THE CARING PRECARIAT:
HOME HEALTH CARE WORK IN NEW YORK CITY

by

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Abstract

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Home health care sits at the nexus of several recent coinciding processes—the fraying of the welfare state, privatization and the externalization of social reproductive costs onto individual families. This dissertation examines the ways in which government funding and public policies structure service delivery and working conditions in the home health care industry in the nation's most populous city—New York City. This study augments in-depth interviews of policy elites, government bureaucrats, employers, advocates and unions with analysis of a new data set collected from hard-to-reach low-wage workers to explore the role of the federal, state and city government in creating and regulating contract arrangements that determine wages and working conditions of a low-wage workforce situated between the formal and informal economy.

Several themes emerge from this research. First, by examining the relationship between the formal, regulated, publicly-funded home health care system and the informal, gray market privately-funded home care system in NYC, I found that the state relies on the informal care economy (and therefore workers working outside of the regulated, formal system) to fill in the care gap created by piecemeal public coverage. Shifts in government regulation, funding and constellations of third party government move the boundaries between formal and informal

jobs—in this case, growing informal work and putting more financial burdens on families. Second, this dissertation explores how a union, namely SEIU 1199, that had previously been unable to raise wages significantly for home health aides, was able to win, remarkably, a living wage by creating and then taking advantage of opportunities to revamp the home health care industry during a period when the State was looking to cut Medicaid. Third, the State, with the help of 1199, facilitated a reorganization of the home health care industry, which led to its consolidation and the growth of Managed Care (which many fear will lead to a decrease in hours of care for patients and less work for aides).

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My graduate school journey started nearly ten years ago when my partner and I put all of our belongings into my 1998 burgundy Toyota Camry and drove east from Berkeley, California to Brooklyn, NY to begin graduate school at CUNY Graduate Center. When we drove into Brooklyn for the first time, through miles of concrete and construction after leaving the beauty of California, I was unsure of whether we made the right decision. Little did I know that it would turn into a beautiful decade full of family, good friends, travel, kids, research, learning and writing. I wasn't aware of the smart and inspiring people I would meet in New York and beyond, who were dedicated, in their own lives and beyond, to making the world a better place. Nor was I aware of the doors that would open to me personally and professionally that would make me a better person, listener, and researcher.

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our cutie-pie baby Jude who I've been able to hold in my arms and whose smile has lit up my last 5 months. You three make my heart sing. Now…let's go drink a beer on our porch, listen to the birds chirp and dream about our next steps.

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Chapter 1: Home Health Care in New York City

Introduction

Home health care sits at the nexus of several recent coinciding processes—the fraying of the welfare state, privatization and the externalization of social reproductive costs onto individual families. This dissertation examines the ways in which government funding and public policies structure service delivery and working conditions in the home health care industry[1] in the nation's most populous city—New York City. By investigating the extent to which funding and regulations create, grow, or deter gray market[2] work in the home health care industry, this research will interrogate if, how and why the state generates low-wage[3], informal work[4], exposing engines of growing overall inequality. This study augments in-depth interviews of policy elites, government bureaucrats, employers, advocates and unions with analysis of a new data set collected from hard-to-reach low-wage workers to explore the role of the federal, state and city government in creating and regulating contract arrangements that determine wages and working conditions of a gendered and racialized workforce situated between the formal and informal economy.

Project Overview

[1] The term industry is defined as "A classification that refers to a group of companies that are related in terms of their primary business activity" (accessed on 4/25/13 at http://www.investopedia.com/terms/i/industry.asp). In this dissertation I use the term industry to include both the businesses that provide home health care services as well as private households who also hire home health care workers directly (not through an agency/business).

[2] Gray market is a term used widely to describe home care workers who are employed directly by private households and whose income is not reported. The gray market workforce is widely acknowledged to be significant, but because of its underground nature, the size, scope and makeup of the gray market has been unquantifiable.

[3] I use the definition of low-wage work used in the 2008 Unregulated Work Survey. "Low-wage industries" are those with median wages for front-line workers below 85% of the city's median wage (which was $13.07 in New York City in 2006 dollars) (Bernhardt, Polson and DeFilippis, 2010).

[4] Informal care in home health care often means unpaid caregiving from a family member or friend. I use the term "informal work" here interchangeably with the term "gray market." For clarity, I will mostly use the term "gray market," except when I discuss how this fits into the broader informal economy literature.

The aging baby boomer population and increasing participation of women in the labor force pose challenges to the way our society undertakes the vital work of caring for the frail elderly and others who need physical assistance, creating what some scholars and advocates call a "care crunch" (Hancock 2002). When compared to other advanced industrial nations, the United States never fully committed to providing such care as a public good and leaves home-based, paid care workers especially vulnerable to low wages and poor working conditions. Despite the vital care that home care workers provide to support individuals and families in New York City, these jobs are among the lowest wage jobs in our economy.

This research comes out my participation in a survey project of the National Employment Law Project, UCLA Institute for Research on Labor and Employment and the Center for Urban Economic Development at UIC which examined workplace violations[5] in low-wage industries in New York City, Chicago and Los Angeles.[6] It became clear during this project and in analyzing the data we collected, that care workers are especially vulnerable to low pay and poor working conditions, but arguably do some of the most important and valuable work in our society—taking care of the most vulnerable. Given my field of political science, I was interested in the fact that government played a particular role in shaping the home health care industry. While obviously government, through public policy, regulations, and sometimes funding, can shape many low-wage industries,[7] it plays a key role in structuring the home health care industry given that the formal agency system is nearly entirely paid for with public funds and because of this, regulations are very strong. On the other hand, a significant portion of paid home health care

[5] Workplace violations are instances where employers were not paying minimum wage, overtime or otherwise not abiding by other workplace laws.
[6] This survey project was called the 2008 Unregulated Work Survey. See Bernhardt et al 2009 for more information.
[7] The low-wage industries in New York City (defined as 85 percent of the city's median wage, or $13.07 in NYC) included: restaurants, retail and drug stores, private households, grocery stores, home health care, social services/child daycare centers/schools, janitorial/security/grounds services, beauty and nail salons, laundry and dry cleaning, food and furniture manufacturing, residential construction, apparel and textile manufacturing, and courier and messenger services.

work is performed in the informal, gray market—this part of the industry is unregulated by government and its size and scope reflect the piecemeal character of public coverage for care. This dissertation takes a detailed look at the home health care industry—a low-wage industry that is inextricably linked to government. This examination uncovers the ways in which the state generates and reinforces low-wage work and creates the conditions for expanding informal work in New York City and is an example of how government policy, regulations and funding structures the low-wage labor market.

By conducting a detailed institutional analysis on the role of government in shaping the home health care industry, my research gives insight into some of the driving forces behind the growing low-wage service economy. I hypothesize that government plays contradictory roles in shaping home-based care. New York State, under pressure from unions and social movement groups, has begun to fill in some of the legal gaps that exist for home care workers and has even exceeded those standards with the passage of the living wage. But much of this care is publicly funded and states are under increasing pressure to reduce costs, which has historically limited the gains these workers have been able to make in terms of increasing wages. The fact that this care is publicly funded, however, has resulted in strong regulations of the formal segment of the industry. The state has actively pushed for the privatization of care, relies on piecemeal service delivery through non-profit and for-profit providers, and maintains clear limits on who is eligible for state funded care, establishing what some experts call the cliff of eligibility. These processes keep wages low in home health care and leave the financial burden to many individual households, many of whom find it difficult to pay for care given the staggering cost of home health care and the fact that the economy has worsened. As one Administration on Aging, Department of Health and Human Services study reports:

> About 11% (3.7 million) of older Medicare enrollees [nationally] received personal care from a paid or unpaid source in 1999. Almost all community resident older persons with chronic disabilities receive either informal care (from family or friends) or formal care (from service provider agencies). Over 90% of these older persons with chronic disabilities received informal care and/or formal care; and about two thirds received only informal care. About 9% of this chronically disabled group received only formal services (Greenberg 2011).

Even those people who get formal care often supplement their formal care with informal care from family, friends or an informal care worker. The state relies on the informal care economy (and therefore workers working outside the formal system) to fill in the care gap created by piecemeal public coverage.

In order to test this proposition, this dissertation asks the following set of research questions. First, how is the home health care industry structured in New York City and what role do federal, state, and local government actors (as policy makers, regulators, and funders) play in this structure? Second, how does the government's role in structuring the formal part of the home health care industry indirectly (or directly) shape the informal part of the industry? Third, what are the wages and working conditions of home health care workers in New York City and how can the structure of the industry help us to understand these conditions of work? Fourth, what political forces operate on these systems of care provision to push care workers toward or away from greater institutionalization, formalization, regulation and public funding? In particular, this study will explore recent changes facilitated by the state budget cycle in 2011 that are greatly shifting the structure of the industry, which impacts home health care workers.

This research employs a multi-method approach, using both quantitative and qualitative analysis. First, it will draw from qualitative interviews with key policy elites in order to a) understand the politics behind and structure of public policies and funding of care, b) identify the institutional and legal settings in which care workers are employed in New York City, and c)

examine the role that government plays in creating, deterring or expanding gray markets or informal care work. Second, it considers secondary research on program structure, public policies, government funding for care, employment and labor law and the institutions that manage this work. Last, it will analyze detailed, representative data (*2008 Unregulated Work Survey*) on the wages, working conditions and the prevalence of workplace violations of home health care workers (working in both the formal and informal economy) in New York City.

The home care workers[8] included in this study are home health aides and personal care aides who care for the sick, elderly and disabled in need of short-term and long-term services. These workers provide companionship and assistance with activities of daily living such as bathing, dressing, toileting, meal preparation, eating and housework. Home health aides have additional training and assist patients with medication and monitoring vital signs. Because public funds pay for the majority of home health care services, this industry is heavily regulated by the state. Home health care workers in New York City are typically employed by agencies (who are subcontracted by the city or certified agencies contracting with the state) or directly by private household employers, or a combination of the two.

Table 1.1: Basic Description of Home Health Care Jobs in New York City

Formal or Informal	**Occupation**	**Employer**	**Payment From**
Formal, agency-employed workers	Home health aide or Personal care aide	A non-profit or for-profit licensed agency	Medicaid, Medicare, private insurance, private household
Informal, gray-market worker	Home health aide or Personal care aide (however this distinction does not exist in the gray market since the training qualifications are not officially required/regulated)	Private Household/Client	Private household

[8] When discussing home health aides and personal care aides (both types of workers) I will refer to them as home care *workers* or home health care *workers*. If I am discussing a specific occupation, I will specify "home health aide" or "personal care aide".

The labor of paid home-based care is heavily female and minority. Over 90 percent of in-home care workers are women (Dresser 2008). Evelyn Nakano Glenn found that women of color and immigrant women are heavily concentrated in "the heavy, dirty, 'back-room' chores of cooking and serving food in restaurants and cafeterias, cleaning rooms in hotels and office buildings, and caring for the elderly and ill in hospitals and nursing homes, including cleaning rooms, making beds, changing bed pans, and preparing food" (Glenn p. 20). Women of color and immigrant women disproportionately provide much of the needed labor supply for in-home care nationally. Though blacks make up 11 percent the total national workforce, the in-home care workforce is more than 17 percent black (Dresser 2008). Foreign-born workers make up 27.1 percent of home health aides and 22.7 percent of personal care aides—this is compared to only 15.5 percent of the workforce nationally is foreign-born (2010 CPS, ASEC supplement analyzed by Smith and Shaefer and reported in a policy brief "By Our Sides," Polson 2011). These percentages increase greatly when looking at the New York City home health care workforce—over 50 percent of whom are immigrants.

Why Home Health Care Jobs are Important to Understand

There are several reasons this research focuses on the home health care industry. First of all, home-based care work is on the rise. In an earlier era, unpaid family caregivers, typically women, tended to perform the majority of care for their children or elderly relatives. Today as more women work outside of the home in the paid workforce, care is more often outsourced to workers outside the family.

Home health care is one of the fastest growing occupations in our economy. Nationally, home health aides and personal care aides are among the top four occupations expected to add

the most employment in the next decade: registered nurses (712,000), retail salespersons (707,000), home health aides (706,000), and personal care aides (607,000). "All have large employment in 2010 and are expected to grow faster than the average of 14.3 percent" (BLS, Employment Projections 2010-2020). The need for home health care workers has increased in recent decades due to changes in the health care system including deinstitutionalization and shorter hospital stays. There has also been a policy push away from institutionally based care and towards home and community-based care, which is typically cheaper than institutional care. The growth of home health care can also be linked to the fact that unpaid family caregivers are finding it more and more difficult to juggle their work with taking care of an elderly or sick relative. One study, conducted by Met Life, found that nearly two-thirds of caring family members reported a loss of earnings due to caring for an elderly relative (National Alliance for Caregiving et al 1999). The primary factor in the growth of home care is the aging of the Baby Boomer population and their strong desire to age in place—one study found that 89 percent of Boomers want to stay in their homes as they age (Clarity 2003). The elderly population is expected to increase by 54 percent between 2010 and 2030, at which point one in every five New Yorkers will be over the age of 65 (Rodat 2010). One report estimates that sixty-nine percent of people turning age sixty-five in the United States will eventually need at least some type of long term care—20 percent will require five years or more (Kemper et al 2005/2006). And as for the elderly population in New York City—they are a sicker population than the rest of the state and this population is getting sicker (Industry Association Interview 1; and Home Care Council of New York City, 2009).

In New York City, home health care workers play a particularly important role in the economy. New York State is home to one of the most "robust and diverse home and community-

based systems of long-term care services in the country" (Rodat 2010). In 2011, there were about 77,000 personal care aides and 78,000 home health aides working in New York City, totaling more than 154,000 aides working in the city (PHI 2012b). In New York City, the number of home care workers is larger than any other occupational grouping in the city—there are more home care workers than there are retail persons or primary, secondary and special ed teachers. In fact, one in seven low-wage workers in New York City are home health care workers (Rodat 2010). It is estimated that "home care aides provide 70 to 80 percent of the ***paid hands-on care in the home care setting***, with the remaining amount provided by licensed professionals—registered nurses, therapists, and social workers" (Rodat 2012a). More than half of the state's home health care workers are employed in New York City (61 percent) (New York State Department of Labor, Occupational Employment and Wages, available at: http://labor.ny.gov/stats/lsWage2.asp.; Rodat 2012a). Furthermore, between 2008-2018, 59,560 new home health care positions are expected to need filled in New York City, most likely employing a "ready supply of immigrant women in need of entry-level employment" (PHI 2012a).

It is important to note that official estimates of home care workers underestimate the critical role played by gray market home care workers in the care economy. While workers employed in the gray market have been widely acknowledged as significant, data does not exist to estimate the size of this workforce (PHI 2003). The Paraprofessional Health Institute estimates that nationally "hundreds of thousands of additional aides are thought to work directly for individuals and their families under private arrangements. This segment is often referred to as the 'gray market,' an acknowledgement of the unknown scale of these arrangements" (Seavey 2011). A recent *New York Times* article reports "the exploding need for long-term care is remaking the

home-care industry, driving more of it underground. Gray market hiring…is a solution that middle-class families are turning to as they face the crushing burden of indefinite home-care expenses" (Gross 2007).

Second, the focus on paid care work inside the home is important because although the home has typically been thought of as the private sphere, it is increasingly becoming a worksite and a place of paid employment for care workers (Hochschild 2003). Yet employment relationships are often nebulous and difficult to regulate in the home. While coverage under labor and employment law does not necessarily result in good treatment of workers in the low-wage labor market (Bernhardt et al 2009), the exclusion of many home-based care workers from these laws does take a toll. Many home health care workers are excluded from existing federal labor and employment laws and New York state laws do not fully compensate. And, despite this coverage, enforcement is difficult, especially when you consider gray market workers who are employed directly by private households. State labor departments are already overstretched and successful enforcement of these laws often depends on workers being willing and able to make complaints about their workplace (which is more possible for union members working in the formal home health care industry).

Third, home health care workers, despite the important work they do caring for the elderly and sick, face particularly low wages and poor working conditions. While many scholars have documented the wage penalties associated with care work (Abel 2000, Budig, Misra 2008, Cancien, Oliker 2000, England, Budig, Folbre 2002, Folbre 2001), it has been found that home-based care workers face an additional "in-home" wage penalty (home health care workers earn between $1 and $2 less than nursing home attendants) (Dresser 2008). Understanding the institutional and structural reasons for this devaluation has been under-theorized.

Fourth, both the formal and informal segments of the home health care industry are structured by government policies, regulations, and funding. While other low-wage industries are surely influenced by government, the size, structure, and scope of the entire home health care industry was established by government policies and funding—namely Medicaid and Medicare. This case study of the home health care industry gives us insight into the varied roles government plays in structuring the bottom of the labor market.

The Shifting Landscape of Care: The Role of Government in Social Reproduction[9]

Home-based care work blurs the boundaries between paid productive work performed at a worksite and unpaid reproductive work typically occurring in the home (Picchio 1992). Social reproduction includes both daily and longer-term reproduction of the labor force, through the provision of basic human needs such as housing, food, health care and childcare. A combination of the state, capital, civil society and the private household has historically provided these services, which are constantly in flux (Katz 2001). Under Fordism, working class struggles won increased internalization of social costs by corporations (including wage increases, health insurance plans, pensions, etc.) or the state (through welfare and other social assistance programs). While the United States never fully recognized care as a public good, it did take some responsibility for caring for society's most vulnerable populations. But since the mid-1970s as a result of increasingly globalized capital and the increased privatization of public goods, this constellation of forces continues to shift with the burden of care increasingly put on individual families and civil society (Beneria 2001; Martin 2010). Neoliberal capitalism "has been marked

[9] Cindy Katz defines social reproduction in the following way: "Social reproduction encompasses daily and long term reproduction, both of the means of production and the labor power to make them work. At its most basic, it hinges upon the biological reproduction of the labor force, both generationally and on a daily basis, through the acquisition and distribution of the means of existence, including food, shelter, clothing, and health care" (Katz 2001: 711).

by a struggle by capital to shed itself of such burdens, leaving it to populations to find their own ways to procure and pay for these services" (Harvey 2011). This shedding process is occurring at the same time as the growth of the low-wage service economy, compounding the struggle of many families to meet their basic needs.

The state shapes the landscape of care in several contradictory ways. First, the federal government has established social insurance and benefits that pays (in part) for the care of the frail elderly and the disabled. Medicaid and Medicare were established as part of the Social Security Act of 1965. Medicaid provides low-income people with medical and health-related services and Medicare provides health insurance to Americans age 65 and over as well as younger people with disabilities. These social insurance programs and benefits were intended to support the elderly and low-income families but also established much of the labor market for home health care workers. At the same time, federal and state governments have adopted labor legislation over the years (albeit patchy)—established to protect the rights of workers. The state's role in providing these social benefits to individuals at a low-cost often contradicts their need to enforce or expand existing labor protections. What began as provisions to support the elderly and low-income people has resulted in a labor system that employs increasing numbers of low-wage workers, who ironically earn so little they are often eligible for state-funded assistance.

Central to understanding the landscape of care in New York City is looking at the established mode of service provision. While cuts in Medicaid and Medicare further externalizes the costs of social reproduction, the gray market of home health care represents a huge arena of untapped potential capital accumulation. Lester Salamon outlines the ways in which the federal government makes use of the private sector and state and local level governments because of the push towards privatization and decentralization. Government uses many tools in its governing;

grant-in aid programs and voucher payments such as Medicare are two examples relevant here. Each of these distinctive government "instruments" has its own distinctive procedures, its own network of organizational relationships and its own "political economy" (Salamon 2002). Many federal programs operate through intermediaries—state and local governments, counties, banks, hospitals, for-profits and non-profits—creating, what Salamon calls, a system of third party government. These tools put the Federal government "in the position of operating by remote control, relying on other entities to deliver the services that government has authorized" (Salamon 2002). While the federal and state governments set many of the priorities, other organizations and agencies actually deliver the services and conduct the day-to-day administration. In order to understand the ways in which home health care work is structured and the ways in which this impacts workers wages and working conditions, we must have a map of how government's priorities get shaped, how services are delivered and how funds are channeled. By looking at the organization of the home health care industry in New York City, we begin to see the multiple and varied ways that government, at all levels, facilitates this externalization and privatization of care.

The role of the state in New York City's home health care industry

Home health care as a social welfare service developed as part of the New Deal legislation to place unemployed African American domestic workers with low-income families whose mothers were incapacitated in some way. Originally, domestic workers were directly employed by welfare departments and were considered public employees. Post-World War II, the need for home health care grew. As a result of social struggles in the 1960s, legislation expanded the labor market for home health care. The 1962 Public Welfare Amendments, the Older Americans Act and Medicare/Medicaid were the public policies that "established a

foundation for a social services labor market within the welfare state" (Boris and Klein 2006). During the 1970s and 80s as the federal government began cutting back on social welfare funding, "states and localities coped through cost-shifting, privatization of services, and 'flexible' labor policies," (Boris and Klein 2006) which distanced them from their responsibilities as the employer of record.

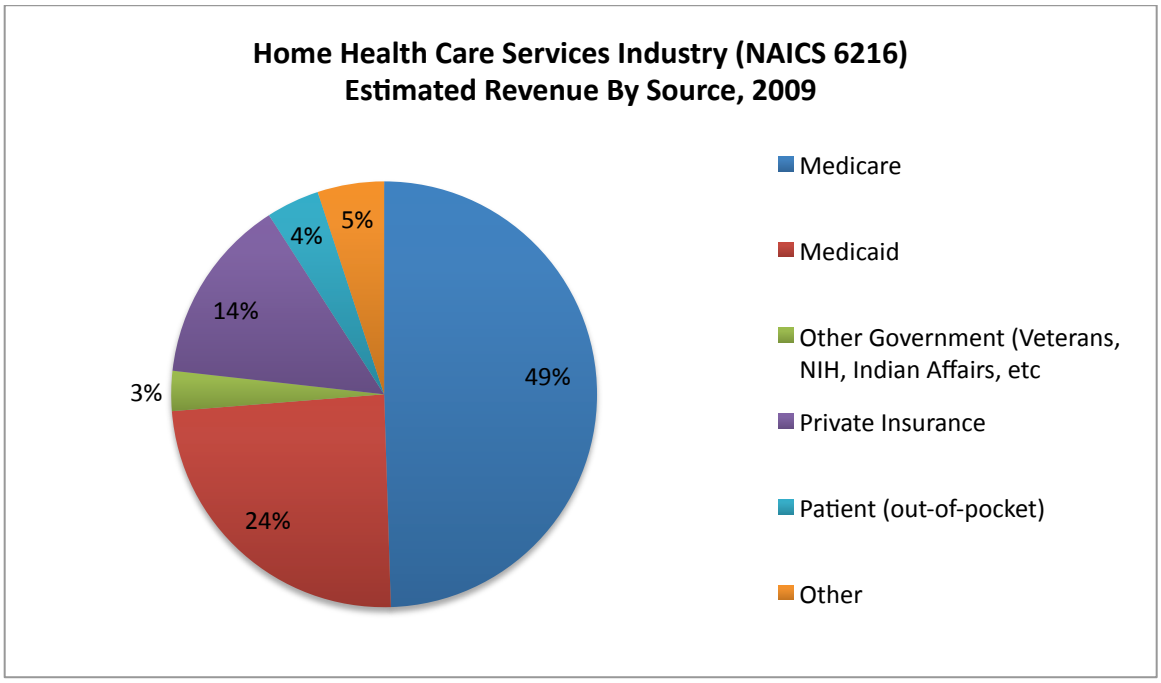
In the late 1970s, Assemblyman Andrew Stein convened hearings on the conditions of New York nursing homes. The state had two options—to push nursing homes to improve or to shift money into home care. The state decided to deinstitutionalize and fund home health care. Originally Medicaid spending in New York City was paid for by 50% federal funds, 25% state funds and 25% local funds. Over time these percentages changed to be 50% federal, 40% state and 10% local (Industry Expert Informational Mtg 1). While many states do not require local contributions, New York is one of a few states that does. This local requirement is greater than any other state. Counties in New York and New York City are required to pay a percentage of the services used within their borders—this was established because many upstate counties did not want to pay for the services being delivered in New York City which accounted for nearly 2/3 of all Medicaid costs in the state (Citizens Budget Commission 2011).

Home health care delivery in New York City has become heavily privatized with contracted and subcontracted private agencies negotiating the relationship between the state, the care receiver and the caregiver. These agencies, many of which are for-profit entities, make their profit from money coming from the public. While agencies are increasingly taking private-pay clients, most of the money that flows into agencies (paying for elder care in the city) is largely from Medicaid dollars. Public funding for care passes through many hands before actually arriving in the hands of the worker (Industry Expert Informational Mtg 1). While for-profit and

non-profit intermediaries, who play a large role in the service delivery of home care, can (and do) make regulation of these jobs easier, they also extract profits from the process of care and have a stake in keeping wages low—New York City agencies take as much as fifty percent of the public funding they receive for administrative and overhead expenses (Bernhardt et al 2007).

The home health care industry is very fragmented despite recent shifts towards consolidation—the 50 largest companies generate less than 25 percent of the revenue nationally. In 1980, only 7 percent of Medicare-certified home care agencies were for-profit, but as of 2007, that number increased to 70 percent. Total revenues for the key home care industries nationally totaled over $84 billion in 2009 (Seavey 2011). As Dorie Seavey of PHI reports: "the Census Bureau estimates that, in 2009 public reimbursement (Medicare, Medicaid, and other government spending) accounted for three-quarters of the revenue received by employers in the Home Health Care Services industry. Private insurance and private out-of-pocket revenue contributed just under a fifth of the total (18 percent)" Seavey 2011) (these numbers represent the funding for the formal sector of home health care and does not include the gray market). Nationally this breaks down as follows: 49% Medicare, 24% Medicaid, 3% Other Government (Veterans, NIH, Indian Affairs, etc.), 14% private insurance, 4% Patient (out-of-pocket), 5% Other (see Chart 1.1 below). These numbers reflect the funding sources for much of the formal home health care industry nationally.

Chart 1.2: Home Health Care Services Industry Estimated Revenue By Source, 2009



Source: US Census Bureau, Service Annual Survey Data, Table 8.9. Available at: http://www.census.gov/services/sas_data.html (Chart From Seavey 2011, p. 23)

Home health care workers in New York City include home health aides and personal care aides (or in New York City they are often referred to as home attendants). Home health aides are workers who work at licensed home care service agencies (LHCSA's) and are paid for mostly with Medicare and Medicaid dollars. These workers are certified to give some medical care in the home and often give care to people who are at the end of an acute care situation. Because of federal regulations, the workers employed in licensed agencies must be authorized to work in the US (thus there are few undocumented immigrants working in these agencies). Home health aides typically start at $8 or $8.50 dollars an hour.

Personal care aides are also employed by LHCSAs but these LHCSAs contract directly with the city and are paid for mostly with Medicaid dollars. Personal care aides tend to care for the elderly who need chronic care. Despite the fact that these workers do not have the same medical training as home health aides, they tend to earn more money per hour since they are

covered by the New York City Living Wage Law, which requires a minimum wage of $10/hour (a consequence of early unionization) (Industry expert informational Mtg 1).

Home health aides are not covered by the city's living wage ordinances because New York City does not contract with home health aide services (only personal care) (PHI 2010). However, due to recent shifts in the industry from the 2011 budget cycle, home health aides have won parity with personal care aides (this will be implemented over the course of several years). I explore these shifts more in Chapter 5.

Forty-five percent of direct care workers (including home health aides and personal care aides) nationally live below 200 percent of the federal poverty level, making them eligible for many state public assistance programs. One recent study found that 46 percent of direct care workers nationally (including home health aides and personal care aides) live in households that use some type of public benefit (Medicaid, food stamps or housing, child care or energy assistance) (PHI 2011).

Regulation of the Workplace

Grants-in-aid and voucher programs deliver financial benefits, while regulatory programs function by imposing restrictions. As Eugene Bardach argues, while regulation may seem like "a cut-and-dried affair consisting of the specification of rules and the enforcement of adherence to them," there is rarely clear consensus about desired outcomes for a regulation or the funds provided to enforce them (Bardach 1989). There are two types of regulation discussed in this dissertation: the regulation of the home health care industry as a whole in New York City and the regulation of the employment relationships within the industry. The home health care industry in New York City is highly regulated—meaning the organizations and companies who run the

agencies have a strong regulatory environment in which they operate (agencies must be certified or licensed in order to operate). This regulation will be discussed further in Chapter 2.

Below I explore the regulations that have to do with the employee/employer relationship and that impact home health care workers directly. The standard employer-employee relationship common during the Fordist era became the structure that labor and employment law was organized around. Workplace regulation—minimum wage, overtime, right to a meal break, the right to organize, to name a few—came out of social struggles for better working conditions during the Fordist era. Home health care workers were excluded from these basic federal labor laws. This exclusion from the New Deal, originally of domestic workers and agricultural workers, was due to the power Southern Democrats held over Roosevelt—they were willing to go along with FDR's New Deal as long as it did not disrupt the Jim Crow culture in the South (Katznelson 2013). This was institutionalized through the exclusion of many home-based care workers from basic labor protections. Domestic workers were excluded from the Fair Labor Standards Act (FLSA) until 1973. In 1973, this exclusion was overturned for domestic workers (although live-in domestic workers are still ineligible for overtime under FLSA), but babysitters and "companionship" workers continued to be excluded. Today, home health care workers (considered legally to be companionship workers) are still excluded from the FLSA. This leaves many home care aides, whether employed by a private household, by state government or through an agency, without a legal right to minimum wage or overtime pay. The Supreme Court in *Long Island Care at Home v. Evelyn Coke* upheld this legal exclusion in 2007. The federal legal protections of home-based care workers are weak, but "the effective protection of these workers is even weaker." Legal protection is not helpful for workers working under the table, since current enforcement strategies rely on workers to make complaints about their working

conditions and very few actually do (Dresser 2008).

New York State has taken steps to cover some home-based care workers who are excluded from FLSA. Home health care workers (legally considered "companionship workers") are covered by NY state minimum wage but have lesser overtime coverage than the federal standard. New York State covers home health care workers for overtime, but overtime pay is one and a half times the minimum wage instead of one and a half times the worker's hourly wage, resulting in less compensation for workers working overtime in NY. Live-in companionship workers are not entitled to any overtime through FLSA or state law.

Agency-employed home care workers possess rights to organize under the NLRA. Agency-employed home care workers in New York City are heavily unionized by SEIU 1199 (and a small percentage are represented by AFSCME DC 1707 and SEIU 32BJ). Personal care aides are largely unionized, but home health aides are less so (and the proportion of home health aides who are unionized has shrunken in recent years due to the growth of certain for-profit CHHAs in Brooklyn—this trend is explained further in Chapter 5).

Gray market home health care workers who are employed by private households are excluded from collective bargaining rights. However, Domestic Workers United, a workers organization based in New York City, is exploring, with the New York Department of Labor, possibilities for expanding collective bargaining rights for domestic workers in New York State (Domestic Workers United 2010).

Government regulations and programs establish administrative procedures, relationships and political economies, all of which vary across place. Therefore, labor markets develop and function alongside locally specific social and political institutions. Brenner and Theodore urge scholars to study the embeddedness of neoliberal restructuring projects "insofar as they have

been produced within national, regional and local contexts defined by the legacies of inherited institutional frameworks, policy regimes, regulatory practices and political struggles" (Brenner and Theodore 2002; also see Peck 1996). Other scholars note that place matters and variations in the characteristics of cities can have important consequences for workers and the markets that shape their opportunities (Dreier et al 2005). This is definitely true for home health care workers in New York City, where "inherited institutional frameworks" have shaped the regulatory and service delivery environment for care, which includes subcontracting relationships which result in a large percentage of the Medicaid rate for care used on administrative costs, rather than on labor costs.

The quality of jobs is tied up with the state budget

Because many care workers are paid with public dollars, the quality of these jobs is closely tied to the financial stability of the states and cities in which these workers are employed. In a federal lawsuit by home care worker Evelyn Coke who lived in Jamaica Queens, the Supreme Court in 2007 upheld a 1975 regulation that excludes home care workers from the Fair Labor Standards Act. Mayor Michael Bloomberg argued that including home care workers in the FLSA would bankrupt the City—raising costs from $279 million to $1.87 billion (Jones 2007). One of the often-cited arguments against inclusion of home care workers in FLSA is the high cost—many argue that by increasing coverage, cities and states will be forced to provide services to fewer people who need it.

Nationally, Medicaid spending is a hot topic and a terrain that will surely be fought over in the coming years. The GOP version of the 2012 budget, released in April 2011, has been noted to include plans to decrease Medicaid funding by $1 trillion over the next ten years—a move that

could result in lower wages for home care workers and/or individual households swallowing more of the costs of care (McKnight's 2011). Medicaid funding will surely continue to be a program that is politically fought over on the federal level.

But, while the federal government is not required to balance its budget, the states are, intertwining the fate of workers with the balancing of the budget. This potentially leaves both workers and patients at risk if statewide cuts decrease services and hours for patients. In New York in 2011, however, SEIU 1199 United Healthcare Workers East, "arguably Albany's most powerful special interest," (Hakim 2010) had enormous success in increasing home health aides' wages (to be on par with the "living wage" that personal care workers get), during a time when the state was committed to reducing Medicaid spending (which totaled a savings of $2.2 billion in fiscal year 2011-2012). While these changes will raise the wages of home health aides to $10/hour plus benefits by 2014, the restructuring of the industry has other impacts on patients and workers. In Chapter 5 I explore how SEIU and their partners were able to have such a significant political impact and what the implications are for such changes on the industry as a whole as well as for workers and patients in New York City.

The scholarship outlined above begins to outline the contradictory roles the state plays in shaping the home health care industry. While Medicaid and Medicare were established to provide much-needed access to health care for the poor, disabled and elderly, the state has begun to roll back these programs. In the 1970s and 80s, New York City began to privatize service delivery for home care, which is increasingly becoming dominated by for-profit (and more recently, managed care) companies. Although many of these care workers are providing services to people who receive Medicaid or Medicare, they are not recognized or considered to be public

employees (Boris and Klein 2008). New York State, with a very progressive Department of Labor and pressure from unions, advocacy and social movement groups, has begun to fill in some of the labor law gaps that exist for home health care and domestic workers but gaps still remain.

The complicated funding streams, policies and regulations and the institutional landscape that shapes the industry impact the working conditions of home health care workers in New York City. As processes of privatization and externalization of care (characterized by cuts to Medicaid and Medicare) increase within home care especially, understanding the effects this has on workers is especially important. Through the examination of the home health care industry which is closely linked to the welfare state, this dissertation explores the varied ways the state and its' "third party government" interact with and shape the low-wage economy. But looking at how public policies shape the more formalized segments of these industries is not enough—it is important to also examine the ways these policies and funding shape the dynamics of the informal segments of care.

Shifts in the Political Economy of Work and Paid Informal Care Work

Scholars across disciplines have documented how economic restructuring has reorganized work, including the growth of the low-wage service economy (Appelbaum et al 2003), the rise of informal, precarious, unregulated and nonstandard employment (Bernhardt et al 2008; Losby 2002; Kalleberg 2000; Portes & Sassen-Koob 1987; Portes, et al. 1989; Sassen-Koob 1989; Rubin 1995) and the substantial growth of income inequality within the US (Hamnett 2003; Beneria 2000). Families are outsourcing care usually because of their own labor force participation—the result is a care economy that is closely tied to the labor market as a

whole. Oftentimes decisions about what type of care an elderly relative receives depends on what is available through the state and/or what the family can afford.

Growing Inequality, the Low-Wage Economy and The High Cost of Care

Scholars have documented the growth of income inequality, especially in large global cities like New York (Sassen 2001). In recent decades, global cities have witnessed a major increase in earnings and income inequality, resulting in a socio-economic polarization. In New York City this disparity was documented as recently as between 2010 and 2011. As census data has shown, in New York City the "[m]edian income for the lowest fifth was $8,844, down $463 from 2010. For the highest, it was $223,285, up $1,919. In Manhattan, the disparity was even starker. The lowest fifth made $9,681, while the highest took home $391,022. The wealthiest fifth of Manhattanites made more than 40 times what the lowest fifth reported, a widening gap (it was 38 times, the year before) surpassed by only a few developing countries, including Namibia and Sierra Leone" (Roberts 2012).

Ruth Milkman documented the link between the proliferation of paid domestic workers who work for higher income households and high levels of income inequality (Milkman et al 1998). A growing set of high-income households demand services provided by a growing class of low-wage workers. Working long hours for low pay, these low-wage workers need cheap goods and services (like childcare or home health care) to support themselves, thus creating an entire sub-economy to serve them. Sassen linked the growth of low wage populations to the demand for cheap goods and services that businesses with poor labor standards (violating labor and employment laws) can afford to produce (Sassen 1994). Low-wage jobs create the need for more low-wage care jobs (Bernhardt, McGrath, and DeFilippis 2008), especially as public

support for care falls short of meeting people's needs.

Care work, specifically labor performed for pay inside the home, is intimately connected with the state of the labor market as a whole. As the population becomes increasingly economically insecure, the pay and security of care workers employed directly by private households also falters. Thirty-one percent of workers in the five boroughs over the age of 18 are employed in low-wage jobs, and that percentage is especially high in the Bronx (42 percent) (Bowles et al 2009). The minimal job growth in 2010 has been within low-wage industries, i.e. those with median wages of less than $15 an hour (NELP 2010). This trend is continuing—of the top ten occupations that have the largest job openings through 2014, only two of them pay a median of more than $28,000 per year (Bowles et al 2009). New York City is becoming too expensive for many families. The Center for Urban Future has documented the high numbers of middle class families who are fleeing the city for more affordable places to live—in fact New York City had a higher net domestic out-migration (-18.7) per 1,000 residents than upstate NY communities that are more commonly thought of as sites of out-migration—like Ithaca (-8.0), Buffalo/Niagra Falls (-7.6), Rochester (-5.8), and Syracuse (-5.1) (it is also important to note, however, that New York City does have a higher in-migration of immigrants than the above-mentioned cities). The key constituencies moving out of the city are individuals with bachelor degrees, families, immigrants, municipal workers and the black middle class in Eastern Queens (Bowles et al 2009).

As low-wage jobs continue to rise, New York families have found themselves in a crisis for care. While public money does exist to pay for home health care, it is inadequate to meet the demands of an increasingly ageing population and continues to be on the state chopping block with ongoing austerity measures. Medicaid was not intended or designed to be a system of long-

term care (Worker Advocate/Policy Organization Interview 5) and many frail elderly who receive funding for care through Medicaid (and Medicare) often do not qualify for the number of hours of care necessary to meet their needs. The result is that often private households who have an agency worker part-time or for a short-term stay, employ workers to stay longer hours, work more shifts (despite being against agency rules) or in the case of Medicare, stay beyond the standard 60 days after an acute incident. Clients or families will pay these workers out-of-pocket what they can for this extra time. Other elderly people (including undocumented immigrants) do not qualify for Medicaid or are unable to complete the Medicaid application process and do not get state support for needed care—these individuals who are unable to get family care either go without or seek home care workers on the gray market, paying out of pocket. In this case, the inadequate funding for home health care structures the size and scope of the gray market.

Home health care workers tend to be an invisible workforce because the work is performed in patient's home. Unlike childcare workers and nannies that can be seen on the streets and in the city's playgrounds, home health care workers tend to be even more isolated in their job as they work one on one with a patient in the privacy of their home. This isolation makes it even more difficult to get a sense of how big the home health care workforce is, especially the gray market who are not tied to any specific institution.

Unfortunately, home health care for elderly or disabled workers is prohibitively expensive for those who do not get state support for care and who do not have private insurance that will cover home care costs. Hiring a home care worker through an agency for custodial care can cost a family as much as $150,000 per year. Gray market hiring is usually a financial decision that families make to avoid the fees of home care agencies (Gross 2007). Home health care agencies are not allowed to charge the state less per hour of care than they do to individual

families. The result is that families must pay $17-$20/hour typically, even though most of the time the workers are getting only $8-$10/hour. If a family hires a care worker directly, they can pay her $12-$15/hour and both the family is paying less and the worker is getting more of an hourly rate (although typically then, these workers have no access to benefits, job security or protection, union representation, etc.).

The Informal Care Economy

Originally conceptualized as a third world phenomenon, the informal economy has inspired new research and debate within more advanced economies (Portes & Sassen-Koob 1987; Sassen-Koob 1989; Portes, Castells, Benton 1991; Stepick 2008), particularly in urban centers (Stack 1974; Lowenthol 1975). The term itself, first coined by Keith Hart in 1973, can be difficult to identify, partially because it is defined in relation to or as an inversion of the formal economy, which is constantly in flux and varies from place to place depending on the regulatory framework (Hart 1973; Ferman, Henry & Hoyman 1987). Most scholars now agree that the informal economy is inextricably linked to the formal economy and includes the production of legal goods or services that are produced or exchanged in a way that is not officially recorded or regulated (Losby 2002).

Some care scholars have begun to use the informal frame to understand the dynamics of the care economy. Mary Tuominen applies informal-sector theory to shifts in the childcare industry in recent decades, arguing that this framework reveals the extent to which the formal-market system depends on informal labor. She identifies women, and disproportionately women of color, as the primary reserve army of labor that provides childcare to working families (Tuominen 1994). Saskia Sassen has focused on the role of immigrant women in the informal care economy—she links the rising dependency of advanced industrialized countries on low-paid

care workers from the South, to the growth of informalization and increasing numbers of self-employed care workers (Sassen 2002). Anderson and Hughes explore the ways care work is shaped by the employment status of workers, looking particularly at the self-employed (Anderson and Hughes 2010).

While extensive scholarship on the informal economy exists in developing and developed countries, there is still a good amount of conceptual muddiness. Much of this exists because the unit of analysis is not always clear – is informality determined at the enterprise or at the job level? One definition of the informal economy as enterprise-based (Thomas 2001) does not capture a growing set of informal/unregulated activity occurring within formal enterprises—for example a company can be fully registered with the state but may hire workers informally and under the table or may not abide by employment and labor regulations for their employees (Hussman 2008). In 2002, the International Labour Organization (ILO) expanded the definition of the informal economy to include "all economic activities by workers and economic units that are—in law or in practice—not covered or insufficiently covered by formal arrangements" (ILO 2002; Alderslade 2006; Chen 2004). It is important to note that this expanded definition broadens the focus of the informal economy to include two dimensions: 1) *informal enterprises:* how production is organized at the establishment or enterprise level and whether it is in compliance with state regulation and 2) *informal jobs:* at the jobs level, whether jobs are in compliance with state regulations (regardless of whether the enterprise is regulated or not).

There are also two other dimensions of the informal economy that often get conflated. If the definition of the informal economy is the production of legal goods and services that are unregulated by institutions of society, this would include *both* work in which income and wages go unreported to the government for taxation *and* work in which compliance to labor laws are

violated. These two types of informality can occur in either formal or informal enterprises. Using analysis from the *2008 Unregulated Work Survey*, Bernhardt et al show that, while labor law violations occur more often in informal enterprises, these violations also occur within formal enterprises (Bernhardt et al 2011). For clarity, I will use the term *unregulated work* for the violation of labor and employment laws, which can occur in jobs where the employer is a formalized enterprise or a private household. Unregulated work is defined as "jobs in which working conditions fail to meet one or more of the standards mandated by the employment and labor laws of the United States"[10] (Bernhardt et al 2008).

For many industries in the low-wage economy, formal and informal enterprises exist side by side—that is, some companies are fully registered and accounted for officially, while other companies exist completely under the radar (and some companies exist somewhere in between). While informal/unregulated home health care agencies surely do exist in the US, "they don't really exist in New York City" (Worker Advocate/Policy Organization Interview 1: 11) due to the high level of regulations in the system (all agencies that deal with Medicaid or Medicare must be certified or licensed to provide care). There have been some instances of formal enterprises (agencies registered with the state) hiring workers with false/fraudulent training papers (these workers are not completely under the radar but are falsely qualified and by state-regulation standards should not be allowed to work at these agencies). But the bulk of informality within home health care takes place in circumstances where the employer-of-record is the private household—families employ individuals outside any regulated institution and pay them with money out of their own pockets, money that is usually officially unaccounted for. This means that families/individuals using gray market care or paying out of pocket because they are ineligible for publicly funded home care (which is often the middle class), are often diminishing

[10] This definition is similar to the definition by Avigan, Bivens and Gammage 2005 (include definition here)

their resources in order to have quality care in the last years of their lives. With the baby boomer generation aging and wanting to age in place, this will have impact the financial stability of this generation as they age. Also, jobs performed in the private sphere are difficult to regulate, especially when the private household is the employer. Because universal access to home health care services are not part of our social welfare state and private pay agency hiring is so expensive, many families see hiring in the unregulated, gray market as their only option. While this type of informal care can be a great arrangement for both families and caregivers, there are dangers that come with a lack of regulations (workers not being trained to deal with sick patients, families being unwilling or unable to offer benefits, job security or consistent, legally-required payment). Because informality is so closely linked to private households, linking care work with the broader socioeconomic changes occurring in the city is essential to understanding the working conditions of informal care workers.

Of particular importance here, the boundaries between informal and formal jobs are constantly in flux and change with any shift in government regulation (Portes et al 1989). Informalization thrives "on governmental deregulation of workplace standards, labor laws, and social safety nets" (DeFilippis et al 2009). Thus, we can expect to see a rise in the use of informal, gray market care as home health care hours and coverage are cut through cuts in Medicaid and Medicare. While there is a lot of debate about rising Medicaid and Medicare costs (and a push to decrease these costs), much of the increase in these programs is due to growing enrollment (Holahan and McMorrow 2012). NY state in recent budget decisions did not change eligibility for Medicaid but, by restructuring the industry it effectively cut the number of hours of care that people were eligible for.

Despite the muddiness of the informal economy concept, the frame is useful insofar as it

highlights the links between the formal and the informal economy within a particular industry. This is especially important for care work, parts of which are publicly subsidized. Unions play an important role in trying to improve/maintain working conditions for publicly paid workers, but as state funding fluctuates, the number of workers operating within the formal/informal economy fluctuates as well. Unionization can increase wages and working conditions for more formalized workers, but because wages are tied up with public funding—higher wages with limited state funds can result in more care work performed informally. As public funding for care decreases, the frail and elderly may go without needed care and the informal economy will likely expand.

Because of the conceptual muddiness of the term "informal" (and the fact that this term in home health care often refers to unpaid family-based care, I will refer to it instead as the "gray market," a term many people in the industry use to describe private household employers hiring home health care workers directly. Understanding the dynamics of the home health care industry—in terms of the size and shape of the informal sector, the extent of regulation, the level of public funding for care, and the extent to which these jobs are covered by employment and labor laws—and linking this to the working conditions of care workers employed in different arrangements will give us insight into the driving factors influencing the quality of home health care jobs. In this dissertation I will build on existing scholarship to provide a theoretical and conceptual map of this complicated industry, and will use new data to analyze the quality of these jobs.

Methodology

This dissertation builds on my previous work on the *2008 Unregulated Work Survey* with a team of scholars from the National Employment Law Project, the Center for Urban Economic

Development at UIC, the UCLA Institute on Labor and Employment, and Cornell University. The Ford Foundation, the John Randolph Haynes and Dora Haynes Foundation, the Joyce Foundation and the Russell Sage Foundation funded this project. This workers survey collected data from 4,300 low-wage workers in New York City, Chicago, and Los Angeles and measured the prevalence of workplace violations across the low-wage labor market. Initial analysis of the results of this survey showed that home-based care workers (both home health care workers and childcare workers) experienced especially high rates of workplace violations and that the rate of these violations was particularly high when workers were hired and employed directly by private households. Thinking about these findings in the context of the home health care industry sparked important questions, which have fueled my dissertation research. Home health care and childcare are both industries that are, at least in part, funded by federal, state and city money. And because care has never been secured as a right in this country, government relies on individual households to foot the bill when children or the elderly don't qualify for care. The formal segment of these industries is both created by and limited by public policy and non-universal public funding for care. While my original goal was to compare the home health care and childcare industries in New York City, complexity of the structure and funding of the home health care industry in New York City was sufficient to justify narrowing the scope of my project just to the home health care industry.

My research mostly pulls from twenty-two in-depth qualitative interviews conducted between January 2011 and September 2011 with home health care industry experts, advocacy organizations, employers, intermediaries, government agencies, industry associations, unions and individuals trying to navigate the home health care system for their loved ones. My research also used secondary research to better understand the structure of the home health care industry and

the recent budget changes that are significantly changing the structure of the industry. Data from the 2008 Unregulated Work Survey were analyzed to understand the working conditions, wages and workplace violation rates of home health care workers—those employed by agencies and those employed by private households. This analysis was limited because of the small sample size of home health care workers in New York City (we interviewed 153 home health care workers in New York City—133 employed by agencies and 20 employed by private households). An examination of the industry across the three cities (New York City, Chicago and LA) would have given me a larger sample size to work with, but the range of variation within New York alone was sufficiently large and complex to narrow the analysis to New York City.

Methodology for the 2008 Unregulated Work Survey

Our survey team created a questionnaire that allowed us to assess whether employment and labor laws were being broken without relying on workers' knowledge of those laws. We used an innovative sampling methodology called Respondent-Driven Sampling (RDS) to conduct our study (Heckathorn 1997; Heckathorn 2002; Heckathorn 2007). RDS is a type of snowball sampling that produces statistically representative data from hard-to-reach populations. This methodology is based on long-chain recruitment—members of the target group who are originally interviewed recruit and refer other members of the target group. By keeping track of the social networks of the workers surveyed and who they recruited, RDS uses a mathematical model to "adjust the sample estimates to reflect respondents' differing likelihood of being captured by the survey technique" (Bernhardt et al 2011).

This is the first labor market survey to employ this method, which historically has been used by the Center for Disease Control to study public health issues like the spread of HIV. This

method has been successful in reaching populations that are otherwise difficult to survey—for example a survey of gay men in Uganda was successful in a place where homosexuality is illegal and heavily looked down upon, and the gay population exists largely underground (Kajubi et al 2007). The 2008 Unregulated Work Survey yielded a representative dataset of the low-wage labor market in New York City, Chicago and Los Angeles that not only measures violations of labor and employment laws (like minimum wage, overtime, retaliation against workers, off-the clock work) but also includes detailed information on workers' demographics, current job, hours worked, pay received, complaints made, etc. Post-sampling weights were applied to the data.[11]

While many low-wage workers, especially undocumented immigrants, fear participating in surveys about their workplace, Respondent Driven Sampling relies on recruitment by trusted friends, family members and colleagues. The high level of undocumented immigrants who participated in the survey—39 percent across the three cities—is evidence that our sampling was successful in including hard-to-reach populations. While some data on the wages and working conditions of care workers in these cities do exist, these data are not representative and

[11] From Bernhardt, Polson and DeFilippis 2010: "One feature of the RDS methodology is the ability to conduct detailed tracking of recruitment patterns throughout the entire sampling period, in order to identify and adjust for deviations from pure random recruitment from respondents' social networks. For example, recruitment might be driven by strong social identities, such as race, ethnicity or age, so respondents recruit disproportionately within their own group. The RDS methodology anticipates that personal networks are not randomly distributed, and therefore adjusts for small to moderate levels of network clustering (people having ties to others like them), in the form of post-sampling weights. For example, if the sample contained more members of a given group than would be expected under purely random sampling, then cases in that group are given less weight in analyses of the data. However, if network clustering becomes pronounced on one or more dimensions, then it is necessary to use additional, external sources of data in order to weight the final sample to be representative of the intended population. In our study, we identified high levels of non-random recruitment among several racial/ethnic groups, as well as between U.S.-born and foreign-born workers. (We did not find high levels of non-random recruitment on other dimensions, such as the workers' industry and occupation, employer or, most importantly, the experience of workplace violations). That meant that RDS generated representative samples within the various race/ethnic/nativity groups, but not across the sampling universe as a whole—in effect, our study generated multiple sub-samples…To address this problem, we generated RDS violation rate estimates within each of the sub-samples (which are representative), and then recombined them using a weighting system based on estimates of the relative sizes of the race/ethnic/nativity groups in order to generate an overall estimate. Specifically, we adjusted New York City's sample to match the racial/ethnic and nativity distribution of the 2007 American Community Survey (ACS), with one modification. Since standard government surveys tend to undersample unauthorized immigrants, we developed an adjustment to the ACS race/ ethnicity/nativity distribution drawing on estimates of the number of unauthorized workers in New York City in 2005."

undercount key populations such as undocumented immigrants, those coming off of welfare, and those employed in the informal sectors of the economy, all of whom make up a large part of these care industries. Of the over 1,432 low-wage workers surveyed in New York City, 10.7 percent (N=153) were home-based care workers. This data provides, for the first time, accurate estimates of workplace violations, wages and working conditions for home health care workers. My involvement from 2007-2010 in the design of the survey instrument, management of the field process in New York City (including hiring and supervising 20 interviewers and translators), and cleaning and analysis of the data well position me to further analyze and interpret the data, which have resulted in several co-authored reports and articles on our findings (see Bernhardt et al 2009; Bernhardt et al 2010; Polson, DeFillipis and Bernhardt 2011; Bernhardt, Spiller and Polson 2012). One such report, *Broken Laws, Unprotected Workers*, brought national attention to the problem of wage theft, appearing in editorials in both the *New York Times* and *Washington Post*.

Chapter Breakdown

Chapter 2 explores the history and structure of the formalized home health care industry in New York City. It provides an in-depth analysis of how the industry is structured in New York, who finances the care and who the main institutional players are. The home health care industry, in New York City in particular, is indeed very complicated and fragmented with numerous funding streams, programs and organizations that make the system run. The programs vary tremendously in terms of: who has financial and regulatory oversight over the programs; whether funding comes through Medicaid, Medicare or both; what aspects of care the certified agencies manage; and how different programs manage their relationships with the LHCSAs who

actually employ the aides. I also explore the subcontracting relationship (between certified agencies that manage nursing services and subcontract out aide services to Licensed Home Care Service Agencies)—this was established in New York City partially to avoid unionization efforts and is not typical of other states who generally have one agency who manages all aspects of care for a patient.

Chapter 3 aims to understand the gray market sector of the home health care industry. While there is very little data on this portion of the industry because of its underground nature, qualitative interviews conducted with industry experts in New York City and families who used the gray market enable me to explore this more informal segment of the home health care industry. My respondents were asked when, why and how their families utilized the gray market and about the process of applying for Medicaid. Families rely heavily on the gray market—this segment of the labor market is critical to meeting families' needs, especially given the fact that state-funded care is not easily available for everyone who needs it. While the formal part of the home health care industry is tightly regulated and has many levels of oversight, the gray market exists completely outside any regulatory or government structure and is almost completely unregulated. The formal part of the industry is geared towards poor and low-income people, while the gray market mostly serves the middle and upper class out of necessity.

Chapter 4 focuses on the experiences of workers within the home health care industry—those workers who work for agencies in the formal market and those who are hired privately in the gray market. This chapter examines the demographics of the workforce, the occupations of these workers (including home health aides and personal care aides), the training requirements, problems with turnover and the legal landscape that home health aides work within, including the labor and employment laws they are covered by. The chapter then turns to an analysis of the

2008 Unregulated Work Survey, examining pay, working conditions, and prevalence of workplace violations among home health care workers in New York City. Violations of labor laws are more prevalent in the gray market than in the highly regulated formal market. While this arrangement can meet the needs of workers and families, jobs are typically more precarious and come without health insurance or other benefits. Unions have played a key role in improving working conditions for formal home health care workers, but informal home health care workers are untouched by these advances. For the agency-employed workforce, unions have had difficulty raising wages (up until their recent success) because the structure of the industry is so closely tied to the state budget and because of entrenched organizational interests (of the various levels of agencies providing care).

The union's biggest victory was increasing wages for home health aides in the 2011 State budget. This victory, however, went along with massive changes to the industry—all of which are explored in Chapter 5. Whether the changes will lead to better conditions for workers and patients in New York City remains to be seen, but many within the industry are skeptical. The changes will shrink two programs with good reputations (New York City's Personal Care Program and the Lombardi program) while growing Managed Care. While state officials believe these changes will lead to large long-run savings for the State, experts fear that it could lead to less home care for patients (which would send patients more regularly back into the hospital, into nursing home care or towards the gray market), less work for [formal] home health care workers, and more stress on families. The changes are also forcing the consolidation of the industry, leaving small businesses at a severe disadvantage. These changes could, in fact, grow the gray market where jobs tend to be more unstable and workplace violations more prevalent.

Chapter 2: The Formal Home Health Care Industry in New York City

Chapter 2 draws on in-depth interviews as well as secondary research to describe the financing and the current structure of New York City's formal agency model of home health care. This chapter reports results from interviews conducted with home care agencies and associations, worker advocates, and government officials. The chapter examines the current structure of home health care in New York City—the history of this system, including changes in health care that have impacted the home health care industry; the system of public payment; and the programs, regulatory bodies, nonprofits and for-profit agencies that shape the industry.

History

Home health care as a social welfare service developed as part of the New Deal legislation to place unemployed women workers with low-income families whose mothers were incapacitated in some way. As a result of the New Deal, the state financed new programs through the Works Progress Administration, which matched homemakers with needy families. As Eileen Boris documents in her book, "before the WPA disbanded in 1942, some 38,000 housekeeping aides, over 90% African American, in 45 states and the District of Columbia assisted needy families." From this New Deal, three legacies were born: the government would pay for home-based care through local welfare agencies; policy experts viewed female public assistance recipients as a ready supply of home care labor; and the exclusion of these workers from basic labor protections would stay in place for the rest of the century (Boris and Klein 2006).

Originally, domestic workers were directly employed by welfare departments and were considered public employees. In New York City, the Welfare Department directly employed homemakers (both childcare and elder care providers) and even opened a Homemaking Center as

a part of the New York City government, which employed its own workers directly for about 30 years. After World War II, the need for home health care grew. Legislation expanded the labor market for home health care: the 1962 Public Welfare Amendments, the Older Americans Act and Medicare/Medicaid were the public policies that "established a foundation for a social services labor market within the welfare state" (Boris and Klein 2006, p. 83).

The 1962 Public Welfare Amendments to the Social Security Act encouraged public welfare departments to identify services that would help the aged or seriously disabled to take care of themselves. The Older Americans Act was enacted in 1965 and it established a federal agency (the Administration on Aging within the US Department of Health and Human Services) and state agencies to address the needs of the older population in the US—to help them maintain their independence and stay in their homes and communities (O'Shaughnessey 2008). These service provisions created the need for a workforce to implement these new priorities—hence the dramatic increase of the publicly paid home health care worker.

Changes in Health Care

As one report on home health care in New York City notes: "Health care is strikingly different from other economic sectors in the intimacy of its services, the emotional involvement of its 'customers,' the complexity of its financing and the degree of governmental involvement in every aspect of its direction and day-to-day functioning" (Inserra et al 2002, p. 5). The home health care industry operates as part of the broader health care industry and is influenced by changes that have occurred in health care in the last several decades, especially with hospitals and nursing homes. Nursing home scandals in the 1970s and early 80s, as well as the process of deinstitutionalization, shifted much of care out of institutions and into the home. Spending on

home health care grew during the late 80s and 90s, especially in New York where nursing home care was expensive and hospitals were increasingly discharging patients earlier (Inserra 2002). Nursing homes were being scrutinized by state government in terms of how care was being delivered resulting in increased documentation/regimentation of that care (LHCSA Interview 2). (See Gass's book Nobody's Home: Candid Reflections of a Nursing Home Aide for more on changes in the industry).

Policy makers are continuing to figure out ways to keep the aging population in the community as long as possible, which is both cheaper for the state and, in some cases, perhaps more humane. Home health care has historically been thought of as a cheaper form of care for the elderly than nursing homes. During the 1980s, the push for fiscal austerity was increasing at the same time that scandals and inhumane treatment in nursing homes were getting more attention. During the Reagan years, Medicare coverage was cut back. While the need for home care was on the rise, the length of stay in hospitals was decreasing, especially when paid for with government funds. In 1985, the federal government introduced stricter eligibility requirements for home-based services (Ortiz 1993).

One specific federal change had a significant influence on hospitals and health care—the shifting of power away from hospitals and physicians to those who paid for it. During the Reagan years, Medicare began to determine how much money they would pay the hospitals, not based on what the hospitals billed for, but based on a diagnosis-related group (DRG), which is a classification system classifying hospital cases into a group of (originally) 467 groups. Medicare would pay the stock amount in the classification system, instead of what was needed for that particular patient (Office of Technology Assessment 1983). Rick Mayes, a political scientist at the University of Richmond described these DRG's in the following way:

> ...the single most influential postwar innovation in medical financing: Medicare's prospective payment system (PPS). Inexorably rising medical inflation and deep economic deterioration forced policymakers in the late 1970s to pursue radical reform of Medicare to keep the program from insolvency. Congress and the Reagan administration eventually turned to the one alternative reimbursement system that analysts and academics had studied more than any other and had even tested with apparent success in New Jersey: prospective payment with diagnosis-related groups (DRGs). Rather than simply reimbursing hospitals whatever costs they charged to treat Medicare patients, the new model paid hospitals a predetermined, set rate based on the patient's diagnosis. The most significant change in health policy since Medicare and Medicaid's passage in 1965 went virtually unnoticed by the general public. Nevertheless, the change was nothing short of revolutionary. For the first time, the federal government gained the upper hand in its financial relationship with the hospital industry. Medicare's new prospective payment system with DRGs triggered a shift in the balance of political and economic power between the providers of medical care (hospitals and physicians) and those who paid for it - power that providers had successfully accumulated for more than half a century (Mayes 2007).

One licensed home care agency director explained to me how these DRGs incentivized hospitals, who were concerned about their profit, to move patients out of hospitals sooner.

> Basically, what they were told is, you know what, if you have an appendectomy, this is what we're going to pay you for the appendectomy. That client could stay in the hospital for three days and then anything past the three days, if there's nothing happening, and if you still have that client in there for that appendectomy, well, you're losing money. So what the hospitals starting doing is that they were now getting the client – well, I've got three days that I'm going to paid on this no matter what. I've got three days worth of money that's coming in. So if I get that client out in two days, I still have three days worth of money. So what did they do? They got that client out quicker (LHCSA Interview 2: p. 4).

Nursing homes began to see opportunities for profit too. While once primarily a place for clients who were very old and sick, nursing homes began to expand their services and provide short-term rehabilitative services for people coming from the hospitals. Sometimes nursing homes became a step in between hospitals and home care, while in other cases, clients went directly to home care (LHCSA Interview 2, p. 4).

On the business side of things, companies were deciding how to expand. Hospital owners decided to own nursing homes and get involved in home care—owning, perhaps, both a certified

and a licensed agency. They were generally able to make money off of clients from the hospitals, through nursing homes and into home health care. The director of a licensed agency described the process in which these companies were profiting off a single client:

> If they were in an acute care setting in the hospital, once they left out of the hospital – say you had a 60-year old person that has a fall and fractured hip, goes to the hospital, stays in the hospital. The hospital is able now to get that client out, as opposed to three days that they were slated to do, well, we can get them out in two days and send them over to the nursing home. So the hospital gets paid for that three days of service, but they did it in the two days. That's profit. Goes into the rehab. That nursing home does rehab services because now they can accept this client needing this rehabilitative help. And it's going to be on a short-term level. They are able to pay for it because that rehab is a higher reimbursed item than your regular nursing home client. Your nursing home client gets X amount of money, but now we have this rehab client that's come in so we decide to have this section of our nursing home just for rehab. We are able to provide those services, client needed skilled services, but not yet in the home. We want to make sure that you're able to go to the home. So now you have the nursing home making that segment of money for the rehabilitative services. It's fair, you know, perhaps very, very good care targeted for that client. And we have to get that client out in a certain amount of time. So then the nursing home says, 'Okay, we've done all we can do. We've made that client reach their rehabilitative potential. They are at their operant level of condition at this point in time. Now we are ready to discharge you to the home. We have to have somebody to take care of you at home. Well, you know what? One of our companies also provides services at the home.' So now you are able to keep that client although the law indicates that clients have the right to make choices between where they want to get services from when they go into the homecare arena. So what the social workers are supposed to do from the nursing home is say 'we have these five agencies that are delivering care here, pick and choose one.' Well, they might do that or they might more target them and say, 'But we know you well and that nurse that was taking care of you here, she also does homecare. Wouldn't you want to stay with us? Here's your choices, but remember we do a good job.' So that client, nine times out of ten, 'I want Kurt as my nurse, he's been doing a good job. He does homecare, too. I'll go with your setting' (LHCSA Interview 2, p. 4).

This had several impacts on home care. First, patients were leaving the hospitals sooner and needed more acute care at home, which led to an increase in the need for home care (and particularly home health aide care). Second, patients were sometimes leaving the hospital while still very sick, and often needed to be re-hospitalized because the original issue was not resolved. Third, clients in home care who were short-term clients tended to be sicker than they previously were. "Now you had more specialization, you had more high tech homecare—[the]

miniaturization of technologies allow for a greater opportunity for services to be conducted in the home, as opposed in an acute care setting" (LHCSA Interview 2, p. 4). Despite the fact that home care is much cheaper than institutionalization, it has become a significant cost for the state of New York, and in 2011 was the focus of major cuts during the budget crisis (the details of which will be discussed in Chapter 5).

Kurt Luggard with Personal Touch Home Care in Brooklyn spoke about the larger problems with how our health care system is organized and run that get in the way of providing quality home care to those who need it. Through this example of someone who has, or is about to develop bedsores, he explains how a health care system that is focused on short-term monetary savings, can create longer-term problems.

> I'm going to give you my… example… You have a client – and what the big thing is right now is to reduce the amount of hours for these clients that get live-in services and more importantly who get split care—that's two 12-hour shifts. But you have a group of clients that if they are not turned and positioned every two hours, they are going to develop a bedsore. If you've got a bed sore… one decubitus can cost over the course of a year about $5,000 in terms of service, nursing visits, supplies, loss time, work time, for people that are caring and all that kind of stuff, about $5,000 a year. Thirty to forty percent of persons who have one bed sore have two. That's just how it is… As opposed to perhaps having a doctor that had ordered an alternating pressure mattress that might cost $350.00 when we started seeing that this client stopped turning and positioning themselves. And even though we have somebody turning and positioning, they'll turn them that way, but next thing you know they are back on their side and you're trying to get them… It will cost you that $400 that the client did not have a bed sore yet and you're anticipating to reduce what we call complications of immobility. But how our medical system works is that that doctor cannot order that air mattress until that client's skin is already broken. You've already lost the war here. As opposed to having given that intervention earlier and preventing it from occurring in the first place, saving you all this money in the long run or educating a group of persons to provide services and giving more money to organizations to give them a little bit of an increase in salary so that they stay with you for a long period of time. And you have an educated workforce that someone can see 'Ms. So and So is getting ready to develop a bedsore. I've seen it. I see the redness in the skin. I've had the class. They told me what to look for. I'm seeing it here. I want to report it.' So again, Ms. Jones doesn't develop the bedsore that's going to cost $10,000…Maybe we weren't going to prevent it at all. Maybe it was going to happen 'cause sometimes stuff is going to happen. But if you save two people out of ten from that, you've saved maybe $20,000 in the course of a year. You multiply that by however many for a $300 air mattress. Buy the damn air

> mattress and protect this client. I've gone to school to become a nurse. I have nurses that are going to school to become nurses. They are looking at this particular client's body and they are saying, 'This client is at risk. I recommend that you buy…' We don't do that crap. Pardon me. Sorry, I get a little emotional. We don't do that stuff because we want to spend money. We do that stuff because we know what's going to happen to that client. And we know that if we prevent it now, then we're, number one, maintaining the integrity of that client, maintaining that client's quality of life, saving money in the long run and saving time (LHCSA Interview 2, p. 26).

Financing

The current government health care programs—Medicaid and Medicare—provide health and medical care to different groups in the US and are the primary payers for home health care. Medicaid is the primary payer of home health care in NY, although Medicare is also a significant payer. "Home care and personal assistance spending in the U.S. economy exceeds $70 billion according to federal national health expenditure accounting for 2008 conducted by the Centers for Medicare and Medicaid Services. Of this amount, total private spending accounts for about $12.5 billion, or 18 percent, and government spending accounts for $57.5 billion or 82 percent" (Seavey 2010 p. 16). In New York State, Medicare costs amounted to about $1,160 million for home health care services in 2009. Medicaid spent about $1,843 million on home health care services and $2,343 million on personal care services (see Table 2.1 below). The New York City Metropolitan Area accounts for approximately 87% of all Medicaid dollars spent on home care services across the state (Rodat 2012).

Table 2.1: Medicaid and Medicare Spending in New York State, 2008/2009

Program	Spending	Year	Amount of money spent
Medicare	Home health care services	2009	$1,160,000,000
Medicaid	Home health care services	2008	$1,842,756,902
	Personal care services	2008	$2,342,910,850

Information accessed from http://www.statehealthfacts.org (a data source from the Kaiser Family Fund). 2009 data was not available for Medicaid spending.

Medicaid: Medicaid is a means-tested social welfare program providing health insurance to America's poor and is available for people who are both low income and with limited assets. The Federal government oversees it but states establish eligibility standards, set payment rates for services and administers its own Medicaid program. Medicaid in NY state provides eligible clients access to home and community-based care for those with chronic conditions and in need of chronic care. Because of the structure of Medicaid, home health care agencies must deal with three levels of government (federal, state and city government) when they administer Medicaid-covered services. And to complicate billing matters even more, some clients (who are elderly and poor) are dually eligible for Medicaid and Medicare (Inserra et al 2002). New York State is one of the few states that require a local government contribution for Medicaid. Local government must pay a percentage of services used within their borders "New York's local governments have the largest responsibility in the nation, in both relative and absolute terms. Until recently, the State and local governments generally paid 25 percent each for acute care services (with the federal government paying 50 percent). For long-term care services, the State generally paid about 40 percent, with local governments paying about 10 percent (and the federal government paying 50 percent)" (Birnbaum 2010).

New York was one of the first states that included home care as a benefit of Medicaid in 1965. However, municipal officers were not very generous in sharing information to this little known benefit. It wasn't actually until the late 1960s during the struggles to expand social benefits that activists discovered this home-care provision in Medicaid. As a result of their community efforts, enrollment in the program began to grow significantly (Ortiz 1993).

New York State spends more on Medicaid than any other state ($54 billion, 41% of which is spent on long-term care, half of that is spent on nursing homes) (Bernstein 2012) and has the

most generous Medicaid program in the country (Eldercare New York, Inc.; Worker Advocate/Policy Organization Interview 4). Of all the states, New York spent the most money per person on home and community based services (in 2005 this was $19,551 per year compared to the US average of $9,459 per year) (Houser 2009). Not only is the per-person spending generous, it is considered generous for several other reasons. First, there is no transfer of assets penalty for Community Medicaid and a person can transfer assets to a family member today, and be eligible for home health care tomorrow. This allows middle and upper class people to gain access to state-funded home-based long-term care. For nursing homes, there is a 5-year look back for transferring assets, meaning if you were to transfer your assets to become legally impoverished and therefore eligible for Medicaid-funded nursing home care, you would have to wait 5 years before that eligibility went through. But the 5-year look-back does not apply to home care. These policies make it far easier for New York residents to get home care than to get into a nursing home. Industry experts explained that a whole industry has arisen to transfer people's assets—mainly elder law attorneys—who manage families' money (at a hefty cost) to deal with long-term care (Union Interview 1, p. 13, 14). Although they can be expensive, these experts are one of the few places New Yorkers can turn to get help accessing (and understanding) Medicaid (although as my interviews reveal in Chapter 3, many times families don't know where to turn to get this information).

Second, home health care in NY is considered more generous because it is possible to obtain around the clock care in the home (24 hours a day, 7 days a week) if it is found to be necessary (Eldercare New York, Inc.). This generosity in hours, however, has begun to be more limited because of state crackdowns and changes in the structure of home health care (as a result of the 2011 budget changes).

Third, New York State allows for partial payment for those whose income is too high to fully qualify for Medicaid (a spend-down policy). Ortiz documents in her article:

> Part of the reason for such a large Medicaid-eligible population in New York State is the permanent spend-down policy not found in most other states. That is, people whose income is too high to make them eligible for Medicaid are able to obtain services through partial payment calculated on the basis of their existing resources; thus the program functions, in effect, on a sliding-scale basis (Ortiz 1993).

One Licensed Home Care Agency director noted:

> If they are above the poverty level, and it depends upon whether or not it's a single or a family, that's how they do the calculation. If they have too much money, then they go into what's called a surplus income program. They have too much money so they have to pay the city out of their pocket so they can spend down on the amount of money that they might already have so that they can remain eligible for the Medicaid level of care…. So basically what's happening is that that client had too much money, but you know what, their healthcare is going to evaporate that money. So they already get into Medicaid (LHCSA Interview 2, p. 11, 12).

Medicare: Medicare is the health care that seniors receive when they turn 65 years old and have a history of paying into Social Security while they were working (they or their spouse) (http://ssa-custhelp.ssa.gov/app/answers/detail/a_id/400/~/how-to-qualify-for-medicare). It is a federal health insurance (administered, paid for, and overseen solely by the federal government) for the elderly and some disabled individuals. Medicare will pay for short-term home health care for an acute problem but the coverage is time-limited and usually people are eligible for Medicare-covered home health care only after hospitalization or an injury of some kind. Medicare does bundled payment or episodic payment for a certain amount of money for 60 days of care for a person with a particular diagnosis—so home health care agencies have to strictly manage the hours in order to make money. For Medicaid, there was no fee for service and no limit, which led to more fraud and overbilling (Union Interview 1, p. 3).

Because Medicaid and Medicare are the primary payers for home health care, the industry (at least the formal part of the industry) is highly regulated. A combination of federal, state, and city regulations, combined with different streams of funding, have generated a complex system in New York City (Rodat 2010). A major policy concern as baby boomers continue to age is whether Medicaid and Medicare will be able to keep pace with this growing population who have already begun to reach age 65 (O'Shaughnessy 2008).

The Structure of the Home Health Care Industry in New York

Two models of home care in US: In the United States, there are primarily two models of home health care delivery for public programs: the agency-based model and the independent provider model. The agency-based model is one in which a third party, usually a home health care company, employs home health care workers and is responsible for ensuring that care is performed for people covered by a public program (Medicaid or Medicare). The independent provider model (as seen in California) is where the consumer of the care is either the sole or joint employer (with another entity or intermediary) of the care worker. The client in this instance is responsible for hiring and firing their home care worker (Seavey 2011). The agency-based model dominates home health care in the state of New York, and in New York City in particular.

The New York City system

For home health care in New York City (and in the words of an advocate for home health care workers), "form follows financing" (Worker Advocate/Policy Organization Interview 1). Since the financing system for home health care in New York State is so complicated, it makes sense then that the structure of the system is difficult to grasp. My interviews with people trying

to navigate the home health care system and those who work in it, reveal it to be particularly difficult to navigate, confusing to everyone involved, highly fragmented, with many overlapping layers (Polson interviews and Surpin 2010). Unlike other states, where typically one organization will provide both nursing and aide services, New York City has one organization (a certified agency including a Certified Home Health Agency (CHHA), a Long-Term Home Health Care Agency (also called a Lombardi) and a Managed Long Term Care Agency) that provides nursing services and supervision and another organization (a licensed agency) that provides home health care (Inserra 2002). Not only is the system complex, but spending on home care is high in New York City compared to other states and the population is large, making New York City "one of the largest markets for home care services in the country" (Inserra 2002, p. 13). Table 2.2 shows how the different programs in New York City are funded.

Table 2.2: Who Funds the Home Health Care Programs Operating in New York City

	Medicaid	Medicare	Individual Health Insurance	Private Household
HRA Personal Care Program	X			
CHHA	X	X	X	X
Lombardi	X			
Managed Care	X	X		X

The Players:

Money comes from:

- Medicaid, Medicare, Individual Health Insurance, Private Households

Regulatory Agencies:

- NYS Department of Health (DOH) regulates home health care services through the CHHAs/Lombardis/Managed Care companies (who subcontract out the home health care services to LHCSAs)
- New York City's Human Resources Administration (HRA) Personal Care Program regulates home health care services through the LHCSAs (there is no intermediary involved)

Contractors:

- Certified Home Health Agencies (CHHAs), Lombardis and Managed Long Term Care companies are certified agencies that contract with NYS Department of Health and manage the coordination of care and hire and manage the professional staff (the nurses, social workers, physical therapists, etc.). They subcontract out the hiring of home health aides to the LHCSAs.
- HRA's Personal Care Program manages the coordination of care and contracts out the hiring of personal care aides to LHCSAs.

Provider Organizations:

- Licensed Home Care Service Agencies (LHCSAs)—Sometimes thought of as employment agencies for home health aides, LHCSAs hire and manage the workforce. They do not contract directly with Medicare or Medicaid but they contract with other long-term care programs (the "Contractors").

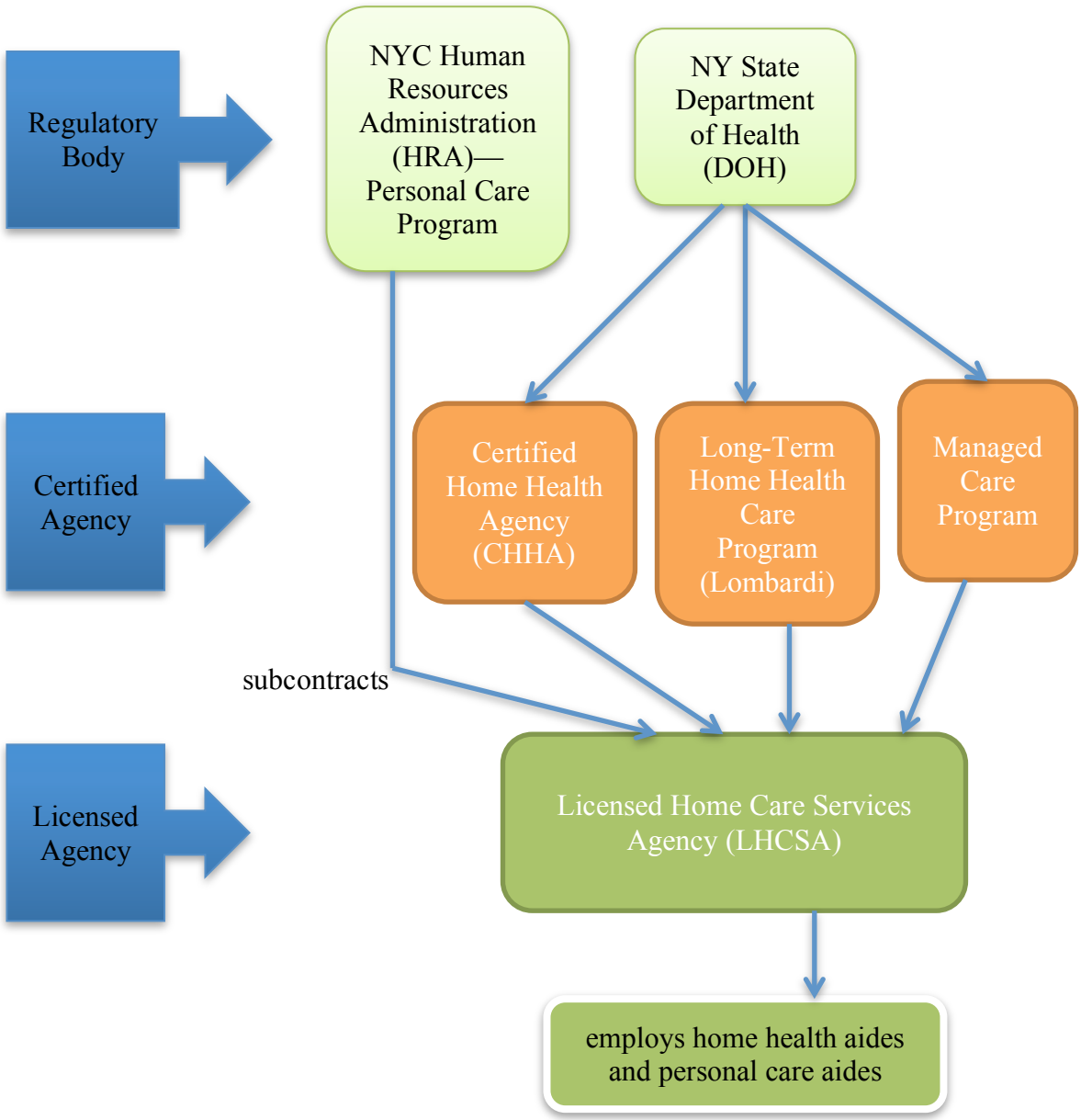
Industry Associations:

- Home Care Council of New York: Represents the interests of LHCSAs who have contracts with New York City's Human Resources Administration.
- NYS Association of Health Care Providers: represents LHCSAs, CHHAs, Lombardis, Hospices and other health related organizations.
- Home Care Association of New York State: represents CHHAs, LHCSAs, Lombardis, Managed Long Term Care Programs.

Workers Organizations:

- Unions: SEIU 1199 (1707 and 32 BJ also have home health care members but their numbers are minimal). Unions represent workers who are employed by LHCSAs. The union bargains with LHCSAs but has tried to make relationships with CHHAs to put pressure on LHCSAs to increase wages. Because rates are set by the state, the union has also had to turn toward the state to try to increase rates so more money could trickle down to workers.
- Worker Advocacy Organization: Paraprofessional Health Institute (PHI) is focused on improving home health care jobs in New York City.

Chart 2.1: Flow Chart of Regulatory Authority and Subcontracting Relationships for Home Health Care Programs in New York City



As Chart 2.1 shows, there are four main home health care programs in New York City (HRA's Personal Care Program plus the three programs highlighted in orange—Lombardis, Managed Care and CHHAs) and two regulatory bodies (the New York City Human Resources Administration and the NY State Department of Health). The city's Human Resources Administration regulates the LHCSAs directly and contracts with them to hire and manage the personal care aide workforce. The DOH regulates and oversees the certified agencies (the CHHAs, Lombardis and Managed Care companies) that then subcontract LHCSAs to hire and manage the home health care workforce. The certified agencies hire the professional staff (nurses, social workers, rehabilitative staff) and subcontract out the paraprofessional staff to LHCSAs. The arrows between different organizational players signify flows of both regulatory control and money flow from organization to organization (see Table 2.2 above for more on where the funding for each program comes from).

Short-Term Care: In New York City, Certified Home Health Agencies (CHHAs) have historically provided short-term acute care for patients (although, over time, they have gotten into providing long-term care). During hospitalization, a patient chooses a Certified Home Health Agency to manage their care during their transition into the home. This care is usually short-term and includes services such as physical therapy, nurse services, and home health care services. Medicare typically only covers these services for a period of 60 days and the care work is performed by a home health aide.

Long-Term Care: If more care is needed, the patient may transition to another program that focuses on long-term care. New York City's Personal Care Program, Long-Term Home Health Care Programs (also called Lombardis after Senator Lombardi who founded the program) and Managed Care companies provide long-term care for patients. The Personal Care Program

(also referred to as the HRA Home Care Services Program-HCSP) provides long-term care, serving the most vulnerable in the city and is actually run and managed by the City of New York Human Resources Administration. It is perhaps the most known program and the simplest to understand (Surpin 2010). HRA's Personal Care Program is currently the largest program for long-term care and serves the majority of clients in New York City (although this is beginning to change—as described in Chapter 5), with enrollment in Dec 2009 at 44,416. Managed Long-Term Care serves 26,272 clients and the Lombardi program serves 14,073 people in New York City (see Table 2.3 below) (Surpin 2010).

Table 2.3: Enrollment in Medicaid Long-Term Care Programs in New York City, Dec. 2009

Program	Enrollment	Date
HRA Personal Care Program	44,416	December 2009
Long Term Home Health Care Program (Lombardi program)	14,073	December 2009
Managed Long Term Care Program	26,272	December 2009

Chart taken from Surpin 2010, p. 22.

Union categorization: SEIU, the largest home health care worker union in the city, categorizes these programs in a way that is useful from a labor perspective. They distinguish between personal care aides, employed by the city's Personal Care Program, and home health aides, employed by CHHA's, the Lombardis and the Managed Care Programs on the other (Union Interview 2). Even though all personal care aides and home health aides are employed through a Licensed Home Care Service Agency (LHCSA), the LHCSAs in the Personal Care Program contract directly with New York City and are covered by New York City's living wage law and are guaranteed $10/hour plus health insurance. The home health aides in the other three programs (CHHAs, Lombardis, and Managed Care) are employed by a LHCSA, which subcontracts with

these organizations that manage the care. So, essentially, the CHHAs, Lombardis, and Managed Care Programs (mostly for-profit companies) act as intermediaries between the state and the employer of home health aides. In the case of the Personal Care Program, New York City acts as the intermediary.

Billing and Service/Hour Caps in these different programs: The Certified Home Health Agencies have carte blanche on how many hours a patient gets. New York City's Personal Care Program is also a fee for service operation, but the city determines hours, not the company. Fees for the Lombardi program and the Managed Long Term Care programs are capped (Lombardi is 75% of average nursing home costs and Managed Care is a flat fee per month) (Union Interview 1, p. 3).

New York City's Four Main Home Health Care Programs

1) New York City's Personal Care Program:

History of program: Understanding the history of New York City's Personal Care Program is critical to understanding its' current structure. While New York was one of the first states to include home health care as a Medicaid benefit (in 1965), the program did not grow until welfare rights activists pushed for the inclusion of more elderly into the program. Activists working with the Office of Economic Opportunity's community action programs in New York City during the late 1960s encouraged older Medicaid recipients to take advantage of the city's home care services and to hire friends and neighbors who were also on public assistance. This program was financed through the city and clients received reimbursement checks for payments to their aides. At this point, the city was the employer of record even though the clients seemed to be the employer. As one personal care aide employer reflected:

> …there were ongoing problems with the payment—the client would be paid by the city and the client would pay the worker. But you know all kind of problems that could cause if the client, well – I wasn't satisfied with you. I'm not paying you your whole check and everything else…. So that's when we [non-profit LHCSA's who contracted with the city] came in. That was back in '79 or '80 (LHCSA Interview 5, p. 21).

In the 1970s, as the Human Resources Administration (HRA) (a city agency) took more control of the program, clients were still allowed to select their workers, but the city began to keep a list of home health care workers. This was a step towards clients eventually losing control over the hiring of their aides. But unlike other city workers, personal care aides were getting lower wages and no benefits and the city began to argue that it was not the official employer of record (and not responsible for paying city wages) (Ortiz 1993).

But as the program grew, the Feds and the city were increasingly concerned that they did not have enough control (regulatory and financial) of the program (Ortiz 1993). As Ortiz documents in her article on the city's Personal Care Program:

> According to the Human Resources Administration, the growth of the program had made bureaucratic management of multiple service allocation increasingly difficult. The administration argued that the new subcontract system, in contrast, allowed for better quality and for communities to meet their own needs more readily. Evidently, economic and political considerations, however, were far more important. The federal government, which provided 50% of the funds, had complained that the previous two-party check system allowed home attendants to avoid payment of federal income and Social Security taxes. In addition, a report from the city comptroller's office estimated that $2.3 million a year had been paid by the city for services never rendered. At the same time, the city was under attack for its treatment of workers and faced an incipient unionization drive calling for civil service wages. In the midst of a fiscal crisis, the new subcontract system allowed the city to increase control of expenditures, while avoiding large wage increases and legal responsibility for the labor conditions of workers (Ortiz 1993 p. 14).

These trends coincided with significant scandals in nursing homes and the state decided to invest more in home care, rather than nursing homes resulting in the explosion of home care in the 80s. In 1980, at the request of HRA, the city began subcontracting non-profit community organizations to take over responsibility for hiring, assigning and supervising workers. Partially

because of the legacy of investing in local community organizations and settlement houses during the War on Poverty in the 60s and 70s, these were the first government contractors (Industry Association Interview 1). Many of these community organizations had begun to lose funding due to cuts in social programs during the Reagan years and these new contracts for home health care acted as a revival to many of these organizations (Ortiz 1993). These non-profit organizations eventually became what we now call Licensed Home Care Service Agencies (LHCSAs).

The city's financial and regulatory control over the Personal Care Program: These changes including increased financial and regulatory control over the Personal Care Program continue today. The New York City Human Resources Administration Personal Care Program is the only program in New York City that is administered and regulated directly by the HRA in New York City (the other programs—CHHAs, Lombardis and Managed Care programs—are overseen by NY State Department of Health). This is by far the most regulated and tightly overseen home health care program operating in the city. Once a patient has a doctor's recommendation for personal care services, the city takes over and has full control over eligibility, level of care, and hours a patient is granted. The city's Personal Care Program does not hire and supervise personal care aides directly—they contract with Licensed Home Care Services Agencies to do the hiring and management of personal care aides. Most of these city-contracted LHCSAs are still non-profit and community-based—though some are for-profit licensed agencies—but if that agency has a city contract, they are limited to making a maximum of three percent profit (the profit is not limited under the other programs operating in the city) (City Agency Interview 1). LHCSAs also hire and manage nurses to go into a client's home every 90 days to check on ambulation and make sure there are no bedsores. CHHAs will overlap with

personal care aides and LHCSAs will sometimes have a CHHA nurse come in, because sometimes 90 days is not enough for nurses to check on clients (LHCSA Interview 6).

The city maintains control over the determination of wages, benefits, and other employment conditions in this program. The personal care workforce in the city program became unionized in the 1980s (Industry Association Interview 1) (SEIU 1199 is the union that most home health care workers are in) and today workers are covered under New York City's Living Wage Law and are entitled to $10/hour plus benefits. The city even limits the salaries of LHCSA managers (LHCSA Interview 6). The living wage law that applies to personal care aides was passed in 2002 and applied to about 50,000 personal care aides. These aides saw their wages increase from $7.69 per hour to $9.60 per hour (assuming the employer pays for health insurance) or $11.20 if benefits are not provided. In July 2006, the living wage increased to $10/hour (or $11.50 if no benefits were included) (Seavey and Salter 2006).

Nine city-run Community Alternative Systems Agencies (CASAs) in the five boroughs provide case management and determine hour eligibility for Medicaid patients who need personal care services. The client fills out an application with their doctor's diagnosis and limitations, the CASA's determine how many hours a client needs by sending out a nurse to do an assessment visit to determine what each client's needs are (City Agency Interview 1). The LHCSA's just follow orders from there and provide personal care aides to the patients who need them for the allotted amount of time given by the CASAs. If a patient does not get enough hours or the CASA tries to reduce their hours, the patient has a right to a fair hearing in the city. One LHCSA director observed that the city may leave hours high because it costs the city too much in legal fees to fight a client through a fair hearing. Some LHCSAs report having a contentious relationship with CASAs. One LHCSA director stated: "Some of the CASA workers are very—there's not a

collegial relationships. It's more contentious. They never answer the phones. They never call back. Then they deny that we ever notified them" (LHCSA Interview 6).

The Medicaid-funded Personal Care Program provides level 1 and level 2 personal care services to Medicaid-eligible individuals. Level 1 includes personal care services with nutritional and environmental assistance to the elderly and disabled—this includes grocery shopping, housekeeping and the preparation of meals. Level 2 includes the nutritional and environmental assistance as well as bathing, escorting to doctor visits, helping with ambulation and grooming. Both level 1 and level 2 are considered long term care because the patients have chronic conditions (as identified by a doctor and monitored by a nurse). The clients they serve tend to be 70-80 years old on average, with multiple needs, illnesses and diagnoses. If a client needs more acute care, they may go back and forth between the city's Personal Care Program and the Certified Home Health Agencies that manage short-term care (City Agency Interview 1; Home Care Council of New York City, 2009).

HRA's program provides services to frail elderly and disabled individuals who are Medicaid eligible. A 1998 United Hospital Fund study found that 85% of Medicaid home care recipients are 60 years of age or older and 22.2% are 85 years of age or over. Most recipients are women (85%) and nearly three-fourths are people of color. One-third of recipients could not speak English well enough to complete the assessments without the assistance of an interpreter. The median number of hours that patients required in the city's home care program were 28 hours and ranged between 2 and 168 hours of needed care per week. They found that home care hours increased significantly with both the degree of cognitive impairment and the number of impairments they had in activities of daily living (ADLs) (bathing, toileting, eating, walking and transferring from bed to chair and back). More than half of Medicaid recipients have impairments

in all five ADLs (Hokenstad et al 1998). There are a large percentage of clients who have behavioral health issues and about 20% of clients in this program are high hour cases (requiring 12-24 hours of care per day) (Surpin 2010).

According to a study conducted by the United Hospital Fund in 2002 comparing the population being cared for in the Personal Care Program and New York City's nursing homes, they found that although nursing home residents are generally frailer and sicker than personal care aide recipients, a substantial amount of patients receiving home attendant services in New York City have similar conditions and needs. Eleven percent of personal care aide recipients and 27% of nursing home residents have complex clinical conditions. Ten percent of personal care aide recipients compared to 6 percent of nursing home residents have severe behavioral problems. Twenty-two percent of personal care aide recipients and 31% of nursing home residents are in Reduced Physical Functioning groups. Fifty-two percent of personal care aide recipients and 85% of nursing home residents are cognitively impaired (Hokenstad et al 2002 p 2, 3).

HRA has tight oversight of the LHCSAs, making sure they follow all of the regulations. They conduct audits three times a year to measure and audit performance indicators on how the business is being done—hiring practices, documentation to make sure there is fingerprinting of the workers and medical exams. They monitor LHCSAs on nursing visits (that they are done every 90 days), on how they deal with complaints from clients, on how they are prepared to deal with worker replacements if a client requests a new worker. If HRA finds an agency to be lacking in a certain area, the LHCSA must do a corrective action. If this is not done, the city can decide not to renew a contract with them the following year.

HRA tightly controls the money flowing into LHCSAs they contract with—monitoring their bank accounts, their revenues and how they spend their money. The LHCSAs bill the state

directly for their reimbursement money, but the city authorizes the services they bill for, manages the program and tightly oversees the money. If at the end of the fiscal year they find that a LHCSA has excess money, they recoup excess revenues.

The Personal Care Program delivers the program with an 8 percent administrative cost. This is a much cheaper than the other programs in NY, which can have an administrative cost of nearly 50 percent. Joe Campanella, the director of the city-contracted LHCSA business association, noted "we are the cheapest game in town" (Industry Association Interview 1). The city also puts a cap on how much the directors of these organizations can make. One interviewee talked about how a large non-profit director who is managing a thousand cases and handling $70-90 million dollars can only make $72,000 year in the Personal Care Program (vs. CEOs who run for-profit care organizations in the city and who make up to $100 million dollars) (Industry Association Interview 1).

The New York City living wage law covers personal care aides (home attendants) employed through the city program—they must get $10/hour plus benefits. LHCSAs pay this wage plus benefits with an average city rate of $16.95/hour to run the program (compared to other programs who get a higher rate from the state and pay lower wages—this will be discussed further in Chapter 4) (Industry Association Interview 1). The city program also has a much higher application rate for personal care aide jobs and has a much lower turnover rate than in the other programs.

The Personal Care Program is shrinking due to the growth of managed care. As several people from the city program complained, managed care has literally been cherry picking the city's clients away from the Personal Care Program into managed care. Citywide, the program has shrunk from 70,000 clients to about 40,000 (35,702 cases in the personal care program in

February 2011) (Doar 2011) and will dwindle even further due to recent changes in the industry, the details of which will be discussed more in Chapter 5.

2) Long-Term Home Health Care Program (the Lombardi Program)

The Long-Term Home Health Care Program (LTHHCP) was established in 1977 because of the work of Senator Lombardi, a Republican Senator from Syracuse who served as chairman of the state Senate Health Committee and the State Council on Health Care Financing. This program is often referred to as "the Lombardi Program" or the "Nursing Home Without Walls." Senator Lombardi, faced with an ailing mother with Alzheimers, championed this program in the late 1970s—it gives individuals the option/opportunity to stay at home, instead of going into nursing homes. Most employers and industry experts I interviewed in the city had very positive things to say about the Lombardi program (Polson interviews). In order to be eligible for this program, an individual must be eligible for Medicaid, have multiple needs, must require three kinds of services—any combination of physical, occupational and speech therapy, nutrition, nursing care, home health aides, Personal Care Services, housekeeping, medical supplies or equipment or social work (Golden Guide, no date). About 60-70% of the program costs are for personal care (Surpin 2010). The Lombardi program provides an array of home care services that nursing home eligible clients need, although they contract out the home health aide services to a licensed home care services agency (LHCSA). Lombardis are slot limited, unlike the CHHAs, where there is no limit on how many patients a CHHA can serve (Lombardi Interview 1).

The critical budgetary driver for the Lombardi programs is that there is a budget cap per individual—you cannot spend more than 75% of the average nursing home rate, which is about $5000 per month, making the home health care cap at around $3750/month per patient (Lombardi

Interview 1). This cap on costs prevents individuals with very complex needs to be taken care of in this program—many of whom usually don't need more than 6 hours of home care a day (Surpin 2010).

3) Managed Long Term Care

Managed Long Term Care is risk-based (not a fee-for-service program). This means that if "care averaged across all members costs more to deliver than capitated payment amounts, the MMLTC [Medicaid Managed Long Term Care] contractor loses money; if it costs less, the contractor makes money" (Saucier and Fox-Grage 2005), p. 1). This type of payment was revolutionary within the health care industry (as discussed earlier with the invention of DRGs). Fee-for-service programs, on the other-hand, typically receive reimbursement for services, and the amount is not capped. The risk-based nature of managed care gives incentive to contractors to manage services and costs closely and is attractive to states because with rising Medicaid costs, it can "achieve budget stability over time through capitation. By paying a single, fixed fee per enrollee, states limit their financial risk, passing part or all of it on to contractors" (Saucier and Fox-Grage 2005, p. 3). In 1997, New York State added its first managed long-term care program to the mix (Saucier and Fox-Grage 2005). From the beginning, it was local providers—the licensed agencies and the CHHAs who were involved in creating this managed long-term care pilot—the creation of this was driven by a knowledge of the local industry and the need to consolidate the industry (to curb costs and to streamline the system). It wasn't until (very) recently (within the last year) that large for-profit managed care companies are getting involved in managing long-term care in New York City (Worker Advocate/Policy Organization Interview 1, #2).

The Managed Long-Term Care (MLTC) program resembles the Lombardi program in several ways—it provides similar services, as well as some others including nursing home care; 60-70% of MLTC costs are for personal care services; and MLTC plans also have a capitated rate. This capitated rate allows the MLTC program to "function, in effect, with a global budget"—one reason why it is appealing to state regulators hoping to curb escalating costs (Surpin 2010). Managed care is responsible for coordinating all care for a patient and not just the care that they provide directly. In order to be eligible for managed long term care, an individual must have a chronic illness or disability that makes them eligible for a nursing home, are expected to need long term care services for at least 120 days, (usually) be at least 65 years or older, and have a willingness to change to a doctor who deals with managed care. All plans accept Medicaid, some accept Medicare and private pay as well (New York State Department of Health, no date).

The Managed Long-Term Care program has grown considerably in the city of NY in recent years—"in New York City, managed care companies have increased their cases from 9,500 to 29,000—a 300 percent increase in just six years (from June 2004 to August 2010)" (Home Care Council of New York City, 2011). Unlike the other programs, Managed Care actively marketed to and recruited the elderly needing home health care for the first time or who are already enrolled in another program. Joe Campanella, who runs the Home Care Council of NY (the city-contracted LHCSA industry association), said:

> So managed care companies started rising like weeds. They started marketing. If you have an elderly grandmother or something like that, they go somewhere, they usually get approached. So they marketed the hell out of it….they started building this empire of home care…they came to look at my cases and said, Joe, you have a whole lot of cases, so they aggressively started to market…this happened about 5 or 6 years ago. What happened with this was I noticed my hours started going up… (Industry Association Interview 1, p. 5).

He, along with others in the industry, suspect that managed care companies have taken clients from the Personal Care Program until they can no longer make money off of them at which point they dump the cases back into the city program—that is why the Personal Care Program is increasingly seeing higher hour cases (LHCSA Interview 6; Industry Association Interview 1).

4) Certified Home Health Agencies (CHHAs)

Certified Home Health Agencies provide home care services to patients immediately after they come out of a hospital stay. These organizations provide nursing, physical, occupational, and speech therapy, medical supplies and equipment, and social worker and nutrition services. CHHAs subcontract out home health care services to LHCSAs—but the CHHA manages the care when an individual comes out of the hospital. Medicare typically pays for this care, but services may also be reimbursed by Medicaid, private payment or by some health insurers.

CHHAs, in order to operate in the city, must have an operating certificate from the state. Currently there is a moratorium on new CHHAs opening in NY (except for Special Needs CHHAS which are discussed later). NY is a certificate of need state, meaning that you must prove there is a need for more services in order to get an operating certificate and be authorized to provide services in NY (Worker Advocate/Policy Organization Interview 1, p. 7). Once a CHHA has its certification, it is very difficult to decertify them. One informant told me that no CHHA has ever lost their certificate, despite the tons of fraud that exists (Union Interview 2, p. 5). CHHAs have been a fee-for service business—up until the 2011 changes, each CHHA had a provider number, they billed Medicaid and got paid, they billed Medicare and got paid (Worker Advocate/Policy Organization Interview 1, p. 2).

Some informants have told me that even though CHHAs were established to provide short-term care, they have become a catchall program for many patients who need multiple services. One CHHA administrator noted that because the Lombardi slots are limited and difficult to get, patients who have applied and qualify for the program but have not gotten a slot, hang around in the CHHA because they still need skilled nursing.

Subcontracting relationship

Licensed Home Care Services Agencies (LHCSAs): All of the above-mentioned programs (the HRA Personal Care Program, Lombardis, Managed Care and CHHAs) subcontract with a Licensed Home Care Services Agency (LHCSA) which directly employs the aides in New York City. Sometimes described as staffing agencies, LHCSAs manage and supervise the home health and personal care aides—recruiting, hiring, training (sometimes), scheduling and paying aides. Aides are considered paraprofessionals and the industry has split from the staff considered more professional (nurses, social workers and physical therapists)—contractors (CHHAs, Lombardis and Managed Care) hire and manage professional staff directly but subcontract out the paraprofessional aides. LHCSA's, while they have the same licensure requirements with the state, actually vary tremendously "depending upon the types of contracts they have, the types of aides they employ, and their business model" (Rodat 2010, p. 15).

There are currently about 750 LHCSAs in New York City—some contract only with the city's Personal Care Program, others contract only with Certified Home Health Agencies (CHHAs), Lombardis or Managed Care companies and some hold contracts with both (sometimes referred to as a diversified LHCSA) (Worker Advocate/Policy Organization Interview 1, p. 4). Some LHCSAs employ as few as twenty aides, while others have multiple contracts and employ

thousands of workers (Rodat 2010). CHHAs or the city's Personal Care Program will order the aide service through one of their subcontractors, tell the LHCSA how many and which hours to cover and the LHCSA sends the aide or attendant into the home for those hours (CHHA Interview 1).

Because of the diverse population of New York City and all of the specific language needs, small LHCSA's have cropped up all over the city that cater to specific ethnic communities—"different ethnic groups carved out a little part of the market for themselves" (Worker Advocate/Policy Organization Interview 4). An unintended result of the growth of these small businesses was that it created a number of "bottom feeders in the industry" (Worker Advocate/Policy Organization Interview 4). Ironically, the state is now pushing for the consolidation of the industry, making it much more difficult for smaller businesses (on the LHCSA and contractor side) to survive in New York City.

Why subcontracting emerged: This subcontracting arrangement was established for a number of reasons. In 1980, New York City's Medicaid-funded Personal Care Program began to hire non-profit agencies to administer the program and hire the aides. Prior to this, the program was administered by the New York State Department of Social Services—in this arrangement, clients hired their own aides and local social service departments administered the program. But training and supervision was inconsistent and payment was often late to workers, so non-profit intermediaries took over (Rodat 2010).

Medicare-funded short-term care in New York City was managed by Certified Home Health Agencies (CHHAs) who, at one time, hired home health aides directly. But CHHAs began to contract out for several different reasons. In order to avoid unionization of the workforce (especially those workers who were connected to the hospital), they contracted out the services to

LHCSAs (Rodat 2010). One union official said "When… the hospitals had control of the program… [and] were mostly union… they kind of explicitly set it up to be a subcontracted program to avoid having the workers union" (Union Interview 1, p. 4). Since this time, hospitals have sold off most of their home health care programs, but there is chatter that some are contemplating trying to integrate them once again as a moneymaking strategy (Worker Advocate/Policy Organization Interview 1).

Another reason CHHAs began subcontracting home health aide services was that the demand for home care workers continued to expand and it got harder and harder to find the right kind of worker for the very diverse population of New York City. One CHHA administrator noted: "It really is a specialty within a specialty that needs a tremendous amount of focus" (CHHA Interview 2, p. 3). One administrator of a Special Needs CHHA[12] in Brooklyn explained the reasons behind the subcontracting. He said CHHAs are responsible for the case management and acute care of patients, which is enough to manage—it was easier for CHHAs to just contract out the staffing services for home health aides, who are paraprofessionals. He expresses a common view, which distances the "professional" nurses from the aides—he sees running a staffing agency (which he considers LHCSAs to be) as very different from the professional work the CHHAs do—in his words "function as a hospital outside of the hospital." He also said there were structural reasons for subcontracting that had to do with the cost reimbursement with Medicaid (and formerly with Medicare)—"you were almost incentivized to have more cost in your base because you would ultimately get reimbursed two years later through your cost reimbursement. You had to be able to afford the cash outlay" (CHHA Interview 1).

[12] A Special Needs CHHA is a CHHA established to serve populations in the city with special needs (two examples of special needs groups are 1) individuals with mental retardation who would otherwise need to be institutionalized or 2) the special needs of the Jewish and Holocaust survivor population).

The state and city supported this subcontracting relationship, seeing the growth of these agencies as good for small business development (Worker Advocate/Policy Organization Interview 4). When licensure was finally required in New York City, the condition under which this happened was that NY allowed for-profit CHHA's to operate. One industry expert explained:

> That was the trade off. For–profits wanted to come in and we kept them out for a long time and then legislation was proposed and in exchange for letting them in we are finally going to force all of these staffing agencies and people who are in the phone books all over the place and who knows who is running them, we are going to force them to be licensed. We are going to regulate that industry. And so that was the tradeoff (Worker Advocate/Policy Organization Interview 1, p. 7).

Licensure of these agencies was required after 1986 [Onecle, no date].

One important result of subcontracting is that it created legal distance between the contractor and the worker. One union researcher with SEIU 1199 identified this as an important reason behind subcontracting from the perspective of the CHHAs: "it is cheaper to cut corners with these regs and it is much better if someone else is cutting the corners… Even if they are still liable for the Medicaid, the liability is not as much, especially criminally and personally. It's not themselves orchestrating this" and hiring the workers directly (Union Interview 2, p. 3).

CHHAs relationship with LHCSAs: CHHAs (as well as Lombardis and Managed Care) have a say in how LHCSAs run their business, but only from a compliance perspective. CHHAs and LHCSAs have a contract between them—CHHAs are certified with the state and are responsible for assuring the LHCSAs are in compliance with state standards. So CHHAs audit before signing a contract and do periodic audits during their contract to make sure the aides are performing the tasks they are supposed to. The CHHAs, although they are not the employer, do actually supervise the aides—usually meeting the aides in the home about two times a month. CHHAs do not have a say in how much a LHCSA pays their workers, but they do give the LHCSA a certain rate per hour of aide service. One CHHA said "But it's a negotiated rate with

the intent that they're caring for – I mean we need them to provide good care for our patients, so we're not incentivized to give them rates that don't allow them to sustain their business" (CHHA Interview 1).

The CHHAs get a rate from the state—usually around $19/$20 per hour of care, the CHHA subcontracts to a LHCSA to provide aide services at a lower rate—usually around $12-$16 per hour. One CHHA I interviewed said this:

> Well we have to run our – you know we have our overhead. Even on the aides, even though we're not running the business we get all the complaints, we get all the issues, we get all the – we've got the oversight, we've got the audits, we've got in overhead – that's what the difference is between what we get and what we pay them is paying our overhead (CHHA Interview 1, p 6).

Unlike for-profit city-contracted LHCSAs who have a profit limit of 2 or 3%, there is no limit to the amount of profit CHHAs can make (CHHA Interview 1).

However, SEIU 1199 did some research on the CHHAs and found out that CHHAs, even though they provide an array of services for patients, actually make the majority of their profits from the home health care services that they contract out—so the $4-$6 per hour they take for overhead, appears to be more than they actually need. Medicaid and Medicare money is actually being used towards funding the profit of these intermediaries. In fact, when I asked one worker advocate about the reasons home health care workers wages remain so low, she said the following:

> In New York City, the CHHAs, their billings to Medicaid, 89% of those billings were for aide services. 89-90%, some of them more than 90%, of their total revenue from Medicaid was not for nurses, was not for therapists, it was for home health aides. So they had to be maximizing that revenue to a pretty penny. On the Lombardis, the long-term home health care was more like 78%-80. But still that is an extraordinary amount of money was all going to[wards] aides (Worker Advocate/Policy Organization Interview 1, p. 9-10).

The larger the CHHA, the more profitable the business can be because all of the money a CHHA spends on home health care is for overhead. So, the larger the CHHA is, the less money per patient that needs to be spent on overhead.

Home health care is actually cross-subsidizing both CHHAs and nursing homes. One advocate who has worked in home care for decades explained that competition with hospitals has been a big driver of why CHHAs have used the home health care money to subsidize their business:

> When you really examine the cost structure, home care has to compete—first of all you can't open a case without a nurse in Medicare and Medicaid, so nurses become essential… So you have to have a nurse. And who are you going to compete with in terms of nurses? Hospitals. And who has the most money in the New York system. Hospitals. So, it's the cost of nurses and then therapists that have driven up the needs of these CHHAs. And if you look closely at the Medicare reimbursement and the Medicaid for the nursing visit it is not sufficient to allow them to compete with the hospitals. So they actually had to use some of the home health aide money to be able to remain competitive with the hospitals. The home care agencies. They are not reimbursed enough on the professional side so they cross subsidize from the paraprofessional side (Worker Advocate/Policy Organization Interview 1, p. 4-5).

She went on to explain that when the Lombardi program was set up, hospitals, nursing homes and CHHAs could sponsor the programs. While hospitals mostly sold their home care agencies in the 1980s, nursing homes still play a role. The accounting rules for Lombardi allowed a parent company/organization to step down the overhead to other related organizations. "So, that has also created, over time, as we cut the nursing home reimbursement, then greater pressure was put on the home care program to provide money to the nursing home (Worker Advocate/Policy Organization Interview 1, p. 5/6)." The home care reimbursement is also cross-subsidizing the nursing homes.

With all of the potential and real administrative waste that can occur through the maintenance of the subcontracting arrangement, it is important to ask why this system is

maintained. There are a lot of people—businesses and organizations—that have a stake in keeping the status quo. In the 2009-2010 NY State Executive Budget, Governor Paterson proposed in the state's budget proposal to do away with the subcontracting relationship (essentially mandating that the CHHAs would have to hire the workers directly) in an attempt to save the state money (Rodat 2010b). This proposal was met with serious resistance from many players within home health care in New York City. "It caused a HUGE furor in the industry and what was a little surprising, it wasn't just the LCHSAs that were going crazy about this (it would mean they would all be put out of business…) but also the CHHAs were bitterly opposed to it, partly because of how they set the rates for many years—that there is basically a cap on the percentage of an agency's cost is limited in administrative in general" (Union Interview 2, p. 4). CHHAs are able to label the whole rate to LHCSAs as "labor costs." If a CHHA suddenly had to take on the extra administrative costs of a LHCSA (like human resources costs of employing aides, payroll, etc.), it would get much more expensive for them. Contracting out to LHCSAs freed up space for them underneath the administrative cap to devote to other administrative things, thus making it more profitable to subcontract (Union Interview 2, p. 4). Home care is a multi-million dollar business in New York City. As one advocate put it:

> It is very easy to categorize and write off behaviors but by the end of the day when I came here and began to explore this question of why and how do we fix it, you begin to understand as you unpack it, that this system was designed deliberately so that people could maximize the revenue stream to their own advantage before it ever got to the worker. And it was only until you looked at the Home Attendant Program where to arrive at the rate, they start with the Living Wage. And when they add on the benefits, that's your base. That is your foundation. It is not, you know, what you spend on the cafeteria, the finance department, the parking lot, you know that has nothing to do with care. What has to do with care is the interchange between the aide and the patient (Worker Advocate/Policy Organization Interview 1, p. 9).

Regulation and Politicization of the Industry

All home care agencies that take Medicaid or Medicare funding are certified or licensed and regulated. Agencies that have contracts with the state government must be certified by the NY State Department of Health. Subcontracted agencies that employ the aides and subcontract with CHHAs, Lombardis or Managed Care companies or with the Personal Care Program must be licensed with the state.

Home health care in New York City is highly regulated—in fact, home health care in NY State and City is often regarded as the most regulated of any state in the US. That said, there is variation in the amount of regulation and oversight depending on the program. The Personal Care Program, regulated by the city's Human Resource Administration (HRA) has stronger oversight than the state's Department of Health (DOH) does in the other programs operating in the city. HRA has very tight control over their program in terms of the regulations and finances. If a LHCSA that contracts with the city is over budget at all, the city recoups the extra money. One LHCSA who only does business with the city said "It's not like a private homecare where you could give bonuses or do other little good things or you're going to go into a hard time, and you need a little more. We need some new computers now. I don't have any money for them. Whereas if you let me hold on to that, I could have" (LHCSA Interview 6). The DOH has tight regulations, but are more hands-off in terms of their oversight. The DOH will come in on a complaint but a couple CHHAs I interviewed told me that they don't really direct the way CHHAs operate, especially when compared to the oversight of HRA (CHHA Interview 2; CHHA Interview 1). One administrator for a LHCSA contracting with both the city and CHHAs deals with both bureaucracies and must follow policies and procedures for both. DOH will just stop in unannounced and want to take a look at the company's books. HRA is more involved in the fiscal and operational part of the LHCSA business, but they will let employers know when

they are coming, so they have a chance to get their records in order (LHCSA Interview 5). But, because of recent fraud within the industry, the state has increased regulation of the industry. There is a demand in the state to recover money because there has been a shortfall, so the state has increased regulations and recovered money, "not because services weren't delivered but because a form wasn't signed or dated at the right time" (LHCSA Interview 4).

Employers have strong feelings about the tight and extensive regulations. One licensed home health care agency that contracts with New York City's Personal Care Program says:

> New York is highly regulated to the point that you want to scream. They keep throwing in more of these oversights, but our monies all come through Medicaid, and the city determines our budget. We're not city; they mandated that they were our only contract, so we couldn't contract with anybody else. They also kept all our salaries. I've been a nurse for 40 years, I don't want to tell you what I should be making and what HRA says I can make (LHCSA Interview 6).

Another employer (who runs a Lombardi program and a LHCSA) said in response to a question about the highly regulated and politicized nature of home health care in New York City: "It makes my hair curl. I think people joke about the fact that there are more regulations for nursing homes and for homecare than there are for nuclear energy" (Lombardi Interview 1). She said the hypothetical positives of such strong regulation is that it does away with a lot of the financial and clinical abuses happening in nursing homes and home care.

> Did it accomplish that? Maybe. Certainly when the federal government made it clear that they no longer wanted to see restraints in nursing homes, suddenly there was an entire change in practice around restraints in nursing homes. So that was a case where federal leadership made a difference. I think what we see now is regulation for the sake of regulation without it necessarily having an impact (Lombardi Interview 1).

She went on to explain:

> Let me give you an example. Part of the regulations call for doctor's orders to be signed every 60 days. In New York City, a lot of Medicaid folks go to clinics and they change physicians so that when they go they don't always see the same physician. Therefore, the physicians are not necessarily happy, anxious, or willing to sign these doctor's orders. So one could say if there's no doctor's order but these are chronic care patients and there's

> no change in the condition, just suck it up and everybody should continue to provide the service. As long as you get the doctor's order signed at some point it should be billable. Or one could say 'too bad, discharge them'. Well the state doesn't allow you to discharge somebody from the program. So you have these rules that don't allow you a choice. And now the state comes in to audit you around the signed doctor's orders. So there is an enormous amount of time and energy being spent right now chasing one's tail in order to comply with rules and regulations that either are not compliable with or just don't make sense (Lombardi Interview 1).

Home health care, because it is so tightly tied to public funding, is highly politicized. One CHHA spoke of both the positives and negatives associated with being a part of such a political industry.

> If you're going to be in healthcare you have to be accepting of the volatility with respect to reimbursement and changes in regulation. The flip side is you don't have to worry about this industry being outsourced to another country – you know, there's always going to be healthcare and there's always going to be reimbursement for healthcare. It just requires you to try to constantly stay ahead of the curve in terms of changes so that you can adapt your business to the change in the healthcare delivery system or the healthcare financing (CHHA Interview 1).

Big business—bigger is easier to make it in industry

The smaller your company in New York City, the harder it is to make it. Currently, we are witnessing the consolidation of the industry. Because of the extensive regulations and overhead, a smaller company is spending more percentage of its costs on overhead, than a larger company. One of the only ways to cut costs is for a company to expand (LHCSA Interview 4). The larger your company is, the more profit you can make. As one LHCSA project manager told me:

> What happens is that once you create your backroom workers and they are able to do the work, then you kind of grow and those workers can manage anywhere from 50 to 150 aides with out any real negative impact on the bottom line. And the larger company is still just paying that salary for that person that's coordinating so you become bigger in scale, but your costs don't necessarily go up with the scale, with you growing in scale. That larger company can probably do more work, but with only expending a little bit more resource than the smaller agency (LHCSA Interview 2, p. 5).

Over time, the business of home care has become more suited for bigger businesses—

several employers told me that smaller companies going out of business has become more frequent. Referring to the recent changes in the industry, one LHCSA employer stated: "The larger agencies, I think, are built to survive, especially now that our environments have changed... They are a little bit better suited to survive it right now" (LHCSA Interview 2, p. 5).

Many LHCSAs and industry experts have said there is a wide variety in the quality of the CHHAs. VNS was often mentioned as one of the best quality companies—they refer to themselves as "the gold standard of care." One LHCSA who does business with multiple CHHAs, including VNS, says "I consider them to be the gold standard in terms of who to do business with" (LHCSA Interview 1). They run their business effectively, but also they are a very large business. "They are gigantic. So they are able to do much, much more. They provide tens of millions of hours a week. They're now a billion dollar company…a billion dollar entity" (LHCSA Interview 1). VNS is one of the few companies that measures the quality of care through scorecards. Other CHHAs will try to dilute the rates and not pay LHCSAs a fair rate for their work, making it harder for a LHCSA to make it in the business. He is very deliberate about who he will do business with for that reason, noting VNS and Independence Care System (ICS) as their main CHHAs (LHCSA Interview 1).

Cooperative Home Care Associates

In the Bronx, NY, there is a well-known worker cooperative that is a licensed home care agency by the name of The Cooperative Home Care Associates. It is an interesting model to examine when trying to understand the pressures companies in New York City have because it is a worker-owned for-profit coop whose mission is to improve the quality of the job for home health care workers. While the coop has made strides in improving the quality of the job for its

home care workers, it has also faced a lot of challenges in raising wages for workers. Although home care workers at the coop get a number of benefits, they still only make $8 an hour for the work they do.

First, I explore a little about the history of the cooperative. Cooperative Home Care Associates was established in 1985. This coop came out of work that was being done by the Community Service Society (CSS) in NY, whose aim was to create decent jobs for low-income New Yorkers. CSS identified home health care as an industry that was socially useful, was projected to grow in the following years and was a low-wage industry that provided work to a lot of New York residents. While the first few years were difficult for the coop to get established and stable, by 1989 the Cooperative had reached its goal of 50% worker ownership and was the first company to offer limited health benefits to its workers. Rick Surpin, the CEO at the time, did have some success in negotiating higher rates so as to increase workers incomes and introduced "modest differential wage increase for more difficult jobs or for weekend work" (Inserra 2002, p. 20).

The Cooperative has had many successes. One problem within the industry in New York is worker turnover and the Cooperative has a strong retention rate compared to other companies in the industry. The director of the coop, Michael Elsas, attributes this to the fact that the members own stock and participate in the running of the company and are more invested in the success of the company. These worker-owners make decisions about what the company should do with its profits (which has gone towards dividends, bonuses, and a 401k plan to name a few).

> We think that worker ownership does in fact lead to more of a stabilization of the workforce. People tend to stay longer. They have a stake in the organization… But we started to find that in an industry where turnover rates, when and if they are measured… run between 50, 60 percent, Cooperative was able – after the few years of getting started – to bring that down to 20 percent (LHCSA Interview 1).

The cooperative is also trying to have an impact on the rest of the industry, which he says are mainly interested in profits: "And the strategy is really to make just as much money out of those companies as possible. That's why they don't pay workers as well as they can. That's why turnover is not a big issue… If you do enough hours in this business, you can make tons and tons of money." He gets frustrated at industry meetings because everyone tries to dismiss the work of the Coop by saying, well you are a coop, you are an outlier. But he stresses that "you don't have to be a co-op to be a good employer."

> My point about the public funding is don't use the rate as an excuse for not doing what you should do. Find a way. Find a way. Why are we different than any other industry? You find a way. When the automobile industry in this country was decimated by the Japanese, they found a way to build a better car. They didn't say that's it, we're packin' up. They found a better way to build a car. You don't not do something because you don't think ya have the money for it. You find a way. You either get the money or you reinvent yourself or you reinvent your company or whatever it is. You don't sit back and say well, I'm not getting the rate. So therefore, I can't do what I need to do (LHCSA Interview 1).

That said, Michael did say himself that it is very difficult to do business on just the rate they are given by the CHHAs. Currently, the Coop operates on an 80/20 split meaning that $.80 on every dollar goes to the worker in the form of salaries or benefits. "That is very, very high." But, Michael notes "Cooperative does have what I refer to as our dirty little secret, which is not really a secret"—that is that Cooperative raises a lot of other money from government sources (wage subsidy programs, Obama's stimulus money). He said:

> …if you are successful, then you can point to that success and people will pay you for that success….But you can't get to that success unless you get the other money. So it's really not 80/20… It's 80/20 when you look at the rate…So for example, I get $1 million to pay for my training. I don't have to take any money out of that $15.00 to pay for that training…. I'm really not operating on 20, I'm operating on 20 percent of the rate. But I have a lot more money coming in" (LHCSA Interview 1).

When I asked Michael what would need to happen for home health care workers to be able to make $15/hour, he said it would have to be legislated through the living wage. "People on the

CHHA side have always told me that unless its mandated, it ain't happening." The industry would have to get a rate increase in order to pay that (LHCSA Interview 1).

Ironically Michael pinpointed the pinnacle of the Coop's success as right before their cooperative became unionized.

> So I think we were successful up until – and this is gonna sound bizarre – up until we unionized. And we love the union. We are partners with the union. We're in alignment with the union. But I'll give you an example. We had a salary scale. Almost every year, 50 percent – half of the workforce – moved up in the salary scale. It was based on the number of hours that you work, which is tied to longevity. And because we're providing full-time work, it's almost like every year that people went up. And it was another quarter, another quarter, another quarter. And I loved it. And at that time, we were getting fairly steady increases in our rates. So you could do it. And we did not give very large, across-the-board increases. Across-the-board would be everybody gets $.20. We tried to focus more of the money on the steps of the salary scale. When we unionized, they didn't want that. Because all of the other companies were paying $7.00, $7.20 an hour or something like that. And they wanted us to be an example. So they wanted us to focus totally on the starting salary. In order to do that, we had to give up the salary scale. You couldn't devote any money to both. Or you couldn't devote enough money to the base wage and then also have money for the scale. We gave it up. And I think it was a big mistake (LHCSA Interview 1).

The cooperative has no pay scale (only remnants of people who had worked their way up to $9.50/hour). But the way it is now with the union, when a worker starts out with an hourly wage of $8/hour, there is no way to move up or increase their wage unless the company gets an increase in their rates, which hasn't happened since 2008. The union was interested in having a higher base rate at the expense of a salary scale because it wanted to pull the industry standard up.

> I also think the union thought – and I certainly would agree at the time – that they would be – they've got the political clout, et cetera. We all thought that they would've been more successful now in getting the system changed – ya know – to getting more dollars flowing to the workers. That's what unions do. They haven't been able to do it (LHCSA Interview 1).

Michael stressed, however, that the union has been successful in this last year (2011)—1199 and Cuomo came together to get the living wage passed for home health aides, so that there is parity with the city's personal care aides. More on this will be discussed in Chapter 5.

Conclusion

As described above, the home health care industry is closely intertwined with the welfare state. Changes in health care in the last several decades have led to an increase in the need for home health care services, sparking a huge growth in the industry. During this time, the business of home care has changed dramatically—while in 1980, seven percent of Medicare-certified home care agencies were for-profit, in 2007 this number increased to 70 percent.

The system of home care in New York City is a very complicated, fragmented and difficult to navigate. The complexity of this non-universal home health care delivery system stems from the multiple and piecemeal funding streams and the "third party government" that has evolved with multiple players and organizations in the system who regulate, fund, manage the care and hire the home health care workers. As we will see in the following chapter, this structure—from qualifying for Medicaid to finding the right home care program—makes for a very complicated system for patients and their families to navigate.

Unlike in other states, a complicated subcontracting system for the hiring of the aides has further muddled the system, which has led to increasing amounts of money being used from public sources for administrative costs, rather than on direct labor costs. While the city and state once used this industry to encourage the growth of small business, it has become increasingly difficult for small businesses on the contractor or subcontractor level to stay afloat. As will be discussed in Chapter 5, recent changes to the industry have accelerated this trend towards consolidation.

This chapter has explored the structure of the formal home health care industry in New York City. Keeping this in mind, in the next chapter, I turn to an analysis of the informal/gray

market part of the home health care industry—when, why and how do families and patients turn to the gray market to hire workers. In Chapter 3, I draw on qualitative interviews with family members who, at one time or another, had to rely on the gray market to provide care for their loved ones. I also draw on data gathered from interviews with industry experts on what they know about the gray market.

Chapter 3—The Gray Market

Introduction

Mary[13]—a college professor at the top of her career who lives in Brooklyn with her husband and teenage daughter—moved her mother into her home when she was no longer able to live alone. With a life full of other responsibilities, including a full time professorship, Mary all of a sudden had to manage her mother's care. At the time her mother moved in with her, she received social security, Medicare and Medicomp [which is a Medicare supplemental plan]. Since Medicare only pays for short-term care, Mary was looking at having to pay out of pocket for her mother's home care, since her mother's income was $210/month over the limit to be eligible for Medicaid (which would pay for long-term care). With the help of a geriatric care manager, Mary discovered that her mother could get Medicaid because of New York's flexible Medicaid eligibility rules, but she would just have to pay the difference ($210/month) in order to be eligible. Her mom was approved for a certain number of hours per week and was provided a home health aide through a nearby home health care agency. But as her condition worsened, Mary needed around-the-clock care for her mom. Her only viable option from her perspective was to pay one of her agency-employed care workers (the one woman who her mother had grown to trust and love) informally to stay past her official hours of agency work and pay her under-the-table, even though this was against the home care agency rules (Family Member Interview 1).

Alex was faced with managing the care of her mother at a much younger age than most. She was getting her life/career started after college when she discovered her mother, who was living with a boyfriend in Vermont had very rapidly declined—the diagnosis was early onset of

[13] I have changed the names of these gray market employers to maintain confidentiality.

Alzheimers disease. With her mom's boyfriend incapable of caring for her, Alex, over the course of a weekend, had her mother staying with her in Brooklyn and she quickly needed to find around-the-clock care. She started the process of applying for Medicaid to get her mother's long term care paid for, but has been unable to unearth all of the necessary documentation from her mother's life (who was not competent enough to help and who had been living in another state). Alex has had to conjure up $5600 a month on average for her mother's care in New York City. She chose to hire home care workers through an agency who could manage the care workers because her mother needed around the clock care—hiring home care workers informally would be less expensive but would be a full time job to manage. Having just come out of college, she could not afford to pay this and so has gathered other family and loved ones to help out with these costs. Recently she had her mom moved to a home in New Jersey that could care for her high needs but for the moment has given up on the Medicaid application since it has been so difficult to apply (Family Member Interview 2).

Rochelle was working on acquiring her Ph.D. while living close to her grandmother in Queens, NY. Her grandmother began to have mild dementia in 1996, but by 2000, her dementia became more severe and her symptoms worsened. Her grandmother was on Medicare and got a pension from her husband, pushing her money just over the eligible limit for Medicaid. After Rochelle's mother passed away unexpectedly, her grandmother's condition worsened and she contacted Visiting Nurses Service to help with home health care. Because her grandmother was ineligible for Medicaid (and Rochelle did not know about New York's flexible eligibility for Medicaid), she had to pay VNS out-of-pocket for care for her grandmother until she was able to transfer her grandmother's assets, after which time she was eligible for Medicaid, who then paid for the care (Family Member Interview 3).

Matt, the head of a home health care agency in New York City, decided to hire a home health care worker for his mother on the gray market (finding an individual to come in and care for his mother outside the agency structure, paying out-of-pocket). Although Matt ran a home care agency himself, he decided his best option was to hire informally because his mother was both not comfortable transferring her assets to her family and with his mother's illness came a resistance from her to have anyone other than a German au pair in her house. Matt, while he didn't agree with his mother's wishes, had to respect them and his only option was to hire informally. Despite his commitment to the formal home health care system, he found that the formal market just did not meet the needs of his family (Family Member Interview 4).

There are several themes that began to emerge during my interviews with individuals who were navigating the world of home health care in New York City for their family members. A theme that continued to come up was the difficulty of getting Medicaid. Some people described it as "having to be a detective" in order to find everything they needed just to be able to turn in the application—usually family members must scramble to find the information (that is not their own and that they had no role in before) from their loved one who is physically or mentally deteriorating. Others describe the system as being set up for people who are cheating the system—the process is demoralizing and the bureaucracies involved assume that people are dishonest when they come through the door. Many of the interviews I did were with people who were highly educated. Despite this fact, a common theme that respondents discussed was how difficult the process was—and this difficulty is not just in applying for Medicaid, but also in navigating the home health care system in New York City—from finding the right kind of

agency, to getting the right assessment of time needed from nurses, to finding an aide/attendant that was a good match for their family member.

If the person needing care is over the eligible limit for assets and income, family members have two options. First, if their income is only slightly over the eligibility limit, individuals may pay the difference (like Mary did for her mother) in order to still qualify for Medicaid, because the idea is that individuals will be depleting their assets on care, so they can be on Medicaid while doing so. However, many people do not know this rule and just assume they are not eligible. If this option is not available, individuals must go through a process of "spending down" (spending the money they have so as to be eligible for Medicaid) or transferring assets to another family member. In New York City, there is currently a 5-year look-back period for nursing home care—if you transfer your assets today, you can be eligible for Medicaid to pay for nursing home care in 5 years. Home health care in NY, however, has a "transfer today, sign-up tomorrow" rule that allows many middle/higher income individuals to get access to state-funded home health care services. These rules, however, are not obvious and I found that in my interviews there was still a lot of confusion about eligibility for Medicaid on the part of families trying to navigate the system and even among professionals working within the system. The reality with home health care is that if your parent/grandparent/loved one is not eligible for Medicaid, the costs of care can be crushing.

My respondents tended to refer to "the one"—or the one aide that was an angel—that came into their house and made their lives easier by connecting with their parent/grandparent. Family members also highlighted the difficulty of maintaining that aide in the household (sometimes their parent would get different funding and they would be forced to work with a different agency; sometimes they needed care beyond what they were approved for so they

would hire aides to stay longer, which is against home health care agency rules but is common practice). Many people talked about becoming an advocate for this special worker when the worker had problems with the agency in terms of not getting paid on time, not getting paid overtime, etc. In these instances, agencies were much more responsive to clients who made a request/complaint than to the worker.

The informal care economy—hiring on the gray market—is an important option for many families. Sometimes people aren't eligible for Medicaid (yet or ever) and must pay out of pocket for care (and it seems pretty typical that families oftentimes go through a period of needing to hire on the gray market while they are spending down or transferring their assets so they are then eligible for Medicaid). Hiring on the gray market is cheaper for families than hiring out-of-pocket through an agency—a family may pay $12/$15 an hour on the gray market, whereas they pay $18/22 for an agency home care worker (only about $8/10 of which goes to the home care worker in the form of wages, although most of these workers do get health insurance).

These stories and themes that came out during my interviews with individuals navigating the New York City world of home health care speak to the complexity of the system/industry itself. Paid for partially by federal/state/local funds and connected with several different programs, managed by certified home health agencies that don't actually hire and manage the aides and performed by aides/attendants whose employer is essentially a subcontracting hiring agency, individuals are forced into slogging their way through a difficult system in order to find care and often struggle to figure out how to pay for it.

The informal home health care market—or as people refer to it and I will refer to it from here on out—the "gray market," refers to the market in which families hire home health aides directly (not through an agency). This part of the industry is generally recognized as a significant

part of the market, but because of its underground nature, it is very hard to get a handle on how big it is, what shape it takes and who the workers and families are who use it. But what became clear during my interviews is that the patchwork nature of home health care coverage leads many families to hire on the gray market—whether to get the family through a period of spending down or transferring assets, perform all the needed care for a sick family member or to supplement what has been inadequately publicly funded and taken care of through an agency. This chapter explores my findings about the gray market in New York—through the eyes of home health care experts and employers as well as families navigating the home health care system. It examines how people enter for formal home health care market, why they make the care choices they do, and when people turn to gray market care.

Gray Market Care vs. Agency Care

First let me start off by stating the obvious—Medicaid and Medicare funded home health care is funded by the government while gray market home health care is funded by individual households. Access to formal, publicly-paid home health care is not universal—the poor and elderly/sick who are enrolled in Medicaid can access home health care as needed (although sometimes approved hours are less than what families think a patient needs); the elderly Medicare population may have access to home health care for a limited amount of time after an acute injury/sickness (but this may not be long enough for a patient to fully recover); private health insurance tends not to cover home health care costs although in a few cases, it does. So, unless you fall into these categories and sometimes even *if* you fall into these categories, you either go without needed care, you need to have a family member provide care or you must pay out of pocket for someone to provide care. Because of the structure of our social welfare state, it

is typically the middle/upper class who must (and frankly can) pay with their own money for care. Michael Elsas, owner of the worker cooperative in the Bronx stated: "when they're not eligible for Medicaid, and the Medicare benefit does not pay for long-term care… you're stuck. If we had a national insurance program, which hopefully we will, we will have long-term care that's available to the population. But right now it's not. So you're forced into that gray market" (LHCSA Interview 1, 21).

Individuals who are not eligible or do not have Medicaid or Medicare (or long-term care insurance or private insurance that pays for home health care) have two options to get paid home care in New York City—they can hire a worker on the gray market or they can hire through an agency. Hiring a worker directly through the gray market tends to be less expensive because you are eliminating the middle-man (both certified and licensed agencies in New York City). The typical rate I heard in my interviews was $12/15/hour for a gray market worker compared to $18/22/hour for an agency worker. Only $8-10 of the money one pays for agency care actually goes to the worker in wages and sometimes a couple more dollars for health insurance, depending on the agency. For someone who needs around 40 hours of care a week—to hire through an agency can be a crushing cost ($20 x 40 hours=800 x 52 weeks=$41,600 a year). For around the clock care, an agency could cost more than $150,000/year (Gross 2007). Needless to say, most middle class and even upper middle class families cannot afford to pay that. Medicaid will cover home health care expenses but only once an individual has transferred, spent down or exhausted all of their assets (which can happen pretty quickly considering the out-of-pocket expense of home care)—a policy some people call "a policy of pauperization" (Mundell 2008).

Agency home health care prices to the private market are regulated by something called the *charge to the public*. It is part of Medicaid/Medicare law at the federal level and it states that

you cannot charge the public less than the state or the feds are paying for that service. As one industry expert put it "if you think about it, if you are Medicaid and you are sitting in an office in Albany writing all these checks, right? And you have a licensed agency that is charging you $20 an hour for aide services and you are paying it but they are turning around and charging the public $15, you are cross-subsidizing that agency" (Worker Advocate/Policy Organization Interview 1, p. 11). Unless agencies were to lower their price to the state/feds (which many argue is not financially feasible given the current arrangement of the industry), their hands are tied in terms of making agency-run home health care more affordable to the private market paying out of pocket. Most of the agencies I interviewed had only a small slice of their company dedicated to private-pay clients. As one of the largest home health care agencies in New York City stated: "the gray market is still a huge competitor" (LHCSA Interview 4).

The Visiting Nurses Service (VNS), the largest not-for-profit home health care agency in New York City, has recently begun to expand their private pay business. A NYT article in 2007 reported that at VNS "15 percent of clients now pay out of pocket, an 11 percent increase over last year, and aides trained in wound care and vital signs are also learning to interact with doormen, use espresso machines or escort a client to the opera" (Gross 2007), signaling the increase in the wealthy hiring home health care workers through agencies. Potential for growth for home health care businesses in private pay clients can only really happen with people who can afford this care, or for those with less funds, for shorter-term, emergency-type care.

The gray market in home health care is very difficult to measure/get a sense of because of its underground and unregulated nature. Official worker surveys undercount gray market workers because most of these workers work under the table and their employer and workers do not pay taxes. So, no one really knows who exactly makes up the gray market, how big it is, what shape

it takes, etc. Home health care expert respondents in New York City agree that the gray market is significant in New York City, even if its size and scope are unknown. One agency employer told me her company had done some market research on the gray market because they are trying to expand the private pay section of their business. While she was not able to give me a percentage of gray market/formal market, she did estimate that of the private pay clients in New York City, 75% of them hire workers on the gray market, while 25% of private pay clients hire through an agency (LHCSA Interview 4).

Analysis below (see Table 3.1) gives us the official numbers that exist of self-employed vs. wage/salary earners for New York City for the categories of "Nursing, Psychiatric and Home Health Aides" and "Personal Care Aides." It is important to note that the Nursing, Psychiatric and Home Health Aides category includes both nursing and psychiatric aides (who are not a part of this dissertation), so the numbers here are not just for home health aides. The "self-employed, not incorporated" category represents the official count of gray market workers. Nursing, Psychiatric and Home Health Aides are 2 percent "self-employed, not incorporated," compared to 85 percent who are wage and salary workers for private and non-profit companies. This proportion of gray market workers would most likely increase if we looked at just home health aides (and excluded nursing and psychiatric aides who are more-likely institutionally-based). The self-employed, gray market personal care aides, represented 8 percent of the occupation, compared to wage/salary workers who work for a private company or a non-profit who account for 79 percent of the occupation. This data gives us a look at the official numbers that exist, but surely undercount gray market workers who are working under-the-table.

Table 3.1: Class of Worker by Occupation, New York City, 2009, 2010, 2011 ACS

	Nursing, Psychiatric, and Home Health Aides		Personal Care Aides	
	Count	**% within Occupation**	**Count**	**% within Occupation**
Self-employed, not incorporated	3371	2.2%	2473	8.2%
Self-employed, incorporated	417	0.3%	276	0.9%
Wage/salary, private	112,479	73.7%	18,761	62.5%
Wage/salary at non-profit	17,864	11.7%	4868	16.2%
Federal government employee	832	0.5%	203	0.7%
State government employee	3,822	2.5%	1269	4.3%
Local government employee	13,800	9.0%	2138	7.1%
Unpaid family member	63	0.0%	0	0.0%
Total	**152,648**	**100%**	**30,015**	**100%**

Mollenkopf and Polson analysis of 2009, 2010, 2011 ACS Combined Microdata Files. This data is filtered to only include workers in these occupations who are currently employed.

One important thing to note—often, even individuals with Medicare or Medicaid use the gray market to supplement their care because they do not always get the amount of coverage necessary. This happens often with Medicare, which has a time limit on home health care coverage (typically 90 days after release from a hospital or after an acute incident), even when the patient still needs care. "Medicare recipients are a big population that goes to the gray market—they may or may not be able to afford to pay but they're not at a Medicaid rate of poverty" (LHCSA Interview 4). When individuals (or their families) have the money and still need help beyond the approved hours from an agency, they will often either ask an agency-employed aide to stay extra hours or they will hire someone new on the gray market. One industry expert explained that "the patient may not have the resources but the daughter or son…they may live out of state, might say, it would make me feel more comfortable if you stayed a few more hours" (Worker Advocate/Policy Organization Interview 1, p. 13). In several of my interviews with family members of those who needed home health care services in New York City, it was common for families to ask agency-employed aides to stay longer or to come

in extra days for more money (under-the-table). Although most agencies discourage/have rules against aides working directly for clients, this type of arrangement occurs frequently, despite the fact that aides can be fired for such an offense (Worker Advocate/Policy Organization Interview 1). Families tend to ask agency-employed aides that they have built a relationship with and whom the patient feels comfortable with, instead of finding someone new on of the gray market. One daughter of an Alzheimer's patient discussed the stress of trying to hide this under-the-table relationship from other aides from the same agency who also worked with her mother (Family Member Interview 1).

One interesting thing about the home health care industry in New York City when you look at it as a whole is that the industry is very clearly and dramatically split. The formal/regulated part of the market is tightly regulated (both fiscally and regulation-wise) by the state and city of New York and the informal/gray market part of the market is completely unregulated and untouched by any government agency. NY is one of the most regulated states when it comes to formal home health care. For example, one industry expert compared New York to Texas.

> Let me give you an example of Texas. There are no requirements for training to do personal care. None. Literally pick up anyone off the street and put them in a home. That is crazy. No criminal research background check—that to me is just nuts. And no supervision. And I asked the Texas people, what about supervision and they said, let the patients supervise the aide. Well, that assumes the patient is capable or that there is a family member. I mean crazy kind of stuff. Now I'm not saying we shouldn't be regulated. I'm just saying that everyone needs to understand that that has added to the cost (Worker Advocate/Policy Organization Interview 1).

The formal market (agency-based) is a part of the social welfare state and is geared towards the poor while the informal market where families must pay out of pocket for care is necessarily used by the middle and upper class. One of the problems that one industry expert talked about for gray market employers was the difficulty of figuring out how to "do what is

right" for their employees—pay social security, Medicare, etc. for their aide. But it is complicated for private households to figure out how to pay taxes for their workers and while some do it, most employers decide it is easier to just hire their gray market worker under the table. Often workers themselves prefer to be paid under the table and in cash. But, as one industry expert describes the process above, she warns against another longer-term issue. By not paying taxes for these workers, "what we are dealing with is a whole, probably thousands of workers, who are not going to be Medicare eligible" in the future. "They are going to hit whatever age they are going to be and they are not going to have access…we are basically creating a new class of uninsured" (Worker Advocate/Policy Organization Interview 1, p. 15).

Turning to the gray market is not always an economical decision but is often times determined by "circumstance or initial access point." One agency employer said: "Oftentimes, families will turn to agencies when they need more care or they experience no-shows, or they got into the system through an agency because they were in the hospital and started with VNS (Visiting Nurses Service)" (LHCSA Interview 3).

One licensed agency administrator I interviewed in New York City had done research on the gray market because her company was looking to expand their private pay business. She said from their research they found three main reasons that individuals or families turn to the gray market for care. First, families often want to hire someone that is similar to them—someone from the neighborhood, someone that is culturally similar or a friend from down the street. Going through an agency essentially means letting strangers into your home, which many people are not comfortable with. As noted above, Matt ended up hiring on the gray market because his mother preferred German au pairs instead of other workers of different ethnicities who are employed by agencies (Family Member Interview 4). Second, a benefit of hiring on the gray

market for some families is that gray market workers can perform certain tasks that agency-employed workers cannot—like administering meds (LHCSA Interview 4). One agency employer said:

> In the senior market, many of the folks that need to hire privately is really for that custodial almost babysitting level of care but that need to administer the meds because you're at work or need to hook up the feeding tube because you're at work or whatever it is. And you can't get that because the licensed agency won't allow them to. They're just not licensed to do that (CHHA Interview 2).

The fact that agency-employed aides can't administer medication and do other certain medical tasks is a real problem for some families who live far away or work and are unable to administer the medication for their family member. And third, of course, is price—the gray market costs less for families and workers tend to make more per hour than at an agency (LHCSA Interview 4).

However, there are also benefits to hiring through an agency if you have the money. One such benefit is that a nurse officially supervises agency home health care workers. Several agency employers of home health aides told me that families contact them wanting to do agency private pay services because of medical problems that were not treated correctly by gray market home health aides who had no supervision and may or may not have had any medical training. One LHCSA employer said "You've got a lot of gray market people that are in there… and can look at somebody and say 'oh no, we've got to get you to the hospital,' but you then have a workforce that is unregulated and unsupervised. And basically there is risk for abuse" (LHCSA Interview 2).

Another benefit of hiring through an agency is that you can rely on consistent care—if an aide calls in sick or cannot be there, the agency finds a replacement and makes sure that someone is there with the sick/elderly person no matter what. The agency is also, perhaps, better equipped

to deal with high hour cases. Alex, whom I spoke about above, needed around-the-clock care for her mother and was unable to manage multiple aides to fill all the hours of coverage her mom required. Despite the cost, the only viable option for her was to hire through an agency because they took care of all the personnel issues and scheduling.

Most families find gray market workers through word of mouth—friends or social networks: oftentimes someone at one's church or synagogue, a neighbor or other friend might recommend someone who they had hired at some point. Wealthier households who have had household help their whole lives, might just train their housekeeper to become an aide (CHHA Interview 2). One leader from the Domestic Workers United and Caring Across Generations said that increasingly nannies and housekeepers across the country "are suddenly being called upon to take care of the ageing relatives of their employers" (Flanders 2012). When families don't have a personal recommendation for an aide, they will search on craigslist or look at advertisements in local ethic papers such as the *Irish Echo*.

Conclusion

In NY State, there are tight regulations of the formal part of the home health care industry. The only people guaranteed access to home health care services are the poor Medicaid population and the elderly on Medicare who need acute, short-term care. Even though NY has a generous Medicaid system (where people can transfer their assets today and get on Medicaid tomorrow OR people who have an income slightly over the eligibility limit can pay the difference and get on Medicaid)—huge chunks of people do not have access to or are unable to get publicly-paid home health care. The result—many people, from the lower middle class to the upper class are paying for services out of their own pockets—a cost that can very quickly eat

away the life savings of families. Medicaid does serve as a safety net for those who no longer have the personal means to buy quality care, but poverty has then become a necessary part of infirmity and care for many New York families and will increasingly become a reality for the baby boomer generation.

The least expensive option, and for many, the only option, is to hire home health care workers on the gray market. While this arrangement can work perfectly for many families, there are risks involved for both the worker and the families in hiring in a completely unregulated sector of the industry. Gray market workers may often make a higher wage than agency workers, but they have no job security, no benefits, no social security, no workplace compensation and also are more susceptible to abuse/isolation within the workplace (and higher prevalence of workplace violations as will be discussed in the next chapter). Families may hire workers with no medical or home health care training, which may ultimately put a patient in danger. Patients may be left with no care if a gray market aide can't make it or decides to leave the job.

One of the dangers of increasing financial strain on states and cities is the decreased funding of care for the poor and elderly. As we face increased austerity measures, we can only expect that patients will either go without needed care, there will be more financial strain on families who are having to take on more of the burden of care or individuals will go into hospitals or nursing homes with increased regularity as their condition worsens (ultimately making care more expensive for the state than if adequate care is given to a patient from the beginning). In Chapter 4, I turn to the experiences of home health care workers in New York City (those who are employed by agencies and private households) to better understand the workers, their jobs and the working conditions under which they work.

Chapter 4: The Workers and Their Jobs

Chapter 4 focuses on the thousands of workers in New York City who provide home health care services to sick and elderly New Yorkers. It begins with the demographics of the workforce. It then discusses home health care jobs—the hiring, training and the daily responsibilities of home care aides in New York City. It explores the existing labor law landscape for home care workers and examines these workers' wages and working conditions in this context. It asks why most aides, while they depend on this job as their sole income, earn so little money that they are eligible for and use public benefits to make ends meet. It explores the critical role that unions have played in organizing the workforce and the challenges they have faced in changing the industry and raising job quality. The union organizes workers, not with the typical employer/employee relationship, but with a much more complicated set of relationships, which includes layers of public funding. It explains recent shifts in SEIUs strategy and their role in the recent industry overhaul in budget session 2011. It concludes by reviewing some of the structural/institutional reasons why home health care workers in New York City remain low wage.

Demographics: Who is Doing this Caring Labor?

Home care is physically and emotionally demanding work that involves caring for the daily needs of a population dealing with sickness, disability, disease or dementia. It is hard work that is not well paid. In fact, the Institute of Medicine recently concluded from a study they did of the health care workforce that a "major factor in the deficit of direct-care workers is the poor quality of these types of jobs. Direct-care workers typically receive very low salaries, garner few

benefits, and work under high levels of physical and emotional stress." The report went on to report that wages were, in fact, so low, that they "do not appear to adequately support the recruitment and retention of these workers" (Seavey 2011, p. 28).

Who are the workers who do this type of work despite the low pay? During my interviews, several people described the home care aides whom they have hired/work with as having a calling to do this type of work (LHCSA Interview 1; Industry Association Interview 1). Many workers have cared for an elderly parent or grandparent in the past and value this type of intimate labor. Family members who have hired aides to care for their loved ones often talked about finding "their angel"—someone who came in and made their loved one feel comfortable, at ease and with a true companion. Several employers and experts who have worked in the field of home health care for decades have described this workforce as extremely dedicated to their patients—"an extraordinary workforce." As the president of the worker cooperative in the Bronx stated, "That's why you look and see and observe during transit strikes or during blizzards, the coverage that we get. In other words, this last winter, which was a very harsh winter [and] in some of the worst storms, we had only a 5 to 10 percent coverage [problem]. That means that 90 percent of those workers trudged through whatever. And they got there. They didn't get there on time. But they got there" (LHCSA Interview 1).

New York State has an estimated home care workforce of 213,000. Of those workers, 61 percent are employed in New York City (approximately 129,000 workers). The home care worker to institutional care worker (who work in nursing homes, etc.) ratio is higher for New York City than it is for the rest of the state, partially reflecting the fact that home care work is easier in a dense city with such a strong public transportation system. Home care work is notably

the largest occupational grouping in New York City, outnumbering teachers and retail salespeople (Rodat 2010).

Demographics on home health aides and personal care aides are difficult to get for New York City only. As one industry expert explained "We do not know what the full capacity of the trained home care workforce is in NY (i.e., number of aides working full-time, part-time, or trained and working in the gray market), nor do we track it in real time. This leads to over-corrections (i.e., training too many aides who don't get full-time work) as well as failures to "fix" the system (e.g., training in foreign languages)" (Rodat email 1/13).

Analysis of the 2009-2010-2011 ACS Microdata does give us some insight into the home care workforce in New York City. Below (Table 4.1) breaks down demographics by occupation—nursing, psychiatric and home health aides[14] and personal care aides—for New York City workers. The workforce is primarily female (91 percent of nursing, psychiatric and home health aides and 92 percent of personal care aides are women). Over half (51 percent) of nursing, psychiatric and home health aides are non-Hispanic black. That 51 percent is made up of 28 percent Afro-Caribbean, 16.6 percent African Americans and 7 percent African (not shown). Twenty-seven percent are Hispanic, over half of which are Dominican (15 percent) (not shown). Personal care aides are largely non-Hispanic black (44 percent) (made up of 20 percent African American, 19 percent Afro-Caribbean and 4.2 percent African) (not shown). Dominicans make up more than half of the 28 percent Hispanic personal care workers (at 15 percent) (not shown).

The majority of workers in these occupations are foreign-born. Seventy-seven percent of nursing, psychiatric and home health aides are foreign born—of this 77 percent, over half (43

[14] These workers include nursing and psychiatric aides who are not a part of this study. Further disaggregation to just look at home health aides was not possible.

percent) are foreign-born citizens. Seventy-two percent of personal care aides are foreign-born, over half of which are foreign-born citizens (36 percent). This means that more than half of these workers speak a language other than English at home (56 percent of both nursing, psychiatric and home health aides and personal care workers). Nearly two-thirds of nursing, psychiatric and home health aides have a high school diploma or less (65 percent) which is similar to personal care aides—68 percent have a high school diploma or less (68 percent). The majority of workers get to work by bus or subway (67 percent of nursing, psychiatric and home health aides and 66 percent of personal care aides). It is important to note, however, that many of these workers have some college, a BA or more (35 percent of nursing, psychiatric and home health aides and 32 percent of personal care aides).

The median personal income for nursing, psychiatric and home health aides in New York City was $22,361 a year. Twenty-seven percent of these workers earned 1.5 times the federal poverty threshold or below. Personal care aides earned on average less than that, with a median yearly income of $19,200 per year. Thirty-three percent of personal care aides earned 1.5 percent of the poverty rate or below.

Table 4.1: Demographics of Employed Nursing, Psychiatric and Home Health Aides and Personal Care Aides in New York City, 2009-2010-2011

	Nursing, Psychiatric and Home Health Aides		Personal Care Aides	
	Count	% within Occupation	Count	% within Occupation
Sex				
Male	13,380	8.8%	2,523	8.4%
Female	139,268	91.2%	27,492	91.6%
Race				
Non-Hispanic White Alone	17,794	11.7%	4,020	13.4%
Non-Hispanic Black	77,173	50.6%	13,105	43.7%
Hispanic	41,468	27.2%	8,407	28.0%
Non-Hispanic Asian	14,296	9.4%	3,890	13.0%
Non-Hispanic American Indian/Other	1,917	1.3%	593	2.0%
Nativity and Citizenship				
Native Born Citizen	34,934	22.9%	8501	28.3%
Foreign Born Citizen	64,891	42.5%	10,829	36.1%
Foreign Born Non-Citizen	52,823	34.6%	10,685	35.6%
Household Language				
English	67,767	44.4%	13,270	44.2%
Other	84,881	55.6%	16,745	55.8%
Education				
No high school diploma	51,288	33.6%	11,160	37.2%
High School Diploma or GED	47,372	31.0%	9,332	31.1%
Some College	37,810	24.8%	7,180	23.9%
BA or more	16,178	10.6%	2,343	7.8%
Transportation to Work				
Auto, Truck, Van	29,208	19.1%	4,494	15.0%
Bus or Trolley bus	44,008	28.8%	8,354	27.8%
Subway or Elevated	57,721	37.8%	11,563	38.5%
Walked only	10,464	6.9%	3,064	10.2%
Other	11,247	7.4%	2,540	8.5%
Household Income				
Under $15K	13,510	8.9%	3,322	11.1%
$15-35K	43,028	28.2%	8,872	29.6%
$35-75K	56,942	37.3%	11,958	39.8%
Over $75K	39,168	25.7%	5,863	19.5%
Poverty				
1.5 times the poverty threshold or below	40,700	26.7%	9,795	32.6%
Over 1.5 times the poverty threshold	111,948	73.3%	20,220	67.4%
Median personal income (not family/household)	$22,361		$19,200	

Mollenkopf and Polson analysis of 2009, 2010, 2011 ACS Combines Microdata Files. This data is filtered to only include workers in these occupations who are currently employed.

Home Health Care Occupations

There are two main types of home health care occupations: home health aides and personal care aides, both of whom care for the sick, elderly and disabled. The funding source essentially drives the two occupations. As one employer of home health care workers explained: "so for example, a home health aide is a worker who works or can work on a Medicare case—Medicare is a federal program and they provide some level of homecare services. Those services are usually on the acute level of care… if you're a 75-year-old who had a hip fracture. You were in the hospital for three weeks. Now you're coming home. So you're entitled under the Medicare program to get six weeks, eight weeks, ten weeks of services of a home health aide. The rest of the world really is what we refer to as PCAs… personal care attendants [aides]. That's home attendants, personal care attendants, PCAs, et cetera... The Medicaid program primarily pays for PCAs" (LHCSA Interview 1). Home health aides have additional training to assist patients with more medical interventions, including assisting with medication, monitoring vital signs and caring for patients needing acute care (acute care is defined as "a pattern of health care in which a patient is treated for an episode of immediate and severe illness or disability, such as the treatment of injuries after an accident or other trauma, or during recovery from surgery. Unlike chronic care, acute care is often short-term" (ABC News 2006). Personal care aides are not required to have extra medical training and often take care of patients who need chronic care or longer term care (not acute care). These workers provide companionship and assistance with activities of daily living such as bathing, dressing, toileting, meal preparation, eating and housework.

There are more than 80,000 home health aides and 47,000 personal care aides employed in New York City (PHI 2010). These occupations are projected to generate the greatest number of new jobs in coming years (see Table 4.2 below).

Table 4.2: Top Six Occupations Generating the Most Jobs in New York City, 2006-2016

	Occupation	No. of positions to be added	Percent Change
1	Home Health Aides	33,400	41%
2	Personal and Home Care Aides	16,200	34%
3	Retail Salespersons	13,300	12%
4	Customer Service Representatives	9,600	15%
5	Accountants and Auditors	9,400	16%
6	Registered Nurses	9,300	13%

From "PHI State Facts: New York City's Home Care Workforce" PHI, NY. December 2010.

Required Training for Home Health Care Workers

The state of New York regulates the amount of hours of training that a home health aide and a personal care aide need before being hired in these positions at regulated agencies—this is in compliance with federal regulations as well. The training for a home health aide is 75 hours. The training for a personal care aide who provides any assistance with personal care (like dressing, bathing, and toileting) must have training of 40 hours (officially known as Personal Care Aide II). Personal care aides who only provide housekeeping and homemaker services (Personal Care Aide 1) are not required to have formal training (Rodat 2010a). Training programs are either administered by a licensed home care service agency (some LHCSAs will only hire workers who have completed their own training program) and some training programs are run independently. Before being employed, workers must have a criminal record check and establish that they are legal residents of the US, which excludes undocumented immigrants and those with criminal records from employment in the formal home health care market in New York City. Some of these people turn to the informal market to get jobs.

There have been several problems with New York's training system because it is decentralized and overseen by several state agencies (including NYS Department of Health and the State Education Department). As one report states: "The collection of varied training policies and programs, overseen by a variety of state agencies, poses numerous obstacles for employers, women seeking employment, and for consumers in search of qualified assistance" (Rodat 2010a, p. 3). One such problem, recognized by the state in 2008, was that some home care training certificate programs had been selling certificates to people who had not actually completed training—they were then hired and worked as home health care aides even though they had not gone through the appropriate training (Rodat 2010a). After the state discovered this problem, they created a registry of all people who begin, finish or drop out of a training program in NY. Employers are now required to check the registry to make sure the people they hire are in the registry. The public has access to certain information on this registry, including whether a certain aide completed the training program.

Another problem that employers identified was that some workers would come to them with a certificate from a training center that was not registered with the state—sometimes these illegal outfits would charge workers up to $500 to go through a training program that was not legitimate. Workers in this case are not qualified to get a job and often lose the money they paid for training (LHCSA Interview 5, p. 19).

Turnover

Turnover has been a big problem in the home health care industry—some people blame it on the quality of the workforce, others the low wages and difficulty of the work. One employer noted that when a person has a choice between continuing to do the difficult work of providing

care for someone or working at McDonalds, a lot of people, especially younger people, end up choosing to work at McDonalds because it is easier work for the same amount of money (LHCSA Interview 6). The turnover rate for the industry remains at about 40-50%, but there is variation within the industry depending on the program and company. Visiting Nurses Service, the largest home health care company in New York City, prides itself on cutting their turnover rate essentially in half—now their turnover rate is about 24-25%. The Home Care Cooperative has gotten their rate even lower to about 20% (although it has been as low as 15 percent) (LHCSA Interview 4; LHCSA Interview 1). Joe Campanella, who is the director of the Home Care Council of New York—the industry association for LHCSAs who have contracts with the city of New York (and employ personal care aides)—reported that LHCSAs with city contracts have an extraordinarily low turnover rate for the industry—on average only 10%. The reason they have such a low turnover? Campanella reports it is because workers are better trained, get better pay, benefits, pensions, time off and vacation (Industry Association 1).

The Legal Landscape of Home Health Care Jobs in New York City

Before we examine what the working conditions and pay are for home health care workers in New York, it is important to first understand the legal landscape that these workers operate under. Unlike most other types of workers, home health care workers are sometimes not covered by the basic employment and labor laws. Because of the Companionship Exemption of the Fair Labor Standards Act (FLSA) home health care workers have been excluded from federal minimum wage and overtime laws. This exemption defines the majority of home health aides and personal care aides as merely companions, not workers, and therefore denies them basic federal wage and hour protection. FLSA, enacted in 1938 excluded domestic workers from

coverage. These workers, however, were extended coverage in 1974 (this included maids, nannies, cooks, landscapers, etc.). During these 1974 debates around coverage issues, Congress carved out two exemptions to coverage of the minimum wage and overtime: 1) "casual" babysitters (persons who perform babysitting on a non-regular basis) and 2) "companionship service" workers (or those who care for the elderly or disabled at home). Unfortunately, Congress did not detail what they meant by companionship services. However, the National Employment Law Project did research into committee reports from 1974 and analyzed discussions that led lawmakers to implement this companionship exemption. Companionship only included people who provided company to an elderly person (not performing tasks such as cleaning, cooking, toileting, bathing—tasks which most home care workers today perform). Also, the 1974 inclusion of domestic workers into FLSA coverage was meant "to include within the coverage of the Act all employees whose vocation is domestic service. People who will be employed in the excluded categories," by contrast "are not regular breadwinners or responsible for their families' support" (Sonn et al 2011 p. 4). Today, however, the majority of home care workers do this work as their primary job and rely on the wages earned here for their families' basic needs. "One survey in New York City reported that 81 percent of home care workers served as the primary breadwinner for their family" (Sonn et al 2011, p. 6).

Despite changes over the last 30 years in the home health care industry and the increasing formalization of this workforce, these workers are still excluded from FLSA even when employed directly by a home health care agency. Under the Clinton administration, the Labor Department proposed narrowing the companionship exemption but Bush halted this process when he came into office. In 2007, the US Supreme Court in the case Long Island Care at Home, Ltd., et al v. Coke refused to overturn the regulation, but said that the Labor Department has the

policymaking ability to deal with the exemption through regulations. President Obama has recently expressed his support for reworking the exemption to cover home health care workers, but the Labor Department has not acted swiftly enough to make this change before the end of his first term.

Fifteen states across the US currently cover home health care workers by their state wage and hour laws. New York State is one of them, filling in some of the legal gaps left by the companionship exemption. State minimum wage law covers all home health aides and personal care aides, regardless of who their employer is. Overtime applies to home health aides and personal care aides, but it is less than the federal standard of 1½ times your hourly rate for each hour worked over 40 hours in a week. In NY, these workers are only entitled to 1 ½ times the minimum wage per hour (which is currently $7.25/hour) over 40 hours in a work week, even if their hourly rate is higher (Seavey 2011). In 2010, overtime protections were strengthened for home care workers employed directly by private households (gray market workers) due to the New York Domestic Worker Bill of Rights, a historic win for domestic workers in NY. This new legislation ensured that gray market workers are entitled to 1½ times their hourly wage (Sonn et al 2011 p. 17). For home health care workers who live in their employers home, overtime only applies after 44 hours of work a week (rather than the usual 40).

Pay and Working Conditions of Home Health Care Workers in New York City

Home health aides, despite increased required training and responsibilities on the job, earn on average $8.00/hour while personal care aides earn $10.00/hour because they are covered under the New York City living wage (this disparity is being rectified and home health aides have recently won the right to a living wage as well—this will be discussed further in Chapter 5).

As the chart below outlines, these wages, even the living wage, falls significantly below the city's median wage ($20.77/hour), making these workers some of the lowest paid in the New York City economy (see Table 4.3 below).

Table 4.3: Wages for Home Health Care Workers in New York City, 2009

Occupation	Hourly Wage
Home Health Aides (starting wage under collective bargaining)	$8.00
Personal Care Aide (starting wage set to New York City Living Wage)	$10.00
All occupations in the city, median wage	$20.77

From "State Facts: New York City's Home Care Workforce." PHI: New York. December 2010.

Below I analyze data from the 2008 Unregulated Work Survey[15]. Out of 1,432 low-wage workers interviewed for the survey in New York City, 153 of them were working as home health care workers at the time of the survey (this is 10.4% of the total New York City sample). This is a strong enough sample to get basic violation rates and job characteristics for home health care workers in New York City. I have also conducted analysis of violation rates and job characteristics by type of employer—for agency-employed workers and gray market workers. Here, the sample is much more limited (especially for the gray market) because of low number of cases. We sampled 133 agency employed workers and 20 gray market workers. Due to the lack of data on the gray market, I have included some of the findings below as indicative (and are pretty consistent across cities when the N is larger) but they must be interpreted with caution (i.e. the N is so low that most differences in violation rates reported below are not significant for the gray market/formal worker comparison—statistically significant differences are noted on the tables with *). Also, in the survey, we unfortunately did not collect enough information from workers to be able to determine what their occupation was—so this sample includes both home health aides and personal care aides (not disaggregated).

[15] All numbers reported from analysis of the 2008 Unregulated Work Survey have been weighted. See footnote in Chapter 1, Methodology section for more information about the weighting.

First of all, the demographics of the sample (see Table 4.4), tend to be consistent with the qualitative data (as well as the ACS demographic analysis in Table 4.1) gathered about the New York City workforce. The workforce is overwhelmingly female (95 percent) . The majority of workers in New York City are foreign-born (66 percent), but the vast majority of these foreign-born workers were authorized (there was only 1 percent unauthorized foreign-born residents, reflecting the tight regulations on citizenship for becoming a home health care worker in the city). The workforce we sampled was racially diverse 30 percent Asian or other, 26 percent Latino/Latina, 23 percent African American or black and 22 percent white.

The educational level of the home health care workers we sampled mirrored that of the New York City demographics cited above—63 percent of workers had a high school diploma or less. That leaves, however, a solid 37 percent of workers in these low-wage jobs who have attained some college or more. This, perhaps, reflects the fact that these home care occupations often serve as an entry-level job for immigrants who are new to this country and whose educational credentials don't translate into higher paying jobs in New York City. Home health care workers in New York City also tend to be older workers. Nearly 61 percent of our sample was over the age of 46. And 53 percent of workers had worked as a home health care worker for 5 or more years.

Table 4.4: Demographics of New York City Home Care Worker Sample			
	All home care workers	Agency-employed home care workers	Gray market home care workers[16]
N	153 (10.4% of full New York City sample)	133	20
Gender			
Male	5%	5%	6%
Female	95%	95%	94%
Immigration Status			
US born citizen	34%	32%	58%
Foreign-born authorized	66%	68%	39%
Foreign-born unauthorized	1%	1%	3%
Race/ethnicity			
Latino/Latina, or Hispanic	26%	26%	33%
Black or African-American	23%	23%	22%
Asian or other	30%	33%	12%
White	23%	18%	32%
Education			
Less than High School, no GED	29%	30%	26%
High School Graduate, GED	34%	37%	17%
Some College or more	37%	33%	57%
Age			
18-25	7%	5%	20%
26-35	15%	18%	2%
36-45	17%	18%	14%
46+	61%	60%	64%
Industry Tenure			
Less than a year	11%	11%	11%
Between 1 and 4 years	36%	30%	71%
5 years or more	53%	59%*	19%*

Polson data analysis of 2008 Unregulated Work Survey.
* The star indicates that the differences between the agency-employed home care workers and the gray market home care workers are statistically significant at <.05.

In our sample, home health care workers had a median wage of $9/hour (gray market workers had a higher median wage at $10/hour which is actually lower than what I heard in

[16] Please note that this data analysis is exploratory given the low N of 20 for grey market home care workers.

qualitative interviews about the gray market which put the going rate for gray market workers at $12-$15/hour) (see Table 4.5). The median hours worked in the workers' last week of work were 40 hours (slightly higher for gray market workers at 43 hours per week). The vast majority of home health care workers had just one employer in the last week (88 percent)—agency-employed workers were more likely to have one employer (92 percent) than gray market workers (67 percent), who were more often juggling multiple employers. Ninety percent of home health care workers are paid by the hour (rather than by the week, bi-weekly, monthly), although this varies greatly by type of employer—agency-employed workers were paid hourly 97 percent of the time compared to gray market workers who were paid hourly only 51 percent of the time. A similar trend holds true for the pay method—83 percent of home health care workers are paid by check—97 percent of agency-employed workers and zero percent of gray market workers. That is, one hundred percent of gray market workers surveyed were paid in cash. In another analysis of the pay type and method within the low-wage labor market, we found that being paid in cash and non-hourly were correlated with higher rates of workplace violations (Bernhardt et al 2009), which is consistent with what I have found here.

Table 4.5: Job Characteristics of Home Care Workers in New York City			
	All home care workers	**Agency-employed home care workers**	**Gray market home care workers**
Median wages	$9/hour	$9/hour	$10/hour
Median hours worked last week	40 hours per week	40 hours per week	43.4 hours per week
Median number of employers last week			
1 employer last week	88%	92%	67%
2 employers last week	11%	8%	32%
3+ employers last week	0%	No cases	1%
Pay type			
Hourly	90%	97%*	51%*
Non-hourly	10%	4%*	50%*
Pay method			
Cash	17%	3%*	100%*
Check	83%	97%*	0%*

Polson data analysis of 2008 Unregulated Work Survey.
* The star indicates that the differences between the agency-employed home care workers and the gray market home care workers are statistically significant at <.05.

Many home care workers, like other low-wage workers in New York City, are experiencing workplace violations (instances where employers are breaking established labor laws) at their jobs. The current minimum wage in New York City is $7.25/hour (it was $7.15 at the time of the 2008 Unregulated Work Survey)—every home health care worker, regardless of his or her employer, is required to be paid at this hourly rate. Home health care workers in New York City had a minimum wage violation rate of 8 percent. When you compare this with minimum wage violation rates in other occupations, we find that the home health care workers actually have a comparatively low minimum wage violation rate (the average of all low-wage workers in New York City was a violation rate of 21 percent). Out of 18 low-wage occupations surveyed in New York City, home health care has the third lowest minimum wage violation rate (behind residential construction workers at 2 percent and teacher's assistants and center-based child care workers at 6 percent). Comparatively, topping the list on the higher range of minimum

wage violations, laundry and dry cleaning workers had a violation rate of 57 percent and childcare workers in private households had a violation rate of 50 percent (not shown) (Bernhardt, Polson and DeFilippis 2010). Home health care's lower violation rate is surely due to the fact that the majority of home health care workers captured in this survey are a part of the strongly regulated and tightly financially controlled agency system in New York City. It is important to note, however, that when you analyze minimum wage violation rates for home health care workers by type of employer, the picture changes. Agency-employed home health care workers have a minimum wage violation rate of 7 percent, compared to gray-market workers who have a minimum wage violation rate of more than double that (at 17 percent) (see Table 4.6). The higher minimum wage violation rate experienced by gray market workers is partially the result of the minimal regulations or methods of enforcement for private household workers.

Table 4.6: Workplace Violation Rates for Home Care Workers in New York City

	All home health care workers	**Agency-employed home health care workers**	**Gray market home health care workers**
Minimum wage violation	8%	7%	17%
Overtime violation	82%	80%	100% (low N)
Off-the-clock violation	85%	83%	96%
Meal break violation	85%	85%	79%
Pay stub violation	19%	5%*	95%*
Retaliation	32%	30%	N/A
Any pay violation last week	68%	63%	100% (low N)

Polson data analysis of 2008 Unregulated Work Survey.
NOTE: The percentage reported is the percentage of workers who experienced a violation who were at-risk of a violation (for example, a worker could only be at-risk for an overtime violation if he/she worked more than 40 hours in the last week).
* The star indicates that the differences between the agency-employed home care workers and the gray market home care workers are statistically significant at <.05.

Overtime violations for home health care workers in New York City, include instances in which the employer did not pay 1½ times the minimum wage for each hour an employee worked over 40 hours of work a week (for live-in workers, overtime was triggered at 44 hours). All home health care workers in New York City had an overtime violation rate of 82 percent[17] (80 percent of agency-employed workers and 100 percent of gray market workers experienced an overtime violation). Compared to other low-wage industries in New York City (which all together had a violation rate of 77.3 percent), home health care workers had a relatively high overtime violation rate (Bernhardt, Polson and DeFilippis 2010).

Home health care workers experienced very high instances of off-the-clock workplace violations (the worker worked before or after their shift without being paid for that time). Eighty-five percent of all home health care workers had an off-the-clock violation (83 percent of agency-employed workers and 96 percent of gray market workers). This off-the-clock violation rate is more than the low-wage worker average in New York City of 69 percent (Bernhardt, Polson and DeFilippis 2010). Probably because these are caring jobs, home health care workers often have a hard time leaving their shift in a timely manner if they are in the middle of helping their client. Employers, however, are required to pay workers for this time and typically don't.

Eighty-five percent of home health care workers experienced a meal break violation (workers had their meal break denied, shortened or interrupted). And nearly one-third of home health care workers experienced retaliation from an employer after making a complaint or trying to organize a union at their job (32 percent). Illegal retaliation included having hours or pay cut, being fired or suspended, being threatened with deportation or firing and facing harassment of abuse from an employer. Family members who hired through agencies that I interviewed

[17] This percent includes only workers who were at risk for an overtime violation (i.e. worked more than 40 hours last week).

reported that often times workers had problems with the agencies they worked for and it wasn't until family members made a complaint that agencies were responsive. Many families said they acted as an advocate for their aides (Polson interviews).

New York state law requires that all workers—whether they are paid by check or in cash—must receive a pay stub documenting their earnings and deductions. This law makes it easier for workers to make a case for non-payment of hours, lack of overtime pay, etc. should the need arise. As one might expect, however, the violation rate for home health care workers varied tremendously by the type of employer. All home health care workers had a pay stub violation rate of 19 percent—5 percent of agency-employed workers experienced this violation (again, a clear result of the strong regulations in this part of the industry) vs. 95 percent of gray market workers. This is closely connected to the pay method used by employers in these parts of the home health care labor market. Ninety-seven percent of agency-employed home health care workers are paid by a check vs. zero percent of gray market workers are paid by check (see Table 4.5).

What do all of these workplace violations translate into? Less money for home health care workers who already earn meager wages. In fact, 68 percent of home health care workers experienced some type of pay-related workplace violation in their last week of work[18] (63 percent of agency-employed workers and 100 percent of gray market workers). This high pay violation rate among home health care workers is significantly higher than the average pay violation rate among the rest of the low-wage labor market in New York City (which was 54 percent) (Bernhardt, Polson and DeFilippis 2010).

[18] This measure includes the following violations: minimum wage, overtime, off-the-clock and illegal deductions from workers paychecks.

As the data above show, workplace laws essentially are not functioning as they should. Although minimum wage violations tended to be lower than in other low-wage industries, home health care workers had higher rates of overtime and off-the-clock violations, which leads to lesser pay for these workers caring for the elderly or disabled. What is even more striking is that workers who are working in the gray market consistently have higher rates of workplace violations than agency-employed workers—making it clear that workers in these jobs are at a higher risk of losing wages through the violation of workplace laws that they should be protected by.

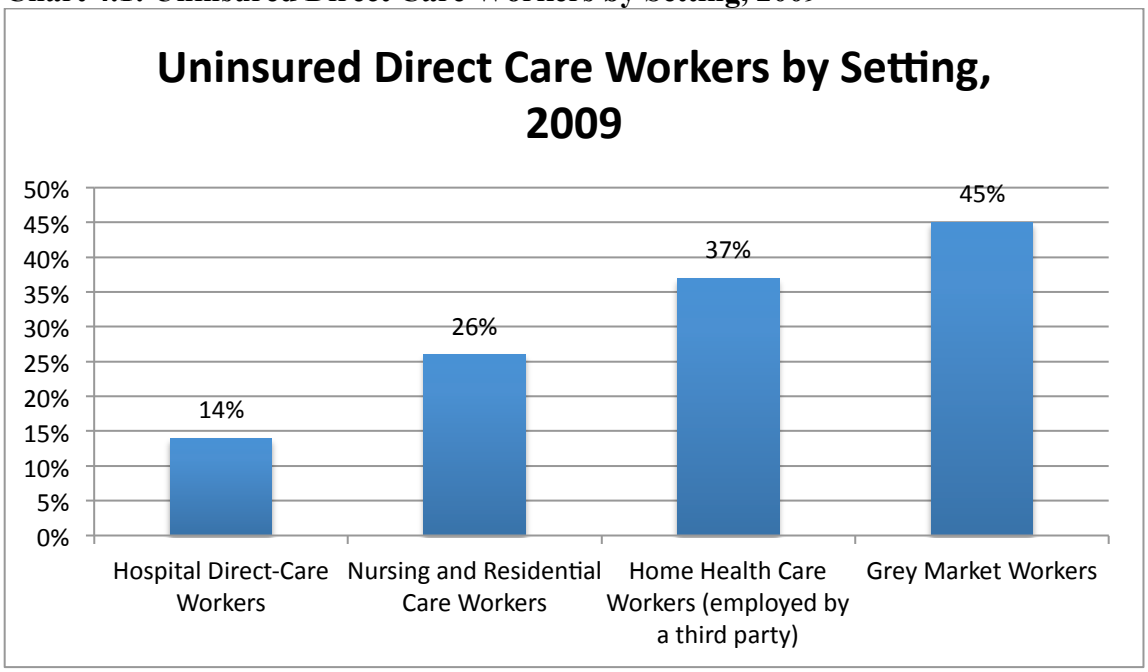
While the reasons why gray market workers fare worse than agency-employed workers cannot be teased out of the data, there are several reasons why they are more at risk for these types of violations. There are both weaker regulations for gray market workers and, perhaps more importantly, fewer mechanisms of enforcement for workers employed by private households. Gray market workers lack an intermediary who can systematically manage the employment relationship—this means that for gray market workers every employment relationship is different, standards essentially do not exist and workers are on their own to negotiate the details around their employment. Private-household employers may not understand their legal obligations or may not have the resources to pay adequate wages and abide by workplace laws (but may have no other choice because they do not have access to publicly-paid home care). Also, while the informality of the employment relationship can be beneficial to all parties involved, private households hiring workers directly to come into their homes may lead to boundaries between workers and families merging.

Health Care Coverage

Home health aides and personal care aides more often go without health insurance than the average working age (under 65) American (18 percent had no health insurance compared to 27 percent of nursing, psychiatric and home health aides and 31 percent of personal care aides). Personal care aides were definitely the worst off in terms of health care coverage compared to other formal direct care workers nationally (Seavey 2011). That said, in New York City, because most personal care workers are covered under New York City living wage laws, they are offered health insurance (or they get a higher hourly wage to compensate). But, it is important to recognize that even in instances where employers offer health insurance, the health insurance deductibles and premiums are often too expensive for home health care workers to afford given their meager earnings, or if the worker does not work enough hours, they will not qualify for benefits. Nationally, only 47 percent of direct-care workers report having employer-sponsored insurance (compared to 68 percent of US workers). And according to the findings of the 2007 National Home Health Aide Survey, when you look at home health aides in particular, only 38 percent had employer coverage (Seavey 2011).

Another national analysis of direct care worker's insurance coverage by setting (hospital, nursing and residential care, home health care and private households) found that institutionally-based direct care workers had a much higher rate of coverage than those workers in the home setting (see Chart 4.1). Fourteen percent of hospital direct-care workers did not have coverage, 26 percent of nursing and residential care workers and 37 percent of home health care workers (employed by a third party). Home health care workers who are directly employed by private households (gray market workers) were found to have an uninsured rate of 45 percent nationally (Seavey 2011).

Chart 4.1: Uninsured Direct Care Workers by Setting, 2009



Data from Seavey 2011 (PHI analysis of 2010 Annual Social and Economic (ASEC) Supplement, Current Population Survey.) Note: The percentage of gray market workers here was from 2009.

The Unregulated Work Survey data shows that 57 percent of home health care workers in New York City were offered health insurance by their main employer. This, of course, also varies tremendously by type of employer—65 percent of agency-based home health care workers were offered health insurance compared to 0 percent of gray-market workers (not shown) (Polson data analysis).

Home health care workers' use of public benefits

Despite the fact that home health care workers rely on their job for their livelihood, it came out during my interviews that many home health care workers are using and often rely on public benefits in order to make ends meet. The Paraprofessional Health Institute found that, nationally, households with direct care workers showed a very high level of reliance on public assistance—46 percent of these households were receiving some sort of public assistance (36

percent were on Medicaid and 29 percent were receiving aid for food or nutrition) (accessed from http://phinational.org/policy/states/new-york/ on 2/4/13). Over fifty percent (50.4 percent) of personal care aide households rely on public benefits such as Medicaid, food stamps, cash welfare or assistance with energy, housing or transportation (Seavey 2011).

The Paraprofessional Health Institute (PHI) is researching this dynamic further, but Carol Rodat, a PHI researcher and expert in the field told me about several workers she knew who were juggling public benefits and their jobs. About one woman she said: "She knew exactly how many hours she needed to cut… 'I can't work that extra hour or I'll lose my New York City housing.' They have it down to a science. So no matter how many of us outside of this dynamic try to tinker with it, there is a logic built in of self-preservation that is always functioning" (Worker Advocate/Policy Organization Interview 1, p. 21). So, although keeping workers' wages low may seem to save money, government actually ends up cross-subsidizing the workers through public benefits.

The role of unions in improving home health care jobs

We can't discuss the plight of home health care workers in New York City without examining the crucial role that unions have played in organizing these workers over the last decade or so. Home health care workers (along with home-based child care providers) have been said to be "changing the face of organized labor" in the US. These workers gained national attention in 1999 when 74,000 workers in Los Angeles voted to enter the Service Employees International Union (SEIU)—this was in fact the largest successful union drive since the sit-down strikes of the 30s (Boris and Klein 2008, p. 32).

In New York City, SEIU 1199 is the dominant union for home health care workers—AFSCME 1707 and SEIU 32BJ also have contracts with some LHCSAs in the city, but their numbers are minimal compared to SEIU. New York City's Personal Care Program was unionized in the 1980s—eventually, in 2002, these workers won the right to a living wage ($10/hour plus benefits). Today, 40,000 personal care aides are covered under 1199's Home Aide contracts (Rodat 2012b). It was more difficult, however, for the union to organize the subcontracted part of the industry (LHCSAs who contract with CHHAs, Lombardis and Managed Care programs)—in 1993 they began organizing workers from their first subcontracted employer—People Care—which did not result in a contract until 2005. Most of the organizing and unionization of this segment of workers (home health aides who work for subcontracted LHCSAs) didn't pick up steam until 2003. The union focused on how they could have more money trickle down from the CHHAs, who were getting $18 to $20 an hour to the LHCSAs who got sometimes as little as $12/hour and paid the workers even less than that (typically minimum wage).

The unions' starting strategy for subcontracted employers was to organize the LHCSAs that did business with Visiting Nurses Service (the largest CHHA in New York City), who were somewhat supportive of their unionizing drive. While VNS was willing to raise their rates to the LHCSAs, they did not require that the subcontractors be unionized (Union Interview 1, p. 5). VNS represented about 60% of the market at this time and many LHCSAs only did business with them (Union Interview 1, p. 1/2).

The goal of SEIU was to get density in the home health care market, "because that's how you ultimately have the power to affect wages and benefits. If you're a minority and you're just succeeding in kind of making a set of employers more expensive…[it] is going to put them at a

competitive disadvantage" (Union Interview 1, p. 3). Today, SEIU estimates that about 85-90% of the personal care aides (in the city program) are organized into a union (mostly SEIU). The subcontracted sector (the home care aides) has been more difficult to organize. At their peak, the union estimated that they had organized about 60% of the market in New York City. But, in the past 5 or 6 years, this percentage has dropped significantly because of growth in the non-union segment of the industry (they estimate that the unions only have about 50% density now) (Union Interview 2, p. 6/Union Interview 1, p. 2/3). Below a union official from SEIU describes the part of the industry that was growing rapidly in New York City:

> Basically it was a set of operators, a lot of them came out of the nursing home industry or the adult home industry, who realized that certified agencies, in particular, didn't have a lot of oversight so if you got a certified agency license you essentially determine how many hours you were going to give a client so you could just make a little bit of money on every hour and do a lot of business. Even though the rates from the state were lower, they gave a huge amount of hours so that expanded the industry significantly but also reduced the union (Union Interview 1, p. 2/3).

A lot of these new certified agencies (CHHAs) and licensed agencies (LHCSAs) operated out of Brooklyn and many of them were Hasidic and Russian-run agencies. The state became concerned because since the rise of these entities, the cost of the home health aide program nearly doubled over the course of 5 or 6 years. Agencies that people in the industry had never heard of were serving a huge volume of clients very suddenly. These agencies were outliers in terms of the amount of hours they would give to a patient with the same type of diagnosis as someone in another agency. The CHHAs would determine the number of hours a patient requires, and CHHAs are the only program (until last year) that had carte blanche on giving out hours—other programs have caps on the number of hours allowed (Union Interview 1, p. 2/3). This corruption, as the state saw it, was one of the main reasons that they targeted the home health care industry during their 2011 budget cycle.

While organizing this population of workers can be challenging, SEIU noted that they have been successful in organizing the workers despite the invisible and decentralized workforce. But the real challenge for them has been trying to raise standards—"being able to raise their standards has been kind of a long struggle which is really the result of the subcontracting system and that you know the agencies compete with each other on price. There's a lot of agencies that are licensed by the state so it's very easy, even if an agency agrees to spend more money for them to then be undercut by a cheaper agency" (Union Interview 1, p. 8-9). For this reason and because they have had more success organizing workers employed by bigger businesses, SEIU has been a driving force in trying to consolidate the industry.

SEIU has taken on several strategies over the years. They went on strike in 2004, which resulted in contracts with a number of VNS subsidiaries (Union Interview 1), but others have referenced this strike "as a miserable failure" since many home health care workers did not feel comfortable leaving their patients (LHCSA Interview 1, p. 5). They have targeted CHHAs to pass down more money to the LHCSAs. They have targeted the state and succeeded in committing 200 million dollars over four years as recruitment of retention money, which went to CHHAs and other home health care programs in order to fund those contracts (however, while some programs/companies passed the money on to subcontractors, others did not and the state did not have the mechanism to enforce it).

SEIU's most recent strategy was to focus on consolidating the industry, getting rid of the bad players and shifting more patients over to managed care. Faced with the state's budget deficit, SEIU helped to steer the cuts towards the bad players in the industry who had impacted union density (Union Interview 1) rather than opposing the cuts, which they assessed as inevitable. In order to accomplish that, they launched a public campaign, which pushed the

narrative of bad certified agencies running up the state's tab (SEIU had a website dedicated to this where they highlighted the offenses of these employers). The union's interests dovetailed that of Cuomo as documented by an article in the New York Times:

> At least one of Mr. Cuomo's major investigations dovetailed with 1199's interests. [The states] inquiry, "Operation Home Alone," cracked down on home health care aides who were not properly licensed, along with the agencies that employed them and the schools that provided them with bogus certifications… While similar prosecutions began during Mr. Spitzer's tenure as attorney general, they were accelerated by Mr. Cuomo's office, and he backed legislation to force all home health care aides to be entered into a state registry, a potentially powerful organizing tool for the union… The union has cheered Operation Home Alone; 1199's president, George Gresham, has praised it, and the union was among the groups that sent a letter to state officials urging them to pass the measure. On a Web site that 1199 opened, homecarecrisis.org, Home Alone is cited for cracking down on disreputable service providers (Hakim 2010).

Cuomo's office said SEIU 1199 had no role in the "Operation Home Alone" effort, but as the article asserts, Cuomo and 1199's interests coincided, setting the stage for SEIU's push for reorganizing the home health care industry to pay for wage increases.

SEIU has learned through their negotiating that licensed agencies (LHCSAs) which are subsidiaries of nursing homes or CHHAs or other larger institutions tend to pay more during negotiations with unions. This is partially because larger agencies have more ability to pay more and because licensed agencies that are connected to larger institutions are more concerned about their reputations and public image than smaller LHCSAs. As one SEIU researcher told me: "When you have this competitive subcontracting, the ONLY thing that matters in their business is cost" (Union Interview 2, p. 5).

Michael Elsas, president of Cooperative Home Care, explained that while the union has had some successes, it has inhibited the potential growth for workers in his company. At one time, the coop was able to create a sliding pay scale for workers, rewarding them for time worked in the company—allowing senior workers to get increasingly more pay the longer they

stayed. But, the union urged them to give up their pay scale, which they did, in order to raise the base rate across the industry. In some ways, Michael regrets this move (getting rid of their sliding scale) because today workers who have worked for their company for decades have no way of increasing their pay, unless they get a rate increase from the state (LHCSA Interview 1, p. 14).

The Impact Subcontracting has on Workers Wages

Before 1995, rates for home health care services were set by cities and counties in New York State according to historical costs, including everything that was determined to be "reasonable." However, in 1995, the state allowed counties to begin negotiating their own rates, which made LHCSAs compete for contracts, which pushed wages down for personal care aides. New York City responded by passing the living wage law, which covered workers who were under public contract. These living wage ordinances, however, did not affect home health aides who were not contracted by the city (but by CHHAs or another program). The managing agency (CHHA's, Lombardis and Managed Care) had more power to force LHCSAs hand at accepting their new rate for an hour worth of an aide's time. Table 4.7 (taken from Rodat 2010b) documents the Medicaid rates to CHHAs, their payments to LHCSAs and the hourly wage of workers (both home health aides and personal care aides).

Table 4.7: Examples of Home Care Service Medicaid Rates vs. Hourly Wages for Home Care Workers, New York City				
	New York City Average Hourly Medicaid Rates	**Payment to LHCSA for Hour of Service**	**New York City Hourly Wage**	**Occupation**
Home Health Aide Service	$20.19	$12.50	$8.00 (entry level)	Home Health Aide
Personal Care Service	$17.48	$17.48	$9.96	Personal Care Aide

Sources: Home Health Aide Service payments from December 2009 DOH Home Health Care Reimbursement Workgroup Interim Report, Appendix D, reflect 2007 payments for CHHA "D" and Subcontractor "3." Personal Care Service payments from FY2009 Cooperative Home Care Associates HA/HSK rate setting sheet. The personal care aide wage increased to $10.00 per hour (New York City living wage) beginning in July of 2009.

As you can see in Table 6, the subcontracting relationship in the Home Health Aide Services significantly eats away at the rate that LHCSAs are receiving to pay their workers. The Personal Care Services, however, skips the middle-man (the CHHA, Lombardi or Managed Care Company) and the Medicaid rate goes directly to the LHCSA so they are better positioned to pay their workers well. The city bills the State separately for their administrative expenses. It is important to revisit here what was discussed in Chapter 2—research performed by SEIU analyzed how CHHAs made their profit—their profit comes primarily from the home health care services that they contract out—the money they take for administrative costs appears to be more than they actually need.

As Rodat documents here:

> Ultimately, having a large home care industry with hundreds of separate entities providing aide services has not been positive for the state's home care aides or their employers. With the industry structured this way, contractors (i.e., CHHAs and other clinical home care programs) are able to use competitive bidding to suppress prices, obtain discounts for volume, and arrange the terms of payment. This in turn compresses wages for home care aides, keeping tens of thousands of New York families in poverty or near-poverty. In most other states, the aide is employed directly by the agency or organization delivering clinical services… The low wages for home care aides reflect the

> industry's reliance on public funding. Medicaid reimbursements, along with subcontracting arrangements, compress wages that might otherwise rise as a result of increasing demand for services. (Rodat 2010b).

The chart below (Table 4.8) (1199 PPA 2009) outlines the amount of the Medicaid rate of pay that is spent on administration and general expenses when you combine these costs for both the CHHA and the LHCSA, which totals to nearly 50% of the Medicaid rate. The fact that 50% of the Medicaid rate in these subcontracted relationships goes to direct labor costs compared to the city's Personal Care Program where about 89% of the Medicaid rate paid to LHCSAs is spent on direct labor costs, highlights the problem with the subcontracted system in New York City (Rodat 2012b). The two-tiered system of delivery in New York City means there is less money available to go to the workers.

Table 4.8: Two-tiered Structure Diverts almost 50% of Medicaid Rate

Administrative and General Expenses			
CHHA			% of CHHA Rate
	Overall Rate	$19.10	
	Admin & Gen	$6.81	35.7%
LHCSA			
	Rate	$12.30	
	Admin & Gen	$2.55	13.4%
	Home Health Aide Pay	$7.50	
	Total A & G	**$9.36**	**49.0%**

Source: "Reforming NY's Home Care System" October 14, 2009, put together by 1199 PPA.

As Carol Rodat explained in her affidavit:

> In the HHA [Home Health Aide] market, the State pays a Medicaid rate to Contractors. The Contractors then subcontract with LHCSAs to provide aides to perform the work. CHHAs take into account their own general and administrative expenses and profit, where applicable, when negotiating with the LHCSAs. As with any business CHHAs seek to purchase HHA [Home Health Aide] services at the lowest price. There is a

> segment of the LHCSA industry that competes on a price basis by underbidding in order to win contracts. LHCSAs also take a percentage of the rate they receive from the CHHAs to cover general and administrative expenses and profit. The result of subcontracting and price competition in the subcontract market is less than 50% of the Medicaid rate paid to CHHAs and then subcontracted to LHCSAs, is spent on direct care labor (Rodat 2012b).

Conclusion

Industry experts have described home care workers overwhelmingly as people who really value caring for others. The workforce is primarily female, mostly people of color, largely foreign-born and tend to be older. Workers are employed in two different occupations—as personal care aides and home health aides. These occupations are projected to generate the greatest number of new jobs in coming years. Training of home health care workers is required for anyone employed by a licensed home health care agency, but training has historically been decentralized and unorganized—the result being an increase in fraud, including some workers paying (and losing) large amounts of money to be trained by an uncertified program. Turnover remains high in this low-wage industry (40-50 percent), but it is lowest in the city's Personal Care Program (10 percent) which offers workers better training, benefits, living wages, pensions and time off.

While FLSA still excludes home health care workers from basic labor protections at the federal level, the state of New York has minimized this gap through state law inclusion—home health care workers are covered by state minimum wage laws, overtime laws and other workplace laws. However, the fact that these workers are legally covered does not guarantee that employers are abiding by these legal standards. As analysis of the 2008 Unregulated Work Survey shows, although minimum wage violations tended to be lower than in other low-wage industries, home health care workers had particularly high rates of overtime and off-the-clock violations, which leads to lesser pay for these workers caring for the elderly or disabled. What is

even more striking is that the data suggests workers who are working in the gray market consistently have higher rates of workplace violations than agency-employed workers—making it clear that workers in these jobs are at a higher risk of losing wages through the violation of workplace laws that they should be protected by. This trend is even more pronounced when looking at health care coverage—65 percent of agency-based workers were offered health insurance by their employer, compared to 0 percent of gray market workers (Polson data analysis). These low-wages, poor working conditions and high prevalence of workplace violations in both formal and gray market home health care jobs lead to jobs that are unable to sustain workers and their families. Many (nearly half of home health care workers) are forced to utilize public benefits in order to make ends meet.

Unions have played a key role in trying to improve home health care jobs in New York City—while they have had some success in achieving union density and improving benefits, it has been harder for unions to increase wages (although they were successful in achieving parity for home health aides in the recent 2011 budget cycle). One of the main problems in improving wages is the fact that they are wrapped up in the state budget. That, combined with the subcontracting structure of care in New York City, which increases administrative costs, has made it difficult for unions to untie more money for workers.

In the following Chapter I begin to explore the changes occurring in the industry as a result of the 2011 budget decisions where the state targeted the home health care industry to begin to reduce state Medicaid spending. Experts agree that these industry transformations will have a big impact on the structure of the industry, on workers and on patients throughout the city.

Chapter 5: Consolidation—Recent Changes to the Industry in New York City

> I mean, I said it to them the other day. I was like 'Guys, you took this business away from the little thugs down here in Brooklyn that have abused it, and you've given it to the mafia for God's sakes. What are you doing? What are you doing?' (CHHA Interview 1—talking about discussing the shift towards Managed Care with state officials overseeing the changes, 11-12)

This chapter explores recent changes to the structure of the home health care industry in New York City and the expected changes this will have on workers. The 2011 budget cycle resulted in a redesign of the home health care system in New York State spurred on by the state's desire to cut costs, eliminate fraud and grow managed care. Largely because of SEIU's organizing efforts, home health aides won a wage increase over the course of several years to reach parity with home health attendants' living wage of $10/hour. Below I will examine the ways in which the industry is changing, the forces behind that change and the impact this will have on patients and workers.

A Problem with Fraud

An SEIU researcher in New York City was digging into the dynamics of the home health care industry to better understand how the industry functioned and who the main players were in order to impact the strategy of 1199's union campaign. As part of his research, he accessed publicly available information using the Freedom of Information Act from the NY State Department of Health and examined data on the home health care industry—information that agencies were required to report. What the union found was the establishment and growth of new for-profit CHHAs that "entered the market and started growing insanely fast—doubling in size every year" (Union Interview 2, p. 1). In fact, between 2004-2007 Managed Long Term Care and

for-profit CHHA's accounted for 96% of the growth in the workforce (this also happened to be the most unorganized sector of the industry by unions) (1199 PPA 2009). The biggest new actors were six CHHAs in Brooklyn that "started out with just a sliver of the market [and grew] to about half of it—both growing in terms of number of patients they were billing for and for number of hours per patient" (Union Interview 2, p. 1). The SEIU researcher said there was nothing in the data that suggested these patients were any sicker than any other patient—they were just being approved for more hours (leading to more money for the CHHAs). Again, CHHAs are the only type of agency in New York City that controls the number of hours a patient gets (except the city program, in which the city controls hours given)—all others have a cap or limit on the hours they are able to bill for. These actors took advantage of this to grow rapidly in the industry.

Statewide there has been a moratorium on new CHHAs being formed, so how did these CHHAs get established? They were established through a loop-hole in the law stating that "special needs CHHAs" could be established—special needs CHHAs serve special needs populations, like those with mental illness, mental disability or certain ethnic constituencies that are currently not being adequately serviced. All six of the Brooklyn-based CHHAs got established as special needs CHHAs. But because of weak enforcement and follow-up, these CHHAs got established under the assumption that:

> they were only going to be serving mentally disabled children and then they were going out and serving everybody. The regs were written very vaguely and they were not being enforced stringently—that has been a big problem because there has not been an active state enforcement of providers…NY [state] is pretty low on the list [of states] in terms of a functioning oversight process" (Union Interview 2, p. 1).

The enforcement agency is the NY State Department of Health. New York City Human Resources Administration enforces the Personal Care Program and has been said to have tight

enforcement and oversight, but NY State Department of Health much less so. These new special needs CHHAs were billing the state at $15/$16/hour, less than the more reputable agencies (VNS charges the state $20) so questions arose about how they made their money. They made their money by doing a tremendous amount of volume. The union saw this as a major problem—these new actors were taking all the patients and lowering standards, facilitating a race to the bottom. So when the state began to say they wanted to cut rates based on the lower rates they were paying these new special-needs CHHAs, the rest of the industry would have been penalized for these bad apples, ultimately reducing the amount of money available for workers. After years of the union's warning signs, the state rates dropped and the CHHAs "really, really got hit hard" (Union Interview 2, p. 2).

The six special needs CHHAs that cropped up in recent years were Excellent Home Care, Extended Home Care, Revival Home Health Care, Family Care, Americare and Girling—most were based in Brooklyn or at least were highly concentrated there and these agencies tended to serve Russian and Jewish populations. Out of these six agencies, four of them have multi-million dollar fraud suits against them. The fraud included faking home health care certifications—agencies would print the certificates for home health aides that have actually not completed the required 76-hour certification program to become aides in New York City. Sometimes agencies would not give the required hours of practical training hours, and sometimes the training schools themselves were not properly certified (Union Interview 2). The other problem is that these CHHAs gave patients more hours than was found to be the case in the rest of the industry (so while the hourly rate was lower than other CHHAs, the number of hours they gave patients was much larger). The state became increasingly concerned about these special needs CHHAs

because they got big very quickly and basically doubled the cost of the program in 5 years (Union Interview 2).

The Politics Behind the Redesign

The main political driver behind the redesign was economic. New York State has the most extensive and most expensive Medicaid program in the US. Spending per enrollee was $9,056 in 2009, compared to the national average of $5,337. The state spends more of its own money on Medicaid than most other states and is one of the few states that require its cities and counties to contribute to Medicaid funding (Russ 2012). In Andrew Cuomo's own words: "It is of compelling public importance that the State conduct a fundamental restructuring of its Medicaid program to achieve measurable improvement in health outcomes, sustainable cost control and a more efficient administrative structure" (accessed from http://www.health.ny.gov/health_care/medicaid/redesign/ on 2/20/13).

SEIU 1199, who played a large role in the redesign, realized that the writing was on the wall for state Medicaid cuts. They decided to get on the side of the state to crack down on the fraudulent part of the industry so there would be more money to invest in workers. And in that sense, they were successful. Because of the large focus on the budget deficit during 2011, the union made the decision "that it made more sense to make the state crack down on that part of the industry" than it did to try and organize it (Union Interview 1, p. 2/3). One union official said:

> We didn't think it was a sustainable model. The people who were in that business are people who Medicaid is essentially their business. They find programs where they can like, you know, in an adult home where they can make a bunch of money in the Medicaid program or transportation. When somebody cracks down they have to find somewhere else. So we thought that was kind of inevitable given the amount of money that was being spent and that money should get reinvested in other parts of the industry. So the state did

> put in this cap this year…it's saving the state a couple million dollars (Union Interview 1, p. 3/4).

During the 2011 budget cycle, they tried to identify areas of the industry that not only were non-union, but also that were not a good use of public funds. Realistically the union thought any proposal that was going to be taken seriously by the state had to be one connected to saving the state money, not putting more money into it. This lined up with their analysis that part of the industry (that was also non-union) was taking advantage of the system and costing the state money. SEIU launched a campaign called the *Homecare Crisis: Hall of Shame* to highlight the fraudulent parts of the industry. The union launched this public narrative about the bad certified agencies that had been running up the tab—it was "just kind of a way to say to the providers that you either have to distance yourself from this or get tarred" (Union Interview 1, p. 9/10). SEIU believed that reorganizing the industry in certain ways would be more advantageous for their workers (Union Interview 1, p. 7/8). Carol Rodat (of PHI) recalls spending an afternoon with the leaders of SEIU with Rick Surpin (of Independence Care System), convincing them why they needed to support the growth of Managed Care. A 2 hour meeting turned into a 4 hour meeting and by the end, 1199 was convinced that higher wages for home health aides needed to come with the consolidation of the industry and the shift towards Managed Care management (Worker Advocate/Policy Organization 1, #2) (more on this below).

After being elected in 2010 with significant union support and with a senior SEIU officer as a close confidant, Governor Cuomo created a Medicaid Redesign Team (MRT) to identify ways to contain state Medicaid costs (Cuomo wanted to cut state Medicaid costs by about $2.85 billion) (PHI 2012a). The MRT was charged with the task of "engaging Medicaid program stakeholders for the purpose of conducting a comprehensive review of and making recommendations regarding the Medicaid program, which shall include specific cost saving and

quality improvement measures for redesigning the Medicaid program to meet specific budget reductions for Medicaid spending" (Rodat 2012b). The MRT was made up of "the major political players that have controlled the Medicaid program in New York, namely hospitals, insurers and labor unions" (de Jung 2011). Notably, the MRT included only one consumer seat, occupied by Lara Kassel, the coordinator of Medicaid Matters New York (MMNY) (de Jung 2011). The home care industry was represented by Carol Raphael (of Visiting Nurse Service of New York) and Eli Feldman (of Metropolitan Jewish Health System which operated a CHHA, Lombardi and Managed Long Term Care Program) and their job was to help structure changes in the home health care industry. SEIU, VNS, MetJewish were a part of the 27 member team, but none of the industry associations representing home care agencies became a part of the Redesign Team.

SEIU was well-positioned to be a central part of this team, partially because the union was central to Cuomo's election because of contributions, union members turning out to vote en masse and operating a phone bank in support of Cuomo (Worker Advocate/Policy Organization Interview 1, #2). Dennis Rivera (the former President of 1199 and current senior advisor to the International President of SEIU) served as the co-chair of the MRT (State of New York Supreme Court). As one union official put it: "This is kind of an opportunity for everyone to come to the table and to shape the change that's kind of inevitable. I think the home care associations just tried to fight and they lost on all of the issues they were pushing," including parity (Union Interview 1, p. 9/10). As one LHCSA employer said: "Cuomo and the union… did come together on the living wage thing. And that's why it passed" (LHCSA Interview 1, p. 18).

It is important to digress a little here to give some background on the political strength of SEIU 1199, which is key to understanding how they were able to succeed in passing the living

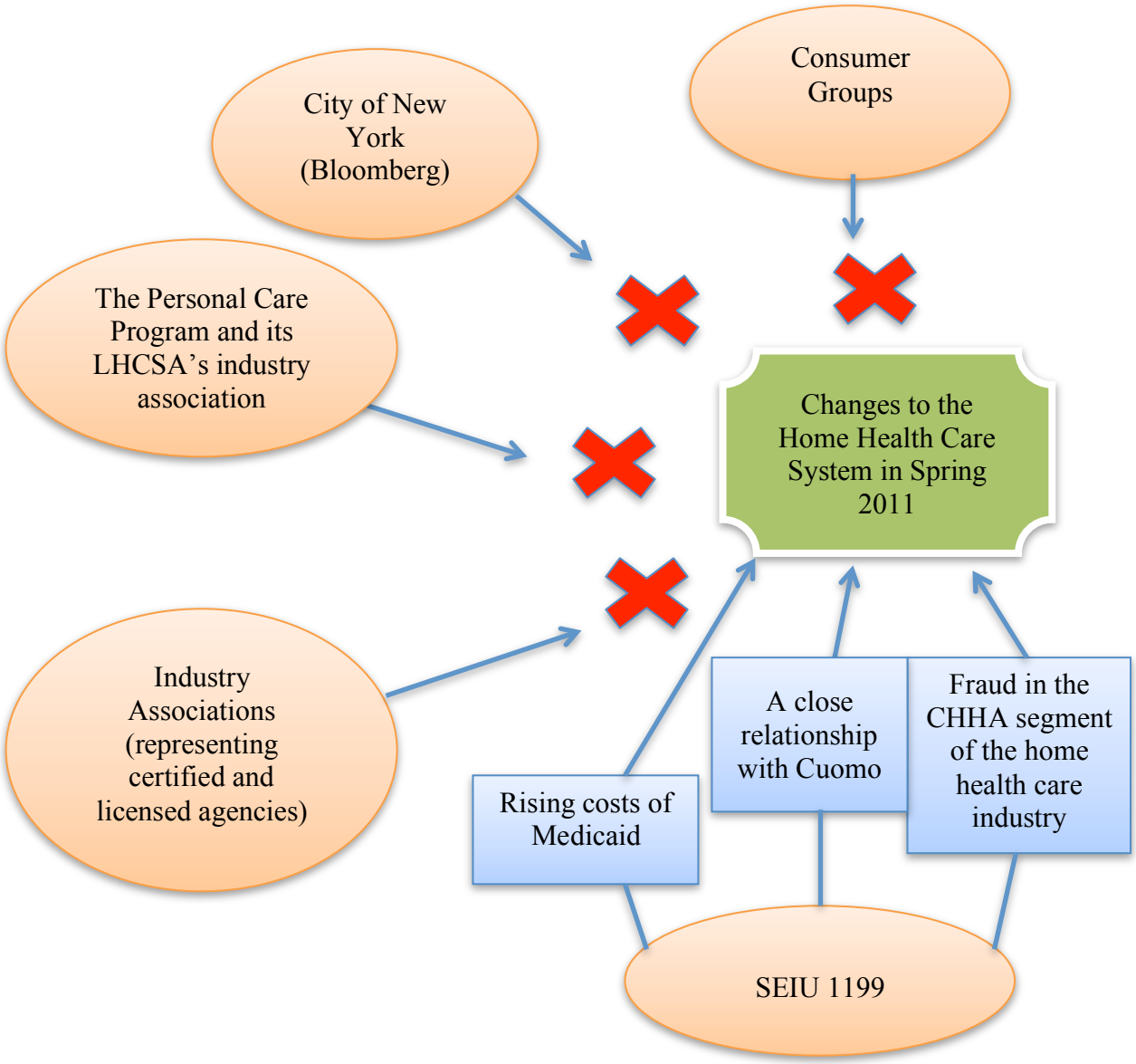
wage for home health aides. New York labor unions have been able to advance their interests by making strong political connections and coalitions in the city and state power structure (Hauptmeier and Turner 2007). Much of this political power has been attributed to labor unions' influence in elections (actual and perceived) (Mollenkopf 1992). SEIU 1199 is one of those unions that has significant political connections and influence in Albany and within the city. As Hauptmeier and Turner describe in their article "Political insiders and social activists",

> Despite a loss of influence compared to the 1960s and 1970s, unions along with political parties are unrivaled at voter mobilization. With their highly regarded phone banks and organizers, New York City's unions are well aware of their appeal to politicians. After successful contract negotiations for seventy thousand members of SEIU/1199 in 2002, in the biggest collective bargaining agreement ever signed in the U.S. health-care industry, Dennis Riviera wrote in a letter to SEIU members: "We also won this agreement for another very important reason—our political strength.... When tens of thousands of our union members volunteer to get out the vote on election day, our elected officials notice. And they respect us" (Hauptmeier and Turner 2007).

With nearly 400,000 members in five states (New York, Florida, Massachusetts, New Jersey and Maryland) plus Washington DC, 1199 SEIU United Healthcare Workers East is the largest local labor union in the world, representing workers in home health care, hospitals, nursing homes, pharmacies and clinics. Their political clout can be traced, in part, to the last three political directors at SEIU: Jennifer Cunningham, Patrick Gaspard, and Kevin Finnegan. Cunningham was once labeled "the most powerful unelected woman in New York politics" by the *Daily News*, and now works for a lobbying firm in Albany and continues to lobby for SEIU (City and State 2008). Cunningham is a long-time friend of Andrew Cuomo (since 1983) and has since provided informal campaign advice to him during his run for governor in 2010. Patrick Gaspard, Jennifer's successor as 1199's political director, was deemed by the Huffington Post as "the most brilliant strategist and organizer you have never heard of" (Stein 2009). Bloomberg's right-hand man Kevin Sheekey referred to Gaspard as "the best political mind in his generation

and maybe the nation" (Stein 2009). He left SEIU to work as "Obama's Karl Rove" and is currently the Executive Director the Democratic National Committee (Labor Union Report 2012). Kevin Finnegan, SEIU's current political director comes with much experience with the start of his political career working for Harvey Milk who became the first openly gay elected official in the US. He also served as Hillary Clinton's political director in her first US Senate race in 2000 and has worked at UNITE (Katz 2009). These political insiders have helped SEIU 1199 East become one of the most powerful unions nationally, but certainly in NY politics.

Chart 5.1: The Politics Behind the Home Health Care Changes, 2011. The chart below represents the main actors in the home health care industry in New York City (in orange) and the politics behind the redesign. The red X's represent a blockage of some kind, which resulted in groups not having much influence on the redesign. The blue boxes represent the circumstances that allowed SEIU to successfully influence (and even shape) the changes that occurred in 2011. Consumer groups were blocked from influencing the debate because the changes proposed to the system were so complex and their concerns were primarily around eligibility and decreasing services. Bloomberg in the City of NY was ambivalent about their ongoing role in administering the Personal Care Program and so did not fight hard for their program. The Personal Care Program itself, although I was told during interviews that they did not agree with the dismantling of the program, were politically unable to fight for it because they take their cues from the city. The LHCSA Industry Association fought for its program but was a very small, one-person organization and had little power to influence state politics. The Industry Associations representing certified and licensed agencies across the state had a losing strategy, which was to resist all changes being made, which landed them with no representation on the MRT. The union, on the other hand, took advantage of several circumstances in order to influence the 2011 changes. First, they accepted the fact that the state would have to make cuts to Medicaid in 2011. They capitalized on and exposed a public narrative about the existing fraud in the industry, since the fraud was occurring in a non-union segment of the industry and was rapidly growing. These circumstances, combined with SEIU's close relationship with Cuomo, put them in a good position to influence the debates for the benefit of home health care workers.



NY State's Medicaid chief, Jason A. Helgerson (formerly Wisconsin's Medicaid Director who was brought to NY specifically to help cut costs) has called "the redesign 'a multiyear march away from fee-for-service' that he says will flatten the spending rate even as the population ages" (Berstein 2012). The state instituted a cap for Certified Home Health Agencies, which basically forces them to go back to the state-wide average for hours per case instead of being a fee-for-service program (Union Interview 1, p. 2/3). They did this because they found that these agencies were huge outliers in terms of the number of hours they would give a patient for the same type of diagnosis.

NY State did not see CHHAs as the only problematic entities running up the state's tab—they also targeted the city's HRA Personal Care Program, which they believed were too generous in the number of hours that they gave out. The state thought the city was giving too many 12-hour cases and so they established this narrative to set the stage for shifting the city's patients (who tend to be the sickest and the most in need of high-hour care) to managed care (Union Interview 1, p. 9 & 19). The LHCSAs in the Personal Care Program and their industry association argued, however, that their patients were the sickest and were actually in need of all of those hours. Nearly everyone interviewed from the city program shared this view and believed they were doing justice to the patients who needed the most care.

However, in budget cycle 2011 NY State put forth a proposal to move many of the patients from the city's Personal Care Program into managed care. 1199, although they may not have agreed with it wholeheartedly, was willing to compromise on this in order to get parity for home health aides. But, surprisingly, Managed Care had very little political role in getting the changes implemented (in the favor of managed care). The companies involved were neutral about the shift (Worker Advocate/Policy Organization Interview 1, #2). Although they didn't

push for this shift, larger agencies like VNS, Met Jewish and Health First were willing to go along with the change (including the wage increases for home health aides) because it would grow the managed care part of their business (Union Interview 1, p. 9/10).

Resistance to these changes, including the shift of patients from the city's Personal Care Program to managed care, was met with little effective resistance. Mayor Michael Bloomberg and Deputy Mayor Linda Gibbs did not put up a fight because, one informant told me, they were ambivalent about the state taking over the oversight from the city—they thought perhaps it was a good thing to give up some of the responsibility of running such a large personal care program (Union Interview 1, p. 11).

Administrators from the Personal Care Program of the HRA were very tightlipped in their interviews with me, making sure not to say too many negative things about the changes since they take their mandates from the Mayor and could not really lobby to keep the program intact. Licensed agencies that do their business with the city in the Personal Care Program, however, were very vocal in their interviews with me on how these changes are really bad for business and bad for patients. They tried to fight for the Personal Care Program. Joe Campanella, the director of the Home Care Council of New York City (the industry association representing LHCSAs with city contracts) noticed that the hours in his cases were going up, but he was losing cases—he found they were going to managed care companies (Industry Association Interview 1). He also reported that managed care was actively recruiting patients from the city's Personal Care Program—specifically cherry picking healthier patients and dumping those patients with higher needs back into the city program. As a report from the Home Care Council of New York City reports:

> The 'dumping' of high hour cases from the MLTCP (managed care) and the 'cherry picking' of low hour cases have severely impacted the average weekly hours delivered in

> personal care—high hour cases now comprise the majority of the program. For example, over 50 percent of patients in the Home Attendant Program [Personal Care Program] receive 50 or more hours each week. The City's Home Attendant Program is not 'generous'; instead, this population is sicker and needs services to remain safely at home. MLTC programs do not want this population unless they receive a higher reimbursement structure to make their bottom line profitable (Home Care Council of New York Coty, 2011).

However, these LHCSAs, many of which are smaller non-profit community organizations do not have much political clout, as is evidenced by their small industry association (a one-person organization that is not heavily resourced), the Home Care Council of New York. The Council did make a strong effort at resisting this change, but the industry association is very small and not adequately connected to NY state politics to have much influence. The industry associations that represent the LHCSAs and CHHAs (the New York State Association of Home Care Providers and Home Care Association of New York State) lost their battles in 2011. As one CHHA employer reflects on her and the industry associations' tactics:

> I guess I think some of our strategies weren't right. I think we should have seen some of the handwriting on the wall that there had to be a fundamental change. And instead of saying no, no, no, no… jumped in. And that's what we're trying to do now…Let's get in there. Let's have a voice in this. Let's not just sit back and let them do this to us (CHHA Interview 2, p. 14).

Politically, it was clear how SEIU and other worker advocates had success in influencing this debate while much of the industry's voice was unsuccessful. However, a missing piece to the puzzle includes the voice and advocacy of clients/patients/consumers of the home health care system. New York's Medicaid Director Jason Helgerson did conduct town hall meetings across the state to allow for consumer input on the potential changes to the system. One informant reported that the main concern from the consumer perspective was the potential loss of hours that might occur for consumers as a result of Medicaid cuts and changes to the system. The most visible advocate for the home care consumers was the Evelyn Frank Legal Resources Program

(Worker Advocate/Policy Organization Interview 1, #2) which "serves as a legal resource for older persons, persons with disabilities, and for the advocates who assist them" (EFLRP 2010). The Center for Independence of the Disabled, New York (CIDNY), the Empire Justice Center and NY Legal Aid also advocated for the consumer in this process. However, as the Empire Justice Center documents in an article entitled "New York Dramatically Expands Mandatory Managed Care for Medicaid Beneficiaries," "[t]he sheer volume of changes proposed to the Medicaid program made lobbying efforts particularly challenging for consumer advocates." They note that the "consumer advocacy community opposed the rapid expansion of mandatory managed care in the Medicaid program and fought against proposals for co-payment increases, limits on services, and restrictions on eligibility" (de Jung 2011). As one worker-advocate who pushed for the switch towards Managed Care told me, the consumer advocates thought that "the personal care program was perfect," even though, in her opinion, the program was growing at an unsustainable rate and contributing to skyrocketing state Medicaid costs (Worker Advocate/Policy Organization 1, #2).

One important change that consumer advocates seem to support is the MRT proposal that would require managed long term care to "offer Consumer Directed Personal Assistance services" (de Jung 2011). This is a statewide Medicaid program that provides an alternative way for consumers to access home care services. Rather than going through a home health care agency, the consumer (or family, friend or guardian who is managing the care) can perform all of the functions previously performed by an agency. This consumer directed program is more popular in upstate NY but has not had much of a presence in New York City. All managed care plans must offer this program as an option to the consumers. Consumers will then have more control over the person they hire, including some extended family members (like an adult child

or child-in-law, although regulations prohibit the hiring of a spouse or parent). The aides that are hired will be trained by the client or his/her family and will be paid by a fiscal intermediary as an independent contractor. Information on the payment process and wages is unclear.

The Industry's Redesign from the 2011 Budget Changes

The state's Medicaid Redesign Team (MRT) has taken on the task of redesigning or reforming the home health care industry in New York. The restructuring of the home health care industry "is intended to place nearly all Medicaid-eligible recipients into managed care plans to coordinate their care needs, and thus better manage their disabilities and chronic diseases—while at the same time, achieving cost efficiencies" (PHI 2012b). Governor Cuomo put together the Medicaid Redesign Team in January 2011 by Executive Order. The MRT gave a report to the legislature in February 2011, which included 79 recommendations, 78 of which were approved by the Legislature as part of the enacted budget. The MRT's initiatives saved the state $2.2 billion in fiscal year 2011-12 and will save the state and federal government a total of $34.3 billion over the next five years. These cost savings were made without any cuts to Medicaid eligibility (New York State Department of Health (b)). As they reported on their website, "personal care spending is on the decline with per-recipient spending reduced to 2006 levels, and spending on home care has been reduced by $300 million since 2010. Without the MRT initiatives, state spending would have grown by $2.3 billion in the 2011-12 fiscal year." They go on to claim that: "The efforts of the MRT will result in a multi-year road map that will lead toward a more efficient program and system that is affordable and will achieve better health outcomes to New Yorkers" (New York State Department of Health (b)). The truth of that statement remains to be seen, but in my interviews with industry leaders and experts, questions

remained about whether all of these changes are best for the industry, best for workers and best for patients. Below I outline some of the basic changes occurring in the industry, some of the apprehensions and concerns that respondents expressed and how different industry stakeholders viewed these changes.

Living Wage: Home health aides received a giant win with the living wage, especially given the state's focus on cutting costs in the 2011 budget cycle. Due to the new Wage Parity Law, over the course of three years (from 2012-2014) home health aides will get pay raises until their hourly rate reaches $10/hour (up from a minimum wage floor of $7.25/hour). Ten dollars an hour is currently the rate at which personal care aides are paid (despite needing less training than home health aides) (New York State Department of Health 2012a). As of March 1, 2012, all home health aides are required to be paid at 90% of the living wage and this will increase until it reaches $10/hour plus benefits in 2014 (see Table 5.1 below). The benefits will be either under a collective bargaining agreement or LHCSAs will have to pay the aide, in lieu of health insurance, what's required by the living wage ordinance by the city of NY. This now governs the New York state budget law (Worker Advocate/Policy Organization 1, p. 10; Union Interview 1, p. 6). This is a huge win for the union, which has had a difficult time increasing wages through contract negotiations. Many of my respondents in the industry believed the only realistic way to get employers to pay their workers more was to legislate the change, which this does, although it is important to note, this is an unfunded mandate.

Table 5.1: Achieving Parity for Home Health Aides in New York City

Effective Date	Wage Requirement	Benefits
March 1, 2012	90% of the Living Wage: $9.00/hr	Either: health benefits as specified by collective bargaining agreement (CBA) current as of 1/1/2011, or an additional $1.35/hour paid directly to the worker (calculated as 90 percent of $1.50/hour, which is the amount required in lieu of coverage provided by the Living Wage Law).
March 1, 2013	95% of the Living Wage: $9.50/hr.	Either: health benefits as specified by the collective bargaining agreement in place, or 95 percent of the amount required in lieu of coverage: $1.43/hour
March 1, 2014	100% of the Living Wage: $10.00/hr.	Employers must meet the prevailing compensation, which is defined as the compensation in the Home Attendant contract as of 1/1/2011, which includes $10 wage, pension, 20 days of paid leave, extra holiday pay and $2.14/hour for health insurance benefits. Benefits and paid time off can be superseded by a collective bargaining agreement.
March 1, 2015	The greater of the Living Wage or the wage required by the collective bargaining agreement in place on March 1, 2015	As stated for 2014, although the Health Exchange could affect the structure and cost of the health benefit as well as the process for accessing benefits.

Source: Paraprofessional Healthcare Institute. 2012. "PHI: Medicaid Redesign, Watch #1. Wage Parity for Home Care Aides." PHI: New York. November 2012. P. 3.

Here 1199 took a lead role in working with the governor to win higher wages for workers while stymying the growth of the non-union segment of the industry. One worker-advocate at Paraprofessional Health Institute—who was also instrumental in the recent parity changes—said:

> the only way we were able to, I believe, get parity was because we went to the state and said redesign the system…And the fraud helped. It helped that Governor Cuomo had busted a bunch of home care agencies that sold training certificates—that he knew there was fraud. He could see it and he distrusted the industry and that is what it took (Worker Advocate/Policy Organization Interview 1, p. 9/10).

The compensation mandates of the Wage Parity Law are unfunded—home care agencies that directly or indirectly receive Medicaid funds are required to pay for this higher compensation without adjusting the Medicaid reimbursement rate from NY state (State of New

York Supreme Court). This Wage Parity Law was implemented at the same time that the state of New York reduced Medicaid payments to home care providers by about $523 million (State of New York Supreme Court). Many of the LHCSAs and contractors I interviewed had grave concerns about this unfunded mandate and how their companies will be able to afford the increase in wages without an increase in the Medicaid reimbursement rate. Many of the employers I interviewed highlighted the fact that the increase in wages has not been met with an increase in rates from the state. As one CHHA administrator told me:

> The problem is the rates are really very much set by government. So when you're giving me 5% and more cuts and then clawing back potentially $11 million based on this ceiling you put on April 1 based on practices years ago, where am I getting this money? Where am I getting it? (CHHA Interview 2, p. 13).

The licensed agencies are responsible for paying the living wage, but they get their money from the CHHAs, the Lombardis and the Managed Care companies whose rates from the state are not increasing (New York State 2012a).

Also, due to the Affordable Care Act changes coming up in 2014 and the wage parity law, licensed agencies will go from paying $1.15 to $2.18 per hour for workers' health insurance. Health insurance will be the biggest cost for agencies after wages. This is too big of a jump for most agencies, especially when considering they are not getting an increased rate to cover the costs. Many agencies will try to offload more of the healthcare costs onto workers (Worker Advocate/Policy Organization Interview 1, #2). This unfunded mandate essentially will force the consolidation of the industry at all levels, as smaller companies will not be able to pay the new costs.

Managed Care Plans will become "the primary payers for home care aide services and a vehicle for implementing the transition to this new wage" (PHI 2012a). Several employers

raised the issue that licensed agencies are getting a lower rate from Managed Care companies than they had been getting from other entities. One LHCSA employer stated:

> There are managed care companies that want to sign contracts with us at a lower rate than we had before because they're getting squeezed. On the other hand, we have to pay the aides more money. So as I'm sure you have heard from everybody you have talked to, these are crazy and challenging times (LHCSA Interview 3).

Another CHHA manager reported:

> I've had great concerns from what I'm hearing from my licensed agency partners is that they're getting calls from all these managed [care companies] for their home attendant program with this varying of rates from Fidelis being a good player saying we'll pay you $18.00 an hour….[to] other agencies saying we want to give you $13.00 an hour…I mean if they are contracting with Medicaid, then shouldn't there be some oversight to see where these dollars are going? Where are they going? And I don't hear or see that. There was some talk that they were going to have kind of rate ranges or whatever, but it's a free for all right now (CHHA Interview 2, p. 11-12).

The LHCSA home health care worker cooperative president in the Bronx said the pay raise to workers will have to come from three sources: 1) from within their own organization, if they can make their organization run more efficiently, 2) from increasing their volume, or 3) from rate increases from CHHAs that they contract with. Michael Elsas, president of the Coop, highlighted an increase in volume as one of the only feasible ways to deal with the unfunded mandate. He said:

> This is a volume business. There are plateaus that you get to. In other words, if I do a million hours, I need a certain infrastructure to do a million hours to 1.5 million hours and still keep the same infrastructure. I don't have to add a whole lot. So in that 500,000 increase there is money to be made. (LHCSA Interview 1, p. 9/10).

***Litigation Challenging the Wage Parity Law*:** Home health agencies, with the support of their industry associations, have brought a suit against New York State and Governor Cuomo charging that the Wage Parity Law is unconstitutional. The law was passed in April 2011 and the litigation was filed shortly after.

According to the documents in a State Supreme Court complaint, the Medicaid Redesign Team (appointed by Cuomo and not including the industry associations of the home care agencies) initially rejected 1199's recommendation for the Wage Parity Law (Proposal No. 61 of the MRT) because it "did not speak to cost savings, quality improvements or enhanced efficiencies. Rather, Proposal No. 61 called for the State to require, as a condition of participation in the Medicaid program, home care agencies to comply with local living wage laws in the geographic region in which they operate" (State of New York Supreme Court, p. 7). Before the design team voted on Proposal No. 61 (at a meeting on February 24, 2011), NYS Department of Health removed this item from the package of MRT proposals without any discussion. On March 4, 2011, the Governor submitted his "30-Day Amendments," which (despite the fact that the recommendations of the MRT did not include this) added a section which applies unfunded wage mandates to covered home care agencies operating in New York City (as well as Nassau, Suffolk and Westchester Counties) (State of New York Supreme Court, p. 7-8). The penalty for not complying with these wage mandates is the forfeiture of Medicaid payments (State of New York Supreme Court, p. 10). This suit was dismissed at the State Supreme Court and is being appealed to the Federal level (Worker Advocate/Policy Organization Interview 1, #2). It looks as if the Wage Parity Law will stand up in court even though it is an unfunded mandate and will negatively impact smaller companies..

Managed Care: The state of New York, like most other states in the nation, faces extraordinary financial strain and is trying to figure out how to cut costs. Two of the greatest costs for the state are in education and in Medicaid. In education, the state has tried to cut costs by increasing classroom size, shutting down schools and firing teachers. On the Medicaid side,

the state of NY has recently focused on home health care and has assessed that Managed Care would not only be able to control costs in the short-term, but would also lower costs for Medicaid in the long run. One LHCSA employer explained:

> Now, in theory, it should work because you are working with a capitated system. The reason why I say "in theory" is this: you are basing it upon the fact that you are saying that perhaps the clients don't get sick or get sicker and that their need for hourly services will not increase. My experience tells me that that's not necessarily the case… So I'm giving you ten dollars to take care of this client. Now, if that client needs less hours at the beginning, then guess what, you're going to make a little money on this. At the end, when the client starts needing more hours of service, well, you're not going to make as much money. So I guess the theory goes is that that organization will do what they can do to maintain that client's wellness so that they will stay without needing increased hours for as long as they can. That way you have profit coming into the organization (LHCSA Interview 2, p. 10/11).

He goes on to explore the possibilities:

> When the client does get sick though, obviously there's going to be more costs involved, but the client might die, the client might need to have acute care setting and go into a hospital and then maybe go to a nursing home so it's not our problem any longer. Or they could come back to us and they might need increased hours. But we've made all this money on the front end. We've got to pay a little bit more money on the backend but it should even off so that we have a profit margin that makes our business profitable. So in essence and in theory, it should work because now you have a system where it is incumbent upon the provider to maintain that client in a constant state of wellness and not to let them slip back and not to let them get ill (LHCSA Interview 2, p. 10/11).

The growth of managed care is a trend that is happening across the country and NY is no exception. As one 1199 researcher told me:

> Because this whole thing of transferring every home care beneficiary to managed care—probably about 2 years ago this would have been controversial but its kind of just the new normal now. And the last 3 months, most of the states where 1199 organizes, they have done this. It is a very big transition and all of the states are doing it… A few years ago, different people would be against it. Mostly people are now saying, how can we make it work for us- how to protect consumers, how to protect workers, what should be carved in, what should be carved out but no one is really saying no. Even if that is people's preference, they have done that calculation and figured that it is not possible (Union Interview 2, last page).

From the state's perspective, the shift to managed care is a positive change. Because it is a capitated program (meaning the state will give Managed Care a certain amount of money per client to manage that client within that budget), the state will know how much money it will spend per patient (with the CHHAs, the CHHA just billed the state for the hours they gave patients and this was not a capped number of hours; for the city's Personal Care Program, the city determined hours given). So, by shifting patients into managed care from the CHHAs and the Personal Care Program, the state is hoping to cut costs. From the provider standpoint, it is "nothing less than chaos right now" (Lombardi Interview 1) with all the changes happening.

Managed Long Term Care enrollment has increased dramatically since 2004, with the majority of the increases happening since the 2011 changes. NY state enrollment in 2004 was around 10,000 and by 2012 it was nearly 70,000 (more than doubling in size since 2010). Ninety-three percent of this enrollment is in New York City. The number of plans available has increased from 16 plans to 38 plans (State of New York 2012).

The city's Personal Care Program has been praised for several reasons, including tight control, regulation and oversight of its contracted LHCSAs, as well as for complying with the New York City living wage law, which has given personal care aides the living wage plus health insurance for years. However, this program has come under scrutiny by the state—the state thinks this program can be run more efficiently by managed care companies. As the industry changes, many of the clients who were a part of the city program will be shifted over to managed care. This will seriously diminish the city program and put more clients and money into managed care. As of April 1, 2012, any patients requiring Medicaid services over 120 days must enroll in a Managed Long Term Care Program or another care coordination organizational model (not yet defined as of 8/11).

Individuals who work in the Personal Care Program in the city feel this shift towards managed care isn't a huge surprise because many of their clients have transferred already in recent years, which has begun to shrink their program. One LHCSA manager said that in the summertime, employees of the managed care companies will sit outside Lincoln hospital and give out teddy bears and cups for free for those who sign up. Many times patients will sign up without knowing that they are signing up for a managed care company to take over the management of their home care (LHCSA Interview 5). While the city's Personal Care Program is not allowed to do any recruiting, managed care and CHHAs have been known to actively recruit patients from the Personal Care Program in order to grow their business. As Toby Edelman (a senior policy attorney at the Center for Medicare Advocacy) says: "Managed care isn't going to help — it's just more money going off the top…The managed care company has to take its cut" (Bernstein 2012).

Vendors (LHCSAs) who have done business primarily with the city of New York in the Personal Care Program will have to manage much more than they previously had because of this shift. As patients move over to managed care programs, LHCSAs will have a huge increase in administrative work since they will have to report to, bill and manage relationships with multiple managed care companies (City Agency Interview 1). One LHCSA provider who has contracts with the city said they had begun to talk to managed care companies (46 of her cases will be transferred to managed care and she will have contracts with 10 different managed care companies) and the main thing they were going to do was send out nurses and cut hours. She doubts that managed care will actually be able to save the state any money: "They don't look at the statistics and the morbidity of their clients, average age is 80-85. These are the sickest

patients… We have some splits that are 12 and 12 [hours]. Usually, they're wanderers, and they're alone at night" (LHCSA Interview 6).

Another major issue for LHCSAs who used to only contract with New York City is that the city paid for LHCSAs' disability insurance, workers comp insurance, etc. and when these agencies contract with managed care companies, they will have to take on this cost themselves. This will make it more difficult for smaller LHCSAs to make it—the city's LHCSA home care association director said only bigger organizations or those with a parent company will make it. The rest will disappear (Industry Association Interview 1). Also, agencies that are in some way diversified (companies that run a home health care agency and something else like senior housing) will be on "sounder ground" (Worker Advocate/Policy Organization Interview 1, #2).

Managed care is insurance. As one CHHA manager said:

> It's truly insurance. You go at risk. You get paid a per member, per month based on your different risk scores and wage index and all the shenanigans they put into that… but it truly is an insurance product. And there is a care management component of that to hopefully influence patients' decisions, behaviors, get them into the right level of care and shepherd them through this crazy system we have. But the patients that are coming now are not the patients that they've had tremendous experience with—[they are sicker and have higher needs] (CHHA Interview 2, p. 11/12).

In fact, many people I interviewed feared that once managed care starts taking all of these really sick patients, they will realize they can't make money off of them and they will dump them back into the city's Personal Care Program. Others I interviewed said that managed care organizations are dumping high hour cases into the hospitals because they can't make a profit on them—when the hospital tries to send them back to the managed care company, they say they don't want them back (LHCSA Interview 5). The only option then is to send the patient back to the city's Personal Attendant Program or into a nursing home (which will ultimately cost the state more money).

Caps on CHHA Spending: The state is doing a couple things that will end up shrinking the CHHAs. They are limiting the amount of time that a patient can be on service with a CHHA and they will put a cap on the amount of money the state will pay for each patient (Todd B).

The reason for these changes was partially because CHHAs did not have a cap on spending, resulting in high costs. Also, because they did not have a cap, they became a "catch-all" for patients who were supposed to be a part of a long-term care program (the city program, the Lombardis or managed care). Some CHHAs I interviewed pointed the finger at the inadequacy of the Personal Care Program to explain why they have become a catch-all for patients. CHHAs were originally designed to provide short-term care—acute care after hospitalization "BANG, BANG, BANG, fix you up, and you're out of here" (CHHA Interview 2, p. 7/8). If a patient required long-term care, they were supposed to be transferred to the city's Personal Care Program. One CHHA administrator told me:

> What happened with the home attendant program [Personal Care Program] is because of the way CASA administrated it, they kept backing up into the hospital causing tremendous length of stay issues in hospitals. So what they did is they designed this bridge program, and what that allowed is that a CHHA could take a patient right from the hospital… deliver the home health aide level services, even if the patient really didn't need any skilled care (which is rare because most people do, especially with the shortened length of stay). They need some assessment and education. But even if they didn't, they would park them at the CHHA. So, [the CASAs] were supposed to come back and pick them up in 45 days… and put them into the home attendant program. However, that didn't happen. So these patients would sit and sit. Well, what would happen is then they didn't want to go to the home attendant program, and we would try to put them in the home attendant program, and they would ask for a fair hearing, and the ALJ judges always side with the patient. And the patient would end up in the CHHA. So there were a lot of funny things that happened, which caused these long term patients to be sitting in these CHHA's (CHHA Interview 2, p. 7/8).

She went on to explain that the state would try to get long term patients back where they belonged—into the Personal Care Program—but as a CHHA manager, she would refuse. She said:

> … they've been in a managed program with skilled services. They're sicker. They're needing more oversight. I'm going to send them to the largest babysitting agency in the world—the Home Attendant Program? No. Not going. So these patients, because they've outlived, now where are they? They're in the CHHA. So it became a catch-all because it has access, and it doesn't have capped access. And it was, frankly, fee for service, so you could afford the patients there (CHHA Interview 2, 9).

The CHHAs were fee-for service on the Medicaid side of things and, according to this manager of a CHHA and managed care program, the inadequacies of the city's personal care program led to the CHHA taking on patients and care they were originally not intended to take on—from her point of view, it was a structural issue and not something that CHHAs should be blamed outright for.

However, many of the LHCSAs who contract with the city's Personal Attendant Program, as well as their industry association based in the city, have another perspective. As one LHCSA manager said:

> Nobody has been monitoring some of the CHHAS that keep these clients on their caseloads for years because of Medicaid. Nobody calls them to task on it. There are certain special needs CHHAS. They're only supposed to be dealing with a certain population… They scooped up as much as they could. Under our contract, we're not allowed to advertise because all of our referrals came from the city. So, these other agencies and the long-term care programs went in and like I said, they raped us. They raped our system. They went into our buildings, took our clients, and promised them the world. Which they could do for two months, but after two months it didn't pay… They would take the two months, give them max and then get rid of them. They're laughing all the way to the bank. It's hard to fight that. I don't fight it anymore because it's a losing battle (LHCSA Interview 6).

A CHHA administrator described how the shift from a fee for service business to an episodic or risk-based business has impacted his "appetite for risk." He is more hesitant now to take on high-risk patients (CHHA Interview 1). Several CHHA and Lombardi managers mentioned that they felt the state was over-reacting to the fraud and punishing everyone instead of going after "obvious abhorrent players" (CHHA Interview 2, 10).

Lombardis Are Losing Out: One, perhaps partially over-looked result of the industry changes is that Lombardis will be losing patients and will be forced to change dramatically. Since many of the patients who need more than 120 days of Medicaid services will be transferring over to Managed Care, Lombardis, who previously took some of these patients, will be left behind. One Lombardi director projected that in 3 years, Lombardis won't exist anymore (Lombardi Interview 1). There are efforts to try to save the Lombardi program because it has a very good reputation—it is thought to be both managed well and good for the patients. Tarki Lombardi Jr., the former NY State Senator who founded this program expressed his concern over the changes impacting the Lombardi program. In an Op Ed, Lombardi wrote:

> In his budget proposals, Gov. Cuomo is rightfully attempting to enroll individuals with complex needs in programs that professionally manage and serve patients. However, as currently written in the budget's language, these patients would all be required to enroll in one type of program only — a managed care insurance model — instead of including and maximizing a program like the LTHHCP [Lombardi program]. This restrictive policy would needlessly dislocate thousands of patients and destroy a program that saves millions of dollars and preserves quality of life (Lombardi 2011).

The state sent a letter out to the Lombardi programs telling them they could "increase your slots all by yourself by 50 percent... But if you do that, you must now apply to become either an MLTCP [Managed Long Term Care Program] or this care coordinator program of which we don't know what that looks like" yet (CHHA Interview 2, 10). But, as one CHHA administrator pointed out "a managed long term care program has to have reserves. You can't just snap your fingers and become one of these things. We're talking millions of dollars in investment and reserves because you're at risk for the nursing home, for dentistry, podiatry, all these services that are outside the scope of what Lombardi was doing" (CHHA Interview 2, p. 10). So, there will be an opportunity for Lombardis to become, what one director called, "Lombardis on steroids" (Lombardi Interview 1)—taking on more care coordination, taking on

more risks. But, since many of them are small, they wont be able to make that transition. One of the expectations for Lombardis is they currently are only a Medicaid business right now, but would be expected to include Medicare as well in the next few years. The state is hoping by including Medicare in their scope of practice they will have a better ability to control the programs and they will perhaps share in some of the savings that accrue on the Medicare/federal side (Lombardi Interview 1).

Forcing Consolidation of the Industry—The Shift Towards Big Business: The NY State Department of Health (DOH) used to promote home health care as a great small business opportunity (Worker Advocate/Policy Organization Interview 1, #2). But, as administrative changes have occurred over time, smaller businesses have found it more difficult to stay in business. With these recent changes to the industry, the real challenge will be for smaller businesses to stay afloat at all. Nearly everyone I interviewed believed that only larger companies, which have more financial and administrative resources, will be able to deal with these industry changes. And this consolidation will happen at all levels of administration and organization—including both licensed agencies that hire the aides and contractors who manage the care. The unfunded Wage Parity Law and other changes from the 2011 budget cycle are forcing the consolidation of the industry. One director of a Lombardi said in ten years the industry will be "unrecognizable—there will be no small providers" left… "there will be fewer providers, more consolidation. It's not a good direction" (Lombardi Interview 1). The LHCSAs that contract with the city, especially, will start to disappear unless they are connected to larger establishments. In the summer of 2011, there were 47 LHCSAs that contracted with the city, down from 65. As one employer who contracts with the city explained: "It is easier to make the

business work if you have a parent company" (LHCSA Interview 5). Once these LHCSAs are forced to do business with managed care, he explained that they cannot use HRA money and many of the LHCSAs don't have money to buy insurance—workers comp, disability—the things that the city currently takes care of financially. The city only covered these expenses until March 31, 2012 (LHCSA Interview 5). He thinks a lot of agencies will disappear because they can't afford to do business any longer, because of the added expense and increase in administrative work due to multiple contracts with different administrative processes. He warned that many of the LHCSAs—non-profits that are barely scraping by—will disappear and it will become a place where only big business with high volume can survive (LHCSA Interview 5).

One employer who runs a LHCSA that contracts with the city and is a part of a larger company in Brooklyn, said of the shift to Managed Care: "My company is a large company so we have the ability to adapt a little bit more easily to the changes in the environment, not that it's not kind of making us uncomfortable, too, but change will do that. But I guess as an organization, we're a little bit more—we're much better positioned to adapt" (LHCSA Interview 2, p. 12).

Interviews with industry experts reveal that the business of home care is changing—those attracted to this type of work historically were social workers and people interested in working with the elderly. But one industry expert told me that managers coming into the industry through Licensed Home Care Agencies, Certified Home Health Agencies, and Managed Care (especially) are increasingly business oriented (Industry Association Interview 1). As of Fiscal Year 2011, Managed Care will be playing a much greater role in home health care in New York City and several people told me that they feared that home health care will increasingly be run like a business, where the bottom line is the only thing that really matters (Industry Association

Interview 1; CHHA Interview 2). One informant who runs a well-known CHHA and Managed Care Provider in New York City spoke about her fear about the shift to Managed Care and the impact this will have on the industry.

> My huge concern is right now, most of the MLTCP's are provider-based. And they start as provider-based like Senior Care and ended up that's gone to Health First. This could just be another big business for the insurance companies to make money. I mean, I said it to them [state officials responsible for the shift to managed care] the other day. I was like guys, you took this business away from the little thugs down here in Brooklyn that have abused it, and you've given it to the mafia for God sakes. What are you doing? What are you doing?... My bigger fear is what happens if these big insurance companies with a lot of money, a lot of advertising dollars, a lot of clout decide this is a great market to get into. And instead of having these programs that are very consumer-centered, goes into what really looks like just a good old insurance plan? So that's my concern (CHHA Interview 2, 11-12).

One worker advocate told me that the big for-profit companies are indeed getting into the mix. In the last year (2012), New York has seen large managed care companies like Aetna and United coming in (Worker Advocate/Policy Organization Interview 1, #2). While managed care was actually started by local NY providers, it will likely be taken over, at least in part, by national managed care companies who see New York City as a huge opportunity for growth.

One question this raises is whether the consolidation of the industry will be better for workers and for clients. In the history of home care in New York City, the state and city encouraged the growth of small home health care businesses, which is partially responsible for the complicated system with multiple players. In some ways, more consolidation might result in an easier navigation for patients and more standardization/reliability for workers. Some people have argued that the multiple small business model of care is perfect for New York City where there are multiple populations who have very specific needs (with specific cultural and language needs). However, one worker advocate argued that a big company could have multiple divisions that meet the needs of different communities. (Worker Advocate/Policy Organization Interview

1, #2). During several of my interviews, including with the workers' cooperative, companies did tell me that VNS, which is the largest home health care organization in the city, is the best to do business with because they pay good rates, have quality of care scorecards and seek business with LHCSAs that are considered good employers. They are "able to do much, much more" because they are such a large business (LHCSA Interview 1). Unions have also had more success when dealing with VNS—because of their size, they are more able to provide a better rate to LHCSAs, which then have more financial ability to pay their workers better (Union Interview 1). While we don't know how company size in the home health care industry in New York City impacts the working conditions for workers, there have been some studies done about whether working for large or small companies tend to be better for workers. The Unregulated Work Survey found that low-wage workers working for larger companies (more than 100 employees) have significantly fewer workplace violations than those working for smaller companies (less than 100 employees) (see Table 5.2 below).[19] Size, however, does not protect workers from violations—it is important to note that large companies (although their violation rate was lower) still had high violation rates.

Table 5.2: Percent of Workplace Violation Rates by Company Size (all low-wage workers in New York City)

	Minimum wage violation rate	Overtime violation rate	Off-the-clock violation rate	Meal break violation rate
Less than 100 employees	24.7	80.8	77.2	76.6
100 employees or more	10.3	58.2	55.8	61.6

From Bernhardt, Polson and DeFilippis 2010.

[19] Unfortunately data analysis for home health care workers in New York City, by company size was not possible due to the small n for smaller LHCSAs. Also, the data may be unreliable considering many home health care workers may not know how many aides their company employs.

The Paraprofessional Healthcare Institute has been documenting some of the changes that have occurred in the industry since 2011. They have found that home care agencies are, in fact, closing. This was an unstated but intended consequence of the legislation, which aimed to consolidate the industry—referred to in the legislation as creating "efficiencies." As PHI documents:

> Smaller *home attendant [personal care aide] agencies* are finding it harder to survive, primarily because they are no longer receiving clients that require 120 days or more of personal care services. At the same time, these agencies' single 'customer,' the city's Human Resources Administration (HRA), has been replaced by a myriad of managed long-term care plans—making contracting a far more complex and expensive process. In addition, the home attendant programs are now responsible for finding, and paying for, workers compensation and general liability coverage, costs that earlier had been borne by HRA (PHI 2012b).

This was consistent with the fears LHCSAs expressed in my interviews. Smaller LHCSAs are also finding it more difficult to survive given rising wage costs—one LHCSA who employed about 350 aides had to close down in Spanish Harlem because of a $500,000 annual increase in wages and no increase in reimbursement rates (PHI 2012b).

In the end, New York was faced with a choice in terms of how to deal with rising state Medicaid costs—they reshape the system (which included consolidation) or they cut benefits, cut the rate to providers or change Medicaid eligibility and make it less generous. The state chose to revamp the system (Worker Advocate/Policy Organization Interview 1, #2).

The Potential Impact on Patients and Families

How managed long-term care companies deal with patients in need of home health care is yet to be seen—will managed care take better care of patients to keep costs down or will they cut costs by cutting needed care? There are potential benefits and dangers in shifting things over to managed care, from the perspective of patients. Managed care may provide consistent

management of care and may cut down on the number of institutions in the system. This complexity of the system, as explored in Chapter 3, has made navigating the world of home health care especially challenging for families of patients seeking care. But, many of the consumer advocates have argued against the growth of managed care, fearing it will lead to a reduction in hours for patients who need the in-home help.

Although the widespread use of managed care within home health care is relatively new (Managed Long-Term Care), lessons can be learned by looking at the model of managed care in health care more broadly and the impact it has on medical services, the doctor/patient relationship, etc. While the intended benefits of managed care include controlling costs and increasing access to health care by making health insurance more affordable (by offering competitively priced insurance), health care costs continue to rise in part because managed care companies have a financial responsibility to their stockholders. Competition between managed care companies has been so intense that it has lead to mergers and acquisitions (as of March 2004, the top 10 largest national health plans covered at least 50 percent of commercially insured persons). There are ethical concerns that financial incentives to doctors change physicians' focus from assuring the well-being of patients to providing care within certain financial constraints (Moore 2009). Studies have also been done regarding the large percentage of administrative costs in for-profit managed care companies. In one study done in California in 1994, administrative costs totaled about 30.9 percent of total revenue in for-profit companies, compared to 3.1 percent in non-profit organizations (Alameda-Contra Costa Medical Association 1995), although as non-profit managed care companies struggle to compete, many have taken similar cost-cutting measures as the for-profit companies have done, blurring the line between for-profit and non-profit companies.

The cap on CHHA services—while it does deal with the fraud going on in the system—may also end up penalizing patients who actually need more care (CHHA Interview 1). Many industry experts I interviewed feared that CHHAs and Managed Care companies, who are mostly concerned about their bottom line, will either not want to pick up or will dump high needs/high hour cases because they are too high risk and will end up costing the companies more money. So, especially if the city's home care program becomes decimated, some industry stakeholders fear these patients might not be able to come home—they will stay in the hospital longer, go into rehab or into nursing homes, which ultimately will cost the state more money (CHHA Interview 1). One informant who has been tracking the changes in New York closely has seen the growth of adult day care facilities (known across the US as PACE—Program of All-Inclusive Care for the Elderly) which provides all of the services of a nursing home, but patients are able to sleep in their own beds at night, often with the help of a home health aide (Worker Advocate/Policy Organization Interview 1, #2). These PACE programs are part of the health care managed by managed care (as of February of 2012, mostly just non-profit managed care in NY) and a 2009 study shows PACE placement has reduced the length of hospital stays (Berger 2012). These adult day care centers, if they continue to grow, may lesson the number of hours a patient needs a home health care aide but will allow patients to stay at home.

Patients who have left New York City's Personal Care Program and gone into managed care are still entitled (due to Section 431) to the same hearing rights they had under the PCP program—if their hours get cut, they are entitled to a fair hearing and the possibility of getting their hours reinstated. According to the claims put into a recent law suit, managed care companies have not been honoring this rule (Worker Advocate/Policy Organization Interview 1, #2) (NY State Department of Health 2012b).

Less care for patients means more stress on families who must make up the difference or pay for gray market care out of their own pocket. One LHCSA director thought the industry would be very different in 10 years. With care becoming more expensive and public funds for care shrinking, people will get a lot less care than they are getting today. She also believes that people will have to dip into their pockets more than they ever had before and the gray market may grow (LHCSA Interview 4).

The Potential Impact on Home Health Care Workers

The biggest positive change for home health care workers in New York City is that home health aides will see an increase in their hourly rate by 2014 to $10/hour plus benefits. This will create parity between home health aides and personal care aides where it did not exist before. This is a huge win for home health care workers in New York City—especially when compared to workers in other states who are not even covered by federal or state minimum wage laws.

Due to the Wage Parity Law, all home health care workers should either get health insurance or get a higher hourly pay rate so they can afford insurance on their own. Unionized employees have their benefits spelled out in their collective bargaining agreements (CBAs), which, due to the rising costs of health insurance premiums have forced the reopening of CBAs recently, resulting in reductions in other benefits to meet the terms of the law. Ironically, this has meant nonunionized workers sometimes get a higher standard of benefits (PHI 2012b).

Even though the hourly rate will go up, hours may, in fact, decrease for workers, making their weekly take-home pay less than before. The changes in the budget will put pressure on intermediaries and LHCSAs to cut costs, which ultimately will result in shorter hours for patients. As the director of one of the largest LHCSA in New York City said:

> So there is always the potential that utilization will come down. And what that will mean for us is our aides will get less work. Or we'll have to work with many more clients to be able to get work. And that may or may not be possible because if the services are all requested in the morning you can't be at more than one place at the same time (LHCSA Interview 4).

Fewer hours for workers means that many workers no longer have enough income to support their families. Several employers reported that their employees are applying for unemployment in large numbers. One LHCSA employer who has about 1400-1500 on her payrolls, said that many of her workers had their hours cut dramatically and others had to seek help through unemployment benefits. "That's another thing, they make all these changes, so these long hour cases are going to shorter hour cases, and then workers want unemployment to make up the difference" (LHCSA Interview 6).

The city is working towards training all home health aides and personal care aides for both jobs so that workers can flow from one case to another (Medicaid or Medicare) without any difficulty. "Because when we put everybody in managed care models and we blend Medicare and Medicaid, we don't want to have to worry about whether or not that person is [trained as] a home health aide" (Worker Advocate/Policy Organization Interview 1, p. 15). With the home health aides receiving the living wage like the personal care aides and personal care aides being trained up, all home health care workers can perform both jobs.

Since the systematic changes have gone into effect, the Paraprofessional Healthcare Institute (PHI) has documented some of the consequences for workers. One (unintended) consequence of the changes has to do with the requirement that Managed Long Term Care Plans continue to contract with the home care agencies that were providing services at the time of the transition to managed care (known as the "continuity of care" provision which aimed to maintain continuity and stability for both clients and workers). While managed care seems to be

complying with this for clients with consistent needs, if the needs of the client change and they require home health aide services, the personal care aide is often dropped and a home health aide is put in her place. This is resulting in the loss of hours and wages for personal care aides. If an aide's hours drop too low, they are also no longer eligible for health insurance (PHI 2012b).

Home health aides have also seen their hours decrease and workers are either working less or trying to get jobs with multiple agencies. Some are turning to the gray market to find employment and some are turning to consumer direction. To facilitate this turn towards consumer direction, licensed agencies are forming fiscal intermediaries who pay the consumer directed aide—they don't hire and manage them, but they process their timesheets and pay them (Worker Advocate/Policy Organization Interview 1, #2).

In order for personal care aides to keep their jobs beyond the next 18 months, they must be "trained up" to have the ability to do the work of a personal care aide and a home health aide. But, a lot of agencies who employee personal care aides do not offer this training—they must seek out the training elsewhere, which can be costly. SEIU is partnering with CUNY to test pilot a program that will upgrade aides—however this will only train about 2000 personal care aides (a drop in the bucket compared to the tens of thousands who need the training) (PHI 2012b). The New York State Department of Health rates do not include the cost of training, which is estimated to be about 10-20 cents an hour. "Without incorporating responsibility for paying for training in the rates, there are likely to be thousands of home attendants [personal care aides] who are not yet upgraded when we integrate Medicaid and Medicare and therefore could lose their jobs – or they migrate to consumer-direction or the gray market" (Rodat email 1/13). The state will end up paying for personal care aides who lose their jobs (due to a reduction in case

loads, the closing of agencies or because aides have not been trained up) as aides apply for Medicaid and/or unemployment insurance.

Conclusion

In 2011, the state of New York, through the yearly budget changes, implemented massive changes to the home health care industry, which will ultimately have a big impact on home health care workers, patients, and families in New York City. Responding to the need to cut state costs and deal with the growing issue of fraud within home health care, the state decided to focus many of the cuts on Medicaid and the home health care industry, ultimately leading to billions of dollars in savings for the state over 5 years. They did so, while at the same time, not cutting eligibility for Medicaid and increasing wages for home health aides (although this mandate is unfunded which will force the consolidation of the industry).

While it is impressive that the state was able to implement these cuts without changing Medicaid eligibility and by implementing the new Wage Parity Law, the structural changes to the industry will shrink the city's Personal Care Program and the Lombardi program while growing Managed Care in the city, which may have unintended consequences on patients and workers. These changes encourage the growth of big business and make it nearly impossible for smaller businesses (on the LHCSA and CHHA side of things) to make it in the industry. More stress will be put on LHCSAs—those currently doing business with only the city will have an increased administrative burden as their patients turn over to Managed Care, while at the same time will be required to cover workers comp, disability and other things like this because the city will no longer cover these costs. LHCSAs have also reported a lower rate from Managed Care than they had previously gotten from the city, or from other agencies.

These changes also do not actually change the current subcontracting system—a system in which administrative costs for two-levels of organizations actually lessens the money available to pay workers and increase wages. While home health aides will see an increase in their wages until 2014, they may actually be getting less hours of work (as utilization goes down), impacting their net take-home pay and perhaps making them ineligible for employer-sponsored health insurance. Industry experts and employers have reported (even shortly after the changes during the summer/fall of 2011) that workers are getting less hours, applying for unemployment in larger numbers and turning to public benefits to supplement their incomes. Caps on CHHAs and the shift of patients from the Personal Care Program to Managed Care will decrease the number of hours that patients are eligible for, which could lead to less care for those who need it, patients going back to the hospital more regularly or going into nursing homes. Less care for patients also means more stress on families who need to care for their loved ones (time stress) or find someone who can (financial stress). We would expect to see a growth in the gray market as hours for patients get cut and patients still need the care—this will mostly be seen with middle income/high-income families while poorer families will not be able to afford to hire on the gray market to supplement the hours, which will lead to less care, more hospitalization or nursing home care. As examined in Chapter 4, a growth in the gray market is also a growth in jobs that tend to be precarious, insecure and without access to benefits.

Chapter 6: Conclusion—The Caring Precariat

This dissertation has explored the home health care industry in New York City—the whole of the industry, not just the formal sector. When one looks at how home care is administered throughout the city, it is important to include both the heavily regulated formal sector of the industry and the completely unregulated informal sector of the industry (the gray market). It is only with this full analysis that we can understand how families get their care needs met, how workers fare in the agency structure and in private households and how the formal system of care structures the size and scope of the informal system.

The home health care industry is intimately tied up with the social welfare state and the health care system in the US (and the changes that have occurred over the last several decades in these systems). The industry is shaped by the priorities set forth by the federal and state government but fully operates as a system of "third party government"—where states, cities, non-profit and for-profit companies run and manage the day to day implementation of providing home care to individuals throughout the city. For-profit companies (and more recently, for-profit managed care companies) have become a much bigger player in home health care in recent years and rely on public money to do business and remain profitable. This system of third party government and the multiple players involved in funding, implementation and regulation of the industry make New York City's home health care system particularly fragmented and difficult to navigate, especially because of the subcontracting relationship that has become the norm in the structure of the industry. These structural issues, along with the fact that many of these jobs are state-funded, have made it difficult for unions to raise wages significantly for formal home health care workers. Despite the fact that home health care workers in New York City are still

low-wage, it is important to acknowledge that these workers are some of the highest paid home care workers in the country, largely because of the work of SEIU.

Because the formal part of the industry was established through the social welfare state, formal state-funded home health care services are mainly provided to the poor and poor/elderly (and to some extent the non-poor elderly although Medicare home health care services are only for short-term acute care). For many families who are not eligible or unable to access Medicaid, they must pay exorbitant amounts of money to hire an agency employee (on the formal side) or they have to rely on the gray market to hire workers, which also gets expensive. The state relies on this gray market workforce to fill in the void created due to a lack of universal access to state-funded care—a workforce who essentially exists completely under the radar and without adequate legal protection provided by the state.

The home health care workforce in New York City is primarily female, mostly people of color, largely foreign-born and older. Significantly, home health care workers are the largest occupational grouping in the city and these jobs are projected to generate the greatest number of jobs in coming years. These jobs are low-wage—the starting wage for formal home health care workers in the city is now between $9 and $10 per hour, compared to the city median wage of $20.77 per hour. What began as provisions to support the elderly and low-income people has resulted in a labor system that employs increasing numbers of low-wage workers paid for by the state, who ironically earn so little they are often eligible for state-funded assistance.

As analysis of the 2008 Unregulated Work Survey data begin to show, gray market home health care workers, although their hourly wage tends to be slightly higher than agency-employed (formal) workers, tend not to have access to employer-sponsored health insurance and have a higher prevalence of workplace violations than agency workers. As many industry experts

fear, the gray market is expected to grow in order to fill in some of the gaps left by the changes to the industry in New York City and by austerity measures. The growth of the gray market will contribute to a larger insecure and contingent workforce that exists under the radar and outside existing regulations.

The 2011 changes to the industry have implications for the current business/care management model in New York City, for patients and for home health care workers. New York State has sought a reorganization of the industry to make the previously fragmented system more streamlined while cutting Medicaid costs. These changes have many advantages. The state's efforts at streamlining the system is very important given its complexity—multiple programs and levels of care management make it, as families and patients have attested to, a difficult system to navigate. That said, increasing managed care's role in the system will not necessarily make it easier for patients and families to navigate, as the basic subcontracting system of delivery still exists. Managed care may coordinate patient's care more effectively at less cost (advocates of the new system say) by taking care of patients early on to curb long-term costs (although opponents think costs will be cut by compromising the quality of care, reducing hours, etc.). With this shift towards managed care, the state can reduce its Medicaid costs and can better estimate its costs (as opposed to the fee-for-service CHHAs who were running up the state tab).

Economies of scale essentially dictate that these changes will push out smaller, community-based companies. The unfunded wage mandate, increasing administrative costs and cutting out help from the city (for insurance, workers comp, etc.), makes it essentially impossible for smaller businesses to make it in the increasingly tight business of home health care. This consolidation of the industry will allow for the wage increases for workers (without the state having to fund it), but it also means that home health care in New York City will no longer be

run by small, community-based organizations/companies, who, some have argued, have more of a pulse on what specific communities need in quality care. This consolidation will also give more power to managed care companies while shrinking the city's program and the Lombardi program, which have been praised by workers rights organizations and consumers respectively. The city program, in particular, has been praised for its tight regulatory and financial control over the program, including regulations on the amount of profit companies could make and giving workers the living wage. The state's DOH, on the other hand, has more lax control and will most likely let managed care run things how they like since that is what is commonplace and managed care is taking on much of the financial risk. The structure of managed care, if managed care's role in health care is any testament, may put the focus on cost priorities over care. While the city's program had a cap on the amount of profit for-profit companies could make using public funds, the state does have a cap for any of the companies they do business with.

The 2011 changes also have implications for patients. The state could have cut Medicaid costs by simply changing eligibility rules and cutting access to care for the elderly and sick. Instead, they took advantage of an opportunity to re-vamp the system of care management to weed out the bad players in the industry (the CHHAs charged with fraud), while increasing wages for workers at the expense of home health care agencies. Patients, therefore, could have faced much harsher cuts and the cliff of eligibility could have been more drastic. While not cutting services isn't a proactive win for patients, in these times of growing austerity, it is notable. The state has also made an effort to lessen the pain of the transitions by implementing continuity of care provisions. While these efforts have been made, there are concerns from industry stakeholders that managed care companies are reassessing patients' needs and recommending less hours of care. As one industry expert warned, cuts will ultimately affect

quality, “cutting into bone” (CHHA Interview 1). This will mean that patients may get less needed care. If this is the case, they will have to rely more heavily on their families and social networks or they will have to hire on the gray market to make up the difference. Less care will mean more financial and time stress on families having to deal with these shifts and some experts fear it will lead to more reliance on nursing homes and hospitals. Those with less resources and fewer reliable social networks will be worse off. As one LHCSA employer explains:

> You have the pressure from reduced amount of economic strength of states who will increasingly look to manage their Medicaid budgets, taking money from Medicaid and using those discretionary funds some place else to solve other problems that they might have and reducing the amount of money going to these managed care companies, which will in turn now renegotiate contracts with agencies such as ours, forcing our margins to become even thinner. That will generate into a reduction of hours for clients that might need more hours of service, as opposed to less hours of service… So if you start providing clients that need more hours of service with less hours of service, they will get increasingly a more ill society. And we’re going to be at the point that, you know what – I don’t want to say that it will be disdainful or, I hate to use the word, it will be almost like, well, they’re going to die. And that’s what’s going to happen. They are going to die because we won’t be able to care for them. So that’s my fear that we will have such a lack of resources where we’ll be making choices probably caring for those clients that will be best able to get benefit from a shortened amount of care and services and those clients that are too ill. There will be decisions that will be made that well, maybe we can’t provide care for Ms. Jones, and they’ll die… (LHCSA Interview 2, p. 23, 24).

Workers will also be impacted by the recent changes to the home health care system in New York City. Home health aides had a huge win with the Wage Parity Law, especially when you consider the simultaneous state Medicaid cuts. Unions had been organizing employers for two decades but had little success in raising wages across the industry, partially because the subcontracting relationship and subsequent administrative costs ate up so much of the state rate for care. Many employers and industry experts thought the only way to increase wages was to mandate it by law. SEIU viewed cuts to Medicaid as inevitable, and therefore, saw the only way to increase wages was to consolidate the industry, taking advantage of economies of scale to pay

for the increases. Because of SEIUs close relationship with Cuomo, as well as their strategy that encouraged cuts to the non-union (and fraudulent) segment of the industry, the state embraced their plan. This higher floor for workers means that those employed in the formal part of the home health care industry will get the city's "living wage" by 2014, including health insurance. The consolidation of the industry will lead to the demise of smaller companies, which may be beneficial to workers in the long-run (if you consider evidence in the low-wage labor market that larger companies tend to have fewer workplace violations). But, while wage increases are a huge win, workers will likely experience a decrease in their hours, affecting their take-home pay. If hours decrease too much, workers will not be eligible for health insurance and may need, as many home health care workers already do, to supplement their income with public benefits.

But, it is also important to understand that SEIU is primarily concerned about their membership—workers in the formal part of the industry. When you look at the industry as a whole—both formal and gray market workers—the picture gets more complicated. Growth in managed care may lead to fewer hours of care provided to patients and a growth in gray market use (this could be mitigated a bit if the use of adult day care facilities grow). As DeFilippis notes: informalization thrives "on government deregulation of workplace standards, labor laws and social safety nets" and in this instance, we see informalization thrive on Medicaid cuts and system reorganization resulting in less formal care for patients. Piecemeal, shifting and shrinking state-funded care will result in the growth of the gray market, which, while important to meeting the care needs of families, creates new problems since the gray market operates under few enforceable regulations and exists essentially underground. These jobs have historically been difficult to regulate, which leads to a workforce that is insecure and unprotected. The gray market, as my analysis of the unregulated work data shows, has a higher prevalence of

workplace violations and less access to health insurance. This population of underground workers will also not be eligible for social security and other safeguards as they, themselves age.

This leads to a number of questions about how a non-universal care economy functions and its reliance on gray-market and mostly off-the-books workers to fill in the void that piecemeal coverage leaves. If, in fact, the gray market continues to rise because of the shrinking of the formal sector, what will the state do to protect private household employed gray market workers? Historically, and mechanically, it is difficult for the state's already overstretched Department of Labor (even a progressive one like in NY state) to regulate employment arrangements between individual families and workers, making the likelihood for abuse and workplace violations much higher.

Another concern that this research exposes is the role of profit in providing care. The state, through Medicaid and Medicare, funds the formal home health care system. When you think about the essence of home care, it is based on the relationship between the worker and the client. But, federal, state and city money is funding the growth of for-profit companies, who essentially are making a profit with government funds, which raises fundamental questions about the role profit plays in our systems of care. It would be more financially efficient for the government to fund home health care jobs directly—either having a state-run home health care program, a voucher system (eliminating the middle man) or a scaled back version where there is one organizational entity providing the service as in the city's Personal Care Program (eliminating the subcontracting relationship). Instead, the system was revamped with the same subcontracting system intact and not tackling the problem that two levels of contracting and subcontracting organizations/companies can eat up as much as 50% of the Medicaid rate for care on administrative costs and profit. Like the city's Personal Care Program, home health care could

be administered for 8 cents on the dollar, rather than 50 cents on the dollar, and that could fund an increase in home health care wages, benefits and training. These types of changes, however, faced a lot of political resistance from players enmeshed in the home health care system, as evidenced by the resistance Governor Paterson received in 2009/2010 when he suggested the elimination of the subcontracting relationship. That said, the 2011 changes made to the home health care system also had resistance from different sectors of the industry, but changes were still made. Did New York State miss an opportunity to revamp the home health care system in a way that eliminates more administrative waste by doing away with the subcontracting relationship? Instead, its reorganization keeps this subcontracting relationship intact and gives more power/business to large, for-profit managed care companies, which have no cap on profit. While this consolidation may cut down on the fragmentation, bureaucracy and complexity of NY's home health care system (something that was desperately needed), does managed care have the best interest of patients and clients in mind, or will cost decisions impede good quality care? This dissertation examines the potential benefits and dangers of having managed care take over (to the detriment of other praised programs), but the answer to that question remains to be seen—we should watch the shift to managed care closely in coming years to see how patients and workers fare.

How to Further Improve Home Health Care Jobs in New York City

While recent increases in the wages of NY home health aides is an important victory, the jobs still remain low-wage. In interviews, industry experts mentioned two ways we could try to improve home health care jobs—increase the role of technology in home health care (which may also actually reduce the number of aides needed) and professionalize home health care jobs.

Several people I interviewed have recommended the increased use of technology in homes—this would help the state cut costs. While homecare seems like the type of job that would be difficult to outsource to technology, there have been new developments called telehealth that are being picked up by companies around the country. Telehealth is remote monitoring with the use of telehealth equipment—the use of devices that operate either over the phone lines or over wireless technology that connect the patient to a care provider. It connects you in real time (like Skype) or it can read your charts over time. In real time, patients can talk to a nurse remotely and discuss how they are feeling, etc. Or there are other programs that look at, for example, the blood sugar of a patient over time. If the blood sugar becomes out of range, the aide knows they need to make a house visit. As one industry expert explained, "You can predict when a patient will have congestive heart failure—that is how sensitive the technology is" (Worker Advocate/Policy Organization Interview 1). But, the city has been very slow to utilize telehealth and it remains to be seen whether technology will fully integrate into the New York home health care industry. If it does, it could both free up more money to increase aides' pay and at the same time, could significantly reduce the number of aides needed. This solution would also decrease a very important part of home health care—the companionship—which may leave the elderly and sick worse off in the long run.

Many of the industry experts who spoke to me recommended that another way we can try to improve home health care jobs is to professionalize the industry—this includes taking over some of the tasks that nurses currently perform. Funding for an increase in wages would come from the cost savings gained by utilizing nurses less often. One industry expert recalled her experiences sitting in on a meeting about redesigning the reimbursement for the CHHAs. She said:

> Boy, when the providers realized that the reimbursement was going to change, it was like a light bulb went on over their head and they almost in unison said 'Oh My God we have to use the aides differently. Because I'm not going to be paid for every nursing visit, then I'm going to use an aide instead of a nurse.' Yeah, right. Duh! It was like I just created alchemy in this room, we just shifted something. The minute we pay differently, the workers are going to be treated differently. And I never believed it until recently but form follows financing (Worker Advocate/Policy Organization Interview 1).

One of the ways to use aides differently is to give them more responsibility and training so they can take on some of the tasks that nurses are currently slated to do. One CHHA administrator spoke about professionalizing the industry as an important step for both improving the wages for home health aides and for saving the state money.

> Well, if I have somebody who gets daily insulin—really from peds, I would teach my 3-year olds literally to inject themselves. Why can't I teach that aide instead of spending those dollars for a nursing visit? Then I could save those dollars to pay the aide more for that visit…[The key is] professionalizing them, opening up scope of practice, changing some of just who is delivering the care to free up the dollars to be able to pass those to the aides (CHHA Interview 2, p. 17).

One Lombardi employer agreed and discussed the absurdity of the limitations on home health aides' scope of practice: "It is my hope that there is a change in some of the scope of practice. So it's crazy that a home health aide can't fill a mediset. It's just crazy. A daughter can fill it. And one of the ways to save would be to teach the home health aides, and then the nurses can check it. But for the nurses to have to go out once a week to fill a mediset is just ridiculous" (Lombardi Interview 1, p. 14).

However, as one industry expert explained, this expansion of home health aide's responsibilities will not happen without a fight, especially with nurses, their professional organizations and policy makers who want to maintain home care as an entry level job. As a LHCSA employer of one of the largest home health agency in New York City said:

> We have actually pushed to have home health aides' scope of practice changed. The problem isn't the industry. The problem isn't the health department. The problem is the state education board. Because the nursing scope of practice is what would need—there

> would need to be a change at that level to permit home health aides to do things like administer medications to non-self directing individuals. [The nursing world] is holding on (LHCSA Interview 4, p.17).

As Boris and Klein outline in their book, *Caring for America*, there has been a long history of nurses trying to professionalize and in the process, trying to distance themselves from home care—nurses associations sought to distinguish themselves from the "uneducated, lower status aides" (Boris and Klein 2012, p. 30). These associations drew the line between where "simple home care" ended and nursing began. In this process, they restricted the tasks that home aides could perform which reinforced home aides' classification as unskilled (Boris and Klein 2012, p 31). One industry expert explained to me that nurses in NY state are resistant to professionalizing aides, partially because their association has a "guild mentality" and has told nurses to fear for their jobs (Worker Advocate/Policy Organization Interview 1, p. 17).

One effort is under way nationally to improve home health care jobs. There is a growing campaign and movement across the country to begin to reshape priorities and make care a right that everyone has access to. The Caring Across Generations campaign aims to build a movement of care providers, care recipients and families to achieve five main policy goals: create new quality jobs in home care; strengthen labor standards and improve job quality for new and existing jobs; train and offer career ladders for workers; create a new visa program and path to citizenship for home health care workers who need it; and increase support for families and individuals in need of support and care. Over the past year, the Caring Across Generations campaign has been holding Care Congresses (a type of town-hall meeting) where care workers, the disabled, elderly and families come together to tell stories about caring for each other, its importance, and the need to value both the care and the workers who do this caring labor. The campaign has organized these events in 17 cities and continues to build relationships across the

country—telling the untold stories of care workers and care recipients, while organizing to win their policy agenda state by state, with the goal of passing federal legislation (www.caringacrossgenerations.org). This type of organizing is important to begin reshaping our country's priorities, making care a public good.

The above-mentioned solutions to improving home health care jobs, refer mostly to the formal market. But, for gray market workers and the families/patients who hire them, more protection is needed, especially since this segment of the industry is expected to grow due to recent industry changes. It is important to note that some protections for gray market workers have been won in recent years through the passage of the Domestic Workers Bill of Rights, due to the organizing of the Domestic Workers United, a New York City-based domestic worker organization (they organize domestic workers including nannies, housecleaners and elder-caregivers who are hired by private households). This legislation guarantees the following basic rights for domestic workers, including gray market home care workers: 1) it defined an 8-hour day as the legal day's work; 2) it entitles gray market workers (as well as other domestic workers) overtime pay at 1 1/2 times the workers' hourly wage (closing existing loopholes); 3) workers are entitled to one day off of work in a week (and must be paid overtime if they chose to work on this day); and 4) it entitles these workers to 3 paid days off after one year of work. The legislation also mandated a feasibility study to be completed by NYS Department of Labor on the possibility of extending collective bargaining rights to domestic workers. While the concrete wins of this legislation is relatively weak, it is an important step in beginning to establish standards in an otherwise unregulated and precarious employment relationship.

Supports for families who need to seek care on the gray market are also desperately needed as evidenced by my interviews with family members of those seeking care. Several ideas

emerged through these interviews. There need to be more experts/coaches/helpers who help individuals navigate the system of care in New York City, especially since it is so complicated and is changing so rapidly. Ideally these experts would be funded by the state or another entity so those of all income levels can access this help and they would not represent any of the for-profit players who want the business of those they are helping. These type of experts were referenced in my interviews, but they are costly and few people know of them. Another idea is to simplify the process for accessing Medicaid for a family member in need—this could be done through making the process easier or having more experts who are able to guide individuals through the process. Families who had to access care beyond what they were formally qualified for often hired agency workers off the books for more hours. The fact that this type of arrangement is against agency rules seemed to cause great stress for families hiring the care worker informally but it did not, as evidenced from my interviews, actually succeed in discouraging this type of relationship. Perhaps changing rules to allow agency-employed workers to work informally could help both workers (who are seeing a reduction in their hours) and families (who still need further care). Families that hire agency workers will also know they are hiring a worker who is trained and certified to provide care in the home. This, however, will surely raise regulation and liability issues. Another important way to help families navigating the gray market, would be to educate families on the existence of the state registry of home health care workers (which lists all workers who have started and/or completed training). Other things that may help to protect workers on the gray market include: more education for private household employers about their responsibilities and duties as an employer; and more financial support for families who are ineligible for state-funded care. These suggestions may help some gray market workers and employers, but ultimately feel about as piecemeal as the industry itself does.

Professionalizing the industry, strengthening labor standards, creating a pathway to citizenship for home care workers, and increasing supports to families are some concrete ways that either advocates have suggested or have come out of this research for improving job quality for home health care workers. Given the reality of growing austerity, these suggestions seem to be perhaps the best short-term answer to the problem of providing care to a growing elderly population and making these jobs good jobs for workers who perform them. But, the example of home health care explored in this dissertation shows the complexity and problems that become ingrained into a system that only guarantees a certain percentage of people access to care—resulting in a cliff of eligibility, families exhausting their savings, patients struggling without needed care or workers impacted by a lack of regulation and paid for by families who may or may not be able to afford decent wages. If this dissertation teaches us anything, it is that systemic change comes with many consequences and ripple effects. For example, how will professionalizing formal home health care jobs impact the jobs and working conditions of nurses? How will it impact the size and scope of the gray market? Without universal access to care and cuts to Medicaid, how can we protect all home care workers and patients, including those who work or hire in the gray market?

Solutions that prioritize all workers and families must include universalizing care, internalizing social reproductive costs (which would include universal access to quality health care, education and elder/child care) and raising the floor for all workers. While these solutions may appear to some as pie-in-the-sky or unpractical, it is important to note that other countries have found a way to take care of their residents, making social reproductive programs universal and often, state-funded. A cross-national perspective here might be helpful, especially as it

relates to Medicaid, which is a means-tested program targeted at the poor. As Janet Gornick recently said in an interview about inequality in the US:

> In the U.S., we tend to rely heavily on programs targeted on the poor, such as TANF, SSI, Food Stamps and Medicaid. We even means-test most types of government supported child care. In many European countries, social policy provisions have a more universal structure. So the rich, the middle class, and the poor are in the same programs. Rich and poor are enrolled in the same health insurance systems, they send their children to the same public preschools, they receive the same family allowances—and so on. That's crucial for building political support for these programs, and that widespread support makes them more stable. Americans, even progressives, often fail to appreciate the importance of universal programs. (Gornick 2013, p. 17).

Creating a universal health care system, which includes universal access to quality home care as needed, would eliminate the need for much of the reliance on the gray market. This along with an increased federal minimum wage that is a family-sustaining wage, which the President recently supported in his inaugural address, would have the most positive impact for both workers and patients of all income-levels. These long-term goals of universal health care and family-sustaining jobs are essential to an agenda that has workers and families best interest in mind.

The Low-Wage Labor Market, Low-Wage Worker Organizing, and the Policy Process

What does this in depth case study tell us about low-wage worker organizing more generally and the broader low-wage labor market? I'll start with what this case tells us about low-wage worker organizing, the policy process, and the politics involved in the changes to the home health care industry.

Central to this story of home health care in New York City is how SEIU was finally able to win the living wage for home health aides after years of organizing with no wage increases and in a political environment where cuts to Medicaid were inevitable. Here, John Kingdon's

work can help clarify the answer to this question. Kingdon's agenda-setting theory starts with the following belief: "The greatest policy changes grow out of that coupling of *problems, policy proposals*, and *politics*" (Kingdon 1995, p. 19). These three things—problems, policy proposals, and politics create a policy window. Kingdon wrote: "Solutions become joined to problems, and both of them are joined to favorable political forces. This coupling is most likely when policy windows—opportunities for pushing pet projects or conceptions of problems—are open" (Kingdon 1995, p. 20).

Problems refers to the process of persuading policy makers to pay attention to a specific issue (over others). SEIU not only took advantage of a problem the state was having, namely increasing fraud of home health care agencies in a time of accelerating Medicaid costs, but they helped to expose this problem in the first place. They helped to create a buzz on the state level about the need to crack down on fraudulent agencies that were costing the state money (which was an abhorrent example of government waste in a time of increasing financial strain in NY).

Which leads to Kingdon's second ingredient for policy change—*policy proposals*, which is the process by which policies are proposed, generated, revised and adopted. These proposals tend to be more successful if they are viewed as feasible, reasonable in cost, appealing to the public and coincide with policy-makers values and goals. After SEIU helped to expose the problem, they then took advantage of the fact that the state was concerned with and focused on this fraud to push their agenda for the living wage. They did this by assessing what was possible and conceding to the shift to managed care, which coincided with the interests of the state—while in other years they had fought state cuts, they saw the writing on the wall that cuts had to be made in fiscal year 2011 and they appealed to the state with the reorganization of the system in a way that met the state's need to curb Medicaid costs. The state had already been interested in

shifting to Managed Long-Term Care and SEIU assessed that this change was inevitable—so, they pushed their agenda by way of Managed Care and consolidation.

Kingdon's third element important for policy change is *politics*, or the political factors that influence agendas, which include interest group campaigns, political climate or mood and political connections. SEIU was able to influence this change because of the size and strength of their union (which is the biggest local union in the world), their politically savvy and their well-connected policy directors over the years who have strong political ties to and influence with Governor Cuomo. Essentially, complexity in its own right—here it is the complexity of the home health care industry in New York City—played a role in the policy process. Consumer advocates, who would have raised more opposition if cuts were made directly to Medicaid eligibility, actually did not have a united front against the shift to managed care, partially because of the complexity of the system and the proposed changes. Cutting costs by reorganizing the system appealed to the state more than cutting eligibility or services directly because, in part, the former did not raise as many red flags for consumer advocates, even though shifting care into the hands of Managed Care may, in fact, result in the cutting of services for patients.

Now, let me focus specifically on the consolidation of the industry. SEIUs strategy to increase wages in the face of growing austerity was to consolidate the industry in order to win wage parity for home health care workers. This consolidation served two purposes for the union. First, larger companies have more ability to fund the wage increase—if more money (in the form of increased rates) isn't coming from the state, it has to come from the companies themselves. Smaller companies margins are too thin to be able to make it under these new conditions and SEIU has historically had greater success negotiating with larger agencies. Second, the consolidation of the industry makes union organizing for SEIU easier, as it resembles the larger

enterprise-dominated Fordist organizing. From a union perspective, their goal is to achieve density in a particular industry and in this case organizing fewer larger companies is easier than organizing many smaller companies, especially given the rapid growth of non-union companies in Brooklyn.

This consolidation of the industry is significant. 1199 had fought for many years to increase wages in the industry with little success (they were successful in organizing workers, winning health insurance and other benefits, but increasing wages was harder). In the home health care industry (as my respondents reported), the ability to pay higher wages was limited by the structure of the industry itself (even the worker cooperative who had workers' best interest in mind and access to other funds, were only able to pay the minimum wage). In this case, SEIU was able to win higher wages, but it did so by shrinking the city-run program and growing the role of corporate for-profit managed care companies. While this was an important win for SEIU, it raises some profound questions. Is pushing the industry towards big business and away from government an effective or good direction to push care work? Will it be good for patients and workers in the long-term? Did the union go too far with this compromise? I fear this short-term win further pushes the responsibility for care into the hands of the private sector, where being profitable and beholden to stockholders drive decisions around care.

But perhaps even more importantly, and as it relates to low-wage worker organizing more broadly, is whether this union strategy of consolidation is one that other unions have pursued (and are pursuing) when they face the difficult task of organizing a fragmented industry. A fragmented industry is "an industry in which no single enterprise has large enough share of the market to be able to influence the industry's direction" (www.businessdictionary.com). In the case of home health care in New York City, which I would call a fragmented industry, SEIU

1199, which is arguably the biggest institution crossing company boundaries in the home health care industry in New York City, played a particular role in consolidating the industry. More research would need to be done on whether consolidation is a strategy that unions organizing in other fragmented industries have adopted. And if so, what does it mean that labor unions are pushing our economy towards greater consolidation? Will this, in the end, further expand income inequality?

My dissertation also raises other questions about the limitations of unions in an economy that increasingly relies on informal work arrangements. While unions organize the formal market and don't espouse to do anything but, how effective is a union strategy that disregards the impacts of their organizing on the gray market? To me, the fact that the gray market will expand with the reorganization of the system that they pushed for, raises the importance of linking union struggles with more informal organizing outside of traditional union organizing. This is essential to a holistic strategy aimed at lifting up working conditions for all home care workers, both formal and informal. In order to deal with this state of affairs, it requires unions to think about these broader questions and connect with other organizing efforts—embracing the "everybody in, nobody out" philosophy.

What does this case tells us about the low-wage labor market more generally and the role of the state in structuring this market? Some overlapping trends can be seen both in the case examined here and elsewhere in publicly-funded industries. Most obviously, shifting government services further into the private sector is a trend that is happening in the case of home health care, and can also be seen in education with decreased funding and the expansion of charter schools, and in hospitals with the decline of public hospitals, which have historically treated patients who do not have access to health insurance. Much of what has been considered "public"

is shifting to be both privately-run and being paid for increasingly by users (increased tuition at public universities, higher tolls on public highways and bridges are examples of this). In many of these cases, as with home health care, these once "public" services are still paid for at least in part by public funds, but become repackaged and shifted to a market-based system where profits can be made without the same level of public accountability.

However, some of the dynamics at play in the home health care industry are specific to this industry. An industry that is most similar to this is childcare. My approach to studying the home health care industry—in particular studying the formal with the informal—is key to understanding the dynamics of the child care industry, in which some amount of care is publicly-funded, and the rest is paid for by private households. My research suggests, that having a whole part of an industry relying on families as employers in an increasingly low-wage economy will lead to poor wages and higher prevalence of workplace violations for workers. This is an important distinction from, say education, in which, if public funding decreases, the quality of education declines, but the work itself does not shift into the informal economy.

Approaching the examination of the childcare industry in a similar way that I have done in my dissertation can further illuminate how the state, through regulations and funding impact these industries, the size and scope of the informal economy and the working conditions of care workers. Childcare workers in NYC fare much worse than home health care workers (Bernhardt, Polson and DeFilippis 2010), in part, because workplace protections are weaker, some public funds pay for unregulated care (as compared to home health care in which all public money pays for regulated care) and much more of the work is performed informally and paid for by private households. While Medicaid is much more extensive and generous than childcare assistance in NY, the childcare industry begins to tell a cautionary tale to home health care—if cuts to

Medicaid and the reorganization of the system drive the industry more towards the informal, grey market, workers will be worse off.

Limits to this Research and Future Research on Care

Originally conceptualized, this dissertation was going to compare home health care jobs and childcare jobs in New York City, Los Angeles and Chicago (the three cities that the 2008 Unregulated Work Survey surveyed). The thought was that comparing these two types of jobs, both of which are partially publicly funded and rely on informal care work to fill in the gaps of the formal, publicly and privately-paid markets, would give us more insight into the dynamics of a public welfare state that plays a part in creating/perpetuating low-wage work in these sectors. Unfortunately, due to the complexity of both the home health care industry and childcare industry in each location, I needed to make a decision to focus in on only one of these industries and in only one city. I still think the broader study is a worthwhile research task and the comparison could give us more insight into the institutional reasons why wages and working conditions remain so poor for workers who provide caring labor.

Because the focus of the dissertation narrowed from care work in three cities (New York City, Chicago and Los Angeles) to one city (New York City) and from two industries (home health care and childcare) to one (home health care), the data from the 2008 Unregulated Work Survey lost much of its statistical strength as the N I was analyzing shrunk from about 750 to about 150 workers. This required me to place a heavier emphasis on my qualitative analysis and the structural/institutional structure of the industry (which provides insights that the quantitative data would not). The Unregulated Work Survey included never-before collected information about the low-wage labor market and has given us detailed information about this segment of the

workforce. However, the survey was not written specifically for, nor was the focus specifically on, care workers. A more targeted survey of care workers would yield more accurate and specific data that would be useful for understanding caring jobs. Specifically, my data did not specify whether workers were employed as home health care aides or personal care aides (which at the time of the survey should have made a big difference in what workers were paid), and the number of gray market workers was low, making comparative analysis difficult.

Focusing on the home health care industry in New York City, however, allowed me to get more in-depth into the industry and understand the specific historical and local dynamics that has shaped and continue to shape the industry. More research could be done on the revolutionary changes that have taken place in New York City within the home health care industry. Because of time and resource constraints, it was only possible for me to conduct interviews about these changes as they were just starting to be implemented. Another round of research at this point and in a couple years would really show how these changes are impacting the industry, workers and patients in New York City.

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