents can take care of the kid's asthma and help them keep doing that. I don't really mind, but it's not really my *job*."

In this case, the provider approached the issue of facilitating health citizenship as a natural byproduct of the trusting relationship that develops between patients and providers. Perhaps as a non-clinical provider she is in a better position to help relatives in a way that does not violate professional codes of conduct that apply specifically to physicians.

One episode stood out as the most provocative example of a physician's role in facilitating health citizenship to non-patient relatives. This physician described his actions as "unlawful" but simultaneously "the right thing to do." He recalled the incident this way:

> "I'm standing outside the room reviewing the patient's medical file before I go in and I see that Katia, my twelve year old patient with severe persistent asthma, has come in urgently because she can't catch her breath. As soon as I open the door, I hear this sound like Darth Vader [he imitates the heavy, low-pitched, scratchy breathing sound]. So I figure, yep, her asthma's flared up again. But when I go to take a listen to her chest I realize the breathing sound is from her dad! So I do her physical [exam] and everything and set her up for a neb.[18] After the neb she's sounding better and I'm about to wrap up the appointment, but I'm still hearing the dad breathe like that while the girl is better now. Anyway, I ended up giving the father a [nebulizer] treatment too, off the books of course. I just couldn't walk away. It was the right thing to do."

---

[18] A nebulizer treatment is a procedure in which a patient inhales a concentrated form of a bronchodilator medicine like albuterol through a mask over the nose and mouth, and this opens the airways.

This incident demonstrates how providers may exercise autonomy in providing medical care to an individual that is not the patient. Whereas the above incident may seem to some to be an obvious transgression of a physician's professional obligations, it underscores the moral conflict that some providers experience in weighing their responsibilities.

As a whole, provider accounts demonstrate that their role as facilitators of health citizenship may take many forms. Through the interactions with their child's provider, caregivers are able to obtain a wide variety of the privileges and benefits that would otherwise remain out of reach, including general health information, personal medical advice, physical assessments, sample prescription and over-the-counter medications, and medical treatments like the nebulizer.

Only one provider mentioned the imbalance of health insurance availability between children and adults as a motivating factor in her decisions to provide certain benefits to the child's caregiver. More often providers seemed motivated by a more generalized feeling of compassion towards parents who are raising their children in destitute conditions that create immense emotional and physical challenges and affect the well-being of all family members. Some providers rationalize their role in assisting caregivers as part of their overall effort and success in helping their patient (the child) to whom they owe a professional allegiance. Other times providers' remarks about children's needs versus the needs of caregivers mirror the rhetoric of policymakers and children's health advocates who believe in guarding the health of children above the needs of other population groups. While the professional and moral appropriateness of providers' actions and attitudes may be debated, it is clear that they occupy a pivotal, if uncomfortable, role as the intermediaries in caregivers' access to health citizenship.

## The Child's Role

The narratives in this chapter have mostly portrayed children as relatively passive subjects in the dynamic between children, caregivers, and practitioners. During my observations of clinical interactions, I did not witness many instances in which children played an active role in establishing health citizenship for their parents. By “active” I mean that children did not initiate conversations with the practitioner about their parent's health concerns. They did not proactively seek information or referrals for health-related support services such as housing or employment advocacy groups. Thus, it would be fair to say that the child was more often simply a passive vehicle for parents to actively access forms of health citizenship. The conversations and behaviors that produced health information and services for parents to achieve health citizenship were not initiated by children, but by caregivers themselves. Thus, whereas children exhibited greater forms of agency and self-care in their own asthma management as described in Chapter 3, children in this chapter remained mostly passive in facilitating their parents' access to health citizenship.

The fact that children are not uniformly passive or active across all situations supports my original argument that distinctions between “childhood” and “adulthood” often produce false dichotomies based solely on an individual's age. Children are not passive beings all of the time and adults are not active beings all of the time. Individuals exercise different levels of agency at different moments based on a myriad of circumstances, of which age is but one factor. I would argue that both children and adults actively employ creative strategies to achieve the end results they desire. Whereas children in Chapter 3 did not take their asthma medications in order to, for example, defy their mother's instructions or gain popularity with peers, adults in this chapter obtain health information and services given the opportunity to interact with their child's medical providers.

Elsewhere I have critiqued the tendency of both policies and public sentiments that treat children as purely passive beings, incapable of self-determination. For example, children are generally sheltered from the negative judgments that are directed at adults who fail to achieve good health, particularly those suffering from so-called “lifestyle” diseases such as obesity or addiction. But as I have demonstrated in each chapter, the actual determination of an individual's ability to care for his or her health is based largely upon structural inequalities that produce the context in which sickness and suffering occur. Given the imbalance of health care coverage, some children are better able than some adults to care for their health by seeing a physician regularly, by obtaining medications and treatments at low cost, and by utilizing information and health education provided during interactions with providers. Thus, to what degree should children be held accountable for their health, and how should this be judged?

This chapter began by demonstrating how social and political conceptions of children as a privileged population have produced an imbalance of care in which eligibility for health care coverage is far greater for children than for adults. Participant narratives demonstrate how, as a result of this imbalance, some adults employ strategies by which they may attain health citizenship through the privileges bestowed upon children directly by the State.

Because notions of childhood are so deeply embedded in American culture, it may seem natural that children today are treated as a privileged population and afforded greater health benefits by the State. However, children did not always occupy an elevated moral or social status across history and culture, as was described in Chapter 3. Children are in a position to act as conduits for their parents to achieve health citizenship because they are culturally and morally constructed as innocent subjects in need of protection. In order to protect them, the State provides children with greater access to health insurance and health services. Likewise, based on a belief that adults are uniformly capable of self-care, the State limits adults' opportunities to achieve health citizenship directly from enrolling in State benefits. The creative strategies employed by adults to access health citizenship through their child are a natural byproduct of the State's imbalanced provision of care.

Given the consequences of being uninsured, it is easy to understand why some adults may try to attain health citizenship through the services and information available for their children. One could even argue that by caring for their own health by any means possible, adult caregivers are in fact looking out for the well-being of their children, who would be further economically and socially disadvantaged were their caregivers to be sick or die. In part for this reason, I do not see this pattern, of adults accessing health citizenship through their children, as an exploitative practice. Rather, I see it as a reasonable adaptation given the harsh reality of their existence, and an effort to extract the maximum benefit possible from their interactions from medical providers. Furthermore, if certain primary health needs of the adult caregiver are in fact managed at an earlier stage during the child's outpatient appointment, it may also be possible that these strategies result in a reduction of adults' reliance on emergency room services for non-emergent needs. Seen in this way, adults' strategies of attaining health citizenship might even constitute economically productive behaviors for the individual, family, and State.

The moral claim on children’s need of protection and of children as the ultimate citizen-subjects allows other populations to become invisible and the State to dismiss its obligations to populations perceived as less morally deserving. It is likely that the protection of children is a less controversial subject for politicians to initiate and for the public to approve. So perhaps the greater allocation of resources to children is simply an easier policy to enact than the protection of other groups of perceived questionable moral status. The experiences and comments by physicians in this chapter, however, demonstrate a keen recognition of the extreme vulnerability of low-income adult caregivers. They illustrate a first-hand account of the negative consequences of the State's imbalance of care in which physicians often feel conflicted, resentful, and at times grateful, for the opportunity to care for adults in ways that the State does not provide. As health policy experts advocate for the expansion of Medicaid benefits to low-income non-elderly adults, I expect that the cultural and political rhetoric that will be used to approve or deny these benefits will highlight conflicting American values of individualism and autonomy versus the right to health and happiness.

# Chapter 6: Conclusion

> “Unless we put medical freedom into the Constitution, the time will come when medicine will organize into an underground dictatorship... To restrict the art of healing to one class of men and deny equal privileges to others will constitute the Bastille of medical science. All such laws are un-American and despotic and have no place in a republic... The Constitution of this republic should make special privilege for medical freedom as well as religious freedom."
>
> - Benjamin Rush MD, Signer of the Declaration of Independence; Surgeon-General and subsequently Physician-General of the Continental army; and Ardent Abolitionist

This dissertation tackled the question: Given the availability of effective and inexpensive medications and services, why do so many children continue to suffer from asthma? Participant narratives illustrate how low-income families in San Francisco contend with the challenges of pediatric asthma management, and why so many are unable to achieve better control of asthma symptoms. Their stories indicate that the cumulative impact of daily life challenges – that are a product of poverty and immigration status, life experience, and organizations of power – have created a situation in which asthma management is difficult, if not impossible, for many low-income families to achieve.

In Chapter 2, I demonstrated how the structural and historical patterns of oppression in San Francisco have predisposed certain population groups to poverty and toxic living conditions that severely limit the possibilities for reducing asthma suffering. I illustrated how fear and distrust are generationally and culturally reproduced, and I argued that decisions about whether and when to seek care are reasonable and understandable in the context of individual experience. In Chapter 3, I chronicled the steps involved in clinical processes of care to illustrate how ambiguity and conflict in notions of children's subjectivity produces a lack of consistency toward children's accountability for self-care tasks that ultimately reduces the quality of asthma care. I also demonstrated how the clinical evaluation process relies heavily on subjective reports and is thus highly vulnerable to inaccuracies. Accordingly, even well-intended efforts to improve patient adherence to prescribed asthma protocols have been met with limited success. Chapter 4 documented the ways in which health insurance documentation requirements serve as *de facto* barriers to care, particularly among immigrant populations, and I established how these barriers account for the significant gap between children's health insurance eligibility and effective enrollment status. And in Chapter 5, I argued that children occupy a privileged status in the health care system based on cultural conceptions of childhood innocence, and yet children sometimes serve as health care liaisons between the State and uninsured parents. These contributions yield important insights not only about why children continue to suffer from asthma, but also why it is imperative that practitioners and policymakers consider the context of individual experience as a basis for judging an individual's capacity to achieve good health.

## Health Reform – Possibilities and Problems

Debates about health care in the United States have not ended with the passage of the Patient Protection and Affordable Care Act of 2010. Given the bipartisan political climate of the United States as well as the overall consensus that the current health care system is inadequate and economically unsustainable, health care promises to remain a topic at the forefront of national concern. This dissertation contributes to these debates by demonstrating how unequal access to health insurance and health services results in greater health care inefficiency and bureaucracy and can sometimes compromise the quality of care to insured individuals.

For example, in Chapters 4 and 5, I described how unequal provisions of health insurance to children and adults has produced a situation in which children have sometimes become a conduit to health care for uninsured parents and siblings. This is significant because it demonstrates how the denial of health care to certain population groups has not entirely prevented their utilization of health services; on the contrary, it has generated new opportunities to access health information and care through the improvised utilization of existing protocols. Practitioners who serve low-income families have frequently encountered such scenarios, and their narratives speak to their uncomfortable position as intermediaries between the State and individuals in need.

And yet, California practitioners are not faced with mandatory reporting legislation, which does exist in certain other U.S. states. In Arizona, for example, A.B. 2008 requires providers to inquire about parents' citizenship status when they bring in their child for medical attention. This approach to immigration reform undoubtedly deters some families from seeking timely medical care for their children. In this case, the State has placed both practitioners and children in the uncomfortable, and arguably inhumane, position as potential immigration enforcement officers. Regardless of any actual effect on the deportation of undocumented residents, this legislation clearly produces greater suffering and sickness among children.

In California, the Medicaid-funded Healthy Families program was expanded in 2002 to include parents of already enrolled children, but the provision was never adequately funded or implemented. I have argued that this reflects ambiguity and inconsistency in the State's commitment to providing for the welfare of adults. Children's coverage, on the other hand, has been expanded and implemented such that insurance enrollment levels have continued to rise steadily, reflecting a greater and more urgent commitment to health insurance for children. Health policy analysts have taken note of these contradictions in health coverage for parents versus children, and their recommendations support the arguments set forth in this dissertation:

> The lack of coverage among parents of uninsured eligible children suggests that one relatively easy way to expand public coverage options for uninsured adults in California is to implement the approved, but unfunded, expansion of Healthy Families for parents of eligible children. This option not only benefits parents, it also would tend to increase enrollment of eligible children in these programs, as indicated by other research (Brown, et al. 2007).

Yet, it is worth noting that this argument in favor of expanding coverage to adults also asserts a concurrent benefit for children that would be effected by such a measure.

The invocation of children in this debate supports my argument in Chapter 5 that the status of children as a vulnerable population group elevates the moral quotient for the urgency and necessity of health care reform.

Whether or not children's vulnerability is used in the service of arguments for expanded health care for adults, it is clear that the uninsured status among children is a family problem that requires a comprehensive family-based solution to adequately address the issue (see Brown, et al. 2007). Based on the findings of this research, I propose that restructuring health care delivery to include a family-based option for care may result in better health outcomes for both children and adults as well as enhanced cost-effectiveness of the State's resources. Furthermore, given the narratives in this dissertation, broader insurance provisions would likely increase health care efficiency by reducing administrative bureaucracy, and consequentially, public efforts to circumvent bureaucracy.

The ongoing need for health care reform has also been exacerbated by the ever-increasing wealth disparity in the United States. In San Francisco, the poorest neighborhoods are gentrifying and the middle class is rapidly disappearing. While some San Franciscans have moved out of state, others have moved to more affordable neighborhoods within the Bay Area, such as Oakland, South San Francisco, and Daly City. As a result, rent has increased in suburban neighborhoods, thereby displacing the long-time residents of lower economic status. In the City of San Francisco, the City's "Bayview Hunter's Point Redevelopment Project" promises to bring better quality affordable housing to San Franciscans, with cleaner neighborhoods, better business opportunities, and safer parks and areas of recreation. The project includes plans to tear down the Potrero housing projects and “deteriorated buildings” where many of the participants in this study currently live (San Francisco Redevelopment Agency, 2006). The rhetoric of the proposed “renewal project” of the 21st century recalls the so-called “Negro removal” projects that displaced thousands of African-Americans in similar circumstances during the 1950s as described in Chapter 2, a fact that has not been lost among many of the current residents of Bayview.

The Patient Protection and Affordable Care Act will effect changes over the next four years that will dramatically improve the quality and affordability of health care, especially for Americans who currently have been excluded from or unable to afford care. Health care provisions for undocumented residents, however, will not change. Polls indicate that the majority of Americans do not support health care for undocumented immigrants, even though the U.S. Department of Homeland Security estimates that 11-12 million have been residing within the U.S. border since 2005 (Hoefer, et al. 2007). As this dissertation has clearly demonstrated, however, policies that exclude certain populations from health care provisions do not ensure that those populations will not seek and achieve some health care provisions by other means. Specifically, the narratives in this study indicate that non-provision of services to some populations directly leads to increased use of costly emergency services, the development of strategies that utilize access to services among insured family members to care for uninsured members, dilemmas of conflicting obligations to moral and professional standards for health providers, and increased health risks and monetary costs to insured individuals.

The United States is the only industrialized country in the world that does not offer universal health care to citizens. American exceptionalism in the organization of health care has negatively impacted the health of the population as evidenced by the fact that, according to the World Health Report, the United States' health care system ranks 27th in the world (Murray and Frenk 2000).[19] While I am confident that the health care reforms of 2010 will contribute to positive changes in the health of the population and the economic sustainability of the health care system, I am concerned that attitudes toward the poor and accusations of individual culpability will continue to alienate low-income minority populations like the participants in this study. The belief that individuals have equal opportunities to achieve good health obscures structural conditions of oppression and minimizes the experiences of people who struggle simply to meet the basic necessities of daily life.

## Integrated Models of Care

Much of the observation portion of this dissertation began at the Pediatric Asthma Clinic at San Francisco General Hospital. As the area's leading asthma specialty clinic, I had the privilege of witnessing how their integrated socio-medical approach was able to

---

[19] These rankings were assessed by comparing “the extent to which investments in public health and medical care were contributing to critical social objectives: improving health, reducing health disparities, protecting households from impoverishment due to medical expenses, and providing responsive services that respect the dignity of patients.”

overcome certain barriers to care that are typically not addressed by most clinics. The integrated approach recognizes that health problems like asthma do not exist in a vacuum. High quality medical services must be accompanied by social support services in order to achieve better overall health. Since the implementation of the 'Yes We Can' Asthma Partnership Program, Asthma Clinic has published their success in achieving lower hospitalization rates, greater number of referrals to primary care providers, increases in controller medication prescriptions, increase in patient use of action plans, and overall reduction of reported symptoms (Thyne, et al. 2006 and 2007). Importantly, these achievements also reduced the direct costs to San Francisco General Hospital in expenditures for treatment of children with asthma and asthma-related symptoms.

As one physician stated, the Community Health Workers[20] at Asthma Clinic are the “cornerstone of the clinic's efficacy”. Community Health Workers play a vital role in serving the “social” needs of patients during their clinical appointment. They provide comprehensive asthma education and they ensure that children and caregivers understand the prescribed treatment plan, in particular the importance of administering medications correctly and reducing triggers in the home environment. I witnessed, for example, how the Health Workers used anatomical models and other educational tools to provide detailed and straightforward (i.e. non-jargon) information including: what is asthma, why do symptoms occur, what are the signs of asthma exacerbations, what are the potential

---

[20] Community Health Workers are specially trained in public health services and in working with low-income minority populations. Their training makes them superbly equipped to deliver the essential social support services that are described here. But because their job does not require an advanced educational degree, their salaries are lower and thus their addition to a clinic staff team would produce a lesser financial burden than would hiring, for example, additional nurses to perform these tasks.

environmental triggers to be aware of, how do medications work, how and when should medications be utilized, and when it is appropriate to seek urgent or emergency care. The initial Asthma Clinic appointment for new patients can last up to two hours total because of the comprehensive medical and support services that are provided. “Regular” patients who present at the clinic for urgent or follow-up care continue to receive extensive education and support that is tailored to each family's needs and the difficulties that are affecting that child's asthma control. Thus, each and every time the child and caregiver are seen at the clinic they receive both medical and social support services.

In addition, Community Health Workers provide support services outside of the clinical appointment. Follow-up phone calls are a regular part of the patient care process; within a few days of their clinic visit, families receive a call from the health worker who asks, for example, 'were you able to obtain your medications?', 'are the child's symptoms improving?', and 'do you have any other questions that I can help you with?'. In addition, home evaluations are offered to Asthma Clinic parents who consent to an appointment in which the health worker visits their home and assesses potential asthma triggers or other environmental factors that may contribute to poorer asthma control. The home evaluations have yielded some of the most dramatic and, ultimately, successful interventions by pinpointing exactly what in the child's environment may be directly causing asthma symptoms and thus eliminating those factors. I witnessed repeated occasions on which the Community Health Workers acted as personal advocates and liaisons with other support services and agencies for housing, insurance, and employment problems that affected a family's overall ability to care for the child's asthma needs. As one of the Community Health Workers put it, “if it means they can't do what they need to for the kid's asthma, then it's my responsibility to help.”

Primary care physicians and lay health consumers are generally awe-stricken when I describe the services that are regularly provided to patients at Asthma Clinic, particularly since the patient population at San Francisco General Hospital is comprised almost exclusively of poor Black and Latino children who do not have private health insurance. The overall success of the Asthma Clinic program testifies to the effectiveness of providing integrated social and medical services. It confirms the NHLBI's four essential components to effective asthma management:

1) Assessment and monitoring;
2) Control of factors contributing to asthma symptoms;
3) Education and partnership with the patient and caregiver in designing the treatment plan; and
4) Pharmacotherapy

And yet, some patients at Asthma Clinic continued to fall through the cracks. Some children's symptoms did not improve, and others seemed unreachable because they did not continue to be seen at the clinic. The discontinuity of care was also frequently reported by providers at the other San Francisco clinics I studied. Thus, despite the overall success of the socio-medical strategy, some children continued to suffer from asthma. I drew upon these case anomalies as a starting point for this research. That is, why did some children not benefit from the types of interventions that were successful for most other children? This dissertation answered that question using participants' stories and experiences as testimony to their ongoing suffering from asthma.

## Recommended Strategies

During the course of my observation and interviews with children and caregivers, I began to develop a list of opportunities for specific, small-scale interventions that could easily be implemented at any clinic, but may be especially valuable for clinics that serve low-income families. Importantly, these strategies and tasks would not require increased expenditures and many could be implemented with minimal change to existing clinic procedures. Some of the recommendations are for practitioners, while others are more likely to be addressed by administrative staff, or if you're lucky, a Community Health Worker. I shared these recommendations during several presentations to practitioners at primary care and asthma specialty clinics, and I received feedback that the implementation of certain recommendations have already yielded favorable results.

### *1. Remember: Patients have multiple residences and multiple caregivers*

During in-depth interviews with children and caregivers I quickly determined that many children reside at more than one home, and many rely heavily on more than one caregiver. Assumptions about the nuclear family structure (i.e. two parents with children in one home) are built into a lot of clinical procedures even though many sensitive providers who work with low-income populations in theory would recognize that this does not occur. Thus, it is important to update clinical procedures to account for the fact that many children have multiple residences and multiple caregivers.

A) Each time you have contact with a patient, update their address and caregiver contact information. Ask directly if the child sleeps or spends a significant amount of time at any home other than the address given. Note – most medical records use a standard contact information form with single lines for “parent” and “address” so it may be necessary to modify this form or at least create space to allow for more information here. Ask directly who should be considered the primary caregiver, and what other person(s), if any, should be listed as caregivers based on the frequency with which the child would rely on the individual for asthma care support.

B) Provide multiple copies of the action plan[21] so that one is placed in every residence where the child spends time on a regular basis.

C) During follow-up calls, make sure that each caregiver has received a copy of the action plan and has an opportunity to ask questions about it. This is especially important because the person who accompanies the child to the clinic appointment may

---

[21] The “action plan” is a piece of paper that outlines specific information about the child's medication and directions for dosing. It also details what tasks are required on a regular basis, what symptoms would necessitate a call to an urgent care clinic or advice nurse, and what symptoms would necessitate emergency care. This self-management tool is already used by most clinics for children with asthma; if not, it is imperative that providers implement it, as it has been proven to be highly successful in improving patient adherence to asthma treatment plans.

not be a primary caregiver. Also, do not assume that caregivers communicate with each other. So if possible, speak directly with each caregiver as standard follow-up procedure.

### *2. Reduce subjectivity, ambiguity and conflict in evaluations and plans*

Solicit greater participation from children during the intake process based on indications of their cognitive and social maturity. Don't assume that children of a certain age do or should do certain tasks. Ask caregivers what they expect of their child in self-care tasks and support that measure of involvement. Understand that, for children who move between multiple households and caregivers, children themselves are the only constant; thus, their experience of symptoms and behaviors should be considered during the intake assessment.

### *3. Recognize Cultural Biases in Patients/Caregivers and in Yourselves (Providers)*

Health care providers should assess their motivations for judging health behaviors and be open to seeing the logic of patients' and caregivers' decision-making processes. Remember that reporting of symptoms and triggers is often influenced by people's beliefs about what causes asthma and what is “good” or “bad” for children's health so listen for indications of how health and risk are interpreted. Use the opportunity to provide clear information if misperceptions interfere with adherence to treatment plans or have reduced the efficacy of symptom reduction. But be sensitive to personal experiences that have generated negative feelings about health providers and institutions.

### *4. Ask for feedback.*

If asked, patients and caregivers freely assert the reasons why asthma management is difficult. Asking families for feedback about the barriers they encounter not only may provide an opportunity to bridge that barrier, it also communicates your recognition and empathy for the challenges that make caring for a child's asthma so challenging, particularly for low-income and immigrant populations.

### *5. Talk directly about all kinds of smoke*

I learned about this strategy from a physician who had discovered a critical gap in patients' and caregivers' understanding about the effect of smoke on persons with asthma. The vast majority of caregivers recognized that “smoking” around children with asthma could trigger asthma symptoms or even an asthma attack. Many spoke freely about their efforts to not smoke inside the house or only smoke when the child was not present. However, as this physician determined, the association of smoke and asthma symptoms seemed to apply only to cigarettes. Several families did not recognize that any type of smoke, not just cigarette smoke, caused irritation and inflammation of the respiratory airways. For example, when certain caregivers admitted during their own health care evaluations that they smoked marijuana or even crack at home, it became clear that they did not recognize that this smoke was also dangerous to children with asthma. These parents expressed concern about the effect of the drugs on the child, but they did not follow through with the same measures that they employed to reduce children's exposure to cigarette smoke. Also, since illicit drugs like marijuana and crack are more likely to be smoked indoors, providers must emphasize the danger of any type of smoke to children with asthma. It is not necessary to probe the caregivers' actual use of illicit substances in order to convey this fact. Instead, providers should simply remind patients and caregivers that all smoke is detrimental to children with asthma, including smoke from any inhaled device (e.g. cigarettes, illicit drugs, hookahs, etc.), candles, fireplaces, and campfires. Such an assertion is less likely to be perceived as an accusation of unhealthy behaviors and focuses instead on the issues specifically relevant to asthma.

These recommendations support my overall argument that asthma management strategies are most effective when they are situated within the context of individual experiences.

I hope that this dissertation will contribute to the knowledge and practice of health care, particularly for low-income minority populations. Although the barriers to asthma management may seem daunting, this dissertation has offered evidence that suffering from asthma can be mitigated by practitioners who communicate empathy informed by an appreciation of the impact of poverty, immigration, and bureaucracies of power; it can be reduced by policymakers who recognize patterns of discrimination and the impact of denying health care to certain population groups; and it can inform health care consumers and advocates that the context of individual experience often limits the conditions of possibility for achieving better control of asthma symptoms. I am grateful to the children, caregivers, and providers who participated in this study for sharing their experiences that have informed this literary contribution.

## Bibliography

Abraham, Laurie Kaye (1994). *Mama Might Be Better Off Dead: The Failure of Health Care in Urban America*. Chicago: University of Chicago Press.

Akinbami, L.J. (2006). *The State of Childhood Asthma, United States, 1980-2005*. Advance Data from Vital and Health Statistics, no 381. Hyattsville, MD: National Center for Health Statistics.

American Lung Association (2010). "Asthma and Children Fact Sheet." *http://www.lungusa.org/lung-disease/asthma/resources/facts-and-figures/asthma-children-fact-sheet.html*, accessed 4/1/10.

Anderson, Elijah (1990). *Streetwise: Race, Class, and Change in an Urban Community*. Chicago: University of Chicago Press.

Ariès, Philippe (1962). *Centuries of Childhood*. New York: Vintage Books.

Baca, George (2005). "Legends of Fordism: between myth, history, and foregone conclusions." *Social analysis,* 48(3):169-178.

Becker, Gay (2004a). "Deadly Inequality in the Health Care 'Safety Net': Uninsured Ethnic Minorities' Struggle to Live with Life-Threatening Illnesses." *Medical Anthropology Quarterly*, 18(2): 258-275.

----- (2004b). Phenomenology of Health and Illness. *In*: Encyclopedia of Medical Anthropology: Health and Illness in the World's Cultures. C. R. Ember, Melvin Ember, eds., 1:125-136. New York, Kluwer Academic/Plenum Publishers.

Berglund, Barbara (2007). *Making San Francisco American: Cultural Frontiers in the Urban West, 1846-1906*. Lawrence: University Press of Kansas.

Berk, M.L., C.L. Schur, L.R. Chavez and M. Frankel (2000). Health Care Use Among Undocumented Immigrants. *Health Affairs*, July/Aug 2000: 51-64.

Biehl, Joao (2009). *Will to Live: AIDS Therapies and the Politics of Survival (In-formation)*. Princeton: Princeton University Press.

Bloom B, R.A. Cohen, and G. Freeman (2009). Summary health statistics for U.S. children: National Health Interview Survey, 2008. National Center for Health Statistics. *Vital Health Stat,* 10(244).

Bluebond-Langner, Myra (1978). *The Private Worlds of Dying Children*. Princeton: Princeton University Press.

----- (1996). *In the Shadow of Illness*. Princeton: Princeton University Press.

Bourdieu, Pierre (1990). *The Logic of Practice*. Translated by Richard Nice. Stanford, Stanford University Press.

----- (2000). *Pascalian Meditations*. Translated by Richard Nice. Stanford: Stanford University Press.

Bourgois, Philippe (1995). *In Search of Respect: Selling Crack in El Barrio*. Cambridge, UK: Cambridge University Press.

----- (2004). "U.S. Inner-City Apartheid and the War on Drugs: Crack among Homeless Heroin Addicts." *In*: Unhealthy Health Policy: A Critical Anthropological Examination, Arachu Castro and Merrill Singer, eds.: 303-316. Walnut Creek: Alta Mira.

Bourgois, Philippe and Jeff Schonberg (2009). *Righteous Dopefiend*. Berkeley: University of California Press.

Brechin, Gray (2008). "Pecuniary Emulation: The Role of Tycoons in Imperial City-Building." *In*: Reclaiming San Francisco: History, Politics, Culture. James Brook, Chris Carlsson and Nancy J. Peters, eds. San Francisco: City Lights Books.

Briggs, Charles and Clara Mantini-Briggs (2003). *Stories in the Time of Cholera: Racial Profiling During a Medical Nightmare*. Berkeley: University of California Press.

Broussard, Albert S. (1993). *Black San Francisco: The Struggle for Racial Equality in the West, 1900-1954*. Lawrence: University Press of Kansas.

Brown, E.R., S.A. Lavarreda, N. Ponce, J. Yoon, J. Cummings and T. Rice (2007). *The State of Health Insurance in California: Findings from the 2005 California Health Interview Survey*. UCLA Center for Health Policy Research, July 2007.

California Children and Families Commission, "First 5 California." http://www.ccfc.ca.gov/, accessed 3/14/10.

California Health Care Foundation (2010). "Consumer Resources: What is Medi-Cal?" http://www.chcf.org/topics/medi-cal, accessed 2/22/10.

California Newsreel (2008). "*Unnatural Causes: Is Inequality Making Us Sick?*" Prod. National Minority Consortia of Public Television.

Castañeda, Heide (2009). "Illegality as a Risk Factor: A Survey of Unauthorized Migrant Patients in a Berlin Clinic." *Social Science & Medicine*, 68(8): 1552-1560.

Cobb, Daniel M. (1998). "Philosophy of an Indian war: Indian community action in the Johnson administration's war on Indian poverty, 1964-1968." *American Indian Culture and Research Journal*, 22(2):71-102.

Csordas, Thomas (1994). *Embodiment and Experience*. Cambridge: Cambridge University Press.

Cunningham, P. and J. May (2006). *Medicaid Patients Increasingly Concentrated Among Physicians*. Center for Studying Health System Change, Tracking Report 16, Aug 2006.

Dawson, Robert and Gray A. Brechin (1999). *Farewell, Promised Land: Waking from the California Dream*. Berkeley: University of California Press.

DeLeon, Richard E. (1992). *Left Coast City: Progressive Politics in San Francisco, 1975-1991*. Lawrence: University of Kansas Press.

DeNavas-Walt, Carmen, Bernadette D. Proctor and Jessica C. Smith (2008). "Current Population Reports, P60-235". *Income, Poverty, and Health Insurance Coverage in the United States: 2007*. Washington DC: U.S. Census Bureau.

Environmental Protection Agency, Ad Campaign 2001, Poster #402-H-01-001, image from St. Paul Public Schools, http://www.studentwellness.spps.org/Asthma2.html, accessed 5/23/10.

Estroff, S. E. (1995). "Whose Story is it Anyway? Authority, Voice, and Responsibility in Narratives of Chronic Illness." *In*: Chronic Illness, S. K. Toombs, D. Barnard and R.A. Carson, eds. Indianapolis: Indiana University Press.

Farmer, Paul (2001). *Infections and Inequalities: The Modern Plagues*. Berkeley: University of California Press.

----- (2006). *AIDS and Accusations: Haiti and the Geography of Blame*. Berkeley: University of California Press.

Federation of American Scientists, Military Analysis Network (1998). "Hunters Point Naval Shipyard." http://www.fas.org/man/dod-101/company/shipyard/hunters_point.htm, accessed 5/8/2009.

Feldman, Allen (1991). *Formations of Violence: The Narrative of the Body and Political Terror in Northern Ireland*. Chicago: University of Chicago Press.

Fox, Cybelle (2009). *A New Nativism or an American Tradition? Federal Citizenship and Legal Status Restrictions for Medicaid and Welfare*. Presentation at the Annual Meeting of the American Sociological Association, San Francisco, CA.

Frates, Janice, Joel Diringer and Laura Hogan (2003). "Models and Momentum for Insuring Low-Income, Undocumented Immigrant Children in California." *Health Affairs*, 22(1): 259-263.

Fronstin, P. (2007). "Sources of Health Insurance and Characteristics of the Uninsured: Analysis of the March 2007 Current Population Survey." *http://www.ebri.org/publications/ib/index.cfm?fa=ibDisp&content_id=3850,* accessed 2/22/10.

Gillissen A. and J. Lecheler (2003). "Corticophobia in Asthma." *Med Klin* (Munich), 15 Aug 2003, 98(8): 417-22.

Gilmour, M.I., M.S. Jaakkola, S.J. London, A.E. Nel and C.A. Rogers (2006). How exposure to environmental tobacco smoke, outdoor air pollutants, and increased pollen burdens influences the incidence of asthma. *Environmental Health Perspectives*, 114(4): 627-633.

Good, Byron (1994). *Medicine, Rationality and Experience*. Cambridge, Cambridge University Press.

Hadley, Jack (2003). *Sicker and Poorer: The Consequences of Being Uninsured*. Washington DC: The Kaiser Commission on Medicaid and the Uninsured.

Heron, Melonie, et al. (2009). "Deaths: Final Data for 2006." *National Vital Statistics Reports*, 57(14): 7.

Hoefer, Michael, Nancy Rytina and Christopher Campbell (2007). Estimates of the Unauthorized Immigrant Population Residing in the United States: January 2006. U.S. Department of Homeland Security: Population Estimates, August 2007. http://www.dhs.gov/xlibrary/assets/statistics/publications/ill_pe_2006.pdf, accessed 5/27/10.

Hopkins, Daniel J. (2009a). "Partisan Reinforcement and the Poor: The Impact of Context on Explanations for Poverty." *Social Science Quarterly*, 90(3):744-764.

----- (2009b). "Racial Contexts' Enduring Influence on Attitudes Toward Poverty." *Social Science Quarterly*, 90(3):77-776.

Horton, Sarah (2006). “The Double Burden on Safety Net Providers: Placing Health Disparities in the Context of the Privatization of Health Care in the U.S.” *Social Science & Medicine*, 63: 2702-2714.

Institute for Health Policy Solutions – California (2005), “Coverage Initiatives” http://www.ihps-ca.org/localcovsol/cov_initiatives.html#map, accessed 3/16/2010.

Kattan, M., et al. (1997). Characteristics of inner-city children with asthma: The National Cooperative Inner-City Asthma Study. *Pediatric Pulmonology*, 24: 253-262.

Kleinman, Arthur (1980). *Patients and Healers in the Context of Culture*. Berkeley: University of California Press.

Kleinman, Arthur, Veena Das and Margaret Lock, eds. (1997). *Social Suffering*. Berkeley: University of California Press.

Ledogar, R.J., A. Penchaszedah, C.C. Garden and Garden Iglesias (2000). Asthma and Latino cultures: different prevalence reported among groups sharing the same environment. *American Journal of Public Health*, 90(6): 929-935.

Madison, Donald L. (2005). From Bismarck to Medicine – A Brief History of Medical Care Payment in America. *In* The Social Medicine Reader, Vol. III. Jonathan Oberlander and Larry P. Churchill, eds.: 31-66. Durham: Duke University Press.

Marrow, Helen (2009). “Promise and Pitfalls: A Case Study of Undocumented Immigrants' Access to Healthcare in San Francisco.” Unpublished work in progress, 12/16/2009.

Mason, Mary Ann (1994). *From Father's Property to Children's Rights*. New York: Columbia University Press.

Massey, Douglas S. and Mitchell L. Eggers (1990). “The Ecology of Inequality: Minorities and the Concentration of Poverty, 1970-1980.” *American Journal of Sociology*, 96:1153-88.

McCormick, Erin (2008). “Bayview revitalization comes with huge price to black residents.” *SF Gate*, January 14, 2008. http://www.sfgate.com/cgi-bin/article.cgi?file=/c/a/2008/01/14/MNF3U8RCT.DTL&type=printable, accessed 1/14/2008.

Minkler, Meredith (1999). “Personal Responsibility for Health? A Review of the Arguments and the Evidence at Century's End.” *Health Education and Behavior*, Feb 1999, 26(1): 121-140.

Murray, Christopher J.L. and Julio Frenk (2000). "Ranking 37th — Measuring the Performance of the U.S. Health Care System." *New England Journal of Medicine*, Jan. 6, 2010, http://healthcarereform.nejm.org/?p=2610, accessed 5/27/10.

Nadadur, Ramanujan (2009). Illegal Immigration: A Positive Economic Contribution to the United States. *Journal of Ethnic and Migration Studies*, July 2009, 35(6): 1037-1052.

National Heart, Lung, and Blood Institute (2007). National Asthma Education and Prevention Program, *Expert Panel Report 3: Guidelines for the Diagnosis and Management of Asthma, Full Report 2007*. Washington DC: U.S. Department of Health and Human Services, National Institute of Health.

Ong, Aihwa (1999). *Flexible Citizenship*. Durham: Duke University Press.

----- (2003). *Buddha is Hiding: Refugees, Citizenship, the New America*. Berkeley: University of California Press.

Orrell-Valente, J.K., et al. (2007). "Parents' Specific Concerns about Daily Asthma Medications for Children." *J. Asthma*, June 2007, 44(5): 385-390.

Passel, Jeffrey S. and D'Vera Cohn (2009). *A Portrait of Undocumented Immigrants in the United States*. Washington DC: Pew Hispanic Center.

Paddock, Catharine (2007). SCHIP Is a Success and Should Be Expanded Say Opinion Leaders. *Medical News Today*. *http://www.medicalnewstoday.com/articles/68759.php*, accessed 2/25/10.

Petryna, Adriana (2002). *Life Exposed: Biological Citizens After Chernobyl*. Princeton: Princeton University Press.

Pine, Adrienne (2008). "Borderland Rumors and the Corporatization of U.S. Healthcare or, Xenophobia as Corporate Strategy." Presentation at the American Anthropology Association's Annual Meetings, San Francisco, CA.

Porter, Dorothy (1999). *Health, Civilization and the State*. London: Routledge.

Porter E. (2006). "Here Illegally, Working Hard and Paying Taxes." *New York Times*, June 19, 2006; A1.

Public Broadcasting System (2006). *"The Great 1906 Earthquake and Fire"*, The Virtual Museum of the City of San Francisco, *http://www.sfmuseum.org/1906/06.html,* accessed 4/21/10.

Quill, Beth E., Lu Ann Aday, Carl S. Hacker and Julie Kay Reagan (1999). "Policy Incongruence and Public Health Professionals' Dissonance: The Case of Immigrants and Welfare Policy." *Journal of Immigrant Health*, 1(1): 9-18.

*Race – The Power of an Illusion*. Prod. California Newsreel. PBS 2003.

Reed, C.E. (2006). The Natural History of Asthma. *Journal of Allergy and Clinical Immunology*, 118(3): 543-548.

Robert Wood Johnson Foundation (2007). "Quick Facts on the Uninsured." Data from the Employee Benefits Research Institute. *http://covertheuninsured.org/content/quick-facts-uninsured*, accessed 3/10/10.

Romano, Andrew (2009). "Wait A Second. Why Shouldn't We Insure Illegals?" *Newsweek*, Sep 14, 2009.

Sack, Kevin (2009). "Defying Slump, 13 States Insure More Children." *New York Times*, July 19, 2009.

"San Francisco Demographic Profile." MOCD 2005-2010 Consolidated Plan. http://www.sfgov.org/site/uploadedfiles/mocd/demoprofile.pdf, accessed 3/31/10.

San Francisco Redevelopment Agency (2006). "Bayview Hunter's Point Redevelopment Project, Five Year Implementation Plan, FY 2006/07-2010/11." City and County of San Francisco: http://www.bvhp-pac.org/docs/BVHP_5-Year_Implementation_Plan_Web.pdf, accessed 5/27/10.

Scheper-Hughes, Nancy (1992). *Death Without Weeping: The Violence of Everyday Life in Brazil*. Berkeley: University of California Press.

*Sicko*, Dir. Michael Moore. Lions Gate Films, 2007.

Smith, J.P. and B. Edmonston, eds. (1997). *The New Americans: Economic, Demographic, and Fiscal Effects of Immigration*. Washington, DC: National Academy Press.

Steinberg, Mary (2008). "In-Depth: Understanding Dissociative Disorders." *http://psychcentral.com/lib/2008/in-depth-understanding-dissociative-disorders/all/1/*, accessed 4/30/2010.

Stephens, Sharon (1995). *Children and the Politics of Culture*. Princeton: Princeton University Press.

Sumchai, Ahimsa Porter (2008). "Black Flight." *San Francisco Bay View*. http://www.sfbayview.com/2010/black-flight/print/, accessed 4/16/2010.

Takei, I., R. Saenz and J. Li (2009). "Cost of Being a Mexican Immigrant and Being a Mexican Non-Citizen in California and Texas. *Hispanic Journal of Behavioral Sciences*, Feb 2009, 31(1): 73-95.

Taussig, Michael (1986). *Shamanism, Colonialism and the Wild Man*. Chicago, University of Chicago Press.

Thomas, Megan and Cara James (2009). "The Role of Health Coverage for Communities of Color." *Race, Ethnicity & Health Care Issue Brief*, Nov 2009. Washington DC: The Henry J. Kaiser Family Foundation.

Thyne, Shannon M., Joshua P. Rising, Vicky Legion and Mary Beth Love (2006). The Yes We Can Urban Asthma Partnership: A Medical/Social Model for Childhood Asthma Management. *Journal of Asthma*, 43: 667-673.

Thyne, Shannon M., Andrea Marmor, Nanette Madden and Gail Herrick (2007). Comprehensive Asthma Management for Underserved Children. *Paediatric and Perinatal Epidemiology*, 21(Suppl. 3): 29-34.

United States Census Bureau (2008a). "Income, Poverty, and Health Insurance Coverage in the United States: 2007," issued August 2008. DeNavas-Walt, Carmen, Bernadette D. Proctor and Jessica C. Smith, Current Population Reports, P60-235. Washington D.C.: U.S. Government Printing Office, *http://www.census.gov/prod/2008pubs/p60-235.pdf*, accessed 2/18/10.

United States Census Bureau (2008b). "San Francisco County Quick Facts from the U.S. Census Bureau." *http://quickfacts.census.gov/qfd/states/06/06075.html*, accessed 4/15/2010.

U.S. Department of Health and Human Services, *Federal Register*, January 23, 2009, 74(14): 4199–4201. http://aspe.hhs.gov/poverty/09fedreg.shtml, accessed 4/26/2010.

Wacquant, Loïc (2004). *Body and Soul: Notebooks of an Apprentice Boxer*. New York: Oxford University Press.

----- (2008). *Urban Outcasts*. Cambridge, UK: Polity.

----- (2009). *Punishing the Poor*. Durham: Duke University Press.

Wallace, Steven P. et al. (2003). “Mexican Immigrants are Generally Healthier, but Have Less Access to Needed Health Care.” *Health Policy Fact Sheet*, UCLA Center for Health Policy Research.

Walter, N., P. Bourgois, H.M. Loinaz, et al. (2002). “Social Context of Work Injury among Undocumented Day Laborers in San Francisco.” *J. General Internal Medicine*, Mar 2002, 17(3): 221-229.

Washington, Harriet (2006). *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial History to the Present*. New York: Harlem Moon.

Yang, Joshua S. and Steven P. Wallace (2007). “Expansion of Health Insurance in California Unlikely to Act as Magnet for Undocumented Immigrants.” *UCLA Health Policy Research Brief*, July 2007.

Yoon, H.L., H. Kitzman and A. McMullen (2003). “Barriers to Anti-Inflammatory Medication Use in Childhood Asthma.” *Ambulatory Pediatrics*, July-Aug 2003, 3(4): 181-190.

Zlolniski, Christian and Juan-Vicente Palerm (1996). Working but Poor: Mexican Immigrant Workers in a Low-Income Enclave in San Jose. UC Berkeley: Center for Latino Policy Research. *http://escholarship.org/uc/item/4g5598p1*, accessed 3/1/10.

## Appendix 1: 2009 Federal Poverty Guidelines

The 2009 Poverty Guidelines for the 48 Contiguous States and the District of Columbia:

| Persons in family | Poverty guideline |
|---|---|
| 1 | $10,830 |
| 2 | 14,570 |
| 3 | 18,310 |
| 4 | 22,050 |
| 5 | 25,790 |
| 6 | 29,530 |
| 7 | 33,270 |
| 8 | 37,010 |
| For families with more than 8 persons, add $3,740 for each additional person. | |

Source: U.S. Department of Health and Human Services, 2010.

**Publishing Agreement**

It is the policy of the University to encourage the distribution of all theses, dissertations, and manuscripts. Copies of all UCSF theses, dissertations, and manuscripts will be routed to the library via the Graduate Division. The library will make all theses, dissertations, and manuscripts accessible to the public and will preserve these to the best of their abilities, in perpetuity.

I hereby grant permission to the Graduate Division of the University of California, San Francisco to release copies of my thesis, dissertation, or manuscript to the Campus Library to provide access and preservation, in whole or in part, in perpetuity.

Author signature

6/8/2010

Date