

Community Health Workers; Addressing the Shortfalls of a Sovereign Profession

by

Liana Rosenkrantz Woskie
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Table of Contents

ACRONYMS.....	3
PREFACE & ACKNOWLEDGEMENTS.....	4
INTRODUCTION.....	7
• Striving for Cost-Effective Care in the United States	
• Recognition of the Importance of Primary Health Care	
• Academic Context	
Part One: Approaches to Healthcare as an Expense and a Human Right	
GOVERNMENT ROLE.....	12
• A Human Right	
• Exploring the Role of Government with Respect to Health Care Equity	
• International Human Rights, Establishing a Right to Health	
• The Applicability of an International Right to Health in the US	
• Reflection	
THE WELFARE STATE.....	18
• Institutional Imbeddedness	
• The Industrialism Theory as Applicable to the US' Welfare System	
• Citizenship; the Significance of Welfare	
• A Discussion of the Failure of the US' Past Welfare Reform	
MEDICAID.....	29
• The Development of Medicaid in the US	
• The Current Condition of Medicaid	
• Providing Adequate Care: Addressing Issues of Cost and Coverage	
THE CASE of MASSACHUSETTS.....	37
• Chronic Disease Management; a Complex Financial Burden	
• An Effort to Address Complex Needs; Current Services	
• Case Management Services, Massachusetts	
• Home and Community Based Services	
Part Two: Medical Expertise: Professional versus Lay Knowledge	
MEDICAL PROFESSIONALISM.....	45
• The Relevance of Paul Starr's <i>the Social Transformation of American Medicine</i>	
• Rise and Decline, Faith in the Dominance of a Sovereign Profession	
• Diversification of the Medical Profession	
• Complexities of Healthcare Distribution and the Development of Healthcare Economics	
• Managed Care	
• Reflection	

LAY KNOWLEDGE.....	60
<ul style="list-style-type: none"> • Combating Complexities of Distribution • The Construction and Potential of Lay Expertise, the Case of AIDs/HIV • The CHW: an Effective Example of Incorporating Lay Knowledge into Health Care Provision • Defining CHWs in the U.S. • Increasing Access to Care 	
Part Three: A Case Study	
PREVENTION and ACCESS to CARE and TREATMENT.....	70
<ul style="list-style-type: none"> • The PACT Project • HIV/AIDs: Embracing and Addressing the Existence of Social Determinants of Health • Development of PACT • Project Outline • Understanding the Specific Role of PACT CHWs • A Deeper Look into the PACT Model 	
OUTCOMES.....	81
<ul style="list-style-type: none"> • Contextualizing the Success of Community Health Workers • PACT Project Outcomes • Reflections 	
ANALYSIS.....	91
<ul style="list-style-type: none"> • Contextualizing Implications • Policy Recommendations • Direct Reimbursement 	
CONCLUSION.....	98
REFERENCES.....	101
EXHIBITS.....	105

Acronyms

AACHW	American Association of Community Health Workers
AIDs	Acquired Immune Deficiency syndrome
AMA	American Medical Association
APHA	American Public Health Association
CD4	Cluster of Differentiation 4
CBO	Community Based Organization
CHW	Community Health Worker
CHW SPIG	Community Health Worker Special Primary Interest Group
CMS	Centers for Medicare & Medicaid Services
CPS	Current Population Survey
DRA	Deficit Reduction Act of 2005
DOT	Directly Observed Therapy
CVD	Cardio Vascular Disease
HCBS	Home and Community Based Services
HIV	Human Immune-deficiency Virus
HMO	Health Maintenance Organization
HRSA	Health Resources and Services Administration
ICESCR	International Covenant on Economic, Social and Cultural Rights
IOM	Institute of Medicine
FFS	Fee for Service
FXB	François-Xavier Bagnoud Center for Health and Human Rights
LIS	Luxembourg Income Study
MCO	Managed Care Organization
MDPH	Massachusetts Department of Public Health
MMCO	Medicaid Managed Care Organization
NIH	National Institute of Health
NUCC	National Uniform Claim Committee
PACT	Prevention and Access to Care and Treatment
PHC	Primary Health Care
PCC	Primary Care Clinician
PIH	Partners in Health
SOC	Standard Occupational Classifications
UDHR	Universal Declaration of Human Rights
UN	United Nations
WHO	World Health Organization

Preface & Acknowledgements

I have been lucky in my life.

I was born to a mother with severe mental illness. Transient, housed and sometimes un-housed, she fought to find herself. She was not able to adhere to her medication regime and could not take care of her children or herself. Lack of support and community aggravated the situation, making her fight extremely demanding. Because of her difficulties, I was adopted early in my life.

My (adoptive) mothers have given me the often rare gift of self-determination. Through their support, they have enabled me to explore a diverse array of interests, allowing me to choose what I would like to pursue. With this freedom, I have found that matters of personal and community-based empowerment resonate deeply.

Within my own communities, the many people who now make up my family have given me an increased awareness of, and respect for, the vulnerability of people who face a wide array of difficulties. I've gotten the chance to learn how to care for people who are not related to me as if they were, and to love people in the face of things that cannot easily be articulated in Times New Roman (or Calibri, as the case may be). Many of my friends' own family members have either passed away or lost their ability to care for others; as a result, my home has accumulated members. The chance to learn how to love people in the face of adversity has been simultaneously the most difficult and most wonderful thing to shape my life. As the lines that separate my family and community dissolve, my family continually expands, making family dinners large, loud and far from boring. The intricately complex ways in which we have supported one another never cease to amaze me. It is not a question of how far this support extends (that question has fortunately never been an issue), but where and how it can be utilized.

I have found that communities have the ability not only to support, but also to cultivate self-efficacy and determination. In an effort to explore manifestations and variations of community support, since a young age I have immersed myself in social justice work and community involvement. In high school I was introduced to an indigenous rights group, Cultural Survival, and instantly fell head over heels. I met a wide array of people in legal, social and anthropological contexts from all over the world, brought together by their common fight to sustain the 'rights, voices and visions' of indigenous communities. The power of commitment and love with which I saw people fighting for their communities was astoundingly beautiful. It instilled in me a deep respect for the autonomy and cultural integrity of a people, as well as the ways in which community power can be harnessed to pursue and achieve truly monumental acts. In Sapulpa, Oklahoma, with the help of Cultural Survival, the Euchee people initiated the Euchee language project in an effort to save their dying native language, and with it a rich cultural history and knowledge. When they began, only five elders knew the language. Now, over a thousand Euchee youth and young adults have participated in the program and can confidently say "yUdjEhanÂnô sôn KAnAnô" – We the Euchee People, We are Still Here.

Interested in the cultural variations of community within the United States, I began reading Thomas White's book, *What's the Matter with Kansas*. The book explores Republican voting tendencies amongst lower income, 'blue collar' citizens in Midwestern

America. As I read, I quickly came to realize that although my up-bringing (largely in Cambridge, MA with occasional visits to Berkley, CA) gave me claim to a liberal openness, I had an ironically narrow understanding of political and, more importantly, social variations in my own country.

I decided I wanted to more thoroughly understand the communities of the country I grew up in. I wanted to get a picture of what exists beyond urban costal regions and my own liberal upbringing. The summer after my freshman year of college I got the chance to embark on a Habitat for Humanity group cross-country cycling trip from New Haven, CT to San Francisco, CA. On the trip, we raised awareness of and support for Habitat for Humanity while building homes with families in need. We got the chance to travel through 13 states and stay with a variety of communities as we went.

Tragically, while we cycled through Kansas, my riding partner was struck by a car, leaving him in a coma for close to a year and impairing his motor and vocal skills to this day. From one hospital to the next, and finally to his home, I was able to witness Dan's intricate care-giving process. Through this process of redefining life, I have gained an appreciation and deep respect for holistic health care, weaving love and a diversity of traditions into biomedical strategies. I have learned to recognize the importance of strong community involvement in an individual's fight for both life and quality of life. I have also been forced to see the limitations of our own broader healthcare system, such as access to care that addresses not only acute medical issues, but also the patient's multi-faceted situation and long-term social and health-related outcomes. As a result, I have begun to explore how non-typical initiatives can begin to alleviate these limitations by redefining norms of medical care.

Working for Middletown's Community Health Center as a college junior, I was introduced to an initiative that worked to address the individuality of patient needs. As a member of Wesleyan's "Health of Communities" course, I evaluated how mobile modes of care could reach high-need public school children by providing Medicaid reimbursable services. This work cemented my interest in what had previously been only a curiosity in public health. Public health and healthcare delivery have begun to provide a framework and focus for my many community and social justice interests. By combining my interests and focusing them on a specific pursuit –equitable health outcomes for marginalized populations –I have had the rare and wonderful opportunity to pair my heart with my academic interests.

Most recently, with the generous aid of the Davenport Grant, I have worked with the Aids Action Committee and Prevention and Access to Care and Treatment (PACT). With these two organizations I have been able to best-practices research, inform curriculum, design my own curriculum, train peer health advocates and, most valuably, learn from peer health advocates.

Through this work, I have found that health and health treatment are innately tied to social aspects of care. The humanistic nature of the connection, commitment and deep understanding that develop between patients and peer health advocates as amazed me. As a result of this work, my interest in the CHW model has bloomed, especially in its relevance for low resource patients who face barriers to accessing and affording care in typical medical contexts.

With this thesis, I hope to further pursue my interest in CHWs and alternative care provision by looking at the interplay between the government's role in providing care to its citizens, gaps that persist, and the potential of CHWs and others to fill those gaps.

With humility, I would like to thank everyone who has helped me in the process of not only writing this piece, which I have found to be an invaluable contribution to my educational experience, but also those who have helped me form a deeply founded love of public health, health policy and the fight to combat unnecessary inequities. Specifically, I would like to thank my family and friends (two groups that I have found often overlap); my housemates: Cait, Gina, Tess and JP (who dealt with me wonderfully after I deleted the latest draft of my thesis four days before it was due, bringing me flowers and food); Jeff Stein (who, to my great benefit, decided to graduate early); the College of Social Studies; PACT; my thesis advisor Laura Stark (who was onboard before I met her, and has remained enthusiastic, thoughtful and reflective throughout the entire process), Peggy Carey Best (who, through the Health of Communities course, introduced me to much of what I write about in this piece) and countless others who have helped me shape and explore my interests over time.

Introduction

Striving for Cost-Effective Care in the United States

When the World Health Organization rated the ‘fairness’ of 191 national health care systems, the United States ranked 54th (WHO, 2000). This ranking put the US slightly ahead of Chad and Rwanda but just behind the Maldives and Bangladesh. In a similar vein, nine years ago the U.S. National Academy of Sciences Institute of Medicine concluded that we experience as many as 98,000 preventable patient deaths in the U.S. health care system every year; over 250 deaths a day (IOM, 1999).

Recently, organizations such as the Commonwealth Fund have provided study after study that fundamentally challenge the conceit in America that the U.S. has the finest health care system in the world (Kenney, 2008). Time and again, the group has shown that the United States falls behind in quality, safety, and efficiency. As Kenney remarks:

The inescapable conclusion is that although we are spending double or more per capita on health care than any other industrialized nation, we are not getting any better results; indeed, in many cases, our results are worse, the vast spending gap notwithstanding (Kenney, 2008).

For example, the US, despite our high per capita spending, has a life expectancy at birth that ranks 27th in the world (Anderson, 2005).

The cover of the Harvard Public Health Review for the winter of 2010 was emblazoned with the intentionally provoking, yet straight forward question: “Can Cost-Effective Health Care = Better Health Care?” (Harvard, 2009). The corresponding article, supplemented with a green-hued image of a sterile hospital corridor, concluded that cost-effective care can, in fact be better care. The author interviews Milton Weistein, the Henry J. Kaiser Professor of Health Policy and Management at the Harvard School of Public Health,

who asserts that many well established cost-effective interventions are underutilized. Alternatively, many expensive and routine procedures lack evidence that they are in fact effective.

In response to a question concerning gaps in spending and performance, Weistein responds, “low-cost areas are using more cost effective services: counseling to quit smoking, colonoscopies, giving beta-blockers to patients after heart attacks. These are all well-established interventions that are effective and also cost effective.” Weinstein adds: “If you do more things that have marginal value and less of the cost effective things that have proven value, then you get places that spend more and get worse outcomes,” (Weinstein, 2009). This statement is especially relevant in light of the current economic recession. As the Obama administration well knows, public spending programs are often simply too expensive to garner popular support.

The disconnect that exists between health outcomes and health spending in this country is a problem, and it is not a simple problem of clinical issues, or incompetent physicians (Kenney, 2008). Dr. Donald Berwick, President and Chief Executive Officer of the Institute for Healthcare Improvement, has said:

The vast majority of medical mistakes are committed not by bad apples, but by good doctors trying to do the right thing, working under conditions that do not account for the fact that they are human (Berwick, 2003).

Charles Kenney attributes this to the fact that we have inherited and unconsciously nurtured a fragmented and poorly designed system of care provision, one that has perpetuated medical errors, leading to the misuse, overuse and underuse of healthcare (Kenney, 2008).

Medical professionals as well as the American public seem to agree that curbing costs is essential to effective health care reform in the United States (Harvard, 2009). It has

become clear that we need healthcare delivery models that can effectively address rising costs, poor access to healthcare and disparate health outcomes. Medicaid, the only federally funded means-tested program in the United States, is the program designed to provide services to low income individuals by cost effectively reimbursing relevant services for those who qualify. Theoretically, this program which has been in existence for 45 years should be acting as a model of how to provide cost effective and equitable care. The program should be closing the gap in access to medical care for those most in need. However, as I will discuss, Medicaid has faced a history of retrenchment and has met substantial barriers in cost-effectively addressing healthcare needs.

In brief, to date the US government has done little to ensure that all Americans have basic, cost-effective health care. Additionally, medical outcomes in this country do not reflect the tremendous amount of money that is currently being spent on healthcare.

Recognition of the Importance of Primary Health Care

Modern public health emphasizes the critical importance that societal factors have on health outcomes. In this vein, public health advocates have begun looking to the primary and preventative health care system to more effectively address the role of social determinants on health outcomes, as well as to humanize patient interactions with the medical system through the establishment of stable primary care relationships.

In 1978, the International Conference on Primary Health Care held in Alma-Ata declared primary healthcare (PHC) as the key to attaining health for all. The conference concluded that PHC should be made universally accessible to individuals and families through their full participation at an affordable cost on a continuing basis. Alma-Ata recognized PHC as the necessary primary contact between individuals and the national

healthcare system. The conference concluded that PHC is the first element in a continuing healthcare process, that it forms an integral part of the country's system and needs to take place as close as possible to where people live and work (Rights, 1988).

Despite an international emphasis on health coverage expansion, the US has been slow to incorporate this philosophy. Since the late 70's, there has been a move in the direction of provision expansion with respect to the diversity and array of services provided in a primary care context, but this movement has been glacial at best (Ameringer, 2008).

Academic Context

In response to the difficulties faced by our current healthcare system, many historians and political scientists have written about the failure of the United States to achieve universal health coverage. In doing so, they often decry the role of the medical profession, which, for much of the twentieth century, resisted government intervention (Ameringer, 2008). However, in focusing almost exclusively on the repudiation of a government-based system, historians and political scientists frequently neglect the intimate complexities of actually implementing a comprehensive health care provision system. As a result, academically distinct accounts have emerged concerning the trajectory of U.S. health policy (Ameringer, 2008). These accounts have been informed by specific lines of inquiry, policy preferences and methodology of individual disciplines. By providing a broad multi-disciplinary framework and concluding with a case study - the Community Health Worker - I hope to narrow the gap between multiple academic perspectives on approaches to health care provision.

In the first section of this piece, I attempt to provide a contextual framework for my later content. I hope to do three things: discuss the relevance of the human rights discourse

with respect to health care provision within the US; look at the role of government in providing social and health-specific services by exploring welfare theories in the discourse of political economy, and finally; discuss the particular case of Medicaid in Massachusetts. Although these topics risk appearing somewhat disconnected from the specific nature of my case study, I find their inclusion to be necessary for a comprehensive evaluation of health equity in the US. I have chosen to begin the thesis with these pieces because of their universal importance; they stand alone in addition to providing the backdrop – and necessity -- for understanding the efficacy of my specific case study.

In the second section, I provide a narrative on the diversification of the medical profession in the US by looking at the changing roles of a range of medical providers, with a focus on physicians. In addition, I look at the incorporation of lay knowledge into this history.

I will conclude with a discussion of Community Health Workers (CHWs) and the Prevention and Access to Care and Treatment Project (PACT). This section is a discussion of the potential of meeting complex health needs efficaciously by incorporating lay knowledge into publicly funded systems of medical insurance. I use PACT as a case study due to both my personal experience with the organization and its broader relevance. My focus on Community Health Workers is meant to exemplify the paradigm shift I support throughout this body of work, one that proposes the individuality of patient needs be attended to in order to promote health equity – and through health equity, citizenship.

The Government's Role

"In a land where all are created equal, which inequalities are we willing to accept?"

-T. R. Reid

A Human Right

President George W. Bush repeatedly assured the American people that they need not worry about their uninsured neighbors, "I mean, people have access to health care in America," Bush told a business meeting in Cleveland on July 10, 2007. "After all, you just go to the Emergency room". Contrary to President Bush's assurance, hospitals in the US routinely turn sick people away if they cannot prove they have the means to pay for services. As the leading textbook on health care law indicates, in the US, this is very much within a hospital's legal rights: "A hospital is not, as a general rule, required to continue treatment in the face of nonpayment bills," (Becker, 2008). You cannot get a regular check up at the Emergency room in the US, you cannot get a physical exam, and in many cases you certainly cannot get care if you do not have the means to pay for that care.

Harvard Economist William Hsiao, who has helped design health care systems for more than a dozen nations, identifies an important question as the primary inquiry into a nation's health provision system. Although the creation of a national health care system involves political, economic and medical decisions, the primary question is one of morality: is health care a human right?

Before you can set up a health care system for a country, you have to know the country's basic ethical values. The first question is: do people in your country have a right to health care? If the people believe that medical care is a basic right, you design a system that means anybody who is sick can see a doctor. If a society considers medical care to be an economic commodity, then you set up a system that distributes health care based on the ability to pay (Hsiao, 2008).

With the exception of the US, all industrialized nations have concluded that health care is in fact a right (Reid, 2008).

Exploring the Role of Government with Respect to Health Care Equity

In many countries, national health insurance has proved to be a major tool for restraining costs and controlling inflation. In the United States however, planning the rational distribution of health care has been a multi-century struggle (Quadagno, 2006). The result has been the duplication of services; unnecessary procedures, tests and drugs; inefficient use of technologies; and rampant inflation, motivating many employers to outsource jobs overseas (Quadagno, 2006). As the prominent historian David Rothman remarks:

Americans do not think of themselves as callous and cruel, yet, in their readiness to forgo and withhold this almost elemental social service, they have been so. This question arises: How did the middle class, its elected representatives, and its doctors accommodate themselves to such neglect (Rothman, 1993).

Over the past three decades, terms that Medical Sociologist Paul Starr famously employed in the 1980s with his work, *The Rise of a Sovereign Profession*, such as “the coming of the corporation,” “the privatization of the public household,” “professional authority,” “sovereignty,” and “rights,” have taken on altered meanings in American culture and in the politics of health care. For instance, as I discuss below, the rise of health care “rights” movements has altered the very meaning of that term, and further changed the role of governments with respect to health care both globally and domestically (Halpern, 2004).

International Human Rights, Establishing a Right to Health

The Human Rights approach seeks to describe, promote and protect, the societal level prerequisites for human well-being. Through this discussion, the ability of each individual to achieve his or her full potential is explored, an inquiry and discussion directly

pertinent to understandings of both health and a society's relationship to health (Mann, 1998).

The importance of Human Rights came to the forefront of international relations following the atrocities of the Second World War. When the United Nations was formed in 1945, the promotion of human rights became one of its objectives. In 1948, the UN General Assembly adopted the Universal Declaration of Human Rights, setting out a basic list of rights as "A common standard of achievement for all peoples and all nations," (Preamble, UDHR). To this day, this declaration stands as the fundamental document of modern Human Rights.

Modern Human Rights have been internationally exalted as a civilizational achievement. Within this context, the UDHR is a document that seeks to identify and agree upon what governments should not do to people and what they should assure for all. This discourse derives legitimacy from having been developed, voted upon and adopted (Rights, 1998). Human Rights do not achieve their status as such through divine inspiration or religion, rather, they are an innately collaborative effort, bringing together participating nations.

The UDHR's focus on societal-level determinants of well-being addresses an array of public health issues and concerns. As aptly noted by Jonathan Mann in the introduction to *Health and Human Rights*, even though the word 'health' itself only appears once in the UDHR, the focus of the Universal Declaration on societal-level health determinants provides public health with a framework, vocabulary and guidance for analysis and direct response. This approach may ultimately prove more useful to promote public health than frameworks inherited from solely biomedical and public health traditions (Mann 1998).

As the Francois-Xavier Bagnoud Center for Health and Human Rights (FXB) promulgates, health informs Human Rights, Human Rights inform health and health and human rights inextricably inform each other (Rights, 1998). There are potential impacts of health policies, programs and practices on human rights. Essentially, health and human rights act in synergy. Violations of any and all human rights may therefore have negative effects on physical, mental and social well-being. As sanctioned by the FXB, "Promoting and protecting health requires explicit and concrete efforts... and greater fulfillment of human rights necessitates sound attention to health and to its social determinants," (Rights, 1998). The way in which a problem is defined largely determines what interventions are deemed reasonable or appropriate.

Recognition of human rights can begin to define the direction and nature of societal change needed to support effective modes of healthcare distribution. Simply taking issues of public health into account at an international level is a move of great significance (Mann 1998). The intersection of health and human rights can therefore be seen as recognition that discrimination and other violations of human rights directly impact health and wellbeing. This is especially evident when considering the UN establishment of the World Health Organization in 1948, which defined health broadly as, "A state of complete physical, mental and social well being, not merely the absence of disease or infirmity," (U.N.T.S. 1946). The WHO constitution goes on to state that the "Enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition," (U.N.T.S. 1946). Because of the connection that health has had to human rights discourse, the societal issues

that largely determine who lives and who dies, when and how, must be dealt with when defining and addressing health related issues in any given country.

The Applicability of an International Right to Health in the US

In her article, *Recognition of the International Human Right to Health and Health Care in the United States*, Professor of Law, Eleanor Kinney argues that the international human right to health creates a right to health care within all nations, including the US. Kinney traces the recognition and implementation of the international human right to health in the United States. By looking at her model, deficiencies of the U.S. healthcare sector become clear, leading to the conclusion that these deficiencies compromise the implementation of a human right to health.

Following the Lockean tradition, Kinney explores the idea of 'negative rights' such as those put forth in the International Covenant on Economic, Social and Cultural Rights (ICESCR). She argues that documents such as the ICESCR can be viewed as customary international law due to widespread international acceptance.

The UN Economic, Social and Cultural Committee publication of General Comment 14 to the ICESCR outlines the international right to health and its implementation and enforcement. Building on the typology of social human rights developed by Asbjorn Eide in 1987, General Comment 14 imposes three levels of obligation: to respect, protect and fulfill (Eide, 1995). The Comment clearly addresses implementation. It imposes a duty on state parties to "Take whatever steps are necessary to ensure that everyone has access to health facilities, goods and services so that they can enjoy, as soon as possible, the highest attainable standard of health" (U.N. Econ. & Soc. Council 2000). According to Comment 14, national health strategies should also identify the most cost-effective way of using resources

towards this end (U.N. Econ. & Soc. Council 2000).

A human right to health is also recognized in numerous other U.N. international human rights treaties that address the needs of historically vulnerable populations who have been discriminated against. Kinney identifies such treaties as, the International Convention on the Elimination of All Forms of Discrimination, the convention on the Elimination of All Forms of Discrimination against Women, and the Convention on the Rights of the Child. All of which directly specify the right to health for respective groups in two ways: by prohibiting discrimination and providing affirmative cohort specific rights to particular types of care (Kinney).

Reflection

Although formal recognition of a right to health has been extremely limited in the US, these international laws can, and should, be seen as binding for all countries regardless of ratification. Despite the US' initial resistance to incorporating the international treaties into constitutional law, wide recognition and acceptance of these statutes in international legislation should make them binding for all member states. Kinney also suggests that the powers accorded Congress in the Constitution support the establishment of federal health programs and also authorize regulation to improve health care delivery and promote public health (Miller, 2002).

While the difficulty of providing comprehensive guidelines for international health provision must be acknowledged, the right to health requires individual nations, such as the US, to take affirmative steps to assure that their residents have access to both affordable health services and population-based public health protection.

The Welfare State

In a discussion of rights, it is often easy to demand more resources, but decidedly more difficult to produce those resources. If social and economic rights are acknowledged as such, then foundations, governments, businesses, and international financial institutions may be called upon to prioritize human rights endeavors that reflect the paradigm shift advocated above (Farmer, 2000). As global interaction increases and state power weakens, it is, in many cases, easy to discern an increasing role for nongovernmental institutions, including universities and medical centers in the provision of health care. However, as Paul Farmer aptly notes, it is also easy to discern a trap:

The withdrawal of states from the basic business of providing housing, education, and medical services usually means further erosion of the social and economic rights of the poor (Farmer, 2000).

It thus becomes increasingly important for states to provide adequate public services to a diversified citizenry. The US however, has struggled both to maintain far-reaching welfare provisions for its citizens.

Institutional Imbeddedness

The US' welfare system is distinct in many ways, some of which result from a certain level of 'institutional imbeddedness'. In comparing the development of the U.S., British, and Canadian health-welfare systems, Carolyn Tuohy argues that "key features of health care systems are 'accidental' in the sense that they were shaped by ideas and agendas in place at the time a window of opportunity was opened by factors in the broader political system," (Tuohy, 1999). There are several significant ways in which today's problems and possibilities are affected by actions taken in the past. Mark Peterson's 1997 model of social learning

considers how current policy is a “legacy” of earlier decisions and non-decisions and how policy changes today will quite possibly have a significant impact on conditions, perceptions, and policy alternatives in the future. Policy legacies “continuously transform the decision matrix of each participant in the policy making process, as well as the capacity of governments to implement and administer particular kinds of public-sector interventions,” (Peterson, 1997).

The Industrialism Theory as Applicable to the US’ Welfare System

Many theories strive to explain and defend the development of welfare states; these theoretic models of development offer a powerful framing mechanism for evaluating the current state of our own welfare state. In her work, *Theories of the Welfare State*, Jill Quadagno lays out what she deems the “Logic of Industrialism”:

As industrialization proceeds, it creates new needs for public spending by reducing the functions of the certain categories of individuals whose labor becomes surplus... because traditional societies are unable to meet the needs of these vulnerable individuals, the state expands more or less automatically (Quadagno, 2006).

In this theory, social benefits become feasible due to the new wealth and expanded surplus provided by the industrialization process and due to the development of an enhanced organizational structure, through which benefits can be distributed (Quadagno, 2006).

After introducing the industrialism theory, Quadagno provides a series of three major critiques: first, industrialized countries have developed welfare states at different points in the industrialism process and these programs take different forms. Second, many non-developed or less-developed countries have constructed welfare or welfare-like systems. And finally, according to comparative evidence, the development of new vulnerabilities in the population does not, in itself, automatically lead to increased welfare expenditures (Quadagno, 2006). However, in their narrowness, these critiques are subject to what Goran Therborn highlights as

the weakness of the first stage of neo-Marxism – a lack of interest in, and attention to, intra-epochal variation and the reasons for it (Therborn, 1986). By embracing the industrialist theory that Quadagno initially presents and transitioning its functionalist arguments into a more comprehensive model that incorporates these academic responses as theoretical answers, discussion of the development of the welfare state can begin to address problems and deficiencies of the market (Therborn, 1986).

As Quadagno aptly notes, not all industrialized countries have developed welfare states at the same time or of the same form. Therborn admits this and notes that the place and meaning of the welfare state in state history is a central problem of state theory, an issue that has been largely neglected (Therborn, 1986). A discussion of the post-Marxist movement addresses this issue. As opposed to viewing welfare initiatives as purely teleological in their conception, this model expects welfare states “to vary widely in structural form, each form should be expected to manifest the relative strength and interrelationship of the classes and their perspectives on welfare,” (Therborn, 1986). As John L. Campbell suggests, in a discussion of fiscal sociology, public finances affect and are affected by a wide range of political, economic, cultural, institutional, and historical factors (Campbell, 164). Pluralist theory, as discussed by Therborn, additionally suggests that social security welfare systems are dependent upon patterns of suffrage and constitutional structures (Therborn, 1986). All of these theories, similar to the statist model, acknowledge that complex factors, such as state structures, have shaped the temporal development of modern welfare states as well as their manifestation (Therborn, 1986).

Much of the US’ healthcare-specific welfare growth, has occurred along familiar regulatory lines, incorporating thin notions of state ability to effectively implement aid programs

and an (often dangerous) reliance on corporate benevolence. Domestically, old welfare programs were restructured and presented as safe options under the New Deal in an effort to secure the allegiance of large organized interests. By incorporating the role of state individuality into theories of welfare development, this line of argument recognizes that developmental trajectories can follow nationally specific processes of political learning. State managers and state-influencing experts operate under and maneuver through various pressures and constraints (Therborn, 1986). Thus, welfare programs will necessarily differ by country history and structure regardless of shared roots in industrialism.

In what may be her most important critique, Quadagno cites comparative studies to prove that the development of new vulnerabilities in a population do not, in themselves, automatically lead to increased welfare expenditures (Quadagno, 2006). She argues that these needs must be translated into policy through some mechanism, the choice of which is related to a country's level of political development (Quadagno, 2006). Ironically, Quadagno comes close to answering her own critique in her earlier discussion of the industrialism theory, "Economic growth and its demographic and bureaucratic outcomes are the root causes of the general emergence of the welfare state," (Quadagno, 2006). Industrialism allows for the development of complex structures of bureaucracy as well as the centralization of federal power – both of which provide the mechanisms through which welfare programs are administered. These independent theories, when taken together, form a powerful model of the theoretical development of Welfare.

Citizenship; the Significance of Welfare

David Brady, a prominent political sociologist from Duke University, conceives of welfare programs not as mechanisms of subversion but as highly influential methods of 'leveling the

playing field', or bringing citizens to equal footing. Citing quantitative cross-national studies, Brady concludes that more effective welfare programs, such as efficacious public health spending, can lead to a larger and more productive labor force, and an increased ability of the public to contribute to the democratic process as functional citizens (Brady, 2005).

Contemporary scholars who address structural features of society as determinants of health, such as epidemiologist Ichiro Kawachi, psychologist Bruce Kennedy, epidemiologist and public health specialist Michael Marmot, and social epidemiologist Richard Wilkinson, have helped create the current narrative founded on the idea of a social gradient in health.

Kawachi and Kennedy's *The Health of Nations: Why Inequality is Harmful to Your Health* (The New Press, 2002) assesses the nature of economic "development" and its implications for the well-being of economic actors across the socioeconomic spectrum. They posit that:

Far from being a benign by-product of capitalism's success...growing inequalities threaten the various freedoms that economic development is supposed to bring about: freedom from want, freedom from ill health, freedom to exercise democratic choice, as well as freedom to pursue leisure and the activities that we have reason to value (Kawachi and Kennedy, 2002).

The ability of an individual to exercise these freedoms decisively affects their health status.

Additionally, Therborn discusses the ability of increasing social distance between societies' poorest and richest to diminish social cohesion, which can ultimately lead to an increase of collective issues and fewer resources to solve those issues (Therborn, 2009). In the face of the complex differences that interact in an industrialized society, welfare programs can act as glue, maintaining effective democracy despite societal development and constant change brought on by industrialization and capitalism. Welfare thus functions as a necessary component of Durkheim's model of organic solidarity, allowing societies to progress by addressing issues of social anomie caused by industrialization.

Many factors, both internal and external, including but certainly not limited to, pre-existing state structures and social factors, have shaped modern welfare states. By combining conceptions of the Welfare state, the industrialism thesis can be broadened to form a comprehensive theory that enables the thesis to depart from limitations of 'description'. In line with pluralist arguments, such as those discussed by Therborn, political outcomes in liberal democracies result from competitive elections among parties and of competitive pressures from a plurality of interest groups, all operating within a given constitutional framework (Therborn 1986).

As Brady points out, liberal economic strategies that focus on social wages to reduce inequities, reach only the working population. Social security transfers ,on the other hand, are an essential component of integrating the elderly, children and those who fall outside of the labor force into society, thus enabling them to function effectively as democratic actors (Brady, 2005). Brady specifically notes public health spending as an efficacious avenue towards promoting social cohesion and civilizational engagement. Efficacious and holistic welfare programs are integral to addressing inequities that stem from interconnected societal dependencies. In the face of inequity, welfare spending is, as Brady concludes, a generalizable, stable and essential poverty-reduction mechanism at both the individual and state level.

A Discussion of the Failure of past Welfare Reform

Although expansionary and enfranchisement-driven when initiated, Welfare in the United States has faced a history of critique and, ultimately, reform. The inability of welfare programs to meet their initial goals cost effectively has fundamentally altered conceptions of welfare programs in the US from their onset. Ideological shifts, made possible due to this instability, have changed the ultimate aims of public assistance programs, allowing for

substantial constrictive reform on both the legislative and ground levels. As Margaret M. Somers and Fred Block explain, these changes have been an effort to make welfare recipients more responsive to market forces (Somers, 2005). These changes have manifested themselves overtly, but also subtly, cyclically feeding into and providing impetus for Somers and Block's perversity thesis. Due to this line of thought, as supported by a number of factors, US welfare distribution has been in conflict with expansionary aims, thus promoting a liberal regime welfare state as opposed to a social democratic regime.

Somers and Block discuss the strength of market-driven theory and its ability to dramatically affect US welfare programs through the promulgation of the perversity thesis. Following a line of Malthusian argument, the perversity thesis places responsibility for poverty on the poor themselves, suggesting that aid only acts to perpetuate dependency and thus poverty (Somers, 2005). They argue that this line of thought prevailed due to national crisis with the existing welfare regime as well as substantial social turmoil – ultimately culminating in major policy alterations to existing welfare programs.

Although Clinton's 1996 reform stands as a prominently overt example of the power of perverse thought, imbedded statist factors have dramatically shaped and restricted welfare programs. Jill Quadagno highlights internal factors specific to the US development of welfare, such as: racist state policies, existing employment-based insurance policies, state-level competition and anti-statist sentiments. Labor movements in the US have also been weak in organizing and focusing labor strength to fight for nationally supported health benefits, which has contributed to the limited nature of US benefit programs (Quadagno, 2005). From the onset of Welfare in the US, these factors can all be seen as allowing for the development of the perversity thesis from a structural standpoint (Quadagno, 2005).

The Medicaid program is an apt example of poor initial implementation, causing 'crisis' and thus departure from initial program goals. Initially, the philosophy behind the Medicaid program was expansionary. As a means-tested program, when it was initiated, states were asked to demonstrate "efforts in the direction of liberalizing the eligibility requirements for medical assistance," (Johnson, 1965). However, due to minimal regulation at the state level and increasingly high enrollment rates in the late 60s and 70s, Medicaid quickly incited heated debate concerning the mission and efficacy of the program. As one Senate committee report noted in 1978, "There is no effective rate setting method by which the State... can determine fair rates to pay prepaid health plans for the care of Medicaid beneficiaries," (Senate, 1978).

Tensions developed between "a medical system geared toward expansion and a society and state requiring some means of control over medical expenditures" (Starr, 380). Conservatives as well as liberals demanded reform, and a new round of governmental initiatives began with the primary goal of cost containment. By the late 1970s, the "conservative assimilation" (Starr, 1984) of health care reform was nearly complete. Apart from a final, futile effort at hospital rate regulation during the Carter administration, federal policy proposals increasingly relied on economic incentives and market competition, which their advocates regarded as both theoretically superior and more practical than comprehensive planning and regulation (Enthoven, 1977, 1980).

Although no major legislative movements were passed, the Medicaid program was changed dramatically through state-level and other implementation level practices, limiting the extent and scope of the program, its availability and usability (Hacker, 2004). The greater the complexity of implementation allowed for greater opportunities for more subtle

forms of change. The medical profession has managed to retain its cultural authority and improve its economic status because public policies have emphasized “redistribution without reorganization” (Starr, 1984).

In addition to obvious state vs. federal level discrepancies in program legislation, other issues of structural distribution contributed to the de-stabilization of Medicaid’s programmatic goals. As Hacker notes, “many social policies divide authority between units of government and private actors, such as providers, unions and employers,” (Hacker, 2004). The place of welfare programs within these systems creates far greater discretionary authority for street level bureaucrats and thus greater variation and inconsistency in the implementation of policy, allowing implementation to vary substantially from one state to the next and ultimately from what policy may officially dictate (Hacker, 2004).

In the case of Medicaid, lack of clarity on the state level and a drastic (arguably unanticipated) increase in program enrollment spurred movements aimed at limiting Medicaid and other means-tested programs in order to curb programs’ substantial costs. Discrepancies in the regulation of programs have enabled a quick departure from initial program missions (Stevens, 2007). Rules governing benefits and eligibility, as well as outcomes that those rules produce as they are carried out, have changed Medicaid’s programmatic goals and shifted conceptions of the system within which it operates (Hacker, 2004).

After a host of implementation problems and little political support after 1973 from the Nixon and Ford administrations, Health Management Organizations (HMOs) gained favored status as an option for Medicaid distribution. Support for HMOs, in addition to financial subsidies, came from both the Carter and the Reagan administrations and fit well

into an era of general deregulation (Oliver, 2004). Policy analysis came to be dominated by neoclassical economics and increasingly focused on “the public use of private interest” (Schultz 1977; Hacker 1997: 44).

Welfare reform (generally conceived), as Somers and Block aptly argue, has not been an effort to dismember the Welfare model, but rather to alter it within existing frameworks (Somers, 2005). The perversity thesis allowed for fundamental shifts both via direct public policy change, but also (and arguably, more importantly) through subtle, but dramatically important implementation-level and advocacy-level shifts. Less overt changes in programs have occurred within the context of existing legislative frameworks, reinforcing the statist view of welfare policy discussed by Goran Therborn (Therborn, 1986).

Poorly implemented public-aid programs embedded in complex pre-existing structures, such as Medicaid, have thus incited fiscal ‘crisis’ that has set the scene for the perversity thesis. Although the perversity thesis has permeated slowly, it has shaped the US welfare system by discouraging “welfare dependency by relying on social programs with complex eligibility rules such as means testing, residency requirements, and family responsibility clauses,” (Quadagno, 2005). This system places blame on the poor for being poor by making services difficult to access and utilize effectively. This attitude makes it especially difficult for the chronically ill, the elderly, and those with expensive conditions who all face increasingly serious barriers to accessing both social and medical care (Hacker 2004).

Although the neo-Malthusian view makes a strong point in suggesting that ill-founded aid programs can be detrimental to society, this overarching rejection of welfare is unnecessary and pre-mature. Because the US’ welfare programs have faced substantial

implementation-level barriers from the onset, it is imprudent to conclude that Welfare's means-tested programs are innately flawed. Neo-Malthusian notions of perversity have promoted an aspiration of 'effectiveness' that is goal oriented and not truly effectual in reaching the people welfare was instated to reach.

As Hacker notes, the Luxembourg Income Study (LIS) shows that the US has the highest level of inequality among wealthy nations, and although income inequality has dramatically increased over time, income re-distribution has not (Hacker, 2004).

When provided efficaciously, aid can act as an enabling agent, giving recipients the tools to be responsive to the market by ensuring equal access to benefits of equal value. This 'social democratic regime' model promoted by Quadagno can in turn promote labor force participation and ultimately encourage individual responsibility (Quadagno, 2005). The goal of welfare should not be an effort to make recipients more responsive to the market; instead, it should be to make welfare more effectively responsive to recipients.

Medicaid

Current arrangements for financing health care in the United States have been hammered out through contentious struggles between social reformers, physicians, employers, insurance companies and trade unions over the proper relationship between government and the private sector. Throughout an entire century, any attempt to enact a form of national or dramatically extended health insurance has been met with a fierce attack by powerful stakeholders who have mobilized their resources (of considerable force) to keep the financing of healthcare a private affair (Quadagno, 2006). As Jill Quidagno accounts:

Whenever government action has seemed imminent, they have lobbied legislators, influenced elections by giving huge campaign contribution to sympathetic candidates, and organized 'grassroots' protests, conspiring with other like-minded groups to defeat reform efforts (Quadagno, 2006).

The only national case in which federal funding has been provided for health care, is the case of Medicare and Medicaid. These programs are aimed at residual population groups -- the aged and the very poor -- groups that private insurers have no desire to cover (Gordon, 2003).

From the progressive era to the 1960s, physicians were vocal opponents of government financed health care. These professionals hoped to erect and maintain a barrier against third-party payers (especially the government) who might intrude upon sacred doctor-patient relationships (Quadagno, 2006). Their fight was fueled by an understanding that, if third parties assumed responsibility for financing care, these parties would need to establish some way to control their financial liability, which would invariably mean regulating physician fees (Quadagno, 2006).

The Development of Medicaid in the US

Since the enactments of the Social Security Act of 1935, there has been an ongoing debate over whether the federal government should sponsor national health insurance legislation (Stevens, 2007). In 1935, President Harry S. Truman repeatedly called for national health insurance, although congress considered, they did not enact, any such legislation (Services, 2008).

Under President Kennedy, political momentum for a comprehensive health provision program grew in the 1960s. This drive was largely due to the failures of enacted federal aid programs and pressure to provide services for elderly citizens. Kennedy sought to reinvigorate the efforts of president Truman, but there was outspoken political opposition to a national health insurance program amongst more conservative populations (Thompson, 1981). Rather than risking defeat for a comprehensive plan that would cover all citizens, Kennedy turned to a more limited approach. His approach focused on demographic groups who were (and are) both vulnerable to the financial burden of healthcare costs as well as unlikely to have access to employer-sponsored coverage: the elderly and the poor (Field, 2007). Passed by the US House of Representatives (307-116) and the US Senate (70-24), on July 30, 1965, President Lyndon Johnson signed legislation that created the Medicaid program under Title XIX of the Social Security Act (Johnson, 1965).

Three distinct components defined the Social Security Amendments of 1965. Medicare part A covered hospital expenses for everyone over the age of sixty-five. Medicare Part B covered physician and outpatient services for the same populations (but with voluntary participation and an annual premium). And Medicaid, or Part C covered various

designated categories of beneficiaries with very low incomes, often those also qualifying for Welfare (Johnson 1965). In contrast to the other two Medicare programs, the federal government and individual states operate and fund Medicaid jointly. Also unlike both Part A and Part B, substantial deductibles and copayments apply for Medicaid recipients.

The title expanded upon the goals of the 1960, Kerr-Mills Act, a limited assistance act for indigent elderly that was implemented more than a decade after President Truman's failed efforts to achieve a national plan in the 1940s (Field, 2007). Medicaid was in many ways Kerr-Mills applied to a much broader patient base; an extension of state welfare provisions, rather than a new health service program. This proved problematic, as the already failing Kerr-Mills Act gave Medicaid an unstable fiscal foundation. The financial inability and thus unwillingness of low-income states to afford medical assistance programs, even when federal matching grants were up to 80% of total cost, had plagued Kerr-Mills (Stevens, 2007).

As noted in the previous chapter, lack of clarity on the state level and a drastic (arguably unanticipated) increase in Medicaid program enrollment since its inception spurred movements aimed at limiting the program in order to curb its substantial costs. In addition, medicine, as Medical Sociologist Paul Starr notes, like many other American Institutions, suffered a stunning loss of confidence in the 1970s. Medical care became a point of critical scrutiny for the American public as costs for medical care continued to rise through the decade (Starr, 1982). Slow economic growth and persistent inflation in the seventies no doubt played a role in the government's shift from redistributive to regulatory politics in health care, but a larger discomfort with and lack of faith in the bureaucratic nature of American health care fueled American discontent with the Medicaid program.

Major defects of Medicaid contributed to these sentiments. These issues arguably lay in a lack of adequate cost projections and cost benefit analyses. The unanticipated nature of the burden of federal contribution necessary to sustain Medicaid is evidenced by Senator Saltonstall's 1966 comment: "There was little discussion of title 19; which certainly has proved to be the 'sleeper' in the bill. I am certain no one dreamt that within the next five years, Medicaid... could come to dwarf Medicare," (Cong. Rec., 1966). The combination of an expansionary program of health services and a program of cash assistance provoked Medicaid's initial dilemmas of costs and rapid political recoil (Stevens, 2007).

Previously, two premises had guided government health policy: first, that Americans needed more medical care-more than the market alone could provide; and second, that medical professionals and private voluntary institutions were best equipped to decide how to organize those services. Until the 1970s, the first of these premises had not yet undermined the second (Starr, 1982).

Although no major legislative movements were passed, the program was changed dramatically through state-level and other implementation level practices, limiting the extent and scope of the program, its availability and usability (Hacker, 2004). As discussed in the previous chapter, these greater implementation complexities have enabled opportunities for more subtle forms of retrenchment within the Medicaid system. Rules governing benefits and eligibility, as well as outcomes from the implementation of those rules, have shifted conceptions of programmatic goals (Hacker, 2004). This process has allowed far greater discretionary authority for street level bureaucrats and thus greater variation and inconsistency in the implementation of the Medicaid program (Lipsky, 1980).

The Current Condition of Medicaid

In fiscal year 2005, Medicaid financed health care for 53 million low-income children, adults, seniors, and people with disabilities at a total cost of \$329 billion (Weissert, 2006).

Currently, Medicaid provides a compilation of programs for different groups of recipients:

- Low-income, uninsured children, some parents, and low income pregnant women;
- Persons who are disabled, including those with mental illness and low-income elderly;
- People too poor to pay premiums and co-pays required for Medicare;
- Safety-net hospitals and community health centers that serve the poor.

Medicaid accounts for 31 percent of all federal outlays in health and well over two thirds of state health expenditures. However, the aspect of Medicaid that has been most troubling, both now but also since its inception, has been its rate of growth (Weissert, 2006). Carol and William Weissert explain this phenomenon, claiming that several aspects of the Medicaid program entail policy choices that affect costs. The first is the number of people eligible for the program; it is an entitlement program, which means that all eligible persons are provided for under the program (Weissert, 2006). In addition, the scope and level of recipients' benefits plays a role, as does the level of payment to providers of a given health care service.

Federal law requires that certain groups of persons be covered and certain services provided to them however, states can expand eligibility to include persons they deem 'medically needy'. State enrollment tends to be cyclical and increases with a poor economy (Weissert, 2006). Because of this, between 2002 and 2004, when many states were seeing greatly reduced revenues and tightened budgets, states tried to control Medicaid spending by raising eligibility standards, reducing benefits, and lowering provider payments (Weissert, 2006). Many states began to embrace 'disease management' programs in their Medicaid provision, programs whereby a state provides a case manager for individuals with specific

chronic conditions such as asthma and/or diabetes. States were moved by the understanding that case managers could provide oversight and treatment plans that could reduce expensive complications which may have required emergency care or hospital stays. Presently, over half of the states have adopted disease management as a component of their Medicaid programs (AcademyHealth, 2005).

Providing Adequate Care: Addressing Issues of Cost and Coverage

Although Medicaid has faced a history of overall retrenchment, when compared to qualifiers who have enrolled in Medicaid, uninsured Medicaid qualifiers or those who fall outside of eligibility guidelines have substantially less access to preventative care. These qualifiers often end up relying on acute services; emergency rooms or hospitals, financially burdening the entire health care system (NCHC, 2009). The costs of providing services to those who cannot pay places strain on hospital emergency services, financially disincentivizing the equitable distribution of care for the hospitals that do end up footing the bill. Uninsured patients end up raising the costs of health care for everyone; the expense of their care is borne by taxpayers through various government programs or through cost shifting by physicians and hospitals to privately insured patients (IOM, 2004). As Jill Quadagno notes in her book *One Nation Uninsured*, "Cost shifting, in turn, forces insurance companies to either reduce covered services or raise premiums, co-payments, and deductibles for people with insurance," (Quadagno, 2006). As premiums rise, fewer employers offer coverage, resulting in an increase in un-insured low income individuals; thus perpetuating a vicious circle.

In addition, discontinuous health care has been shown to be nearly as detrimental to health as a complete lack of insurance. According to Olson et al. (2005), continuity of

coverage is extremely important in determining the quality of health services provided. While Olson found that lacking health insurance experience increased unmet health needs, his study also found that people lacking coverage for even part of the year also have significantly less access to preventative care, and have increased unmet medical care and unfilled prescriptions (Olsen, 2005).

Continuous coverage, whether public or private, protects qualifiers' health significantly. However, the Current Population Survey (CPS), which is often used to estimate and analyze percentages of the uninsured, does not differentiate between those who are underinsured and those with comprehensive coverage (CVC, 2008). Thus, in addition to those who do not have any insurance, individuals with only partial coverage constitute a "hidden uninsured" group in the United States, leading to underestimates of the 'uninsured' population in the country (Olson, 2005).

As financial strain tied to the issue of the un(and under)insured continues to grow, states have taken the lead in developing proposals to reform their health care systems and to significantly increase the number of people with health care coverage. As of July, 2009 three states, Maine, Massachusetts and Vermont, have enacted and are implementing reform plans that seek to achieve near universal coverage for residents (Kaiser, 2009). In addition, many other governors and legislators have announced comprehensive reform proposals or have established commissions charged with developing recommendations on how to expand coverage. Currently, 14 additional states are moving toward comprehensive reform.

It has been shown, however, that low-income individuals, even when fully insured, still face significant barriers to utilizing health care services. De Voe et al.'s 2007 survey of

Oregon families who qualified for public aid, found that families with insurance remained worried about whether they could use the insurance, particularly about whether clinicians would accept the insurance and whether the insurance would cover enough of the services so that health services remained affordable (De Voe, 2007). Although invaluable, insurance does not necessarily equal access. Significant barriers remain even for those who both qualify for and receive Medicaid.

The Case of Massachusetts

As discussed in the previous chapter, a number of states have begun to turn to the possibility of more extensive health insurance programs. Some have even moved in the direction of universal coverage, an effort to have all individuals covered within a single system. The drive in this direction been fueled by a desire to have all residents insured and able to access healthcare, but also to make sure that there is a universal option and the uninsured are not utilizing medical services that they are then unable to pay for.

In April 2006, Massachusetts enacted a comprehensive health care reform law, “An Act Providing Access to Affordable, Quality, Accountable Health Care,” (or Chapter 58). The goal of the legislation was to move the state toward universal health insurance coverage through a series of reform measures. The measures included a requirement that all state residents have health insurance and also created state-subsidized health insurance plans for low-income adults who lack access to other insurance options. This move increased the percentage of Medicaid qualifiers who were enrolled in the program, which is known as MassHealth.

Because the Massachusetts reform initiative can be viewed as a possible model for national reform, the progress of Chapter 58 has been followed carefully at both state and national levels (Kaiser, 2009). Assessments done on various aspects of the reform, including its impact on state finances, safety net providers, and employers make Massachusetts a valuable case study. In September of 2009, under the Access Project, the Kaiser Family Foundation produced a report: “Consumers’ Experience in Massachusetts: Lessons for National Health Reform,” (Kaiser, 2009). The report made clear that

Massachusetts' move to universal coverage has been beneficial in many regards, but that substantial barriers remain for many of Massachusetts' highest need patients:

- Public programs have increased access and provided affordable insurance coverage options for low income individuals. The expansion of the Massachusetts Medicaid program and the creation of Commonwealth Care, a program that subsidizes coverage for adults under 300% Federal Poverty Level, have reduced the uninsured rate for low-income residents and allowed many people to gain access to affordable coverage and obtain care.
- However, some people are still struggling to afford coverage and care. Low-income workers with access to employer-sponsored coverage, as well as moderate-income individuals without access to employer-sponsored coverage, are both ineligible for state subsidized insurance. Coverage options for these individuals often remain unaffordable.
- System complexities can lead to gaps in coverage. With the multitude of programs offered by Massachusetts, all with varying eligibility and programmatic rules, residents with fluctuating incomes and employment statuses can fall through the cracks. These individuals, and others who are ineligible for existing programs, still rely on a health safety net program to obtain services and aid in paying for needed care.
- People with chronic conditions still face greater cost barriers to care. While nominal co-payments may be affordable for people who need care only occasionally, lower-income people who need ongoing care may quickly find the out-of-pocket costs unaffordable.
- Fear of incurring unaffordable medical bills and medical debt remains a barrier to accessing needed health care. Unaffordable medical bills and pre-existing medical debt still create anxiety and cause many to delay or forgo needed services.
(All bullet points taken directly from the Kaiser 2009 report)

It becomes clear that although universal coverage is a monumental step towards increasing access to health care, it cannot stand alone and in fact requires supplementary mechanisms in order to ensure the equitable and universal distribution of the so called 'universal' coverage.

Chronic Disease Management; a Complex Financial Burden

The overall lack of resources that the Medicaid program has faced, paired with increasing patient needs, has led to an exploration of programmatic costs. Recent studies have been conducted in order to determine patient utilization of the Medicaid system and

how this information could provide a more comprehensive solution to addressing qualifiers' needs cost effectively – thus making the program more sustainable.

The Faces of Medicaid: Recognizing the Care Needs of People with Multiple Chronic Conditions, published by the Center for Health Care Strategies with three editions to date, is a groundbreaking examination of the patterns of multiple chronic conditions among Medicaid beneficiaries and the resulting expenditures associated with these patients (Kronick, 2009). The analysis seeks to answer two key questions: What is the prevalence of chronic conditions within the Medicaid population, and; are there patterns of conditions that can inform the development of more appropriate guidelines, care models, performance measurement systems, and reimbursement methodologies (Kronick, 2009)?

The study has found that:

Within the Medicaid program, the elderly and adults with disabilities make up only 25 percent of beneficiaries, but account for a majority of program spending. Within this population, fewer than 5% of beneficiaries account for more than 50% of overall Medicaid costs.¹ Most of these high-cost beneficiaries — many of whom have multiple chronic physical and behavioral health conditions — receive care within an unmanaged fee-for-service delivery system, and the majority of them would benefit greatly from more integrated systems of care. By better understanding the specific health conditions of these beneficiaries, states can make more informed decisions about how to best manage care, thereby improving health outcomes, increasing quality of life, and controlling program costs (Kronick, 2009).

As a result of this work, and other similar studies, it is now well known that a very small subset of Medicaid's more than 60 million beneficiaries account for the majority of Medicaid spending. These high utilizers overwhelmingly have multiple chronic diseases, making integrated and holistic care an integral component of driving down unnecessary cost utilization due to poor care coordination.

An Effort to Address Complex Needs; Current Services

Due to the high costs of serving multiple chronic disease patients, as well as their disproportionate utilization of the Medicaid program, I focus on addressing the needs of this 5% of beneficiaries - the highest-need, highest-cost beneficiaries (and qualifiers) within the Medicaid program. In addition, this thesis focuses on Massachusetts as a specific case study due to the expansion of Massachusetts' Medicaid program in order to achieve universal coverage, and the corresponding research published on Massachusetts' MassHealth program. As noted earlier, lawmakers commonly cite Massachusetts as a model in care provision and health policy, making a comprehensive understanding of what does and not work in this state universally relevant.

Developing a clearer picture of multiple chronic disease individuals as well as the health plans responsible for managing care for millions of beneficiaries has been a complicated task for states. As a result of the complex and multi-faceted needs of these patients, a number of services have been enacted under the Medicaid plan. Two of these non-typical services are discussed below: case management and home and community based services. These programs are both very promising in their aim to extend the scope of services offered under MassHealth but, as currently implemented, both programs have substantial limitations.

Case Management Services, Massachusetts

States are able to use discretionary authority in the distributive mechanisms that provide qualifiers with Medicaid services. This means that programs and services provided vary substantially by state. Many states employ what are commonly known as 'case-managers'. Case management consists of services which help beneficiaries gain access to

necessary medical, social, educational, and other services, allowing patients to better manage complex medical plans. “Targeted” case management services are those aimed specifically at special groups of enrollees such as patients with developmental disabilities or chronic mental illness. The Centers for Medicare & Medicaid Services (CMS) ensure that case management services will be comprehensive and coordinated, and will include an assessment of an eligible individual; development of a specific care plan; referral to services; and monitoring and follow-up activities.

However, case management is often viewed by the CMS as a means of controlling widespread improper billing of the Medicaid program by states, for services mandated by other programs. This understanding of the role of case-management prompted Congress to address the problem of improper billing in the Deficit Reduction Act of 2005. The DRA redefined the scope of allowable case management services, strengthened state accountability, and required that CMS issue cost-saving regulations (CMS, 2007). This legislation has further framed case management as a cost-containment mechanism, rather than an effort to help recipients navigate the system, improving the coordination of patient care.

Theoretically, case management has substantial potential for high need, low income chronic disease patients who face barriers in both accessing and managing affordable quality care. Due to the limited nature of these services by state however, patients with extreme care coordination and guidance needs are left wanting. In Massachusetts, for example, case management services are further limited to providing care to individuals infected with HIV/AIDs. Special consideration is given to settings of service, specifically staffed congregate residential housing programs that meet the Department of Public

Health's AIDS Bureau funding requirements. With respect to funding, the national procedure code for Targeted Case Management is T1017 – this means that patients are billed in 15 minute intervals, capped at four intervals, or an hour of case management services. Additionally, this code is *only* applicable for MassHealth members who have been diagnosed with AIDS and who are living in congregate AIDS housing.

Although case management services are reimbursable by the Medicaid program, they are reimbursable for an extremely small population and have relatively stringent limitations on usage.

Home and Community Based Services

Another, better received program that works to address complex care is Medicaid's Home and Community Based Services program. This is a program that allows patients to receive care from their homes, enabling greater community immersion and participation on the part of the patient. The program, known as HCBS, has been slowly increasing its percentage of the Medicaid budget (Uninsured, 2009). HCBS is interesting in that it attempts to expand the Medicaid program, the breadth and thus reach of services provided. HCBS, or Medicaid 1915c, began with 8 waivers in 6 states in 1982 and by 2005 increased to 272 waivers throughout all 50 states. However, HCBS focuses largely on covering the elderly and those with disabilities. The program does not reimburse adult Medicaid enrollees with chronic diseases, such as HIV/AIDS, diabetes or CVD. As discussed earlier, low-income individuals with co-morbidities often face substantial barriers to accessing care in an institutional setting and have difficulty coordinating multiple therapies and adherence plans as well as utilizing social support networks. These patients are also some of the US' highest

emergency room utilizers, placing substantial budgetary pressures on local hospitals and even community health centers.

HCBS waivers allow states to waive specific requirements of the Medicaid program. For example, states are allowed to target specific population groups, limit the number of waiver slots, limit the program to selected geographic areas, limit services and provide services otherwise not covered by the Medicaid plan (Uninsured 2009). In a 2009 Kaiser report, Medicaid experts recognized that “equalizing access to home and community based services is one way to reduce the institutional bias in Medicaid and to help reduce variation in spending for people who require long-term services and support” (Uninsured, 2009). Participants have noted that in order to expand access to HCBS, states need to ensure community-based capacity and reduce geographical variation in the availability of services and providers.

As of September 2009, there were 2.8 million Medicaid recipients receiving HCBS services, and 300,000 individuals on the waiting list. As states take major steps to shift the delivery of long-term services and supports to both the community and the home, the importance of well managed, well executed case management has grown (Watts 2009). However, most people living in the community with long-term services needs rely on substantial help from friends and family. The majority (85%) of total hours of care received by people living at home with long-term care needs are unpaid (LaPlante, 2002). This can be extremely problematic for some of the highest need low-income chronic disease patients whose families may not have the luxury of a fixed income and/or ‘leisure’ time.

Despite an overall trend of retrenchment and the array of ongoing challenges facing state Medicaid programs today, there is a commitment to expanding HCBS. This

commitment however, is limited in its scope, focusing on elderly and disabled patients. Although the move to HCBS is beneficial in extending the reach of holistic patient care, by leaving low-income chronic disease patients out of the reach home-based benefits, the Medicaid program incentivizes caseworkers to provide preferential services. Caseworkers, already limited in their ability to provide constructive and in depth aid, are further strained by current economic conditions. The recession has been the dominant driver of Medicaid spending and enrollment growth as well as changes in policy for fiscal years 2009 and 2010. As noted in another recent Kaiser report, “rising unemployment, sharp declines in state revenues and higher demands for public programs, such as Medicaid have left states with severe budget gaps” (Smith, 2009). The American Recovery and Reinvestment Act proved critical in helping states balance budgets and protect Medicaid programs, but states have still felt a tremendous pressure to control Medicaid spending growth.

Medical Professionalism

We must cease once and for all to describe the effects of power in negative terms: it “excludes,” it “represses,” it “censors,” it “Abstracts,” it “masks,” it “conceals.” In fact, power produces; it produces reality; it produces domains of objects and rituals of truth. The individual and the knowledge that may be gained of him belong to this production (Foucault, 1980).

The power of the social processes sustaining the provision of health care lies in their ability to positively produce and reshape the identities and imaginations of those who serve within and are served by the system.

Alternative healers, such as midwives, chiropractors and homeopathic healers etc. and lay health workers, such as Community Health Workers (the focus of following chapters) have been proven, both throughout history, as well as with recent care provision systems, to provide care and supplement existing provision systems effectively. Simply stated, they have been shown to save money for the systems within which they operate. Yet, the power of trained and established medical workers to protect the market domain of their profession has kept these healers, especially Community Health Workers and other lay healers, from being seen as a go-to model for providing health services.

In order to understand the current state of the American medical system - who holds authority with respect to medical information and who does not - it is imperative to understand how it has developed. Many medical historians have traced the history of medicine in the United States, describing an apparent divergence from systems of lay-knowledge toward the more ‘sovereign profession’ of medical providers in the 19th century. This transition has shaped the understanding of what constitutes a medical expert, and has in turn shaped the development of medical practice in the United States, creating what Foucault might deem a ‘self-referencing’ professional hierarchy.

As demonstrated by Paul Starr and other historians, the development of the American medical profession has been dramatically shaped by internal actors and societal framework. In the recent past, a move toward the bureaucratic distribution of medical knowledge within more highly structured systems of provision has eroded faith in medical professionalism and enabled alternative sources of care provision to enter the field.

The Relevance of Paul Starr's *the Social Transformation of American Medicine*

More than twenty years ago, Paul Starr's *The Social Transformation of American Medicine* stimulated academic dialogue across disciplines, exploring medicine's historical trajectory and inciting discussion of its future. Though not embraced by all fields (notably the history of science), it was an investigation of medical care that had unprecedented scope and narrative power, garnering substantial praise as well as numerous prizes.

In fields such as political science, sociology, and economics, the book represented a new model for the study of the complexity of professions—promoting both historical understanding as well as a complex appreciation of the multiple factors determining the trajectory of professional authority within the medical field (Wailoo, 2004). The multidimensional significance of Starr's *Social Transformation* has particular pertinence for today's discourse on medical efficacy. The broad scope of the book, which has made it unpopular in some disciplines, is nonetheless fitting. By drawing constructively from multiple fields, Starr was able to document central contentions and synthesize his narrative within a broader social and political context. The useful discourse provided by this interdisciplinary exchange provides insight into the status of professional sovereignty in a changing health care system as well as health policy scholarship today (Wailoo, 2004).

In a recent retrospective on *The Social Transformation*, academics from a variety of disciplines agreed that the work was most valuable in its portrayal of a coherent image of the complex worlds of health care, health policy and their place in American history. Starr's book did this by effectively casting American medicine and American society as reflections of one another (Jost, 2004). This framing revealed key trends and forces that had previously been obscured by mono-perspective approaches to the development of healthcare in the United States:

The changing nature of medical care and medical practices made more sense when understood in the context of broader societal trends; the multiple facets of American culture and values were newly revealed through their incarnation in health care settings (Wailoo, 2004).

The central message of *The Social Transformation of American Medicine*, that "The dream of reason did not take power into account," was arresting in its applicability to a broader social and political understanding of health (Starr, 1984). Within this grand narrative, Americans were better able to comprehend their own personal stories, reflecting upon their roles as patients, caregivers, and citizens (Wailoo, 2004).

The rise of the medical profession pushed a wide range of alternative and lay healers to the margins, inaugurating a growing medical hegemony. Concerned with the accumulation of professional power, and not a celebration of medical ideas or practices, Starr's work focused on the politics of the medical profession, the creation of cultural authority as well as the intricate negotiations that have allowed the profession to build and maintain an elevated status (Jost, 2004).

Rise and Decline, Faith in the Dominance of a Sovereign Profession

In the early years of the twentieth century, the ideas of progressive reformers were central to medicine's rise to power. The roots of progressivism lay largely in natural sciences; the rational, scientific approach to solving problems that these various disciplines employed (Ameringer, 2008). Advances in technology and the rise of progressive thought surrounding the growth in popularity of natural science disciplines began to separate allopathic medicine from 'unschooled', self-described healers.

The concept of 'regulating' competition for the 'public interest,' based on scientific principles and standards formulated by experts, developed at the turn of the century. Medical licensing, which had taken hold in the late 1800s, acted as a mechanism to both define and shape the medical profession. Progressives believed that science was too complex for public consumption, and that only experts had the ability to apply scientific principles to public problems in an objective and orderly fashion (Starr, 1982). Due to advanced knowledge and training, perpetuated by competitive licensing and training programs, physicians were presumed to be the only ones capable of determining their own technical standards (Ameringer, 2008). This elevated the status of physicians and distinguished medical work from other commercial pursuits.

In addition to increasingly stringent licensing procedures, codes of ethics were the principal means of regulating competition in the professional regime (Ameringer, 2008). First enacted in 1847, the American Medical Association (AMA)'s Code of Medical Ethics dealt directly with issues of maintaining the integrity of medical professionalism. Rules governing professional conduct, did not, however extend to practitioners outside the profession. The code encouraged physicians to "bear emphatic testimony against quackery

in all its forms.” Beginning in the 20s and 30s, the code was enforced in such a way that people practicing the art of healing outside of accepted biomedical norms of care provision became targets of physicians and medical societies (Ameringer, 2008).

Michael Shadid, a controversial Syrian-American physician called for cooperative medical efforts in the late 20s, lamenting the ethical ‘fall’ of the AMA and the medical profession generally, stating that:

Like so many political parties, [the AMA] originated as a forward-looking association that fought for much-needed improvements, only to degenerate into a bureaucracy upholding the status quo. Many years ago the AMA forced out of existence the “diploma mills” and raised standards of medical schools throughout the country; it brought about an increase in the amount of training required of physicians; it combated the spread of quacks, false cures, and patent medicines making misleading claims. It established a code of ethics that was originally drawn up for the protection of the public against unscrupulous doctors but which now is twisted so as to serve for the protection of unscrupulous physicians against the public (Shadid, 1939).

The rise of the medical profession’s professional dominance was accompanied by the building (or often rebuilding) of medical institutions sometimes accompanied by public relations campaigns that stressed the miracle of science (Stevens, 1998). In addition, historian of science, Barbara Rosenkrantz suggests that despite a genuine need and desire for more effective medicine, the status quo within the medical profession has represented a persistence of the powerful relationship between security and social authority that deeply conflicted (and continues to conflict) with physicians’ efforts to bring about concerted change within the system (Rosenkrantz, 1985). This brings to light an interesting parallel with the institutional imbeddedness of the American Medicaid system, which is similarly tethered to pre-existing norms of care provision and incentive structures within those systems.

The structural imbeddedness of the American Medical system can be viewed, in many ways, as an echo of Alexis de Tocqueville’s 19th century assertion that these

professions become a natural aristocracy when a nation eschews class distinctions and yet endorses order (Rosenkrantz, 1985). Americans valued achieved distinction, enhancing the standing of professional men. As fears over corruption and disruption of the social order mounted in the decades before and after the Civil War, physicians increasingly assumed prestigious public roles (Rosenkrantz, 1985).

The emergence of a new professional identity in medicine began at the turn of the century, but it was not simply a transformation of vocation authorized by the growth of scientific knowledge. Relations within the profession were profoundly altered as well; practice drawn from science did not transmit ethical principles in the same way that the tradition of medical ethics and etiquette had previously done.

Additionally, professional dominance has been both shaped and reified by a substantial built environment. The construction of impressive scientific centers and medical schools, their associated complexes as well as the transformation of hospitals from destinations of last resort to 'modern temples of science' embodied and 'emplaced' the cultural authority of scientific medicine (Pescosolido, 1992). This built environment, in tandem with Starr's account of the rise of professional dominance, has overshadowed medical beliefs and values that come from less established origins. This built profession and the prestige that surrounds it have stood between the elite world of science and public culture (Sloane, 1999; Rosenberg, 1987; Hollingshead, 1968).

In 1934, the Bureau of Medical Economics of the AMA prepared a study on contract practice, group practice, and 'sickness insurance'. The report was composed of ten principles, playing out the formation of private health plans (Fishbein, 1947). Included

among these ten principles were stipulations that spoke directly to maintaining medical professionalism, such as:

- All features of medical service in any method of medical practice should be under the control of the medical profession. No other body or individual is legally or educationally equipped to exercise such control.
- No third party must be permitted to come between the patient and his physician in any medical relation. All responsibility for the character of medical services must be borne by the profession.
- The method of giving service must retain a permanent, confidential relation between the patient and the family physician. This relation must be the fundamental and dominating feature of any system.

In addition, the report stipulated that:

- Systems for the relief of low income classes should be limited strictly to those below the comfort level standard of incomes.

According to Medical Political Economist Carl Ameringer, once issued, the ten principles became the template for the delivery and finance of healthcare in the United States for the next several decades. However, implementation tactics that followed their issuance, such as the specific targeting of non-AMA approved organizations, loss of hospital privileges, license revocation and expulsion from state and local medical societies among other punishments if physicians and other healers did not comply with the AMA's principles, soon became the norm (Ameringer, 2008). This behavior raised questions over the extent of the medical profession's power: should the medical profession have carte blanche in order to regulate the healthcare system and did anti-trust law apply to this situation (Ameringer, 2008)? In response to the AMA's stringent enforcement tactics, in 1938 the Department of Justice served notice to the AMA, indicating that the AMA had gone too far.

Diversification of the Medical Profession

The number of providers in non-typical bio-medical fields dramatically increased in the 1950s and 60s due to increasing demand. Between 1950 and 1967 the number of

providers in older professions, such as pharmaceuticals, dentistry and nursing, doubled. In addition, new health professions, such as physical therapists and dietitians tripled during this period (Gross, 1984). These new healthcare providers sought access to hospital infrastructure, technologies and insurance re-imburements. Although blind faith in the medical profession began to erode much earlier, The AMA actively continued to curtail efforts of non-physicians to provide healthcare services. According to Lester King, the AMA was in fact founded to help allopathic or biomedical physicians oppose 'unorthodox' practitioners (King, 1982). Medicine's fight for dominance of the field continued well into the 1960s as alternative care providers continued to vie for professional status.

Medical societies in a number of states implemented "basic science laws" requiring non-physicians to complete scientific competency tests as a prerequisite to licensure; this practice is believed to have been implemented following the belief that few sectarians, or unorthodox practitioners, could pass a test of basic science (Ameringer, 2008). According to Ameringer, as the number and type of competing providers increased in the twentieth century, orthodox medicine engaged private accrediting bodies to further exclude sectarians from hospitals, government facilities and insurance arrangements. The most prominent of these organizations was the Joint Commission on Accreditation of Hospitals, of which the AMA, the American College of Surgeons, the American College of Physicians as well as the American Hospital Association were all founding members (Ameringer, 2008).

The purported basis for excluding non-physicians from hospitals, technology and insurers was 'the proper care and treatment of patients.' Competing health providers allegedly lacked physicians' advanced training, legitimacy and specified areas of relevant expertise (Legal Conference, 1964). As Stanley Gross asserts, medicine's claim that its

competitors were incompetent largely was inaccurate. Gross sites midwifery as an apt example of opposition to this claim. Lay midwifery predated modern medicine, and, as late as 1910, midwives attended to over 40 percent of all births in the US (Gross, 1984). Studies clearly indicated that midwives significantly reduced infant mortality, leading some to believe that midwifery's success, not its failure, was the reason for its suppression (Gross, 1984).

Not only did many non-physicians provide and supplement quality health care, they did so more cheaply than their physician counterparts. Before the advent of public programs of assistance (such as Medicare and Medicaid in 1965), in the United States the poor chiefly relied on nurses, midwives and other alternative providers for their primary source of medical care (Ameringer, 2008).

As Economist Reuben Kessel wrote in the 50s, the medical profession acted almost like a large social club, composed primarily of people who shared similar views (Kessel, 1958). Surveys in the 1950s indicated public dissatisfaction with the medical profession, as satisfaction fell, medicine's history of discrimination (racial, gendered and religious) for admission to medical schools and elite positions within the field came into sharp focus. In a powerfully bold statement, Kessel claimed,

Minority groups whose culture and values are different from those of the majority could rationally be discriminated against in admission to medical school because they are more difficult to control by informal controls after they are out in medical practice than is characteristic of the population at large (Kessel, 1958).

Similar to other established institutions in the U.S., the medical profession underwent a fundamental reassessment in the 1960s. Although dissent began much earlier, the political climate of the 1960s allowed for reevaluation and restructuring that could not have been possible in earlier decades.

Ultimately, the U.S. Supreme Court and Congress prompted the Federal Trade Commission and the Justice Department to essentially change the rules of the healthcare system. No longer able to restrict competition, once-powerful medical societies gave way to HMOs and other corporate arrangements (Ameringer, 2008).

Complexities of Healthcare Distribution and the Development of Healthcare Economics

As a physician who has worked for much of my adult life among the poor in Haiti and the United States, I know that the laws of supply and demand will rarely serve the interests of my patients

- Paul Farmer

In response to the development and pervasive effects of healthcare as a substantial force within the United States economy, the academic discussion of healthcare economics which began to take shape in the 1930s, bloomed in the 1960s. Stimulated by the work of Martin Feldstein, Selma Mushkin, Kenneth Arrow, Gary Becker and Herbert Klarman, the economics of health took an econometric and theoretical turn. Implications drawn from the work produced by these health care economists have been undeniably influential. The work of the 1960s overwhelmingly concluded that when cast in a strictly neoclassical economic framework, health care is inherently subject to market failure due to an inefficient allocation of scarce resources (Wasunna, 2006). Essentially, in order to provide equitable health care to all individuals in need, the work of these economists implied that there must necessarily be a mechanism in place to counter the inevitable market failure that health faces when placed in a neo-classical framework. This work served as a solid justification to use welfare services to combat the potential scarcity of medical resources and the resulting inequitable distribution of care.

The relationship between wanting health care and receiving it appears simple, but is made complex due to lack of medical knowledge and transparency. The 'consumption' of a

medical 'treatment' requires information about various aspects of existing health status, improved health status, treatment availability, effectiveness etc. (McGuire, 1988). As Arrow noted in the 1960s, the medical profession specializes in the supply of information – influencing what health treatments are both demanded and utilized (Arrow, 1963). The demand for health care involves a huge amount of uncertainty, especially for individual consumers, which makes both treatment and informational characteristics important.

As demonstrated clearly in this case, informational and decision-making features are central to the issue of 'agency-relationship' whereby the doctor acts as an agent on behalf of and in the interests of the patient. In the context of the consumption of health care, the individual's want for improved health status is one feature of a much more complex process which leads to the ultimate utilization of health care. The role of the agent changes according to the differing levels of resources an individual might hold. This is especially pertinent for low-resource patients with both acute and chronic medical conditions. A visit to the doctor's office often necessarily includes the characteristic of passing the burden of decision making from the patient to the care provider, which becomes intensified in the case of low-resource patients with a lack of health literacy (McGuire, 1988).

Managed Care

In tandem with Consumerist theory work, there has been an academic and policy-based attraction to market based solutions for issues of the cost effective and efficacious provision of health care (Wasunna, 2006). Pushed by economists, models such as HMOs (which, unlike traditional health coverage, set guidelines under which doctors can provide services) attempted to pair market and federally funded mechanisms to provide care more effectively in the US. The rise of a market-oriented health care system and health policies,

which Starr foretold, in many ways brought about a 'privatization of the public household,' a transfer of responsibility for medical care from the collective to the individual (Schlesinger, 2004).

At the outset of the health maintenance strategy, the primary model for HMOs was the prepaid group medical practice. Paul Ellwood, a physician specializing in rehabilitation medicine, promoted the term *HMO* and saw it as the building block for an entirely different approach to health care reform (Ellwood et al. 1970, 1971). Ellwood had the notion that organizational integration, better management, and competition would improve health services and that policies based on consumer choice were preferable to the command-and-control regulation then dominating proposals for national health insurance in the late 1960s and early 1970s (Oliver, 1991).

Ellwood persuaded the Nixon administration to make HMOs a centerpiece of its health care program in 1970–1971, working with congressional staff in lobbying for the HMO Act of 1973 (Oliver, 2004). Paul Starr notes the timely connection that Ellwood made with key Nixon appointees in the Department of Health, Education, and Welfare (DHEW) as well as the political significance of Ellwood's strategy (Oliver, 2004).

However, despite a strong push for HMOs in the early 70s, in contrast to horizontal integration and corporate conversions to for profit status, vertical integration of the health care delivery system lagged considerably behind (Oliver, 2004). Starr reviewed the many challenges faced by the development of HMOs and their disappointing growth in the decade after federal legislation to foster their growth was passed in 1973 (Brown, 1983). However, Starr correctly anticipated that HMOs had the potential to become powerful engines of change in the health care system:

If government and employers paying fringe benefits put pressure on American medicine to minimize its costs to society, the movement toward vertical integration (that is, to HMOs) will ultimately predominate. In that event, the likely trajectory of organization will lead increasingly toward corporate HMO networks (Starr, 442).

As noted by Thomas Oliver, in the decade following publication of *The Social Transformation of American Medicine*, the growth of HMOs accelerated remarkably. By the mid-1990s, HMOs and other forms of managed care became the standard for employer-sponsored coverage as well as for state Medicaid programs (Oliver, 2004).

According to the dominant theories of the public uses of medical care, financial and social organization of medical systems is a primary factor in determining individuals' uses of services (Andersen 1968, 1995). Responses to illness and disease on the individual level are not, as Starr pointed out, 'unfettered'. Rather, As Bernice Pescosolido reflects, the public's use of health care represents a bargain struck between the offerings of providers of different healing systems and the preferences of individuals. In response to Starr's work, Pescosolido notes that:

When legal restrictions and large infusions of capital are combined with the enthusiasm for science, the community options for the general public changed. In addition, the visibility of symbols of scientific medicine (e.g., new hospitals, ambulances, emergency rooms) pervaded the larger culture (Pescosolido, 2004).

A history of professional dominance overshadowed or even prohibited the use of other systems of medicine, virtually predetermining the public's choice and, ultimately led to more managed and regulated forms of care (Pescosolido, 2004).

Reflection

Currently, medicine and health care again appear as a focal point of public interest, a discourse curiously similar to the context of Starr's 1980 publication. In 1980, divergent paths were marked by a political transition, a wave of change in ideological and partisan commitments often referred to as 'the Reagan Revolution' (Wailoo, 2004). Today, tensions

are more internal to American medicine and health culture—an unyielding rise in medical spending, an enduring sense that Americans are not getting a good value for their ‘health care dollar’. Though ostensibly distinct, these two juncture points are similar in that they both rest upon the shifting foundations through which Americans balance individual and collective responsibility. By so doing they begin to define what they perceive as the legitimate scope for market forces and government intervention (Jost, 2004). For that reason, the lessons that Starr derives concerning medical authority and the dynamics of change in health policy are as relevant today as they were three decades ago.

Starr’s book presented a picture of medicine that explained much of what was happening in the contemporary realm of the politics of health care and social policy more broadly (Wailoo, 2004). It appeared in the midst of Ronald Reagan’s first term as president, a time when many Americans thought that society itself stood at a crossroads: “between liberalism and conservatism, between an active government defined by the New Deal and the federal programs of the 1960s on one side and an escalating skepticism about government on the other” (Jost, 2004). This crossroads was accompanied by a rising faith in the marketplace as well as faith in private enterprise as the solution to social problems.

However, during this same period, discussions over national health insurance resonated in public discourse. Starr’s book both acknowledged and spoke to an audience that was considering these questions. It inserted the medical profession into debates that dealt with overarching questions of the American government’s purview with respect to social aid, market interactions and enterprise. It also pointed out that these problems were not in fact new, but as Mark Schlesinger aptly puts it, “stretched back over decades and even centuries, and were intimately related to America’s contested past—from the laissez-

faire environment of the nineteenth century to the Progressive Era, Great Depression era, and advent of modern federal activism, through the New Deal, and into the sixties,” (Schlesinger, 2004). Tensions over health insurance, government, and the private sector were framed as new components of a long political, economic, and cultural domestic history (Wailoo, 2004).

Through this reframing, the message of the doctor’s path both to and from professional sovereignty and professional dominance can be embraced and explored by an understanding of larger trends in professional organization and conceptions of health’s place within neo-liberal understandings of market mechanisms.

As the general public comes to recognize and respond to its health problems in a broader context, scientific medicine has acted to eclipse the existence of alternative sources of care, particularly under conditions of illness and when individuals seek a solution that is only ‘good enough’ (Pescosolido 1992). Yet, as proven by many, individuals faced with the prospect of ‘consuming’ medical goods are neither rational cost-benefit calculators, nor simply puppets of elite members of the community (Pescosolido, 1992).

Lay Knowledge

Growth of GNP or of industrial incomes can, of course, be very important as means to expanding the freedoms enjoyed by the members of the society. But freedoms depend also on other determinants, such as social and economic arrangements (for example, facilities for education and health care) as well as political and civil rights (for example, the liberty to participate in public discussion and scrutiny).

-Amartya Sen, Development as Freedom

Combating Complexities of Distribution

The striking advances made in pathology and microbiology in the late nineteenth century made social factors seem less germane in the etiology of disease. But humans are, in Aristotle's words 'social animals', for whom the social and biological are inextricably linked (Anderson, 2007). Although not easily quantified, reasons contributing to health-related disparity are largely due to social factors. This disparity both creates, and is created by, dramatically imperfect medical knowledge within the consumer base. Because of this, programs designed to address these inequities must consider the dynamic and multifaceted nature of an individual's illness experience and the psychosocial factors that impact engagement with disease and healthcare (PACT, 2008).

Medical therapeutics cannot be fully understood separately from questions of knowledge construction, so our conception of scientific practice must therefore be furthered by careful attention to the local details of medical cause and work (Epstein, 1995). However, organized medicine has traditionally been slow to accept the fact that social factors play an important role in disease, let alone embrace the approaches necessary to combat inequalities that result from these factors.

The concept of ground-up information dissemination, made famous by Frederick Von Hayek and expanded upon by thousands, has been an enduring counter-suggestion to

more centrally planned theories of state organization. This line of thought is especially pertinent when discussing state involvement in medical care provision. The need for policy makers to design and implement a program that is able to meet the needs of some of the country's highest-need, lowest-resource citizens is an extremely difficult task.

In their article "Public Health Research and Lay Knowledge," Jennie Popay and Gareth Williams conclude that public health research (whatever the disciplinary perspective) should provide an understanding of contemporary health problems that is simultaneously robust and holistic. If public health research is to do this, it must incorporate and develop the theoretical and conceptual insights that can be offered exclusively from lay knowledge (Popay, 1996). This theory can also be applied to medical distribution or the monitoring of distributed services, in the form of Health Promotion. By putting care management into the hands of 'lay' health workers, these works are able to join medical services with an intimate understanding of patients' social and health related contexts, ensuring an efficacious allocation of goods and utilization of available services.

The Construction and Potential of Lay Expertise, the Case of AIDs/HIV

The AIDs/HIV movement has particular significance in deviating from and thus (re)setting biomedical norms. As Academic Steven Epstein remarks: "One of the most striking aspects of the conduct of AIDs research in the United States is the diversity of the players who have participated in the construction of credible knowledge," (Epstein, 1995). According to Epstein, the failure of experts to 'solve' the problem of AIDs quickly and effectively has eroded faith in the sovereign dominance of the medical profession and thus opened space for dissent.

Epstein asserts that activist movements, through amassing different forms of credibility, can in certain circumstances become true participants in the construction of scientific knowledge; they can (within definite limits) effect changes in both the 'epistemic practices of biomedical research and in the therapeutic techniques of medical care' (Epstein, 1995).

Successful lay inclusions into biomedicine have considerable implications for the understanding of broad phenomena such as the cultural authority of science and medicine. The public reception of scientific claims, the boundaries between science and society, the relationships between doctors and patients and the tension between expertise and democracy within complex and differentiated societies all come into question (Epstein, 1995). As Pierre Bourdieu accounts, activists can and have transformed the field's mechanisms of operation and revamped how biomedical knowledge is both made and distributed by introducing new 'currencies' of credibility into circulation, and hence succeeding in establishing a value for those currencies within the medical field (Bourdieu, 1990).

However, with advocacy movements arise the issue of accurate representation. As Epstein aptly notes, activists and people with AIDs or HIV overlap, but are not isomorphic. Whether activists meaningfully represent the populations and individuals they intend to thus becomes a meaningful question (Epstein, 1995). Epstein notes the potentially dangerous irony of many activist movements, using AIDs as an example:

"On one hand, by pursuing an educational strategy to disseminate AIDs information widely, activists have promoted the development of broad-based knowledge empowerment at the grassroots (level). On the other hand, as activist leaders have become full-fledged experts themselves, they have often tended to replicate the expert/lay division within the movement itself by constructing what Elbaz(...) describes nicely as a divide between the "lay expert" activists and the "lay lay" activists," (Epstein, 1995).

Epstein recognizes that many experts are themselves torn over the relationship between participatory democracy and the development of effective therapies and care provision generally.

While it seems clear that biomedical expertise does have a certain degree of authority with respect to modern biological medicine, it cannot be contested that patients themselves have the most intimate understanding of their own circumstances.

The CHW: an Effective Example of Incorporating Lay Knowledge into Health Care Provision

“[We connect people] with other social services to create a more coherent chain that people can follow. That’s the extra mile and the extra connection that’s provided [by] a community health worker that nobody in the clinical office has the time or flexibility to do.”

- PACT CHW

Properly trained and supervised Community Health Workers are a form of ‘lay’ health workers. They have been shown to improve access to care, decreasing health disparities (MDPH, 2009). In its 2002 report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, the Institute of Medicine found that, “Community health workers offer promise as a community-based resource to increase racial and ethnic minorities’ access to healthcare and to serve as a liaison between healthcare providers and the communities they serve.” The Institute of Medicine specifically recommended that programs supporting “the use of community health workers... especially among medically underserved and racial and ethnic minority populations, should be expanded, evaluated and replicated” (Smedley, 2002).

There are four main stages within the diversity of functions and models of CHW service delivery: *client advocacy, health education, outreach, and health system navigation* (MDPH, 2009). Within these roles, CHWs have been widely recognized as vital to health care

and public health systems worldwide for many years. Historically, the emergence of CHWs in the US was a response to persistent poverty. In the 1960s, CHWs played a key role in the community health center movement. Subsequently, special projects funded by public and private grants produced significant evidence of the efficacy of CHWs in health promotion and increasing access to health and human services. In Europe, Asia and Africa, CHWs have played a role in the health of their communities for several centuries. The World Health Organization has formally recognized this role since the 1970s and by the American Public Health Association in 2001.

CHWs have yet to be integrated as professionals in the mainstream American health care system. This is despite increased utilization of CHWs by public and private sector providers and a growing body of research about the positive impacts CHWs have in improving access to health care, reducing health disparities, improving quality of care, and controlling costs. The CHW field lacks a unified professional identity and is still defining its scope of practice and its core knowledge base. As a result, training and educational opportunities for CHWs vary widely.

Community health workers can play an important role in improving health care quality on the level of the patient, the provider, and the health care system to improve health outcomes and ensure effective, safe, timely, patient-centered, equitable, and cost-effective delivery of health care. The Institute of Medicine includes and recommends CHWs as part of a “comprehensive, multi-level strategy to address racial and ethnic disparities in health care.” In addition, the Pew Commission says that CHWs “offer unparalleled opportunities to improve the delivery of preventive and primary care to diverse communities,” (IOM, 2008). As a result, CHWs can strengthen community capacity to

improve social determinants of health, including inadequate education and lack of access to health insurance.

It is widely recognized by health experts and policy-makers that health disparities are not only due to poorer access to prevention and health care services but are also influenced by social, economic and environmental conditions (Marmot & Wilkinson, 2003). Along these lines, the Healthy People 2010 (a program run by the Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services) goals highlighted the need for approaches to address social inequities that increase communities' health risks.

By definition, community health workers engage with patients within their homes and communities and take a holistic and patient-centered approach to the care of their patients. They ensure that patients effectively and safely follow treatment recommendations *within the home* and ensure that patients access and utilize the health care system when necessary to avoid delayed diagnoses, worsened health status, or adverse reactions. They have been widely used to reduce health disparities by working with patients marginalized by race, income, lifestyle choices, or geography.

Defining CHWs in the U.S.

Coordinated efforts to professionalize the field in the U.S. began in the 1990s when the term Community Health Worker was agreed upon as an umbrella term for more than 60 job titles. The Massachusetts Department of Public Health (DPH) defines CHWs as Public Health workers who apply their unique understanding of the experience, language, and/or culture of the populations they serve in order to carry out one or more of the following roles:

- Providing culturally appropriate health education, information, and outreach in community-based settings, such as homes, schools, clinics, shelters, local businesses, and community centers;
- Bridging/culturally mediating between individuals, communities and health and human services, including actively building individual community capacity;
- Assuring that people access the services they need;
- Providing direct services, such as informal counseling, social support, care coordination, and health screenings; and
- Advocating for individual and community needs (MDPH, 2009).

This definition is similar to one recommended by the Standard Occupational Classification Policy Committee of the Bureau of Labor Statistics for inclusion as a Standard Occupational Classification (21-1091). At the invitation of the Bureau, the following definition was submitted by the American Public Health Association CHW Special Primary Interest Group (APHA CHW SPIG) and is endorsed by the American Association of CHWs (AACHW). In January 2009, the Office of Management and Budget officially published the 2010 Standard Occupational Classifications (SOC) listing in the Federal Registrar, which includes a unique occupational classification for Community Health Worker (SOC 21-1094).

A Community Health Worker (CHW) is a frontline public health worker who is a trusted member of and/or has an unusually close understanding of the community served. This trusting relationship enables the CHW to serve as a liaison/link/intermediary between health/social services and the community to facilitate access to services and improve the quality and cultural competence of service delivery. A CHW also builds individual and community capacity by increasing health knowledge and self-sufficiency through a range of activities such as outreach, community education, informal counseling, social support and advocacy (MDPH, 2009).

The 1998 National Community Health Advisor Study categorized CHW functions into the following seven core areas (Rosenthal, 1998):

1. Cultural mediation between communities and health and social services systems (How to use these systems, increase use of preventative care and decrease urgent or emergency care);
2. Provide culturally appropriate health education and information (prevention related information, managing and controlling illnesses such as diabetes and asthma);
3. Assuring that people get the services they need (case finding, motivating and accompanying patients to appointments and follow-up care, making referrals and promoting continuity of care);

4. Providing informal counseling and social support (individuals and groups, to improve mental and physical health);
5. Advocating for individual and community needs (serve as intermediaries between clients and bureaucratic entities);
6. Providing direct services (basic first aid, health screening tests, medication adherence);
7. Building individual and community capacity (facilitate health behavior change; act as community leaders to bring about community-wide change).

Historically, the emergence of CHWs in the US was a response to persistent poverty. CHWs were key members of the Community Health Center movement in the 1960s. Since that time, special projects funded by public and private grants have produced significant evidence of the efficacy of CHWs in health promotion and increasing access to health and human services (MDPH, 2009). As the role of CHW became more professionally defined, standardized training for CHWs began to develop in different regions of the country through the 1990s. Recently, federal agencies and state legislatures have implemented policies and legislation to address the growing use of CHWs, specifically focusing on training and certification (MDPH, 2009).

Increasing Access to Care

Improvements in four key domains of health care – access, quality, disparities and cost – are closely interrelated. For example, making services more accessible to and improving the quality of those services for vulnerable and underserved communities often helps to ultimately reduce health disparities within given communities (MDPH, 2009). CHWs are able to improve access to care by using lay knowledge to close the gap created by dramatically imperfect medical knowledge within the consumer base (as discussed above). This has manifested itself in a number of ways. Access to care, according to the Institute of Medicine, is “the timely use of personal health services to achieve the best possible health outcomes” (Millman, 1993). Both timely use of services and optimal health outcomes are

dependent upon having health insurance to cover costs of services, having a regular primary care physician, and receiving preventive education and services (MDPH, 2009). It has been well documented that CHWs are highly effective in recruiting and enrolling individuals in health insurance plans, linking individuals with primary care physicians, and ensuring the use of preventive care (Swider, 2002).

CHWs have played an important role in the early success of health reform in Massachusetts by contributing their skills to the work of Outreach and Enrollment grantee organizations funded through health reform legislation. The role they have most commonly played has been in helping to identify and assist uninsured residents to enroll in publicly or privately funded insurance plans. To date, far more uninsured people than had been estimated have been identified and enrolled in MassHealth and Commonwealth Care plans. This success helped to offset the cost of care for uninsured or underinsured Massachusetts residents.

Most organizations that received Outreach and Enrollment Grants from MassHealth employ CHWs to locate, screen, and enroll residents in appropriate plans (Glenn, 2008). Based on legislative specifications for these grants, MassHealth gave funding priority to organizations whose staff offered the greatest knowledge of the community, linguistic and cultural sensitivity, and had the technical skills needed to assist residents with enrollment. These skills are most commonly offered by—and indeed help to define—community health workers (MDPH, 2009; Glenn, 2008).

Another important aspect of gaining access to care is having a regular primary care provider who coordinates patients' care and offers a medical home. Many CHWs successfully link individuals and families to primary care providers after assisting them with

enrollment in health insurance and ensure ongoing connections through case management activities (MDPH, 2009). Research has shown that CHWs who perform case management activities are more successful than workers who make a simple one-time contact at engaging and helping sustain patients' relationships with providers (Andrews, 2004; Swider, 2002).

Additionally, CHWs have proven effective in improving patient health more generally by enabling patients to access a wide variety of preventive health services. These services include but are not limited to: general education and referral for chronic and acute health conditions, comprehensive peri-natal care, preventive health screenings, and immunizations (MDPH, 2009).

As evidenced by the diversity of patient-specific tasks that CHWs perform, the strength of the CHW model lies in the ability of CHWs to supplement existing health care frameworks, providing medical knowledge in an accessible context for patients who would not have access to it otherwise.

Prevention and Access to Care and Treatment

In 2008 Richard M.J. Bohmer and Josh Friedman published an article in the Harvard Business Review, “Partners in Health: The PACT Project,” (Bohmer, 2008). They began the article, with an astounding story:

In October of 2002, Hector, a 36-year old Puerto Rican man was treated at Boston’s Brigham Women’s Hospital for neurotoxoplasmosis, a parasitic infection of the brain. This infection was commonly found in HIV-positive patients prior to the availability of effective drugs, but since the advent of highly active antiretroviral therapy, it usually only afflicts patients who are not receiving treatment. When he was admitted, Hector’s immune system was severely depressed (CD4 count of 24), an indication that he had not been adhering to his Antiretroviral therapy (ART). A native Spanish speaker with limited English comprehension, Hector was discharged after ten days with prescriptions for 17 drugs, referred to an infectious disease clinic for an appointment he never attended, and seen by a visiting nurse at home. Hector’s physicians chose not to prescribe ART, reasoning that he would not be compliant. Seven weeks later, Hector was readmitted to BWH with swelling in his brain attributed to worsening toxoplasmosis. After surgery and 18 days in the hospital, Hector was discharged with 10 new prescriptions and instructions in English. Two months later Hector was readmitted again with eplectic seizures and renal failure. The next day, Hector was introduced to the PACT project. Three years later, Hector had no detectable viral load, his CD4 count was over 200 (an important land-mark, colloquially deemed “undetectable” in the HIV community), and he was adherent with his medications. Hector has not required hospitalization in the past three years (Bohmer, 2008).

The PACT Project

The Prevention and Access to Care and Treatment project (PACT) located in Codman Square Boston, MA has carefully monitored the progress of its patients and the outcomes associated with the project’s intervention. As a privately funded organization often having to vie for extremely competitive research grants, their methods are optimally cost-effective and well documented. For these reasons, as well as the pertinence of Massachusetts as a state that mandates ‘universal’ health coverage, I will provide a thorough picture of the PACT project.

PACT provides community-based access and treatment to some of the hardest to reach HIV patients in the greater Boston area. Currently, PACT is jointly run and in part funded by Partners in Health (a 501©(3) non-profit) and Brigham Women’s Hospital, Harvard Medical School’s major teaching hospital. The HIV patients enrolled in PACT are referred to by providers as having “failed standard care.” These patients frequently utilize emergency care, requiring regular hospitalization for acute recurrences of symptoms. Nearly all PACT patients are Latino or Black men and women who live below the poverty line in Boston’s poorest neighborhoods. The vast majority of whom are also MassHealth, and thus Medicaid patients.

Those afflicted with not only HIV/AIDs, but also multiple chronic diseases are increasingly contending with other complex issues such as: homelessness, hunger, substance abuse and mental illness (Gordillo, 1999). Budget pressures, meanwhile, force cuts in the number of ancillary support staff (such as social workers and case managers) who help maintain the overall well-being of HIV patients, holistically engaging them in therapeutic relationships that help keep them healthy and out of hospitals (PACT, 2006). Due to the complex nature of co-morbidities compounded with social factors, focused support for populations that bear the burden of chronic disease is necessary if we hope to thoroughly address issues of disease in a cost-effective manner.

HIV/AIDs: Embracing and Addressing the Existence of Social Determinants of Health

Over the past decade, the face of HIV/AIDS has changed dramatically. It has transitioned from a disease affecting middle-class gay men to an urban phenomenon that largely affects poor, black, heterosexual women. Although white men who have sex with men still comprise the highest number of individuals living with HIV in the United States,

they are not the population most frequently progressing from HIV to AIDS, and in many cases death. In fact, in 2007 black men and women, who constitute only 13% of the United States population, accounted for more than 51% of AIDS cases and more than 50% of AIDS deaths in the United States (CDC, 2007). Furthermore, an increasing number of individuals living with and dying from AIDS are female and acquired their HIV through heterosexual transmission (CDC, 2007).

In Boston, a black woman infected with HIV who lives in Roxbury (a poor and predominantly black neighborhood) is 15 times more likely to die from AIDS than a white man also from Boston (Furin, 2008). Why is it that black women in the United States bear a disproportionate burden of HIV related disease and death?

This question has not been answered biologically; HIV does not behave more aggressively in black women, or lead to diseases that are more deadly (PACT, 2008). Rather, reasons are related to forces of marginalization, negatively impacting access to and utilization of available resources and medical technology.

Development of PACT

The Prevention and Access to Care and Treatment program (PACT), has used the concept of peer health promotion to address the needs of impoverished, minority individuals with advanced HIV/AIDS. The program works out of Boston and serves individuals who have faced extreme difficulties with adherence to the complex drug regimes and care plans required of HIV/AIDS patients (Furin, 2008).

HIV is a disease associated with poverty and social inequities, conditions that hamper the delivery of adequate medical care. In many ways, HIV epitomizes the need for holistic, well-managed, cost effective and efficacious medical provision. Treatment of HIV

infection requires complex multi-drug regimens, adherence to which is imperative to maintaining sustainable levels of disease. If a patient acquires drug resistance, the resistance can be transmitted to others, posing a substantial and extremely expensive public health threat – with respect to both lives and money.

The increasing availability of drugs, both antiretrovirals for HIV/AIDS as well as other therapies, has raised the question of proper delivery and application of these drugs to low-resource areas. Lack of infrastructure has been a long-cited reason to withhold drugs in settings of extreme poverty (Behforous, 2004). In opposition to this view, Boston's PACT program demonstrates the potential feasibility of community-based HIV/AIDS prevention and care (PACT, 2008). Drawing from the successes of intensive TB therapy administration programs, Partner's In Health (PIH)'s Community Health Worker (CHW) model thoroughly and holistically addresses the needs of patients who require intensive drug therapy. They have attempted to prove that, in settings that lack requisite healthcare infrastructures, variants of directly observed therapy of highly active anti-retroviral therapy can prove extremely successful (Behforous, 2004).

Following the success of Partner In Health's Zanmi Lasante program in Haiti, the PACT project was initiated in Boston with an understanding that many of the social determinants of disease found in low-resource countries were mirrored in low-resource demographic areas of developed countries. PIH's domestic home in Boston, at the Division of Social Medicine and Health Inequalities at Brigham Woman's Hospital, is in close proximity to Mattapan, Dorchester and Roxbury, the city's lowest income and subsequently lowest resource neighborhoods.

Comparatively high prevalence of HIV and other diseases, as well as high rates of multi-drug resistant strains of HIV due to unstable access to treatment and care in these neighborhoods sparked the domestic PACT program. In facing these needs, the PACT project has attempted to institute a program that addresses all aspects contributing to the health of high need, low resource patients.

Project Outline

PACT CHWs are drawn from the communities they serve; they have firsthand knowledge of the obstacles faced by patients in their daily lives. Because of this, PACT CHWs develop a rapport with their patients, gaining trust and forging partnerships that allow for meaningful exchange and therapeutic alliances (Behforous, 2004). Their activities include, but are not limited to, accompaniment to medical appointments, adherence and harm reduction counseling, assistance with social crises, such as homelessness and domestic violence; education; and provision of support and encouragement (Behforous, 2004). The continuity and responsiveness of care, the willingness of CHWs to commit to their patients and the CHWs ability to manage the entire context of the patients' experience of illness, make the program unique (Furin, 2008).

Patients receive monthly, weekly or daily home-based support services depending on their needs. In addition to regular health promoters, PACT has more intensive Directly Observed Therapy (DOT) CHWs who serve patients who have experienced failure of the standard PACT health promotion program. These DOT CHWs visit their patients in their homes once daily to provide support and encouragement for the patient while they take their daily dosage of antiretroviral therapy (selected by the patient's referring physician).

Understanding the specific role of PACT CHWs

CHWs can be family members, friends, or even patients who provide health education, refer people who are ill to a clinic, or deliver medicines and social support to patients in their homes. They do not supplant the work of doctors or nurses; but serve as a vital interface between the clinic and the community. As such, they have the ability to enhance the relationship between patients and medical professionals, as they are of similar cultural background as their patients, negating a certain amount of hierarchy in the relationships they form. This role contrasts specifically with the traditional doctor-patient relationship, which I have shown earlier, to be one evolved along an unequal power dynamic. These qualities enable CHWs to have a working knowledge of not only the life circumstances of their clients, but the cultural health-related norms surrounding particular diseases as well as social connotations and practices associated with specific and general illness. This knowledge improves the ability of the CHW to provide comprehensive, relevant and effective care.

Their ultimate aim is to help patients adhere to medication and treatment recommendations in the hopes of reducing related opportunistic illness, expensive hospitalization and often death. But CHWs also provide patients and their families with social support, collaborating with other agencies to make sure that patients have adequate food, housing, mental health care, and substance abuse counseling (Furin, 2008).

No other program in the country has created a similarly multi-tiered and individually tailored program for patients who are failing chronic disease care. PACT CHWs differ from other home-based providers funded by MassHealth, such as visiting nurses, health aides, and personal care assistants, by relying on a patient specific approach to health care

provision. While many Boston clinics and hospitals offer clinic-based adherence education via pharmacists or nurse educators, many of PACT's patients do not attend or respond to clinic-based interventions. Furthermore, these interventions are limited as practitioners cannot take into account the full context of the patient's life and experience, as witnessed and negotiated in the home setting. Although visiting nurses can assist patients in health education, in organizing their pillboxes and taking their pills, they often do not have the time or training to extensively counsel or educate patients. Additionally, health insurance companies will only reimburse visiting nurses for a short period of time and for an acute need (such as after hospitalization or for acute care). Most home health aides and personal care assistants can assist patients in getting to their appointments or in bathing and other activities of daily living, but are often not trained or expected to provide medication adherence support and holistic health counseling. PACT CHWs also differ from case managers, as case managers often have very heavy case loads, are office based and focus more generally on needs such as housing, food and insurance (PACT, 2008).

A Deeper Look into the PACT Model

Upon hire, PACT CHWs receive 60 hours of didactic training and 60 hours of field based training. Didactic training is based upon a sixteen-session training manual that has been developed with the help of experts in health education, community health and health literacy as well as community health workers and the patients they treat. CHWs also receive training from other accredited agencies, such as the Latin-American Health Institute or the Community Health Education Center at the Boston Public Health Commission. Following initial training, CHWs continue to receive between five and eight hours of training and supervision per week, including individual clinical supervision from social workers ,

consultation with a psychiatrist, training and consultation from the Brigham and Women's Domestic Violence team, substance abuse and harm reduction teaching, and medical training focused on HIV specific care, medications and adherence.

After training, CHWs begin to work with patients. At intake, the CHW evaluates patient needs and characteristics, adherence strengths and barriers, environmental and social context, and social support networks. The assessment is completed over a four week period. Based upon the initial interviews, a personalized service plan is structured. CHWs employ motivational interviewing techniques in order to help the patient develop and identify personal goals as well as break those goals down into small, workable steps (PACT, 2009).

Providers might suggest goals of their own for the patients care. While these goals are highly respected and viewed with respect to the patient's medical context, patient goals are often very different and include many of the smaller steps that might ultimately lead to the goals put forth by their referring physicians. Patient goals, instead of focusing on CD4 counts, may include functional status, appearance, or social standing. These individual goals may have to do with a patient's desire to appear healthy, to be able to participate in everyday activities, such as grocery shopping or walking for fitness, they could also have to do with social stigma, fitting into old clothing and generally working towards living a 'normal' life. The CHW ties these goals into those of the referring provider and helps the patient see how improved medication adherence and efficacious resource utilization can lead to their desired outcomes.

Patients are encouraged to play a very active role in accomplishing goals: each step of action within a patient's action plan will be taken by either the CHW or the patient. When

possible, family members and other care givers are incorporated into the action plan (PACT, 2008). These plans are also updated and revised regularly according to the individual patient's progress and or changing needs.

During a patient's initial assessment, the patient's support networks are explored. If family or friends are willing and able to participate in the care of the patient, they are recruited, trained, and supported in this role. If there are limited human resources available, then CHWs work with patients to restore or build those connections.

CHWs also facilitate referrals to service agencies providing assistance with financial, housing or legal issues. Although they do not provide case management services, CHWs promote good and regular communication between the patient and case manager, help the patient navigate the complex social system structure, and teach the patient how to advocate for him or herself in order to receive services for which the patient is eligible (PACT, 2008). CHWs quickly discover the structural and systematic barriers that commonly interfere with the patient's ability to practice health promotion and harm reduction, making these activities critical for comprehensive care.

The core of PACT's health promotion intervention is based upon the patient health promotion and harm reduction curriculum. This curriculum is made up of 20 modules that are delivered by the CHW to their patient two to three times per month over a six to nine month period. These modules are meant to inform the patient in an engaged manner, working to more fully understand both their diseases and effective methods of dealing with their illness. The curriculum is informed by cognitive behavioral therapy and motivational interviewing techniques. Each module takes an average of one hour to complete, and is conducted by the CHW in their patient's home. Modules are meant to build knowledge and

skills through subject such as: “HIV 101” and “The Importance of Adherence,” “Getting your Prescriptions Filled” or “Communicating Effectively with your Provider.” There are modules that address social support and self efficacy, such as: “Building Resources and Social Supports” and “Embracing your HIV Disease and Taking Charge,” (PACT, 2009). Issues of harm reduction and other preventative measures are covered, such as those pertaining to sex, drug use, and domestic violence.

All of the training is geared to specific patients, most material is designed to combat low health literacy and utilize pictures, diagrams and clear wording in order to make messages available to patients with low levels of medical knowledge. When they enter the program, patients are given workbooks so that they can keep track of their health progress, and record new insights. Patients are also encouraged to record exercises with diagrams such as “social support wheels,” conduct pre-visit preparation sheets before seeing their providers, and post-visit summaries after doctor visits tracking frustrations, future questions and successes/failures (PACT, 2009).

In addition to the more teaching-based roles that CHWs take, they also accompany patients to key medical and social appointments. With the pre-visit preparation sheet mentioned above, the patient identifies questions and issues he or she hopes to bring up with their provider. During the visit, the CHW is able to share insight on progress as well as support the patient.

CHWs often communicate with providers through various mediums, such as e-mail or phone in order to discuss patient progress and treatment plans. CHWs make themselves available to be personal experts on their patients’ care – and the receipt of that care. CHWs work with providers to help providers understand how they can most effectively work with

their patients. They are able to provide insightful feedback to providers concerning how the patient assimilates information and counseling received in the office. This is meant to combat medical miscommunication, which often leads to high levels of medical non-compliance amongst high need patients. These roles highlight the revolutionary nature of this intense and personal departure from medical norms described in earlier chapters.

NOTE: For more information on the PACT model, please see Exhibits 1-4.

Outcomes

Contextualizing the Success of Community Health Workers

Connecting patients with primary and preventive care and helping manage chronic conditions has proven key to curbing unnecessary medical costs (MDPH, 2009). Therefore, providing care in teams that help ensure patients receive the preventive education, support and care can help them avoid acute illness or complications. This, in turn, can help decrease unnecessary and expensive hospitalizations and increased costs that are often incurred by the overutilization of emergency services (MDPH, 2009).

CHWs have specifically proven to help reduce health care costs by helping people—often uninsured or publicly insured—to utilize the health care system more effectively. They have had an impact on cost savings in a number of ways, including complementing clinical services as part of an integrated care team, connecting patients with a medical home for primary and preventive care, and reducing inappropriate use of emergency departments through patient navigation and care coordination (MDPH, 2009). Studies publicized in the 2009 “Community Health Workers in Massachusetts: Improving Health Care and Public Health Report,” have shown that employing CHWs can result in cost savings not only in the long run, but also in the short term:

- A one year pilot program of Molina Healthcare in New Mexico showed that CHWs who worked on teams with social workers were able to help high-risk patients with multiple health problems use the plan’s services more effectively. CHW services provided to 15 plan members over six months led to a cost savings of \$7,676 during that period (NCVI, 2007).
- CHRISTUS Spohn Health System in Nueces County, Texas, has observed reductions in inappropriate Emergency Department usage based on the services their four full-time CHWs provide within the system’s hospital and health centers. CHRISTUS Spohn estimates that the average savings to the hospital per ER patient assigned to a community health worker is \$56,000 over the course of a year (Dower, 2006).

- In Baltimore, CHWs worked intensively with a Medicaid sample of 117 African American men with both hypertension and diabetes to help them manage both conditions. ER visits declined for the men by 40% compared to the period prior to the CHW intervention, and hospital admissions declined by 33%. These changes yielded an average cost-savings per patient of \$2,245 (Fedder, 2003).

In Massachusetts, the potential for improving cost effectiveness and efficiencies of health care interventions, by improving care utilization and quality is evident when one considers the extent, patterns, and costs of preventable hospitalizations in the Commonwealth (MDPH, 2008). In 2002-2003, African-Americans and Hispanics had more than two times the rate of preventable emergency department visits than whites, reflecting a higher rate of emergency room visits overall for these populations compared to whites and other groups (MDHCFP, 2005). This difference indicates a serious discrepancy; less comprehensive access to primary care for African-Americans and Hispanics in Massachusetts.

PACT Project Outcomes

In Boston, PACT has employed CHWs as key salaried staff in an effort to improve care delivery and health status among the area's most marginalized and least successfully treated HIV/AIDS patients. Through its work, PACT has led to a decrease in MassHealth costs of 2.4% for a closely studied sample of the above mentioned patients after receiving CHW interventions (Behforouz, 2007).

Results from PACT show that the use of CHWs for HIV patients can significantly increase CD4 counts (a sign of improving immune system function), lower viral loads, reduce opportunistic illness and preventable emergency room visits and hospitalizations as well as increase appropriate utilization of outpatient and pharmaceutical resources (PACT, 2006). Since its

foundation, PACT has hoped to improve client's outcomes and reduce overall healthcare system costs through effective disease management. Using hospitalization data from Brigham Women's and affiliated hospitals, PACT has attempted to measure the impacts its health promotion has had on patients' healthcare costs.

The results that have been collected from the PACT project itself have been surprising. Primary outcomes of interest for the PACT program include survival, opportunistic illness, rates of hospitalization, CD4 counts and HIV viral loads (Behforous, 2004). After the first year of the program, there was a 87% retention rate, a 97% adherence rate and most excitingly, 73% of patients achieved undetectable HIV loads (Behforous, 2004).

In reviewing PACT data collected between July 2003 and February 2008 (the most comprehensive set of data available) patients had a 70% retention rate at 12 months and a median duration in the program of 13 months. Seventy-two patients enrolled since July 2003 have received at least one year of services and thirty-one patients enrolled since July 2003 have received at least two years of services. Tables one and two show the CD4 results of 72 PACT clients after 12 months and of 31 patients after 24 months. A majority of clients show maintained (47%) or improved (35%) CD4 counts at 12 months. It is important to keep in mind that given the eligibility criteria for PACT, most, if not all, clients would have deteriorated or passed away without PACT intervention.

Table 1: CD4 Results after 12 Months of PACT

Baseline CD4 Count cells/L (# of patients)	<50	50 - 199	200- 500	>500	Declined	Maintained	Improved
<50 (16)	4	6	6	0	0	4	12
50-199 (18)	5	7	6	0	5	7	6
200-499 (28)	0	3	18	7	3	18	7
>500 (10)	0	0	5	5	5	5	0
Total (72)	9	16	35	12	13	34	25
% of Total	13%	22%	49%	17%	18%	47%	35%

Table 2: CD4 Results after 24 Months of PACT

Baseline CD4 Count cells/L (# of patients)	<50	50 - 199	200- 500	>500	Declined	Maintained	Improved
<50 (6)	1	1	2	2	0	1	5
50-199 (9)	0	5	4	0	0	5	4
200-499 (14)	0	0	8	6	0	8	6
>500 (2)	0	0	0	2	0	2	0
Total (31)	1	6	14	10	0	16	15
% of Total	3%	19%	45%	32%	0%	52%	48%

As CD4 counts improve, health care expenditures -- more specifically inpatient costs -- have been shown to decline. A study of 2003 health care expenditure by Kelly Gebo of Johns Hopkins found that people with CD4 counts above 500 have an average annual cost of \$21,869, as compared to average annual costs of those with CD4 counts below 40, which is \$57,565 per year (Gebo, 2006).

Table 3: Comprehensive Costs (in US Dollars) of HIV Care Stratified by CD4 Count

CD4 Count (cells/L)	Antiretroviral Costs	Other Medical Costs	Inpatient Costs	Outpatient Costs	Total Costs
<50	16,830	7,887	27,473	4,729	57,565
50-199	14,853	5,180	10,549	4,506	35,483
200-499	12,424	3,305	6,827	3,927	26,848
>500	11,674	2,691	3,987	3,151	21,869

PACT also analyzed several years of MassHealth claims and encounters data for patients enrolled in PACT. After taking into account enrollment timing and data issues, there was sufficient data for the analysis of 19 MassHealth enrolled PACT patients. The analysis includes at least two years' worth of data for all patients and four years of data for 16 of the patients. Results are summarized in table 4. They show a small increase in MassHealth costs in the first year of PACT enrollment (\$11,931 or 1.7%) as compared to the 12 months before PACT enrollment. Although this might appear unfavorable, it is in fact a positive increase. It is a demonstration of patients' more comprehensive understanding and use of available resources, including anti-retro viral drugs. This means that patients are taking medications regularly – a positive indication that future cost will be lowered due to effective resource utilization.

Accordingly, results after the second year of PACT enrollment show a decrease in MassHealth costs (-\$10,974 or -2.4%) as compared to the 12 months before PACT enrollment, despite continued utilization of resources and continued ARV use (PACT, 2008). This trend also represents a deceleration in spending as compared to the annual growth rate

of overall MassHealth expenditures, which have averaged roughly 8 to 9% (PACT, 2008).

Table 4 shows de-identified MassHealth data by PACT patient.

Table 4: MassHealth Expenditures (in US Dollars) Pre and Post PACT Enrollment

Client	MassHealth Costs 13-24 Mo Pre PACT Enrollment	MassHealth Costs 12 Mo Pre PACT	MassHealth Costs 12 Mo Post PACT Enrollment	Comparison or 12 Mo Post PACT to 12 Mo Pre PACT	MassHealth Costs 13-24 Mo Post PACT Enrollment	Comparison of 13-24 Mo Post PACT to 12 Mo Pre PACT
1	17414	26845	27450	605	35748	8904
2		1234	613	(621)		
3	4801	14663	26348	11685	5991	(8,672)
4	9095	55873	20303	(35,570)	41524	(14,349)
5		2221018	115289	(105,729)		
6	26556	51547	147705	96159	15922	(35625)
7	34938	40942	26736	(14,206)	47997	7055
8	4322	5511	9192	3681	1261	(4250)
9	79031	16354	14679	(1676)	4426	(11928)
10	9987	9971	12857	2886	16753	6782
11	17609	14425	27823	13398	15280	855
12	31685	25876	32790	6914	28828	2951
13	30383	36443	44720	8277	58398	21954
14	13769	23988	33611	9623	16940	(7047)
15		30540	4263	(26,277)		
16	16898	16793	25208	8416	21671	4879
17	33199	41757	30920	(10,837)	52978	11221
18	29072	33780	63205	29425	68982	35202
19	25867	47512	63289	15776	18607	(28905)
Total	384628	715072	727002	11931	451306	(10974)

A further examination of MassHealth data reveals a continuation of promising trends. MassHealth expenditures by provider category, 24 months pre and post PACT enrollment show that spending on inpatient services dropped from \$397,848 to \$239,676 (40%), while spending on pharmacy increased from \$432,645 to \$565.184 (30%). A review of the detailed MassHealth pharmacy data using National Drug Codes shows that the majority of the

increase in drug expenditures occurred with ART drugs. The medical and hospital services delivered before PACT enrollment are replaced after PACT enrollment by the health maintenance and prevention costs of medications, outpatient care and mental health counseling (PACT, 2008). Given PACT's efforts to increase adherence to ART and decrease hospitalizations, these trends are consistent with aims to decrease acute usage of MassHealth funds and increase sustainable and efficacious use of long-term care. In the long-term these trends will ultimately increase quality of life as well as decrease overall medical expenditures – with the exception, of course, of effective pharmaceutical utilization.

When looking at the PACT project's outcomes, it is important to recognize that although eligibility criteria for the program have shifted over time, PACT has consistently treated patients who have been deemed medically 'non-compliant', 'non-adherent' or 'unreachable' by referring clinicians. Non-compliance for HIV/AIDS patients with high viral loads and low CD4 counts often means nothing less than the risk of multi-drug resistance as well as, in many cases, death (PACT, 2005). Multi-drug resistance requires a patient to move up an entire class of drugs, increasing their pharmaceutical bills as well as their daily ARV intake regimen. This drug resistance is common in low resource contexts, where intermittent availability of therapy is the norm. Moreover, as discussed above, the patient population for which PACT proposes this intervention is one of the highest-cost populations currently served by MassHealth; the cost of their healthcare would very likely exceed MassHealth's average annual expenditure growth in the absence of its effective intervention (PACT, 2008).

Reflection

Data and experiences thus far have indicated that the PACT project has the potential to educate and empower patients to take control of their HIV and accompanying co-morbidities. In doing so, PACT has enabled patients to reduce their reliance on costly medical services for episodes of acute, preventable illness. These benefits have been paired with decreased hospitalizations, higher levels of self-efficacy and overall increased levels of societal functioning (Behforous, 2004). Although salaries of US-based community health workers are relatively high compared to CHWs in developing contexts (such as Haiti) the reduction in the number of hospitalizations for recurrent opportunistic infections suggests that the intervention is cost effective for patients who have been unable, without PACT, to adhere to complex antiretroviral regimes (Behforous, 2004).

In addition to project specific data, published research suggests a strong correlation between health promotion and reduced healthcare costs for HIV/AIDs patients. Average monthly healthcare expenditures were found to be over four times higher for HIV patients with CD4 counts below 50 compared to patients with CD4 counts greater than 500 (Bozette, 2001). A similar study showed costs to be 2.6 times higher for patients with CD4 counts below 50 versus those with CD4 counts above 350 (Chen, 2006).

Furthermore, quantitative data representing both improved health in patients as well as positive changes in health behaviors and adherence to treatment, is augmented and made far more powerful by the very real ways in which PACT patients have experienced improvements in quality of life. The PACT CHW model has the potential to build a support network and prevent patients from falling through the 'cracks' of the healthcare system.

Due to its successes, the PACT model has received the attention and support of the National Institute of Health (NIH). The model is currently being replicated by other organizations in several locations in the United States. Accepting the successful history that PACT has had with HIV/AIDS patients, PACT is now beginning to look at how this program could be applicable for multiple chronic disease treatment. PACT has begun adapting the core program to focus on diabetes through a pilot program at the Codman Square Health Center, as well as on the special needs of a cohort of homeless patients with multiple poorly controlled chronic diseases through a MDPH-funded collaboration with Boston Health Care for Homeless (PACT, 2008). This summer (2010) they will extend pilot programs to sites in western Massachusetts in an effort to more broadly address the needs of Massachusetts citizens with complex co-morbidities.

Additional Tables:

BWH Cost Comparison: Frequency and Costs of Inpatient Hospitalization before and after PACT Enrollment (n=40)

	12 Months Before Enrollment	12 Months After Enrollment	Difference (% change)
Total Hospitalizations, n	23	20	-3 (-13%)
Hospitalized at least once, n (%)	12 (30%)	11 (28%)	-1 (-8%)
Total inpatient days	236	154	-82 (-35%)
Inpatient days per patient	5.9	3.9	-2.0 (-34%)
LOS per admission, mean	10.3	7.7	-2.6 (-25%)
LOS per admission, median	10.0	5.0	-5.0 (-50%)
Total hospital costs, US\$	516206	258520	-257686 (-50%)
Hospital Costs per Admission, mean	22443	12926	-9517 (-42%)
Hospital costs per admission, median	17407	9512	-7895 (-45%)

CD4: All Subjects

	Baseline	6 months	12 months
Number of Observations	32	30	25
Number of Subjects with CD4<200	19 (59%)	12 (40%)	9 (36%)
Mean absolute CD4 (cells/mm cubed)	164 (141)	219 (152)	272 (182)
Mean (SD) Log10CD4	1.92 (0.665)	2.12 (0.543)	2.24 (0.594)
Mean Change in Individual Log10CD4 from Baseline	N/A	0.171 (CI: -0.024 – 0.367)	0.261 (CI: 0.061 – 0.461)
	N/A	P = 0.0136	P = 0.0086

Analysis

The community is who feels it. They are the ones that drive the services. So the sustainable funding is for the community health workers, but the reality is the sustainable funding is for the community.

-PACT CHW

Outcomes resulting from both PACT and other CHW organizations have had interesting implications for the potential of government involvement in health care provision. As discussed in prior sections, by introducing new ‘currencies’ of credibility into circulation, and by succeeding in establishing a value for those currencies within the medical field, lay health care providers (such as CHWs) have, and can continue to, transform the medical field’s mechanisms of operation; changing how biomedical knowledge is both made and distributed.

The consumption of a medical treatment requires information about various aspects of existing health status, improved health status, treatment availability, effectiveness, etc. (McGuire, 1988). As Keith Arrow has observed, the medical profession specializes in the supply of information – influencing what health treatments are both demanded and utilized, is still relevant (Arrow, 1963). Informational and decision-making features continue to be central to the issue of ‘agency-relationship’ whereby the doctor acts as an agent on behalf of and in the interests of the patient. By loosening its hold on the ‘supply of information’, the medical profession can increase medical knowledge and transparency amongst consumers, enabling a more equitable distribution of medical knowledge – effectively leveling the playing field. Community Health Workers have shown their ability to do this effectively.

It must be noted that ceding professional legitimacy to alternative healers and health workers is a complex and by no means simple suggestion. As history has shown, resistance to the integration of the medical profession has persisted despite the proven effectiveness of alternative models. However, not-for-profit, educational and community health based organizations have increasingly been able to both fund and publicize the successes they have had with alternative and supplementary sources of care. Ironically, this newfound ability paired with a financial tightening of the federal budget, may open the door for regime shifts of professional legitimacy.

Community Health Workers are not an end-all answer to our nation's health care issues. They do however, shed light on a powerful mechanism for viewing health care provision, one that fundamentally forces the biomedical system to address the complex and often intimate factors contributing to a patient's health. By considering the dynamic and multifaceted nature of an individual's illness experience and the psychosocial factors that impact engagement with disease and healthcare, they integrate the patient into his or her own care provision.

Wondering why people *do not* change is a common frustration for health professionals (Miller, 2002). It often seems apparent that what a person may be doing is not working well or is in fact self destructive; there are seemingly simple alternatives, yet the person's behavior persists. Even in the face of life threatening conditions such as diabetes, heart disease and HIV, issues of medical non-compliance exist.

A more productive question than wondering why people *do not* change, has been a question recognized by the incorporation of Community Health Workers into care provision systems, why *do* people change?

Contextualizing Implications

MassHealth and Commonwealth Care both maintain goals of expanding access to health insurance and improving the quality of care. Both programs serve low-income individuals who cannot get health insurance from another source, such as their employers. In addition, the subset of individuals who are eligible for each program, but not enrolled, tend to be those who could benefit from either assistance with health system navigation, health literacy, or health care awareness.

CHWs have contributed to the goals of expanding access and improving quality care in primary and preventive health, management of chronic illness, and the coordination of multiple supports and community-based services for those with long-term care needs. CHWs are also skilled in patient advocacy, outreach and insurance enrollment, especially for culturally and linguistically diverse populations. Expanding the integration of CHWs into outreach activities and care teams could further the Commonwealth's health care reform goals of reducing the rate of un-insurance in Massachusetts, reducing health disparities, and containing health care cost growth while improving the quality of care being delivered.

Policy Recommendations

In an effort to not only critique the current system but provide for potential pragmatic and meaningful intervention, I offer a series of ways in which CHWs could be incorporated into the existing Medicaid system. In order to support continued progress toward universal coverage and minimize the impacts of people losing coverage, even temporarily, institutionalizing reimbursement and funding for outreach and enrollment grants could be an invaluable option (Long, 2008). Discussed below are a number of tangible ways in which this could be done in Massachusetts:

Chapter 58 of the new MassHealth Health Care Reform Outreach and Education Unit mandated by the legislature in FY08 appropriated \$3 million to MassHealth to award outreach grants to community-based organizations (CBOs) that provide MassHealth and Commonwealth Care enrollment assistance, education and outreach activities directly to consumers. Two types of grants were awarded. The first is for grantees who have developed effective community-based strategies for reaching and enrolling eligible individuals into MassHealth and Commonwealth Care. With respect to this grant type, Chapter 58 explicitly recognized that certain individuals may require “individualized support due to geography, ethnicity, race, culture, immigration or disease status and representative of communities throughout the commonwealth.” The Commonwealth’s SFY 2008 and SFY 2009 budgets continued these outreach grants with a \$3.5 million appropriation to MassHealth (MDPH, 2009). As demonstrated in the previous section, PACT CHWs have proven successful in enrolling, and maintaining the enrollment of their patients. This success led to more effective use of pharmacy resources and a related 40% drop in inpatient service usage amongst PACT patients.

MassHealth provides care through several different delivery systems, including fee-for-service (FFS) and managed care. For individuals under the age of 65 who are not in an institution and do not have other health insurance, an individual can choose to enroll in the state-run managed care option, called the Primary Care Clinician (PCC) Plan, or in one of four participating Medicaid managed care organizations (MMCOs). The MCOs contract with and negotiate rates with their own network of providers who provide all medically necessary services to MCO enrollees. MMCOs have some latitude to spend their capitation rate, within parameters, as they choose, including to support CHWs or CBOs that employ

CHWs. MassHealth could provide financial incentives or otherwise encourage (e.g., through contract negotiations over performance measures) these providers or health plans to integrate CHWs into their current outreach activities and/or care models and care teams. As demonstrated, PACT CHWs have interfaced effectively with existing care provision teams, coordinating with physicians and other care specialists to develop and follow comprehensive action plans for their patients. Using patients' health as an indicator, clients have shown maintained (47%) or improved (35%) CD4 counts under the care of integrated, CHW/medical teams.

Pay-for-Performance strategies could be employed as well. Chapter 58 mandated rate increases for hospitals and physicians to be implemented over a three year period starting in SFY 2007. In SFY 2008, Chapter 58 required that a portion of the rate increase for acute hospitals (roughly \$20 million of \$76.5 million) be contingent upon adherence to certain quality standards and performance measures, including the reduction in health disparities. As such, MassHealth implemented an acute hospital pay-for-performance (P4P) program in October 2007, and plans to expand the pay-for-performance program to the PCC Plan, nursing facilities and MMCOs. These pay-for-performance programs may provide an opportunity to encourage the use of CHWs as part of the systematic adjustments that providers may make in the process of providing care and services to patients (MDPH, 2009). While it could be challenging to develop a specific measure that directly delivers an incentive to providers who use CHWs as part of the health care team, CHWs could be used to increase performance in specific clinic measures such as patient follow-up, outreach and medication adherence (such as in the case of PACT CHWs).

Performance is an area in which CHWs have had unparalleled success with extremely high need chronic disease patients. As demonstrated in the Outcomes section, 73% of patients achieved undetectable HIV loads, leading to decreased annual MassHealth expenditures over a two year period. In addition, patient outreach conducted by CHWs has led to increased social activity, community involvement and general life-functioning of PACT patients. This has enabled many low-resource patients to effectively re-integrate themselves into communities; functioning as parents, friends and citizens. Due to PACT's focus on low resource patients and neighborhoods, this success has begun to combat general health disparities in the Boston area.

Direct Reimbursement

MassHealth directly pays providers who meet its regulatory provider eligibility criteria set forth in 130 CMR 450.212, and who provide MassHealth-covered services to enrollees. Participating providers enter a provider contract with MassHealth and are assigned a provider billing code and service codes to submit claims for payment. MassHealth and federal Medicaid provider and procedure codes do not currently recognize CHWs as providers who can bill the program directly for services provided to MassHealth enrollees. CHWs' services are also not recognized for claiming purposes. However, the federal government and some states are moving in this direction.

Ultimately, MassHealth could explore the possibility and impact on patient health of directly reimbursing CHWs and CHW services by adding CHWs as a recognized and billable MassHealth provider type. This would require new regulations, rate development/fee schedules, provider qualifications (education, training, and certification), Medicaid state plan development, etc.

In July 2007, the National Uniform Claim Committee (NUCC), which maintains a Health Care Provider Taxonomy Code Set classifying providers for coding on claims, adopted a series of changes to the code set, including adding CHWs as a provider category (Code 172V00000X). The NUCC uses HRSA's definition of CHW included in the CHW National Workforce Study and categorizes CHWs under "Other Service Providers." The NUCC is a voluntary organization that manages a standardized data set for non-institutional providers to transmit claims and encounter information to and from payers. The NUCC is chaired by the American Medical Society and includes CMS as a critical partner (Rush, 2007). While this change does not alter current Medicaid payment policy, it opens the door at an administrative level for providers to claim for CHW services from payers (Rush, 2007).

Conclusion

Liberals have always claimed that the liberal state-reformist, legalist, and somewhat libertarian-was the only state that could guarantee freedom. And for the relatively small group whose freedom it safeguarded this is perhaps true. But unfortunately that group always remained a minority perpetually en route to becoming everyone.

- Immanuel Wallerstein

Currently, medicine and health care are a focal point of public interest, a discourse curiously similar to the context of Starr's 1980 publication. In the 80s, divergent paths were marked by a wave of change in ideological and partisan commitments often referred to as the 'Reagan Revolution' (Wailoo, 2004). Today, tensions are more internal to American medicine and health culture—an unyielding rise in medical spending, and the enduring sense that Americans are not getting a good value for their 'health care dollar' (Jost, 2004).

Though ostensibly distinct, these two juncture points are similar in that they both rest upon the shifting foundations through which Americans balance individual and collective responsibility; by so doing, they begin to define what they perceive as the legitimate scope for market forces and government intervention (Jost, 2004). For that reason, the lessons Starr derived concerning medical authority and the dynamics of change in health policy are as relevant today as they were three decades ago. In its inability to treat the intimately complex needs of certain patients, the rise of the medical profession as a sovereign entity has posed a substantial threat to the true well-being of marginalized populations within our society.

As our biomedical interventions have become more advanced, our capacity to distribute them equitably has further eroded. Increasingly sub-differentiated specialization, an emphasis on laboratory research and acute care have all played an important role in the medical profession, and thus the provision of health care services. Scientific medicine has

raised expectations and costs, but has failed to confront the social consequences of its own success. As a society, we find ourselves tied to acute care and episodic, specialized contacts with physicians. In tandem with this system of health care provision has come evidence of widespread dissatisfaction with the quality of care, as it is experienced by Americans. Yet, medical training still proscribes and rewards behaviors that may or may not be consistent with the most humane and cost-effective provision of care (Rosenberg, 1997).

For the great majority of Americans, dissociation from the highly technological medical system is unthinkable. Historian of science Charles Rosenberg notes that changes in re-imbursements will not necessarily alter this felt reality (Rosenberg, 1997). It is impossible to understand America's health care expenditures without understanding the allure of scientific medicine and the promise of healing, as well as the rich and complex history of medical professionalism and prestige in the United States (Rosenberg, 1997). These factors contribute to the substantial institutional imbeddedness of the current medical system, making deviation from systematic norms difficult with respect to both garnering support as well as amassing financial resources.

Despite the imbedded nature of the American system of health care provision, the current widely publicized crisis in healthcare funding may well create the conditions for fundamental structural change. While the basis for intervention spurred from this crisis focuses largely on cost cutting, limiting the discussion to financial issue would be inappropriate due to the gravity of social aspiration involved. A comprehensive argument for efficacious care must not only incorporate a discussion of the economic merits of such a pursuit, but also the structural and moral context of the situation.

As discussed in the section on Welfare, political economist David Brady conceives of equitable health infrastructure as a highly influential method of bringing citizens to an equal footing. Efficacious health spending, he concludes, can lead to an increased ability of people to contribute to the democratic process as functional citizens (Brady, 2005). Although not an end-all answer, the incorporation of CHWs into the Medicaid system is an invaluable exploration of this frontier. By creating more transparency within the consumer base, especially for those who face substantial barriers in accessing and utilizing medical care, the US can simultaneously explore not only what is most cost effective, but also what is ultimately just.

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Exhibit ONE: Case Manager vs. CHW

	<u>Case Manager</u>	<u>PACT Health Promoter</u>
Primary Focus	<ul style="list-style-type: none"> • Assist clients with housing, transportation, and food needs • Provide referrals to other public service providers • Very limited healthcare role 	<ul style="list-style-type: none"> • Assist clients with health management, health education, and medication adherence • Help clients access the healthcare system, accompany them to medical appointments
Background / Certification	<ul style="list-style-type: none"> • College-educated, often with Masters in Social Work degree or equivalent experience 	<ul style="list-style-type: none"> • No prior medical training • Prior experience with HIV, local community
Case Load	<ul style="list-style-type: none"> • Up to 300 clients per case manager 	<ul style="list-style-type: none"> • No more than 20 clients per health promoter
Service Location	<ul style="list-style-type: none"> • Based in hospital, clinic, or case manager's office 	<ul style="list-style-type: none"> • Home-based services
Funding	<ul style="list-style-type: none"> • Department of Public Health or other public agency 	<ul style="list-style-type: none"> • Charitable donations

Exhibit TWO: Typical Day for a PACT CHW

Typical Health Promoter Day

- 9:00 AM Monthly HP Meeting for case-based learning
- 10:00 AM Travel; call MD about Client 102's relapse
- 10:20 AM Accompaniment of Client 86 to Quarterly HIV visit
- 11:45 AM Write up progress note
- 12:00 PM Travel/Lunch
- 12:30 PM Mental Health Rounds with Dr. Kates
- 1:30 PM Travel
- 1:45 PM Home visit with Client 192; Administer Module 13 of curriculum
- 3:25 PM Write up progress note
- 3:30 PM Travel to Office
- 3:45 PM Call Client 54's case manager at LAHI to ask about HDAP application
- 3:55 PM Write progress note
- 4:00 PM 1:1 with HPPM
- 5:00 PM Day ends

Exhibit THREE: PACT Qualification Criteria

	Initial Criteria (1998 – 2001)	New Direction (2001 – 2006)	Recent Adjustments (2006 – present)
Location	<ul style="list-style-type: none"> No defined criteria 	<ul style="list-style-type: none"> Located within 20 minute driving radius of PACT headquarters 	<ul style="list-style-type: none"> Located in one of 13 specific Boston neighborhoods Other neighborhoods considered based on proximity
Poverty Level	<ul style="list-style-type: none"> No criteria 	<ul style="list-style-type: none"> Receiving or eligible for SSI, Medicaid/ MassHealth, or Free Care 	<ul style="list-style-type: none"> No poverty criteria
CD4 Count	<ul style="list-style-type: none"> No criteria 	<ul style="list-style-type: none"> <350 OR <15% on at least one occasion in past year 	<ul style="list-style-type: none"> <500 or <18% on most recent blood draw (must be within 6 months)
Viral Load	<ul style="list-style-type: none"> No criteria 	<ul style="list-style-type: none"> >1000 on at least two consecutive blood draws in past year 	<ul style="list-style-type: none"> >1000 on at least two blood draws in the past year including the latest blood draw within the last three months
ART History	<ul style="list-style-type: none"> No criteria 	<ul style="list-style-type: none"> Prescription for ART throughout past year, OR Non-prescription due to MD assessment of non-adherence any time in past year 	<ul style="list-style-type: none"> History of non-adherence to ART First prescription of ART at least 6 months before referral OR non-prescription due to MD assessment of non-adherence any time in past year

Exhibit FOUR: PACT Model: Transition between CHW, DOT-Plus and Monitored Self-Administration

