

HEALTH INSURANCE UNDER THE PATIENT PROTECTION AND AFFORDABLE
CARE ACT: THE ROLE OF STATE BASED HEALTH INSURANCE EXCHANGES
AND NAVIGATOR PROGRAMS IN ENSURING HEALTH COVERAGE FOR
VULNERABLE POPULATIONS

by

REINETTA THOMPSON WALDROP

(Under the Direction of Joel M. Lee)

ABSTRACT

The U.S. has finally moved towards the reform of its health system. On March 23, 2010 the Patient Protection and Affordable Care Act was signed into law by President Barack Obama. With goals of expanded health coverage, access to quality, affordable health care, and reducing health care costs, the law sought to ensure that eligible U.S. citizens had health insurance regardless of ability to pay or existing medical conditions. Key to meeting the goal of providing health insurance was the creation of state Health Insurance Exchanges (HIEs). To support the provision of guaranteed health care coverage to millions of uninsured and at-risk/vulnerable populations HIEs were mandated to contract with community based organizations and consumer advocacy agencies to serve as navigator programs. These agencies were charged with reaching, educating, and enrolling individuals into health plans. Establishing HIEs to serve as public marketplaces for purchasing health plans is new to the U.S. private insurance market. Thus, selecting business models and creating governance structures were key to HIE

effectiveness in carrying out federally mandated functions. Also, ensuring the use of navigator strategies that were successful in reaching at-risk/vulnerable populations was critical. This research examined the creation of State Based HIEs in sixteen states and the District of Columbia to assess HIE business models and governance structures. It also explored traditional patient navigator programs to identify strategies proven to be successful in reaching at-risk/vulnerable populations for the delivery of health care services and treatment.

Findings show that choice of business model (state agency, quasi-governmental, or non-profit) and governance structure (board membership apportionment, appointment, and composition) could impact HIE effectiveness. Key was removal of certain design issues and barriers that impacted effective operation. A review of traditional navigator programs identified strategies that were successful in reaching at-risk/vulnerable patients and facilitating treatment and care. Program elements such as advocacy, ethnic and racial concordance, and use of navigators who had experienced the same illness, were among some of the factors that were identified as elements of successful strategies. This research is expected to provide baseline information on the development of State Based HIEs and HIE navigator programs as health reform in the U.S. continues to evolve.

INDEX WORDS: U.S. health reform, PPACA, Health Insurance Exchanges, governance structure, government business models, navigator programs, navigator program strategies, at-risk/vulnerable populations, uninsured non-elderly adults.

HEALTH INSURANCE UNDER THE PATIENT PROTECTION AND AFFORDABLE
CARE ACT: THE ROLE OF STATE BASED HEALTH INSURANCE EXCHANGES
AND NAVIGATOR PROGRAMS IN ENSURING HEALTH COVERAGE FOR
VULNERABLE POPULATIONS

by

REINETTA THOMPSON WALDROP

BS, Howard University, 1973

M.S., The Georgia Institute of Technology, 1982

A Dissertation Submitted to the Graduate Faculty of The University of Georgia in Partial

Fulfillment of the Requirements for the Degree

DOCTOR OF PUBLIC HEALTH

ATHENS, GEORGIA

2013

© 2013

Reinetta Thompson Waldrop

All Rights Reserved

HEALTH INSURANCE UNDER THE PATIENT PROTECTION AND AFFORDABLE
CARE ACT: THE ROLE OF STATE BASED HEALTH INSURANCE EXCHANGES
AND NAVIGATOR PROGRAMS IN ENSURING HEALTH COVERAGE FOR
VULNERABLE POPULATIONS

by

REINETTA THOMPSON WALDROP

Major Professor: Joel M. Lee
Committee: SU-I Hou
Curtis A. Harris
Deborah Murray

Electronic Version Approved:

Maureen Grasso
Dean of the Graduate School
The University of Georgia
December 2013

DEDICATION

This dissertation is dedicated to my children Stephanie, Angela, and Melvin Jr. Each provided love and support from near and far that sustained me through this journey. Thank you for your constant encouragement and for your praise of even my smallest accomplishments. Your personal accomplishments in life have served as a barometer for reaching my goal of earning a doctoral degree. Special love and gratitude is given to Angela, who was with me from beginning to end, spending countless hours and nights quizzing me before tests, reading papers, and worrying that I was not getting enough sleep, all while encouraging me to continue to reach for my dream. Also, to Dutchess Waldrop aka “wo-man’s best friend”, who loved me unconditionally through this process and who listened to my every frustration, never once talking back or questioning my decisions.

This dissertation is also dedicated to my family and friends in Philadelphia and Atlanta who encouraged me and gave me reasons to believe that I could even do this. To my nieces and nephews, I hope I have been an inspiration and proof that it is never “too late to educate”! To my Atlanta running buddies, Anita, Sylvia, Cheryl, and Ruby, who understood that I needed to put our gatherings on hold for a minute, allowing me time to work hard toward this academic success story. Thank you my “Sistas”, and let the theatre, movie going, and shopping trips once more begin. To anyone else who encouraged me or just thought about me my heart is filled with love and gratitude for all of you.

ACKNOWLEDGEMENTS

This dissertation would not have been possible without the guidance and support of my dissertation committee and my Morehouse School of Medicine family.

To Dr. Joel Lee, Dr. SU-I Hou, Dr. Curtis A. Harris, and Dr. Deborah Murray, each of you have given me a reason to smile and to know that earning a doctoral degree is a joy in and of itself. Thank you to Dr. Lee for your guidance, patience, and continued support through my determination to write this manuscript at break-neck speed, and for challenging my thinking along the way. To Dr. Hou, thank you for taking the mystery out of social and behavioral theory and for teaching me that theory can have practical purpose. To Dr. Harris, thank you for hanging in there with me and for your incredible attention to detail. And finally, to Dr. Murray, whose knowledge of this topic has proven to be invaluable from day one, and who has become my “kindred doctoral spirit”.

To my Morehouse School of Medicine family, I extend my greatest appreciation for your support of my journey. To Dr. Patricia Rodney and Dr. Beverly Taylor, thank you both for your encouragement and belief in me from the very beginning. To Dr. Stephanie Miles Richardson, your unending commitment to providing me the opportunity to “do what I had to do” and “be where I had to be” will never be forgotten. To my faculty colleagues and members of the staff, thank you for your words of encouragement and concern, and for making sure that I had “done my homework and studied for my exams”. Lastly, to my students thank you for reminding me that this degree was my academic destiny.

TABLE OF CONTENTS

| | Page |
|--|------|
| ACKNOWLEDGEMENTS | v. |
| CHAPTER | |
| 1 INTRODUCTION | 1 |
| 1.0 Overview | 1 |
| 1.1 The Patient Protection and Affordable Care Act of 2010..... | 1 |
| 1.2 Purpose of Research..... | 3 |
| 1.3 Research Aims | 6 |
| 1.4 Research Questions | 9 |
| 1.5 Research Design and Methodology | 10 |
| 1.6 Background | 13 |
| 1.7 Summary | 16 |
| 2 LITERATURE REVIEW | 17 |
| 2.0 Overview | 17 |
| 2.1 General Literature Review Section..... | 18 |
| 2.2 Manuscript 1 Literature Review Section | 53 |
| 2.3 Manuscript 2 Literature Review Section | 82 |
| 3 AN ASSESSMENT OF STATE BASED HEALTH INSURANCE EXCHANGE BUSINESS MODELS AND GOVERNANCE STRUCTURES | 122 |

| | |
|--|-----|
| 3.0 Abstract..... | 123 |
| 3.1 Introduction..... | 124 |
| 3.2 Literature Review..... | 130 |
| 3.3 Methodology..... | 140 |
| 3.4 Results..... | 142 |
| 3.5 Conclusion | 148 |
| 3.6 Summary..... | 150 |
| 3.7 References..... | 151 |
| 3.8 Appendix..... | 155 |
| 4 THE IDENTIFICATION OF TRADITIONAL NAVIGATOR PROGRAM STRATEGIES TO INFORM HEALTH INSURANCE EXCHANGE NAVIGATOR PROGRAMS FOR OUTREACH, EDUCATION AND ENROLLMENT OF VULNERABLE POPULATIONS IN APPROVED HEALTH PLANS..... | 169 |
| 4.0 Abstract..... | 170 |
| 4.1 Introduction..... | 171 |
| 4.2 Literature Review..... | 175 |
| 4.3 Methodology..... | 199 |
| 4.4 Results..... | 202 |
| 4.5 Conclusion | 206 |
| 4.6 Summary..... | 208 |
| 4.7 References..... | 210 |
| 4.8 Appendix..... | 218 |

| | |
|--|-----|
| 5 CONCLUSION..... | 226 |
| 5.0 Overview..... | 226 |
| 5.1 Research Questions and Research Findings | 227 |
| 5.2 Reform of the U.S. Health System: Final Thoughts | 232 |
| 5.3 Proposed Frameworks for Sustainability | 235 |
| 5.4 Challenges & Recommendations for Future Research | 241 |
| 5.5 Research Limitations | 249 |
| 5.6 Implications for Public Health | 250 |
| 5.7 Summary..... | 253 |
| REFERENCES..... | 255 |
| APPENDIX | 278 |

CHAPTER 1

INTRODUCTION

1.0 Overview

The purpose of this chapter will be to guide the reader through this body of work and to provide the basis for how this dissertation topic will be addressed. It will start with brief comments on the purpose of the Patient Protection and Affordable Care Act (PPACA) and its overall goal of guaranteeing near universal health insurance coverage for all U.S. citizens. A more detailed look at the law will be provided in the Literature Review Chapter. This chapter will also present information on the purpose of this research, acquaint the reader with the research questions, and finally address the research approach and methodology that will be used. It will end with a background section that will summarize the two major subjects of this dissertation research, namely State Based Individual Health Insurance Exchange (HIE) Marketplaces and Health Insurance Exchange navigator programs. Unless otherwise noted, all references singular or plural in this dissertation to a HIE marketplace will refer to the Exchange established for individual purchases.

1.1 The Patient Protection and Affordable Care Act of 2010

In response to rising health care costs and an increasing number of uninsured individuals, on December 24, 2009, the U.S. Congress passed the Patient Protection and Affordable Care Act. On March 23, 2010, the President signed the Patient Protection

and Affordable Care Act (P.L. 111-148) into law. On March 30, 2010, the Health Care and Education Reconciliation Act of 2010 (P.L. 111-152) was signed into law. The two laws are collectively referred to as the Affordable Care Act (ACA) (Congress, 2010). For this research when referencing the law, the terms Patient Protection and Affordable Care Act (PPACA) and Affordable Care Act (ACA) will be used interchangeably. The PPACA seeks to: (1) expand health coverage; (2) ensure access to quality, affordable health care; and (3) contain the growth of health care costs (CMS, 2012; Democratic National Committee, 2010; Congress, 2010; Shi & Singh, 2012).

The underlying tenet of the law is that all U.S. citizens will have access to quality, affordable health care, thus reforming the U.S. health care system to guarantee near universal health coverage for almost 40 million eligible individuals (Democratic National Committee, 2010; Elmendorf, 2010). Providing health insurance coverage to millions of U.S. citizens who have never possessed the resources to secure health care will require the development of an insurance marketplace that is structurally different from the traditional private market and current publicly funded government programs. To aid in the provision of health insurance coverage for all U.S. citizens, the law requires that states establish HIEs which will serve as marketplaces for the purchase of affordable health plans. According to the Department of Health and Human Services (DHHS), the PPACA is also intended to:

“... [create] new competitive private health insurance marketplaces – called Affordable Insurance Exchanges or “Exchanges” – that will give millions of qualified individuals and qualified small employers access to affordable coverage. Exchanges will help qualified

individuals and qualified small employers shop for, select, and enroll in high-quality, affordable private health plans that fit their needs at competitive prices. Exchanges will also assist eligible individuals to receive premium tax credits and cost sharing reductions or help individuals enroll in other Federal and State health care programs. By providing one-stop shopping, Exchanges will make purchasing health insurance easier and more understandable and will put greater control and greater choice in the hands of qualified individuals and small businesses” (DHHS, CMS, & CCIIO, 2012d)

State HIE marketplaces are a cornerstone of the PPACA and their role in ensuring health insurance coverage for the uninsured, including at-risk/vulnerable populations will be the subject of this dissertation research. The DHHS is the designated Executive Branch department tasked with establishing and promulgating agency rules, regulations and guidance associated with the establishment of HIEs at the state level.

1.2 Purpose of Research

A principal component of the PPACA is the provision of health insurance coverage for uninsured U.S. citizens. A major goal of the Act is the provision of near universal health insurance coverage for the first time ever in the United States. An additional goal is the provision of accessible, affordable, and quality health care for all U.S. citizens while reducing the cost of care associated with all health services. In an effort to reach these goals and to meet the statutory requirements of the law, states are mandated to establish HIE Marketplaces (Congress, 2010, pp. Part III, Sec 1321). To carry out this mandate, states have been given three options for establishing their HIE marketplace: 1) establish a State Based Exchange, 2) establish a State Partnership

Exchange, or 3) default to a Federally Facilitated Exchange (DHHS, 2012b). Regardless of the option chosen, HIEs will serve as public marketplaces for the purchase of affordable health insurance, and the individual exchange is viewed as a key factor in ensuring the enrollment of eligible individuals into qualified health plans (QHPs).

To reach uninsured and at-risk/vulnerable populations, the law requires HIEs to establish navigator programs. HIE navigator programs will use community based organizations and consumer service agencies to provide outreach and education to uninsured and at-risk/vulnerable populations, aimed at enrolling them into health plans offered through the exchange. Researchers generally agree that there is no one single definition for what a navigator program is, or for what it does. However, for this research a distinction will be made between what are known as patient navigator programs and navigator programs established under HIEs. HIE navigator programs will be defined as a federal mandate for the facilitation of outreach, education, and enrollment of at-risk/vulnerable populations into qualified health insurance plans. For this research, those programs that assist patients in facilitating the delivery of clinical health services will be referred to as traditional patient navigator programs. The use of these programs to facilitate the delivery of health services for illnesses, such as cancers, where research has documented disparities in treatment and care has been a longstanding practice.

While the DHHS does not provide a formal definition for at-risk/vulnerable populations in any of the guidance it has prepared for establishment of HIEs or navigator programs, the Centers for Disease Control and Prevention (CDC), an agency within the DHHS defines other at-risk/vulnerable populations as being "...defined by socio-

economic status, geography, gender, age, disability status, risk status related to sex and gender, and among other populations identified to be at risk for health disparities” (CDC, 2013).

For purposes of this research, the terms at-risk/vulnerable populations and at-risk/vulnerable groups will be used interchangeably, and will refer to those individuals or groups noted in the CDC definition with the exception of geography and disability status. Also, because they are generally covered by Medicare, Medicaid, or State Children’s Health Insurance Programs (SCHIP), elderly individuals and children will not be included in the definition of at-risk/vulnerable populations for this research. More specifically, this research will focus on low-income, racial and ethnic minority groups, culturally diverse groups with limited English proficiency, and groups whose medical circumstances render their receipt of care especially burdensome without support and advocacy. Also, for this study, uninsured employees of small businesses will also be considered an at-risk group because of their economic circumstances. In researching a definition of vulnerable populations, it was discovered that the term at-risk/vulnerable populations can be viewed differently depending on the research discipline, (e.g. health care, sociology, psychology, criminal justice, emergency preparedness, etc.), and include any number of at-risk/vulnerable groups (Ruof).

HIEs are viewed as a key factor in the enrollment of vulnerable, uninsured, and otherwise eligible individuals into affordable, qualified state health plans. They will serve as marketplaces where consumers will be able to purchase individual health insurance through non-group health plans that have been approved by the state.

Affordability has traditionally been the factor excluding these groups from the pool of health insurance options generally available to the public and through employer sponsored group health plans. Based on eligibility requirements and conditions set forth in the law millions of vulnerable individuals will be eligible for subsidies to help purchase health insurance through HIEs, thus making health insurance affordable (S. R. Collins, Robertson, R., Garber, T., Doty, M.M., 2013; Cunningham, 2010).

However, the use of HIEs and mandated navigator programs to facilitate enrollment of at-risk/vulnerable populations into insurance programs is new, both to the insurance market and to individuals who have never purchased or enrolled in health insurance plans. Therefore, the purpose of this research will be to examine the role of State Based HIE marketplaces and navigator programs in ensuring health coverage for at-risk/vulnerable populations who have traditionally been excluded from private insurance markets and publicly financed health programs.

1.3 Research Aims

This research has three specific aims. The first is to provide an overview of health reform and the PPACA mandate for the establishment of HIEs and their role in making health insurance coverage available for vulnerable U.S. citizens. This aim will include an examination of: 1) health reform efforts in the U.S. and how we have reached this point of near universal coverage; 2) federal requirements for the establishment and design of HIE marketplaces; and, 3) how HIE marketplaces operate in the State of Massachusetts and in European national insurance markets.

The second aim of this research is to provide a review of the governance structure /business model, governance appointment and composition of State Based HIEs. Even with a set of minimum guidelines from the DHHS, states have been given considerable latitude in designing and implementing their state HIE marketplaces (Blavin, Blumberg, Buettgens, Holahan, & McMorrow, 2012). This includes the business model, and governance structure under which they operate, including the apportionment, appointment and composition of their governing authority.

Thirdly, this study will examine the use of traditional navigator programs in the delivery of clinical health services. It will examine the strategies used to engage individuals in seeking care, explore the at-risk/vulnerable populations served by traditional navigator programs, and examine the characteristics that navigators must possess to be effective facilitating services. HIE navigator programs are mandated at a minimum to provide outreach, education, and enrollment of at-risk/vulnerable populations into approved qualified health plans. Also, while not officially termed navigator programs, public and private organizations such as the American Association of Retired Persons, officially sanctioned employee unions, and certain group purchasing insurance plans have used navigator program strategies to facilitate enrollment of targeted groups of individuals into group insurance plans. Thus, the use of navigator like programs outside the field of health service delivery aimed at enrolling specific populations into insurance programs has been a long standing practice.

Navigator programs in HIE marketplaces, while not delivering patients to a point of service for the provision of care, will nonetheless guide and facilitate the same kinds of

socially, economically, culturally and medically at-risk individuals to enrollment in health insurance plans. To be successful, it is theorized that exchange navigator programs will need to incorporate many of the characteristics and strategies proven to be successful in facilitating vulnerable patient groups into programs of care. A review of the literature is expected to identify strategies associated with successful patient navigator programs. These strategies will be explored to determine if their adoption by HIE navigator programs will garner the same success in reaching at-risk/vulnerable populations for enrollment in HIE qualified health plans.

Early Research on HIE and Navigator Program Design

The PPACA HIE marketplace is in its infancy. Therefore, no quantitative data to examine the success of enrolling at-risk/vulnerable populations into HIE marketplaces exists. Thus, an empirical research approach using information or experiences from a variety of sources as well as information empirically derived from evidence based practice will be used for this research. Early HIE marketplaces and navigator programs will undergo changes as markets mature, health plan options change, and state and federal rules and regulations governing their operation evolve. An empirical research design will allow for a qualitative review of how HIEs are established and designed to function at implementation. It could also aid in the development of a baseline for future studies.

The value of this early research on HIE governance and navigator program design is that a synthesis of state government and legislative actions, data and information from health research organizations, literature review findings, and rules, regulations and

guidance from the Department of Health and Human Services (DHHS), can offer a comprehensive snapshot of program operations at inception. Thus, this research could provide a baseline for improving the future design of exchanges. States that have defaulted to a Federally Facilitated Exchange and those now implementing State Partnership Exchanges may find this research of value should they move to State Based Exchanges in the future.

Going forward, the empirical findings from this research could help to improve future navigator program designs. They could lead to increased program success for outreach, education and enrollment of uninsured and at-risk/vulnerable populations into HIE approved health plans.

1.4 Research Questions

Two research questions have been identified for this study:

- *Research Question 1:* Do business model and governance structure design including governing authority composition impact the effectiveness of State Based HIE agencies?
- *Research Question 2:* Do traditional navigator programs that facilitate health service delivery to at-risk/vulnerable populations provide evidence of proven strategies that can be used by State Based HIE navigator programs for outreach, education and enrollment of at-risk/vulnerable individuals into qualified health plans?

To address these research questions, this study will examine evidence based findings on governance of agencies created by state legislative action. It will also explore the strategies used by traditional navigator programs that can be adopted by HIE navigator programs to facilitate outreach, education and enrollment of at-risk/vulnerable populations into qualified health plans.

1.5 Research Design and Methodology

This dissertation will use a qualitative methodology for synthesis of data, information, and empirical research findings that have informed practice in organizational governance and navigator program strategies. In some instances, public use datasets providing descriptive data on states, the demographics of their uninsured populations, and their proposed HIE plans, are available for download from secured governmental websites. These datasets will be used where possible to synthesize data pertinent to this research and to generate descriptive statistics.

The DHHS deadline for states to create State Based exchanges was in December, 2012. States choosing to implement state partnership exchanges were required to notify DHHS by February 15, 2013. According to a Kaiser Family Foundation Report on State Decisions on Health Insurance, as of June 20, 2013, 16 states and the District of Columbia had elected to set-up State Based exchanges, 7 states had declared an intention to operate hybrid state – federal partnership exchanges, and 27 states had elected to default to federal-facilitated exchanges (H. J. K. F. Foundation, 2013b). Inclusion and exclusion criteria are presented below.

Inclusion criteria

The sixteen states plus the District of Columbia that have elected to operate State Based individual HIE marketplaces will be included in this study. Through exchange websites, these states have begun to communicate information with their citizens on the status of their HIE marketplaces and how they are designed to operate. They have included information on the legislative action creating the exchange, information on approved qualified health plans, and the purpose of the HIE marketplace. Also, state information available on DHHS and CMS websites, as well as data collected and made publicly available through DHHS reporting mechanisms will be used for this research. Specific sections of the PPACA as signed into law will also be cited in this research. Journal articles and reports on reform of the U.S. health system, uninsured and at-risk/vulnerable populations, health insurance marketplaces, navigator programs, and the economic implications of health reform have been published by highly respected health policy and research organizations. These include Robert Wood Johnson Foundation, The Commonwealth Fund, the Henry J. Kaiser Family Foundation, and Trust for America's Health, and others. Data collected and made available through these organizations' websites will also be used in this research.

Research on traditional navigator programs that have guided at-risk/vulnerable populations has produced empirical evidence that certain strategies are necessary to ensure the success of such programs. Many studies have shown consistency in the kinds of strategies used to effectively promote and engage at-risk/vulnerable populations in seeking health care services. Likewise, in facilitating the enrollment of targeted

populations into endorsed health coverage plans, public and private organizations have used many of the same strategies to reach their targeted populations. The use of those strategies to facilitate outreach education and enrollment of at-risk/vulnerable populations will be explored.

Exclusion criteria

Federally Facilitated Exchange models are being implemented by the Department of Health and Human Services in 27 states which have chosen not to implement State Based or State Partnership Exchanges. These will not be considered in this research. Also, due to the large degree of variability in how State Partnership Exchanges are being developed, and the wide range of scenarios emerging for the sharing of Exchange responsibilities between state and federal governments, this model will not be considered in this research. Also, each state is allowed significant latitude in setting up its small business exchange. Therefore, given the potential for wide differences in how small businesses are defined and in individual state rules, SHOP Exchanges will not be included in this research. Finally, in response to Comments published in the Federal Register dated March 27, 2012, related to the PPACA and to the Establishment of Exchanges and Qualified Health Plans that "...the definition of "State" include Territories", the DHHS published the following final rule:

“Response: The definition of State is based on section 1304 of the Affordable Care Act, which does not include Territories. Section 1323 of the Affordable Care Act addresses Territories in the context of Exchanges and is not within the scope of this regulation.” (DHHS, 2012c).

Because U.S. territories are not being included in DHHS regulations related to the establishment of exchanges, they will not be included in this research.

1.6 Background

America's journey towards the reform of its health care system has been a long one dating back almost 100 years to 1912 (Blumenthal & Morone, 2010). Attempts to fix the system have been plagued over decades by a number of factors, including: 1) a lack of political will; 2) the powerful influence of certain industries and industry related lobby groups; 3) the competing interests of payor and provider systems; 4) the economic impact of steady increases in the cost of care and rising rates of reimbursement; 5) costly government health care programs; and 6) costly improvements in medical technology and related technology services. All of these factors have had the combined effect of creating a fragmented system of care that welcomes those with the financial means to traverse the system, and turns away those who become vulnerable due to social, economic, cultural, or costly medical conditions.

The PPACA represents a turning point in the reform of the US health care delivery system where attempts at reform have spanned nearly twenty presidential administrations (Blumenthal & Morone, 2010). Over that time improvements in the availability of health care through programs such as Social Security Disability, Medicare, Medicaid, the State Children's Health Insurance Program (SCHIP) and specific grant funded service initiatives have made health services available to many vulnerable groups. However, while the PPACA will improve the availability of affordable care for at-risk/vulnerable groups who are not eligible for existing public programs, certain reforms

under the Act are also designed to reduce burdens associated with the cost of health coverage for all U.S. citizens. This research will provide a brief review of the social, financial and economic factors that led to passage of the PPACA, while trying to place into context why HIE marketplaces are an essential component of health care reform in the U.S.

Establishment of HIE Marketplaces under the PPACA

HIEs are not a new concept in the provision of affordable health coverage. Several European countries have successfully integrated HIEs into their national health insurance programs, the result being that almost 100% of citizens, including at-risk/vulnerable populations have health coverage (Enthoven & van de Ven, 2007; R. Kreier, Zweifel, Peter, 2010; Reinhardt, 2004; Van Ginneken & Swartz, 2012; Van Ginneken, Swartz, & Van Der Wees, 2013). Additionally, within the U.S. the State of Massachusetts initiated state wide health reform in 2006 which has been successful in providing near universal health insurance coverage for all Massachusetts residents, including at-risk/vulnerable groups through the availability of premium subsidies. By 2009, more than 97% of Massachusetts residents had health insurance coverage (Bigby, 2009). However, a near universal program offering affordable health insurance coverage on a national level for all U.S. citizens represents a new chapter in this country's quest to reform its health care system. Therefore, understanding how HIE marketplaces have operated in European health care markets and in the State of Massachusetts, could inform decisions on their function and operation on a national level.

Navigator Programs under the PPACA

The PPACA mandates the establishment of HIE navigator programs to support the outreach, education and health plan enrollment of individuals eligible for purchase of health insurance through exchanges (CMS, 2012). At-risk/vulnerable populations will need to be guided through the maze that will characterize exchange marketplaces and through the multiple options that will exist under qualified health plans. It will be the primary function of HIE navigator programs to accomplish this. Specific strategies to engage in navigator activities will be developed by the organizations selected to serve as exchange navigator programs. While navigator programs must meet certain minimal requirements as set forth in DHHS guidance documents, states can put in place additional requirements based on knowledge of their uninsured and at-risk/vulnerable populations and the capacity and make-up of the community based organizations expected to respond (Saly, 2013). While this will allow states the flexibility they need to implement navigator programs that meet their individual state needs, it also means that they are likely to design their navigator programs with different strategies and program features in mind.

Community based organizations that carry out HIE navigator program functions will develop different operational approaches to meet DHHS rules and regulations. Additionally, organization goals and missions, the type of at-risk/vulnerable populations served, and strategies used to reach those groups could make a difference in how selected CBOs achieve HIE navigator program goals. Thus, one objective of this research will be to create a typology of proven strategies that can be used across the continuum of organizations and agencies involved in carrying out HIE navigator activities.

1.7 Summary

Examining the establishment, design and governance of State Based HIEs, and identifying successful navigator strategies for reaching at-risk/vulnerable populations is an important step in determining whether HIE marketplaces and navigator programs can meet the goals of the PPACA. Using the findings from this research to create baselines in these areas presents an opportunity to evaluate the effectiveness of HIEs and HIE navigator program strategies in the future. Such evaluations can assist in moving towards best practice models that address market changes in which could impact the roles of HIEs and HIE navigator programs in ensuring health insurance coverage for at-risk/vulnerable populations. The chapters that follow will present more information on how HIEs and HIE navigator programs can be successful by examining design issues, barriers and lessons to be learned from other health reform initiatives both in the U.S. and in Europe.

CHAPTER 2

LITERATURE REVIEW

2.0 Overview

Chapter 2 of this dissertation will present a review of the literature most relevant to this research topic. It is divided into three sections: a general literature review; a review of the literature addressing the major elements of Manuscript 1; and a review of the literature addressing the major elements of Manuscript 2.

Section 2.1: the general literature review will explore health care reform in the U.S., the passage of the Patient Protection and Affordable Care Act (PPACA), the economic issues associated with health reform, the Massachusetts Health Reform Initiative of 2006, and the World Health Organization (WHO) call for universal health coverage with a look at the status of America's health on the global level, particularly as it relates to at-risk/vulnerable populations.

Section 2.2: the literature review associated with Manuscript 1 will address establishment of State Based Health Insurance Exchanges (HIEs) and examine the business model and governance structure including apportionment, governance appointment and composition of the governing authority. It will also explore the design issues and barriers that have impacted HIE marketplace performance in the State of Massachusetts and in Europe for lessons that can be learned.

Section 2.3: the literature review associated with Manuscript 2 will examine the concept of at-risk/vulnerable populations and the risk factors that lead to their vulnerability. It will also examine the use of traditional patient navigator programs to identify strategies that have proven successful in facilitating service delivery to at-risk/vulnerable populations.

Special Note: Projections on the number of uninsured and at-risk/vulnerable individuals who will benefit from the provisions of the PPACA continue to be fluid. Most estimates are that 40 million U.S. citizens will be covered by this law (Committee, 2010; Elmendorf, 2010). Therefore, in the context of general information, the 40 million number will be used in this report. However, in instances where a report or article cites a different number, that number will be used when referencing that report information. Also, Tables presented in this chapter are numbered consecutively throughout the chapter beginning with Section 2.1.1 General Literature Review and use the format Table 2- #.

2.1 General Literature Review Section

To understand how the PPACA and America's pursuit of near universal health coverage impacts the accessibility, availability, and affordability of health care for vulnerable and uninsured populations, it is important to appreciate this country's long journey towards health care reform. To that end, a synopsis of U.S. health care reform and the myriad of factors, past and present that have acted in concert to push the U.S. towards a national system of health care is in order. The summary of reform efforts will highlight those presidential attempts that have failed as well as those that have been successful.

Many health care economists, policy makers, health policy research organizations, and government officials believe that America's health care system has been broken for a long time (Committee, 2008; Sheehan, 2010). In the almost 100 years before passage of the PPACA, numerous legislative attempts to bring about meaningful change to the US health care delivery system were largely met with partisan opposition. In particular, efforts on the part of early Presidents such as Herbert Hoover, Franklin Roosevelt, and Harry Truman, and later efforts by Presidents Richard Nixon and Bill Clinton, and by Senator Ted Kennedy to create a national health insurance program were all soundly defeated under pressure from well financed and politically well connected professional associations and lobbying groups (Blumenthal & Morone, 2010). Over the years, attempts to fix the system have been met with mixed success. Those attempts have encountered barriers that have been political, economic, financial and social in nature. Furthermore, those barriers have had the greatest impact on at-risk/vulnerable populations including the uninsured and working poor, whose socio-economic, cultural, financial status, and oftentimes chronic medical conditions, have made them least able to access systems of care. In large part, their inability to access care is due to a lack of affordable health insurance (Shi & Singh, 2012; Shi & Stevens, 2010). The PPACA is poised to change the way America delivers health care and how at-risk/vulnerable populations will access and afford care in the future.

On December 24, 2009 the U.S. Congress passed the Patient Protection and Affordable Care Act. On March 23, 2010, the Act was signed into law by President Barack Obama. As its main objectives, this law seeks to: (1) expand health coverage; (2)

ensure access to quality, affordable health care; and (3) contain the growth of health care costs (CMS, 2012; Democratic National Committee, 2010; Congress, 2010; Shi & Singh, 2012). The underlying tenet that all U.S. citizens will have access to quality, affordable health care suggests that health insurance coverage will be available to 94% of U.S. citizens and extend to almost 40 million uninsured eligible individuals (Democratic National Committee, 2010; Elmendorf, 2010). The provision of health insurance coverage to almost 40 million eligible individuals will not only improve the health of at-risk/vulnerable populations that have not had an entrée into the health care system for the care they need but will, in the long-term, improve the overall health of the U.S. as a nation which has a World Health Organization (WHO) overall health status ranking of 37th in the world (WHO, 2000). Thus, providing health insurance coverage to millions of U.S. citizens who have never possessed the resources to secure health care will require the development of a marketplace that is structurally different from the traditional U.S. health insurance market.

2.1.1 Health Care Reform in the U.S.

1912 – 1960: America's journey towards the reform of its health care system has been a long one. Early efforts date back almost 100 years starting with an attempt by President Theodore Roosevelt in 1912 to endorse social reforms that included consideration of a national health insurance system (Blumenthal & Morone, 2010). Going forward from 1930 to 1935 under Presidents Herbert Hoover and Franklin D. Roosevelt, there was a growing recognition that health coverage for U.S. citizens was beginning to present economic problems. Despite a bold move on the part of Congress to

enact the Sheppard-Towner Act of 1921 which provided federal funding to improve the health and lower the incidence of mortality among women and children (Shi & Singh, 2012), calls for a national health insurance plan were largely ignored. Finally, the call for social policies to secure employment, retirement, and medical care to limited groups of individuals eventually resulted in passage of the Social Security Act (SSA) of 1935 under President Franklin Delano Roosevelt (Blumenthal & Morone, 2010). Fearing that Congress would not act favorably on both a social reform act and a bill for national health insurance, Roosevelt chose to spend his political capital on social reforms for which he had more votes in Congress. Continued presidential and legislative efforts post SSA failed to garner the support necessary to enact a national health insurance program, including provisions for comprehensive health insurance as part of the then existing Social Security Act. Between 1945 and 1949 under President Harry Truman renewed efforts to mandate national health insurance post World War II were met with fears of socialism and potential requirements for desegregation in the south (Blumenthal & Morone, 2010). Later, under Presidents Truman and Eisenhower, various conferences and commissions convened to support reform of the health care industry (Blumenthal & Morone, 2010), but it was not until President Lyndon Johnson came to office that the first major efforts to reform health care insurance met with some success.

1965 – 1968: Two major exceptions to the failed efforts to reform the U.S. system occurred in 1965. Under President Lyndon Johnson passage of Medicare and Medicaid represented the first successful attempt to guarantee health care coverage to millions of vulnerable U.S. citizens under federally funded subsidy programs. Finally, on

July 30, 1965 as Titles XVIII and XIX respectfully of the Social Security Act, Medicare and Medicaid legislation to reform the delivery of health care to the nation's elderly and poor was signed into law (Blumenthal & Morone, 2010).

As Title XVIII of the SSA, Medicare guarantees health insurance to the elderly as a part of their social security retirement benefits, and is today, the nation's premier health insurance program for persons age 65 and older and certain disabled groups. Today, Medicare consists of four distinct parts: Part A (Hospital Insurance, or HI); Part B (Supplementary Medical Insurance, or SMI); Part C (Medicare Advantage, or MA); and Part D (the outpatient prescription drug benefit). Part A is financed primarily through payroll taxes levied on current workers and their employers which are credited to the HI trust fund. Part B is financed through a combination of monthly premiums paid by current enrollees and general tax revenues and is credited to the SMI trust fund. As an alternative, beneficiaries can choose to receive all their Medicare services through managed care plans under the Part C, MA program with payment made on their behalf in appropriate parts from the HI and SMI trust funds. The Part D drug benefit, funded through a separate account in the SMI trust fund, is financed through general revenues, state contributions, and beneficiary premiums (Davis, 2009; O'Sullivan, 1998; Shi & Singh, 2012). Decades later, the Medicare Part A program would be in jeopardy of insolvency and serve as one of the major reasons for the advancement towards a national system of health care.

Two different studies on the financing of Medicare Part A projected insolvency for the program. According to a 2009 Congressional Research Service Report for

Congress, the Medicare program Board of Trustees has provided insolvency projections for the HI Trust Fund since 1970. (Davis, 2009; O'Sullivan, 1998). In 1970, insolvency of the HI Fund was projected to occur in 1972. In 1998, O'Sullivan (1998)(O'Sullivan, 1998) projected insolvency in 2008; a 2009 Congressional Research Report by Davis (2009)(Davis, 2009) followed a financial upswing at the end of the Clinton administration and pushed out the projected Part A insolvency to the year 2017.

Medicaid, as Title XIX of the SSA was enacted as a state program with federal assistance using a Federal Medicaid Assistance Percentage (FMAP) match and guarantees health insurance coverage to low income women and children found to be eligible based on state eligibility requirements (Shi & Singh, 2012). In recent years states have shown increasing evidence that they are not in a financial position to fund increases in the state portion of their traditional Medicaid programs due to increasing numbers of eligible individuals, dwindling state revenues, and partisan politics.

Both programs represented a national attempt to offer health insurance to vulnerable groups through programs that guaranteed subsidized care. Additionally, as entitlement programs, individuals who apply and meet the eligibility requirements of Medicare and Medicaid must be enrolled regardless of the cost or availability of budgeted funds. Thus, by the early 2000's, increasing costs associated with both programs would place the continuation of these programs for a growing number of at-risk/vulnerable populations in jeopardy of insufficient funding (Shi & Singh, 2012; Shi & Stevens, 2010). As a practical matter, insufficient funding generally resulted in a reduction in the kinds of services provided, particularly for Medicaid enrollees.

1969 – 1989: Following the passage of these two programs, legislative efforts to bring about a national health insurance program continued in earnest under five additional presidents, Richard Nixon, Gerald Ford, Jimmy Carter, Bill Clinton and George W. Bush. From dueling proposals between President Nixon and Senator Ted Kennedy in 1974, to the presentation of a Health Security Act to Congress in 1993 by then President Bill Clinton, to the expansion of Medicare to cover prescription drugs under President George W. Bush in 2003, the growth in health care expenditures now had the public's attention (Blumenthal & Morone, 2010; Shi & Singh, 2012). Also during this time special initiatives and programs funded through federal grants to community based organizations (CBOs) and states, and direct federal budget allocations to the Centers for Disease Control and Prevention (CDC), were aimed at improving health care delivery to vulnerable groups to reduce disparities in outcomes that were now prevalent in at-risk/vulnerable populations. This increased the government's investment in providing affordable care to at-risk/vulnerable populations.

During the almost forty years between the passage of Medicare and Medicaid, and full implementation of the expansion of Medicare to include prescription drugs in 2006, the health care system in America became challenged by increasing costs, higher demands for services, and medical conditions that took on a chronic rather than an episodic nature. In the early 1970's Richard Nixon pushed for an increase in the number of health maintenance organizations (HMOs), a private market approach viewed at the time as providing high quality care in fiscally controlled environments (Blumenthal & Morone, 2010). His attempts to increase the number of HMOs to help drive down health

care costs created only 174 HMOs, falling far short of the 1700 anticipated through passage of the Health Maintenance Organization Act of 1973 (Shi & Singh, 2012). During the 1980's under President Ronald Reagan additional attempts were made to slow down the health care economy which was beginning to consume a larger and larger percentage of the nation's gross domestic product (GDP). The result was various federal laws and agency rules and regulations to reform payments to control hospital and outpatient services costs (Shi & Singh, 2012). Most notable was implementation of the prospective payment system which changed the payment methodology structure of the Medicare program based on the grouping of diagnoses into defined categories referred to as Diagnostic Related Groups (DRG's) (Shi & Singh, 2012). In addition during the Reagan years, paradigm shifts in the mid to late 80's led to major changes in the way stand-a-lone hospitals operated, moving more towards business models leading to a proliferation of new systems for the delivery of care such as managed care organizations, preferred provider organizations, and HMOs. These changes were viewed as necessary to reduce the rising cost of health care as evidenced by an almost three-fold increase in U.S. national health expenditures from \$255.7 billion dollars in 1980 to \$724.0 billion dollars in 1990 (Shi & Singh, 2012).

1990 – 2009: By the early 1990's this tenuous state of health care and health care economics, gave way to the introduction of President Bill Clinton's Health Security Act in 1993, the first attempt since Richard Nixon's Comprehensive Health Insurance Plan in 1973 (Blumenthal & Morone, 2010). However, the use of political outsiders to formulate his plan for universal coverage with little engagement of members of Congress

was not viewed favorably and thus, failed to receive significant Congressional support. The Clinton Administration's next attempt to provide health care coverage to a vulnerable group was successful passage of the State Children's Health Insurance Program (SCHIP) in 1997 (Blumenthal & Morone, 2010; Shi & Singh, 2012). Under President Bill Clinton, this bill was enacted to ensure that children of individuals considered to be the "working poor" would be eligible to receive health services which were unavailable to them through Medicaid. The working poor came to be defined as working parents who did not make enough to be able to afford the health plan offered through an employer, but made too much to be eligible for Medicaid (Shi & Singh, 2012). A large consequence of the "working poor" designation was that in 1996, one year before SCHIP was enacted, there were 10 million uninsured children in America (D. G. Smith, 2008)

Between 1990 and 2009, significant dollars flowed through agencies like the Centers for Disease Control and Prevention (CDC) to address specific diseases and medical conditions that disproportionately affected at-risk/vulnerable populations. Over that almost twenty year period the CDC budget increased from \$1 billion dollars in 1990 to \$10.0 billion in 2009 (Altman, 1990; CDC, 2009a). Through this increased funding significant investments were made in grant funded initiatives to support programs that addressed disparate care in illnesses such as cardiovascular disease, diabetes, hypertension, breast cancer in women, prostate cancer, HIV/AIDS, and increased rates of smoking (CDC, 2009b). Investments of this magnitude for these and other medical illnesses all of which impact at-risk/vulnerable populations at a disparate rate have fueled

many debates about the cost of health care and the need to reform the health care system to provide national health insurance coverage. The overall effect of these far reaching government investments was a political landscape that became inundated with opportunities for reform and overwhelmed with economic and financial failures that potentially left the system worse than it was before reform efforts. Therefore, movement towards some type of national system of health care similar to that of many European nations with lower cost per capita, higher life expectancy, and more stable health care delivery systems became a watershed moment of the 2008 Presidential Campaign and an imperative for the U.S. A timeline of health reform efforts in the U.S. from 1912 through 2009 as published by the Kaiser Family Foundation is presented below as Table 2-1.

2.1.2 The Patient Protection and Affordable Care Act of 2010

The next successful attempt to guarantee health care coverage to millions of uninsured U.S. citizens came in 2009 under President Barack Obama with passage of the Patient Protection and Affordable Care Act. In 2009, President Obama earnestly began his campaign commitment to bring about health care reform and to make health insurance coverage available for every American. On December 24, 2009, the U.S. Congress passed the Patient Protection and Affordable Care Act.

Signed into law on March 23, 2010 and also referred to as the Affordable Care Act (ACA), this law, while not without its political and economic critics, represents a sweeping change in the way that the American system of health care will operate in the future. An underlying tenet of the PPACA is that all eligible U.S. citizens will have access to quality, affordable health care. This means that health coverage will be

Table 2-1: Timeline of Major U.S. Health Reform Events 1912 – 2012

- **1912:** Endorsement of Social Security as a party platform including national health insurance (President Theodore Roosevelt)
- **1930-34:** Call for Social Policies to secure employment, retirement and medical care (President Hoover)
- **1935-1939:** Continued push for national health insurance following passage of SSA (President Franklin D. Roosevelt)
- **1940-1945:** 2 senators introduce legislation to operate health insurance , including provisions for universal comprehensive health insurance , as part of SSA (President Franklin D. Roosevelt)
- **1945-1949:** Post World War II mandate for national health insurance. Opposed due to fear of socialism and potential requirement for desegregation in the south (President Truman)
- **1950- 1954:** Various conferences and commissions convened to support reform of healthcare industry (Presidents Truman & Eisenhower)
- **1956 -1959:** Military Medicare enacted; legislation introduced to provide health insurance for SS beneficiaries (President Eisenhower)
- **1960 -1964:** Ground work for enactment of Medicare and Medicaid (Presidents Kennedy & Johnson)
- **1965-1969:** Medicaid and Medicare incorporated under the SSA (President. Johnson)
- **1970-1974:** Sen. Ted Kennedy proposes national health insurance; countered by President Nixon’s Comprehensive Health Care Plan (President Nixon)
- **1975-1979:** Sen. Kennedy introduces another national health insurance proposal (Presidents Ford and Carter)
- **1980-1984:** Various laws enacted to reform healthcare payment programs for cost control, equity, and efficiency (President Reagan)

- **1990- 1994:** Health Security Act – detailed plan sent to Congress calling for universal coverage, employer and individual mandates, competition between insurers, and government regulation to control costs. (President Clinton)
- **1995 -1999:** HIPAA, Personal Responsibility and Work Opportunity Act (TANF) (President Clinton)
- **2000 -2008:** Expansion of various government funded programs to cover more preventive care services; Medicare Part D goes into effect. (President George W. Bush)
- **2009 - Present:** Health Care Reform takes a new turn:
 - **2009:** President Barack Obama introduces sweeping health reform legislation to congress
 - **2010:** President Obama’s health reform program, the Affordable Care Act passes congress
 - **2011:** States immediately begin to challenge the constitutionality of several features of the law
 - **2012:** Supreme Court rules that only one component of the law is unconstitutional
 - Mandate requiring states to expand Medicaid are struck down
 - Individual Mandate is upheld

Source: Henry J. Kaiser Foundation (K. F. Foundation, 2009)

available to 94% of U.S. citizens and extend to almost 40 million nonelderly uninsured individuals (Elmendorf, 2010) . Through nine distinct titles the PPACA addresses all of the essential components of health care that represent the backbone of reform. Several titles address issues of workforce development, program transparency, medical therapies,

revenue provisions and other system related reforms. Two of those titles have components that directly impact consumers including uninsured and at-risk/vulnerable populations. Those two titles and the components of each that relate to uninsured and at-risk/vulnerable populations are presented in Table 2-2.

While at-risk/vulnerable populations will benefit greatly from the PPACA, it was not intended to improve the health care of vulnerable and uninsured persons alone. It is important to note that while the PPACA presents distinct areas of focus that impact the delivery of health care services to all U.S. citizens, the Act "... preserves the current private-public system of employer-based coverage, and [preserves] Medicare and Medicaid..." (CWF, 2010).

Many of the immediate improvements in quality and affordable care eminent from health insurance market reforms that began in 2010 and impact all U.S. citizens, including at-risk/vulnerable and uninsured populations (Committee, 2010; Congress, 2010; Goodwin, 2010). A summary of those reforms is presented in Table 2-3.

These reforms will have the combined effect of creating a more improved health care environment for access to quality, affordable health care. However, the reform feature that bans the denial of health insurance coverage for pre-existing conditions will be especially important for vulnerable individuals with medical conditions for which they have never sought care. In a survey of uninsured adults, 40% of whom will be eligible for subsidized premiums, Cunningham reports that over a one year period, 65.7% did not get, or delayed getting, needed medical care, generally for chronic medical conditions

such as diabetes, hypertension, heart disease, and cancer. Additionally, 57% reported problems paying medical bills (Cunningham, 2010). Thus, removing the previous ban on

Table 2-2: Titles and Essential Components of the PPACA with Direct Impact on Uninsured and At-risk/vulnerable populations

| Title and Description | Essential Components |
|--|---|
| Title I: Quality, Affordable Health Care for All U.S. citizens | <ul style="list-style-type: none"> • Elimination of lifetime and unreasonable limits on benefits • Assistance to those uninsured because of pre-existing conditions with later requirements to cover all pre-existing conditions for children and adults • Required coverage of preventive services • Dependent coverage extended to age 26 • Caps on insurance company non-medical, administrative expenses • Prohibition on rescission of health insurance policies |
| Title II: The Role of Public Programs | <ul style="list-style-type: none"> • Expansion of Medicaid programs • Website enrollment for public health care programs • Maintaining CHIP income eligibility levels through 2019 |
| Title IV: Prevention of Chronic Disease and Improving Public Health | <ul style="list-style-type: none"> • Development of school based health clinics • Oral health care prevention education campaigns • Require Medicaid coverage for counseling and pharmacotherapy to pregnant women for cessation of tobacco use • Incentives for Medicaid recipients for participation in health lifestyle programs. |

Source: (Committee, 2010)

Table 2-3: Summary of Health Insurance Market Reforms under the PPACA

| Population Affected | Reform Feature |
|--|--|
| Protection for all U.S. citizens: | <ul style="list-style-type: none"> • Insurance companies banned from rescinding coverage when people get sick • Ban on yearly and life-time caps on coverage • Provision of free preventive care services |
| Protection for Children: | <ul style="list-style-type: none"> • Ban on denial of coverage for pre-existing conditions • Expansion of coverage for children under their parents insurance policies until age 26 |
| Protection for Adults: | <ul style="list-style-type: none"> • Ban on denial of health coverage for pre-existing conditions (2014) |
| Medicare Recipients: | <ul style="list-style-type: none"> • Medicare Doughnut Hole rebates: Medicare recipients to receive \$250 rebate once they hit the Part D R_x Drug coverage gap |
| Vulnerable and Uninsured Populations: | <ul style="list-style-type: none"> • Access to Care for at-risk/vulnerable populations: Eligible U.S. citizens presently uninsured will be enrolled in a national program of health insurance similar to that operating in many European countries • Community Health Centers and National Health Service Corp to receive funding to serve more low-income and uninsured individuals |
| Insurance Carriers: | <ul style="list-style-type: none"> • Annual review of insurance premium increases require submission to DHHS and relevant state agencies for justification for premium increases • Report share of premiums spent on non-medical costs • Ban on medical underwriting and pre-existing condition exclusions • Prohibited from denying coverage or setting rates based on gender, health status, medical condition, claims experience, genetic information, evidence of domestic violence, or other health-related factors |
| Companies and Small Businesses: | <ul style="list-style-type: none"> • A reinsurance program will help offset the costs of premiums for employers providing retiree health benefits • Small businesses offering health care benefits will be eligible for tax credits |

Source: (Committee, 2010; Congress, 2010; Goodwin, 2010)

health coverage for pre-existing conditions will ensure that many vulnerable and at-risk/vulnerable groups will be able to seek care for medical problems that have impacted their overall health status for many years.

The most far reaching component of the PPACA that relates specifically to at-risk/vulnerable and uninsured populations is the establishment of HIEs. For the first time ever in this country's history a government entity will be tasked with guaranteeing health insurance coverage for millions of uninsured eligible individuals. This is particularly important for at-risk/vulnerable populations who have not had access to the care and services needed to improve their health status due to either an inability to afford health insurance coverage, or ineligibility to participate in publicly funded health care programs. Thus, after almost 100 years of trying to reform the U.S. health care system, the passage of the Patient Protection and Affordable Care Act of 2010 serves as the backdrop against which the U.S. officially moves towards a near universal system of health coverage that includes at-risk/vulnerable populations and the uninsured.

2.1.3 Economics of the U.S. Health Care System

Throughout America's journey towards health reform many factors have led to a progressively more costly and exclusionary system. Those factors have been described as social, economic, medical, and technological in nature (Ginsburg, 2008; Shi & Singh, 2012). Table 2-4 categorizes and presents major factors which have contributed to a costly system of care that has traditionally excluded at-risk/vulnerable populations and the uninsured.

In addition, a lack of political will to address a sector of the economy that continued to grow at a rate that outpaced inflation adds a political dimension to the mix of factors that have increased the cost of health care in America. In a 2008 report on soaring health care costs, the Democratic Policy Committee recognized that “Eight years of inaction contributed to high health care costs and a rising number of uninsured” (Committee, 2008).

The convergence of all of these factors set America on the brink of bankruptcy for two of its major health care entitlement programs with components that support at-risk/vulnerable groups – Social Security and Medicare. Medicare is the nation’s health insurance program for elderly individuals and retired persons age 65 and older and for certain vulnerable groups such as disabled adults and children, and individuals with end-stage renal disease. Almost from its inception, the Hospital Insurance (HI) trust fund has faced a projected shortfall. The insolvency date has been postponed a number of times, primarily due to legislative changes that have had the effect of restraining growth in program spending.

A major goal of the PPACA is to contain costs. The cost of health care in the U.S. has risen by more than \$2.4 trillion in the past 48 years since the passage of Medicare and Medicaid, the first two publicly funded health care programs. Over that same time period, the average cost per capita has risen by \$7,835 (Shi & Singh, 2012).

Table 2-4: Factors leading to a High Cost, Exclusionary System of Care

| Category | Factor |
|----------------------|--|
| Social | <ul style="list-style-type: none"> • increases in the number of uninsured individuals • increases in the numbers and kinds of vulnerable groups • increases in the number of aging individuals and in the number of years they can be expected to live • increases in the number of individuals enrolled in publicly financed health programs |
| Economic | <ul style="list-style-type: none"> • increases in the cost of government funded health care programs • increases in the cost of employment based health insurance plans • increases in the overall cost of care • changes in the structure of delivery systems such as acquisitions, mergers, and closures |
| Medical | <ul style="list-style-type: none"> • increases in the prevalence and incidence of chronic diseases in almost all age groups and particularly in at-risk/vulnerable populations • decreases in primary and preventive care services • the proliferation of managed care systems and other forms of service delivery • issues associated with defensive medicine, medical malpractice liability, and tort reform • increases in the cost of drugs, pharmaceuticals and the use of durable medical equipment • advances in medical care leading to more specialized procedures. |
| Technological | <ul style="list-style-type: none"> • advances in medical technology and technology related services |

Source: (Shi & Singh, 2012)

In a 2008 report on soaring health care costs, the Democratic Policy Committee noted that:

“Skyrocketing health care costs – including insurance premiums, co-payments and prescription drugs– are contributing to the current economic crisis, weighing heavily on family, business,

and government budgets. Inherited flaws in our health care system have led to higher health care costs, reduced access to care, and inconsistent quality of care throughout the country ” (Committee, 2008).

In addition, real per person spending on health care has increased rapidly, rising over 40 percent in the past decade alone. In 2011, the U.S. spent a total of \$2.7 trillion on health care, which represented \$8,680 per person or 17.9% of GDP. (CMS, 2011). This is more than twice the average of other industrialized member nations in the Organization for Economic Cooperation and Development (OECD) (Anderson & Frogner, 2008).

Growth in U.S. national health care expenditures can also be examined from the standpoint of cost per capita. Data on cost per capita has been captured since 1960 the first year that statistics on national health care expenditures were collected (Shi & Singh, 2012). Even if the difference in per capita expenditures between 1960 and 1970 were annualized to arrive at an estimate for the cost per capita using the year that Medicare and Medicaid were enacted (1965) as a base, the U.S. amount per capita has increased by \$7835 in the 48 years since the passage of the first major government financed health care programs (see Table 2-5).

In combination, factors such as increased numbers of vulnerable and uninsured individuals, increases in the cost of government financed health care programs, higher costs as a result of advances in technology, and changes in the structure of delivery systems including acquisitions, mergers and closures, have paved the way for economic consideration of health reform in the U.S. In the absence of health reform, studies have

shown that sustained increases in national health care expenditures and per capita amounts could increase national health expenditures as a percent of GDP to as much as 19.8% by the year 2020 (Keehan et al., 2011).

Increases in Incidence and Prevalence of Chronic Disease

The incidence and prevalence of chronic diseases among at-risk/vulnerable populations has been on a steady rise. Research has found that:

- among U.S. citizens, seven out of 10 deaths each year are from chronic diseases;
- In 2005, almost one out of every two adults had at least one chronic illness;
- Health disparities in chronic disease incidence and mortality are widespread among members of racial and ethnic minority populations; and
- When compared to Whites, African-American U.S. citizens have a higher rate of death from heart disease; and American Indians and Alaska Natives have substantially higher rates of diabetes
- More than 75% of the nation's health care spending is on people with chronic conditions (CDC, 2009b).

A 2009 CDC report on the cost of chronic disease shows that between FY2000 and FY2009 more than \$755 billion dollars was spent to address chronic medical conditions known to disproportionately impact the health of at-risk/vulnerable populations (CDC, 2009b). Table 2.6 below shows the CDC's estimated price tag for chronic disease conditions. Diabetes, cardiovascular disease and stroke account for 57% (\$429 billion) of the \$755 billion dollars on chronic illnesses. It is generally known that with proper exercised, diet and lifestyle changes these illnesses can be prevented

Table 2-5: U. S. National Health Expenditures, Selected Years

| Year | Amount (in billions) | % of GDP | Amount per Capita |
|-------------------------------------|---------------------------------|-----------------|------------------------------|
| 1960 | \$27.3 | 5.2 | \$147 |
| 1965* | \$51.05 | 6.2 | \$251 |
| 1970 | \$74.8 | 7.2 | \$356 |
| 1980 | \$255.7 | 9.2 | \$1,110 |
| 1990 | \$724.0 | 12.5 | \$2,853 |
| 2000 | \$1,378.0 | 13.8 | \$4,878 |
| 2009 | \$2,486.3 | 17.6 | \$8,086 |
| * author annualized estimate | | | |

Source: Shi & Singh: Delivering Health Care in America, 2012)

In a 2010 Research Brief, the Center for Studying Health System Change reports that “ Almost 40% of uninsured people eligible to receive subsidies through the exchanges have chronic conditions or report fair or poor health...” (Cunningham, 2010). Thus, the PPACA’s emphasis on prevention could improve the health of millions of at-risk/vulnerable individuals who are disproportionately affected by these chronic illnesses.

Table 2-6: CDC Chronic Disease Price Tag

| The Chronic Disease Price Tag— Estimated Annual Direct Medical Expenditures* | |
|---|---------------------------------------|
| Cardiovascular disease and stroke** | \$313.0 billion in 2009 ⁴⁷ |
| Cancer | \$89.0 billion in 2007 ⁴⁸ |
| Smoking | \$96 billion in 2004 ^{***23} |
| Diabetes | \$116 billion in 2007 ⁴⁹ |
| Arthritis | \$80.8 billion in 2003 ⁵⁰ |
| Obesity | \$61 billion in 2000 ⁵¹ |

* Different methodologies were used in calculating costs.

** Includes heart diseases, coronary heart disease, stroke, hypertensive disease, and heart failure combined.

*** Average annual expenditure, 2001–2004.

(Source: CDC The Power of Prevention, 2009)

Increases in Health Insurance Premiums

Research shows that there is one additional factor that has contributed heavily to the financial and economic burdens of the U.S. health system, and that is the insurance industry. Unlike health insurance in many European countries which is controlled by the government through a national health insurance system or through regulated private insurance markets (Muennig & Glied, 2010), the American system of private health insurance has been largely unregulated on a national level. That liberty has extended to

its market operations, the kinds of health plans and services offered, and to the cost of premiums charged for those health plans (Fera, 2013; Shi & Singh, 2012). In his article entitled *Massachusetts Health Care Reform: The View from One Year Out*, Jonathan Gruber (2008) notes that expanding access to private health insurance would not have addressed the issue of health insurance coverage for at-risk/vulnerable populations in Massachusetts. He draws the conclusion that a private market with “high and variable premiums” and incomplete coverage would not be affordable for at-risk/vulnerable groups who do not have access to large employer pools or public insurance (Gruber, 2008). Gruber and others report that health reform that has led to coverage for over 500,000 uninsured and at-risk/vulnerable populations in Massachusetts could only have occurred through a program of subsidized premiums (Bigby, 2009; Gruber, 2008; Steinbrook, 2006).

The increased cost of health coverage has led to increased premium costs for both employers and employees leading to a large number of uninsured workers. Increases in the premium costs for employer sponsored plans often results in an increase in the employee portion of premiums accompanied by a decrease in benefits. This has led to an increase in the number of small businesses that can no longer afford to offer health insurance coverage and an increase in the number of working poor. In his article on small business health exchanges and the need for value in lower cost health plans, Jon Kingsdale (2012) is clear that the reason why small employers currently do not provide insurance for their employees is that “...cost is the main obstacle” (Kingsdale, 2012).

Covering the Cost of Health Reform

From an economics perspective, the Congressional Budget Office (CBO) and the Joint Committee on Taxation (JCT) estimate that "...[both pieces] of health reform legislation would produce a net reduction in federal deficits of \$143 billion over the 2010–2019 period as a result of changes in direct spending and revenues". That figure includes \$124 billion in net reductions from the health care and revenue provisions and \$19 billion in net reductions from the education provisions (Elmendorf, 2010).

Both the CBO and the JCT estimate that by 2019, the combined effect of enacting both bills would be a reduction in the number of nonelderly people who are uninsured by about 40 million (Elmendorf, 2010). These estimates suggest that millions of uninsured and at-risk/vulnerable groups will be eligible for insurance coverage as a result of the savings derived from both pieces of health reform legislation. This leaves it entirely possible for a health reform law to achieve near universal coverage for all U.S. citizens for the first time in U.S. history.

2.1.4 Massachusetts Health Care Reform

The PPACA was modeled after the Massachusetts Health Reform Act of 2006 (Ericson & Starc, 2012; Gruber, 2011). After decades of increasing health care costs, increasing numbers of vulnerable and uninsured individuals, increases in the state's contribution to publicly funded health insurance programs, and other health related issues that mirrored the problems faced by the nation, the state of Massachusetts enacted legislation to control health care costs. With bipartisan support the Massachusetts legislature responded with the passage of Chapter 58 of 2006: AN ACT PROVIDING

ACCESS TO AFFORDABLE, QUALITY, ACCOUNTABLE HEALTH CARE
(Massachusetts, 2006).

Massachusetts had traditionally experienced health care costs higher than the national average. Compared to a national rate of growth of 6.9% between 2000 and 2004, health care costs in Massachusetts increased by 7.4% for the same time period; and per capita expenditures in Massachusetts were at \$6,683 in 2004, as compared to \$5,283 nationally (Bigby, 2009). Massachusetts ranked 35th among other states for avoidable hospital use and costs, as measured by the Commonwealth Fund Scorecard on Health System Performance (Bigby, 2009). Average yearly spending on health insurance premiums in 2006 for a Massachusetts family totaled \$12,363, approximately \$1,000 over the national average of \$11,381 (Bigby, 2009). Leaders recognized that \$61 billion dollars could be saved between 2009 and 2020 by slowing the rate of increase of health care costs in Massachusetts by as little as 1% (Bigby, 2009). Coupled with a federal match of \$385 million dollars in jeopardy of being returned to the federal government by the CMS, Massachusetts embarked on a plan to provide subsidies to low-income individuals to purchase insurance (Gruber, 2008). CMS accepted the state's plan, and this marked the beginning of health reform in the State of Massachusetts.

The Massachusetts Health Reform law had at its core a mandate for all citizens of the state to have health insurance coverage (Bigby, 2009; Gruber, 2008; Steinbrook, 2006). Because it maintains an employment rate higher than the national average, the result is a higher number of employees covered through employer sponsored health plans (Gruber, 2008). Additionally, only about 9% of the nonelderly population is uninsured,

compared to a national rate of 18% (Gruber, 2008). At the time of its passage, based on an annual state survey, it was estimated that the average number of Massachusetts residents without health insurance coverage was 550,000. Using state estimates, the health reform plan was anticipated to provide coverage to approximately 515,000 (93.7%) at-risk and uninsured individuals, leaving only 6.3% (35,000) of the uninsured population without coverage (Steinbrook, 2006). In 2009, just two years into the Massachusetts health reform model, the rate of uninsured residents stood at 2.6%. Today, the State of Massachusetts has the lowest rate of uninsured residents in the nation.

Covering at-risk/vulnerable populations and uninsured individuals using subsidies to support the purchase of health insurance has made a significant difference in the number of at-risk individuals who have insurance coverage in Massachusetts. The state's Commonwealth Health Insurance Connector, designed to function as a HIE, was created to serve as a central purchasing pool for the sale of insurance at lower rates than non-group plans offered through the private market. The availability of subsidies through the HIE for families with incomes up to 300% of the federal poverty level (FPL) made insurance affordable. Even for the working poor, who could be expected to have incomes above the 300% FPL a limited coverage plan could be purchased at a cost of approximately \$200.00 per month for individuals (Gruber, 2008). The success of the Commonwealth Health Insurance Connector in providing subsidized care to at-risk/vulnerable populations and uninsured residents provides evidence that subsidized premiums can make a significant difference in the ability of vulnerability populations to afford health insurance coverage.

The overall success of the Massachusetts Health Reform Plan has manifested itself in residents reporting a medical home as a stable source of care with increases in preventive care and dental care visits. This is in contrast with individuals covered by public health insurance programs who have experienced barriers in access to primary care physicians and specialists (Bigby, 2009). Ericson and Starc (2012) also report that hospitalizations for preventable illnesses have decreased while increases have occurred in the number of outpatient visits (Ericson & Starc, 2012). With the exception of children's visits to the emergency room, overall emergency room visits have not shown the level of decrease expected over time; and the percentage of covered individuals with out-of-pocket expenses has decreased (Bigby, 2009; Ericson & Starc, 2012).

However, it must be pointed out that the Massachusetts plan has not been without criticism and studies have shown that there are lessons to be learned. The single most widely criticized aspect of the Massachusetts plan is its expansion of health insurance coverage while leaving reform issues associated with rising health care costs to be addressed later (Bigby, 2009; Ericson & Starc, 2012; Gruber, 2008; Holtz-Eakin, 2011; Steinbrook, 2006). Douglas Holtz-Eakin (Holtz-Eakin, 2011) contends that the Massachusetts "coverage first" approach encouraged large scale coverage of all residents without addressing costs and delivery system reforms. He further asserts that this approach has led to individuals "free riding" the system by purchasing health insurance coverage for a few months, engaging in expensive care, and then dropping coverage. The effect is a net loss of revenue when three to four months of premium payments fail to cover the total cost of care rendered during the period of insurance coverage. He also

suggests that the coverage first approach has increased state health program costs by 42% since 2006, increasing projected spending of \$725 million in 2009 by 10%. While issues related to the Massachusetts “coverage first, costs later” approach have produced problems for the state, the PPACA appears to have struck a balance with many coverage and delivery system reforms being undertaken at the same time.

In a June, 2011 report from the Robert Wood Johnson Foundation, Long, et al. (Long, Stockley, & Dahlen, 2011) present a synthesis of key findings from research on the impact of health reform in Massachusetts on non-elderly uninsured adults. Table 2-7 shows that strong gains in insurance coverage, lower rates of uninsurance, gains in access to care and improvements in the affordability of care have positively impacted non-elderly uninsured adults. Additionally, since implementation of health reform, research shows that while gains in the first year of reform were slow, gains have been made in subsequent years in access, use, and affordability of care by those same non-elderly adults (Long, et al., 2011).

Of all the gains made by the Massachusetts health reform initiative, it is reported across all data sources that the number of uninsured have been on a steady decline since its implementation. Using different survey instruments, the percent uninsured in Massachusetts in 2006, before implementation of reform was reported at 13.6% by the Current Population Survey (CPS) and 10.2 % by the National Health Interview Survey (NHIS). For that same year, the two surveys reported the U.S. percent uninsured at 20.2% and 19.8% respectively. In 2009, both surveys reported that the percent uninsured in Massachusetts had declined from 13.6 % to 5.9 % (CPS), and from 10.2% to 5.2%

(NHIS). Percent uninsured figures for the U.S. in 2009 were reported to increase from 20.2% to 22.3% by the CPS, and from 19.8% to 21.2% by the NHIS (Long, et al., 2011). Reducing the vulnerable and uninsured in Massachusetts by as much as 8% in year three of implementation during a recessionary period, while the national percent of uninsured continued to increase, does present some evidence that health reform can increase the insurance rate of at-risk and uninsured populations giving access and affordability that has not been available to these groups in the past.

Table 2-7: Key Findings - Impact of Massachusetts' Reform on Non-Elderly Adults

| |
|---|
| ✓ There have been strong gains in insurance coverage for non-elderly adults under health reform. |
| ✓ Over time, uninsurance in Massachusetts has been consistently much lower than in the nation broadly. |
| ✓ There is no evidence that the expansion of public coverage has led to the crowd-out of employer-sponsored coverage. |
| ✓ There is evidence of gains in access to and use of care under reform, although not across all measures. |
| ✓ There have been improvements in the affordability of care, particularly as measured by the share of adults forgoing care due to costs, although these improvements have tended to erode over time. |

Source: (Long, et al., 2011)

Lessons for national health reform based on Massachusetts findings have also been reported. Table 2-8 provides a synopsis of those lessons as presented by different researchers. There are many key elements of the Massachusetts health reform act that have contributed to a low rate of uninsurance among state residents including at-risk/vulnerable populations. Also, many of the same components of the Massachusetts

plan served as the model for the PPACA. Key among these are: 1) the individual mandate requiring every resident to have health insurance coverage; 2) creation of a HIE; 3) employer mandates to “play or pay”; 4) Medicaid expansion provisions; and 5) provision of subsidized premiums for eligible individuals.

The Massachusetts Health Reform Plan serves as possibly the best model we have for gauging the potential for the PPACA to meet its aims of expanding health coverage, and access to quality, affordable care, particularly for at-risk/vulnerable populations and uninsured U.S. citizens, with long term potential for lowering the cost of health care.

2.1.5 The WHO Call for Universal Health Coverage

On December 12, 2012, the United Nations General Assembly adopted a resolution urging governments to move towards providing all people with access to affordable, quality health-care services. This concept has been increasingly recognized since the World Health Organization (WHO) published its *World Health Report 2010*. That report, as well as other WHO publications, presented findings on health status and financing of health for its member countries dating back to the first WHO report on health in 2000. In doing so, reports show that the U.S. has not fared well for overall health ranking, and amenable mortality, which disproportionately impact at-risk/vulnerable populations.

From a global perspective in a comparison of total health expenditures as a percent of GDP for almost 200 member states, the WHO reports that from 2000 to 2010, U.S. health expenditures as a percent of GDP increased from 13.4% to 17.6% (WHO, 2013). In 2000, at 13.4 %, the U.S. was 7.8 percentage points (13.4 – 5.6) higher than the

200 states median value of 5.6% (WHO, 2013). In 2010, the U.S. was 11.1 % percentage points (17.6 – 6.5) higher than the median value of 6.5% (WHO, 2013).

Table 2-8: Lessons from Massachusetts Health Reform Initiative as Identified by Independent Researchers

| Source | Lesson |
|----------------------|---|
| (Long, et al., 2011) | <ul style="list-style-type: none"> • <i>Complex reforms can be carried out quickly and effectively:</i> a strong outreach and enrollment system can be implemented quickly and effectively, with a net result of significant gains in health insurance coverage and access to care • <i>The gains of reform can be sustained in a weak economy:</i> Massachusetts health reform gains have remained despite an economic downturn; uninsurance has remained historically low and employer sponsored insurance remains strong • <i>Increased coverage does not necessarily equal improved access, costs:</i> improved access initiatives took priority over addressing health care costs in 2006 to avoid as delay in expanding coverage; strategies to reduce costs are underway as reported in 2011 • <i>National Data Sources are limited for State Applications:</i> In current national surveys, state sample sizes are small, the range of issues limited, and lags in data availability affect timeliness in assessing impacts; improvement can be made using state representative samples, expanding content, releasing data more quickly, and developing a more uniform data collection effort to provide consistent data across states. |
| (Gruber, 2008) | <ul style="list-style-type: none"> • <i>New pooling mechanism for provision of insurance:</i> subsidized insurance premiums either through the government or private insurance pools is critical. In their absence carriers will be hesitant to offer insurance or will do so at high prices, fearing adverse selection and high-cost exposure. • <i>Affordability:</i> a substantial reduction in the number of uninsured will require large subsidies, with choices in coverage, premiums, and out-of-pocket expenses that are affordable thereafter. • <i>Mandates:</i> near universal coverage requires mandates to obtain some type of insurance coverage |

- ***The Power of Consensus:*** highly politicized HIE boards must be moved to consensus on critical decision making issues by executive leadership that understands and can delineate the positive and negative consequences of board action

A median GDP percentage change from 2000 to 2010 of 0.9% for all member states (6.5 – 5.6), and a U.S. GDP percentage change of 4.2% (17.6 – 13.4) for that same period, reveals that U.S health expenditures grew at a rate of more than four times that of health expenditures grew at a rate of more than four times that of the median value of 200 member states. This comparison presents evidence for how fast U.S. health care expenditures as a percentage of GDP have grown in a global context over ten years.

Also, in a global context, and relative to the 34 member OECD countries, in 2000, the U.S. spent \$4570 per capita on health care, more than double the mean value of approximately \$2068 for the 34 member countries. In 2010, US per capital spending on health care was reported to be \$7923, which was 58% higher than the median OECD per capita expenditure for all member countries of \$3330 USD (OECD, 2013)

Despite national health expenditures that are the highest percentage of GDP in the world, and per capita spending that is more than double the median expenditure of the 30 industrialized OECD nations, the United States ranks 37th in the world for overall health status (WHO, 2000). In their study of amenable mortality among 16 OECD nations, Nolte and McKee (2008) researched the causes of death considered amenable to health care and included selected childhood infections, treatable cancers, diabetes, cardiovascular and cerebrovascular disease, and hypertension, certain heart disease

conditions, and complications of common surgical procedures. Amenable mortality is defined as premature death in individuals aged 65 years and younger from causes that should not occur in the presence of timely and effective health care (CDC, 2004). It is estimated that in America more than 100,000 deaths occur each year from conditions that are preventable and treatable with access to timely, affordable and available health services (E. Nolte, McKee, M., 2008). Averaged over a ten year study period which reported on variations in amenable mortality in 16 of the most developed nations in the world (E. Nolte & McKee, 2011), that number is estimated to be over 1 million deaths in the U.S. Ranking 16 out of 16, this compares negatively to the other 15 developed nations who were also subjects of the report. Of those 15 developed nations, several have national systems of health insurance coverage. While amenable mortality fell in all countries, Nolte and McKee attribute the poor performance and relatively slow improvement for the U.S. as compared with other nations to “the lack of universal coverage and high costs of care” (E. Nolte, McKee, M., 2008).

Closer to home, Schoenbaum et al. reported that in America there are strong associations between poverty, race and amenable mortality rates at the state level (S. C. Schoenbaum, C. Schoen, J.L. Nicholson, & J.C. Cantor, 2011a). Their 2011 study showed “a more than twofold variation in amenable mortality rates across the country... [which] were strongly associated with the percentage of state populations that were poor or black”. (S. C. Schoenbaum, et al., 2011a). Using CDC Multiple Cause-of-Death data files, and U.S. Census population data, the authors noted that amenable mortality was lowest at 63.9 deaths per 100,000 people under the age of 75 in Minnesota, to highs of

142.0 in Mississippi, and 158.3 in the District of Columbia. Overall, higher rates of amenable mortality were found in the southern states. In addition, they found strong correlations between state rates of uninsured and lower rates of preventive care. The authors anticipate that the PPACA, through its enhanced coverage of at-risk/vulnerable populations could result in improvements in care for at-risk/vulnerable populations and amenable mortality data for the nation as a whole. However, many southern states have chosen not to establish State Based or State Partnership HIEs. Many have also elected not to expand their Medicaid programs. Both of these decisions could result in large numbers of at-risk populations in southern states remaining uninsured. A recent Kaiser Family Foundation report indicated almost 5.2 million non-elderly adults in four southern states and the state of Ohio will remain uninsured based on state decisions not to implement a Medicaid Expansion program. In Texas alone that decision will affect more than 1 million individuals, approximately 20% of the state population (H. J. K. F. Foundation, 2013f)

Finally, the *2006 National Health care Disparities Report* issued by the Agency for Healthcare Research and Quality (AHRQ) notes that many minorities are “...more likely than others to be diagnosed with late-stage breast and colorectal cancers, are disproportionately affected by diabetes and heart disease, and are more likely to die from HIV”, further noting that “disparities related to race, ethnicity, and socioeconomic status still pervade the American health care system” (E. Nolte & McKee, 2008). In a survey of 186 health care leaders between June 14 and July 20, 2011, the Commonwealth Fund/*Modern Health care Health Care Opinion Leaders Survey* found that “*Approximately*

eight of 10 leaders believe the U.S. health system has failed to achieve equity for at-risk/vulnerable populations on the specific domains of quality, access, and outcomes”.

The full report found that,

“...there are substantial disparities in health and health care for at-risk/vulnerable populations such as people with low incomes, the uninsured, and minorities. Ninety percent of respondents to the latest Commonwealth Fund/*Modern Health care* Health Care Opinion Leaders Survey think the current health system is unsuccessful in achieving equity on the whole, and approximately 80 percent feel it is unsuccessful in achieving equity in terms of access, quality, and outcomes for at-risk/vulnerable populations” (Stremikis, Berenson, Shih, & Riley, 2011).

In a rating of the U.S. health system’s achievement of equity for at-risk/vulnerable populations, the Common Wealth Fund reported that:

- Relative to quality, “or the extent to which care is effective and well-coordinated, safe, timely, and patient-centered”, 81% of health care leaders rated the U.S. system as very unsuccessful/unsuccessful
- Relative to access, “as measured by participation in the health care system and the affordability of insurance coverage and medical services”, 82 % of health care leaders rated the U.S. system as very unsuccessful/unsuccessful
- Relative to outcomes, “which include measures such as life expectancy, mortality, and prevalence of disability and limitations because of health”, 77% rated the U.S. system as very unsuccessful/unsuccessful. (Stremikis, et al., 2011).

2.1.6 Section Summary

Successes and failures over nearly 100 years of reform efforts have placed in context the enormity of the legislative efforts that led to signage of the PPACA in March of 2010. Equally significant is its potential to improve the health of all U.S. citizens, but most especially uninsured and at-risk/vulnerable populations who have not had the financial resources to navigate a complex system of health care. It is clear that issues associated with access, quality, affordability, disparities, and inequity in care all contribute to poor outcomes for these groups. This is also evident in the U.S. rankings of 37th in the world for overall health status, and 16th out of 16 for the highest rate of amenable mortality among OECD nations. Information gathered and synthesized from a myriad of different sources including the success of components of the Massachusetts Health Reform Plan that shaped the PPACA, suggests that access, quality, and affordable health care for at-risk/vulnerable groups is achievable through the PPACA. The next two literature review sections will explore the role of HIEs and HIE navigator programs in making improvements in health possible for at-risk/vulnerable populations.

2.2 Manuscript 1 Literature Review Section

This literature review for Manuscript 1 will address the establishment, design, and governance of State Based Health Insurance Exchanges.

To facilitate the entry of millions of uninsured U.S. citizens into the insurance market, the Patient Protection and Affordable Care Act (PPACA) calls for the establishment of Health Insurance Exchange (HIE) marketplaces (Bloombreg, 2012; CMS, 2012, 2013a; Congress, 2010; DHHS, 2012b). Under the law, states can choose to

implement one of three HIE models: a State Based HIE, a State Partnership Exchange, or a Federally Facilitated Exchange (DHHS, 2012a, 2012c). This review will examine those three models and the requirements for the establishment of each as set forth by federal mandate. This will include the federal rules and regulations under which they will operate and the mandated functions they are required to carry out. The Department of Health and Human Services (DHHS) serves as the designated Executive Branch agency tasked with establishing and promulgating rules, regulations and guidance associated with the establishment of all HIEs (DHHS, 2012c) . Specific guidance from the DHHS has been handed down on the establishment of HIEs, on HIE functions mandated by federal statute, and on HIE business model and governance (DHHS, 2012b, 2012c). Additionally, guidance has been provided on the development of programs to reach uninsured and at-risk/vulnerable populations, including the mandate to contract with community organizations to carry out navigator activities. However, while HIE establishment is mandated by federal statute, their design, governance structure/business model, and make up of their governing boards have been left to the discretion of each state. The specific state legislative actions regarding these elements will be presented in this literature review.

HIE marketplaces have operated in many European countries for decades, and have been a part of the State of Massachusetts health reform effort since 2006. For that reason, HIE establishment and design in these markets will be reviewed for lessons to be learned. Finally, while created by state law, State Based HIEs are required to carry out mandated functions that are tied to the goals of a federal law. This includes contracts

with external agencies such as community based organizations (CBOs), and non-profit and consumer advocacy agencies to serve as navigator programs. Thus, the potential exists for failures within the HIE or with its contracted agencies to impact the delivery of services. To address this possibility the concept of systemic risk which examines the dependence of government entities on external contract agents will be explored.

2.2.1 Establishment of Health Insurance Exchanges

The Patient Protection and Affordable Care Act signed into law on March 23, 2010 by President Barack Obama mandates the establishment of HIEs in all states and the District of Columbia (Congress, 2010). In general, the purpose of a HIE is to serve as a public market for the purchase of affordable non-group health insurance plans (CMS, 2012). More specifically, the DHHS defines an Exchange as: "... a competitive organized marketplace to help consumers and small businesses buy health insurance in a way that permits easy comparison of available plan options based on price, benefits, and quality" (DHHS, 2012b; DHHS, et al., 2012d).

Funding Health Insurance Exchanges

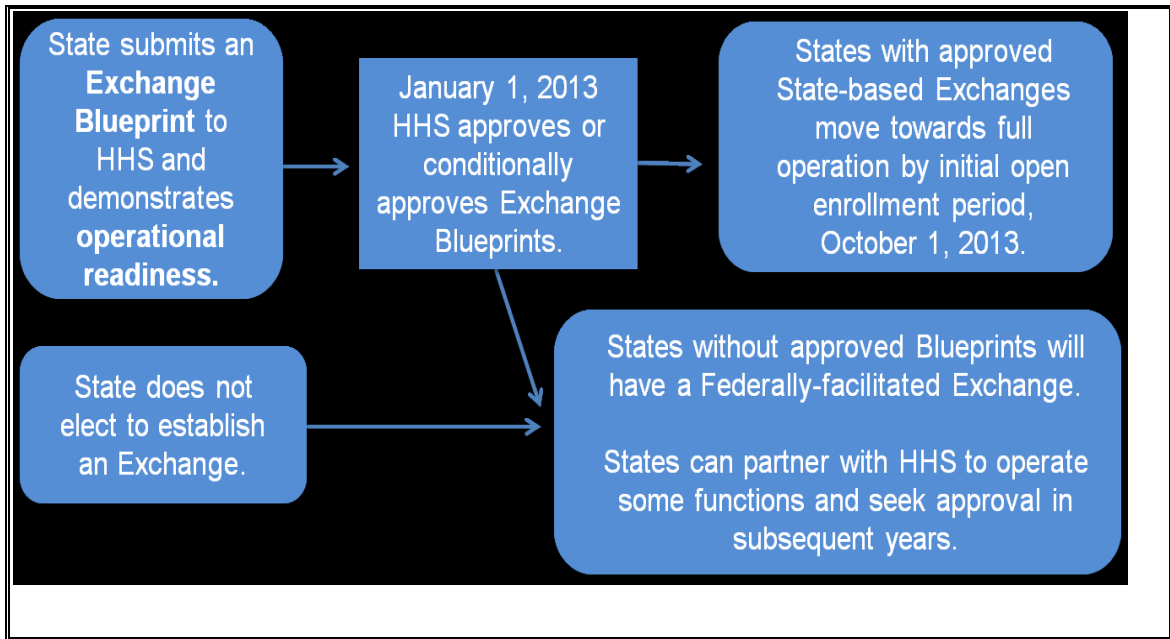
Meeting the goals of the PPACA, for expanding health coverage and ensuring access to quality, affordable health care, will depend on all states and the District of Columbia implementing HIE's which are expected to begin enrollment of eligible individuals on October 1, 2013 (DHHS, 2012b). To help achieve these goals, the DHHS has made available approximately \$3.6 billion dollars over the past three years to states to support planning, establishment, and implementation of State HIEs (H. J. K. F. Foundation, 2013a). In a phased approach under the funding opportunity *Cooperative*

Agreement to Support Establishment of the Affordable Care Act's HIEs (Funding Opportunity Number: IE-HBE-12-001 CFDA: 93.525), funding grants provided states with assistance for initial planning activities related to implementation of their Exchange (DHHS, et al., 2012d). Level One Establishment Grants were available to all states regardless of the type of Exchange being implemented. Initial planning activities under Level One Establishment funding focused on nine core areas: 1) Background Research; 2) Stakeholder Involvement; 3) Governance; 4) Program Integration; 5) Regulatory/Legislative Actions; 6) Technical Infrastructure; 7) Finance; 8) Resources and Capabilities; and 9) Business Operations. The DHHS awarded Level One Establishment grants to 48 states and the District of Columbia on September 30, 2010.

Level Two Establishment grant funding was available only to states choosing to implement a State Based Exchange. With a focus on marketplace planning and implementation activities, 12 states and the District of Columbia indicated their intent to operate State Based Exchanges in their initial FOA responses and, in conjunction with their Level One Establishment grant funding, were awarded Level Two funding as well. Subsequent Level Two Establishment funding was made available to those states that later declared their intent to establish State Based Exchanges. (DHHS, et al., 2012d; H. J. K. F. Foundation, 2013a). A flow chart indicating the sequence of actions for establishment and approval of Exchange plans developed with the support of Level One or Level Two Establishment Grant funding is provided below as Figure 2-1.

Health Insurance Exchange Models

The PPACA authorized the establishment of two HIE models: a State Based Exchange model, and a Federally Facilitated Exchange model (Bloomberg, 2012; CMS, 2012; Congress, 2010). The DHHS is directed by law to establish a Federally Facilitated Exchange (FFE) in any state that does not declare in writing an intent to establish a State Based Exchange (Congress, 2010). The deadline for a Declaration Letter to operate a State Based Exchange was December 14, 2012 (CMS, 2013d). In any state where there will not be an operational State Based Exchange in place by January 1, 2014, the DHHS is required to set up a Federally Facilitated Exchange (DHHS, 2012b). On January 2013, the DHHS issued new guidance on the establishment of a State Partnership Exchange or hybrid model (CMS, 2013a). This hybrid model was established to help states with mandated functions that they are currently challenged to implement due to resource constraints or capacity issues. The application deadline for establishing a State Partnership Exchange was February 15, 2013. Rules, regulations and ongoing guidance concerning the establishment of HIEs are the responsibility of the DHHS to promulgate.



Source: (CMS, 2012)

Figure 2-1: Exchange Establishment and Approval Flow Chart

HIEs are intended to provide a public marketplace for the purchased of health insurance plans mainly by at-risk/vulnerable and uninsured non-elderly individuals. This would include individuals who do not qualify for public health insurance programs such as Medicaid, SCHIP, or Medicaid Expansion in the case of those states that implement an expanded Medicaid program. According to the DHHS, “by pooling people together, reducing transaction costs, and increasing price and quality transparency, Exchanges are designed to create more efficient and competitive health insurance markets for individuals and small employers” (DHHS, et al., 2012d). Thus, how states establish and design their HIEs is critical to their success (Merlis, 2009).

State Based Exchange models: Through the establishment of State Based HIEs, states have the unique opportunity to impact insurance affordability, access to care, and the provision of services to vulnerable and uninsured populations. Key to this opportunity is the design of state Exchanges, in particular their governance and operating structures. Under the PPACA, states have been given three options for the establishment of State Based Exchanges. Exchanges can be established as newly created entities; as entities within existing state government agencies; as non-profit organizations; or as multi-state regional agencies (Bloombreg, 2012; DHHS, 2012a; Jost, 2013; Kingsdale & Bertko, 2010; Van de Water & Nathan 2011). Sixteen states and the District of Columbia have passed legislation creating their State Based Exchanges (H. J. K. F. Foundation, 2013a). A list of those states officially submitting Declarations Letters to implement State Based Exchanges as of May 13, 2013 are shown in Table 2-9.

A state's choice to create its own Exchange allows significant flexibility in its Exchange design, business model, governance structure, and management framework. It also allows states the flexibility they need in designing programs to address the unique needs of their at-risk/vulnerable communities. While DHHS has provided guidance on the kinds of activities that must have stakeholder involvement, states electing to implement State Based HIE's are able to maintain control of processes for identifying and selecting CBO's, non-profit agencies, and consumer advocacy agencies to carry out certain mandated functions.

Federally Facilitated Exchange models: The PPACA provides for the federal government to operate an insurance Exchange, known as a Federally Facilitated

Exchange, in any state choosing not to establish a State Based Exchange (Congress, 2010; DHHS, 2012b). For states choosing to default to a Federally Facilitated Exchange, HHS will structure the Exchange so that state knowledge and expertise can be integrated into the Exchange to the greatest extent possible. In doing so, the DHSS has indicated they will work with states to “preserve the traditional responsibilities of State insurance departments when establishing a Federally Facilitated Exchange ... [and will work in concert] to harmonize Exchange policy with existing State programs and laws wherever possible” (DHHS, et al., 2012d). Under Federally Facilitated Exchanges, states will continue to maintain responsibility for approving qualified health plans to be offered in their state through the Federally Facilitated Exchange (DHHS, et al., 2012d).

By choosing not to establish their own State Based Exchange, states with Federally Facilitated Exchanges relinquish much of their control over the operating functions of the Exchange to the federal government. This includes the kinds of agencies and organizations chosen to support navigator functions, and how certain other mandated contractual activities will be managed. States choosing to default to a Federally Facilitated Exchange have been largely governed by Republicans.

Table 2-9: States Issuing Declaration Letters to Establish State Based Health Insurance Exchanges as of May, 2013

| <i>State</i> | <i>Declaration Date</i> | <i>State</i> | <i>Declaration Date</i> |
|-----------------------------|-------------------------|---------------|-------------------------|
| California | July 10, 2012 | Massachusetts | July 10, 2012 |
| Colorado | October 8, 2012 | Minnesota | November 15, 2012 |
| Connecticut | July 12, 2012 | Nevada | December 14, 2012 |
| District of Columbia | November 15, 2012 | New Mexico | December 13, 2012 |
| Hawaii | June 7, 2012 | New York | November 15, 2012 |
| Idaho | December 14, 2012 | Oregon | July 6, 2012 |
| Kentucky | November 14, 2012 | Rhode Island | July 5, 2012 |
| Maryland | October 9, 2012 | Vermont | July 9, 2012 |
| | | Washington | July 10, 2012 |

Source: (CMS, 2013d)

State Partnership Exchange models: State Partnership Exchanges represent a hybrid Exchange model. They are based on Federally Facilitated Exchange models where states have accepted responsibility for a particular component of the Exchange, leaving other components to the federal government for development and implementation (Kaiser Family H. J. K. F. Foundation, 2013a). In its guidance on the establishment of State

Partnership Exchanges, DHHS has outlined various options that states have to provide input on the establishment of their Partnership Exchanges, and as a result a variety of partnership options have evolved. One of the first hybrid models to be approved by the DHHS was for the State of Utah. Under its Exchange model, Utah has requested to be allowed to operate its Small Business HIE, turning over the Individual Exchange to the federal government (Norman, 2013). Other states have elected to turn over their Information Technology mandated components to the government for implementation due to the resource and capacity constraints associated with making eligibility requirements across all government programs available through a Web portal (Kaiser Family H. J. K. F. Foundation, 2013a). Researchers agree that DHHS acceptance of this model for implementing a State Partnership Exchange is representative of their willingness to cooperate fully with those states that have limitations in implementing all of the functional aspects of an Exchange.

DHHS views partnership Exchanges as stepping stones to the establishment of State Based Exchanges when and if state resources and capabilities permit. With an expectation that states be actively involved in Partnership Exchange operations, DHHS guidance states:

“A State Partnership Exchange enables a state to ...continue to play a primary role in interacting with issuers and consumers in the state, and make recommendations as to how local market factors should inform the implementation of Exchange standards” (DHHS, et al., 2012d).

As of May 2013, seven states had submitted Declarations of Intent to the DHHS to establish State Partnership Exchanges. Those seven states are: Arkansas, Delaware, Illinois, Iowa, Michigan, New Hampshire, and West Virginia. Utah's exchange represents a specially structured partnership which does not adhere to DHHS guidance.

Health Insurance Exchange Mandated Functions

Whether State Based, Federally Facilitated, or State Partnerships, DHHS has handed down specific functions that all HIEs are required to comply with. Many of these functions are directed at promoting competition among health insurance issuers, increasing consumer choice relative to the number of plans offered and the benefits associated with each, ensuring transparency on the cost and quality of plans, and promoting enrollment, eligibility determination and information availability to eligible individuals. Table 2-10 offers a summary of these functions.

DHHS guidance allows for many of these functions to be contracted out by the Exchange (CMS, 2012). Thus, state control over the type of Exchange they will establish is important to managing many of the contractual arrangements that are allowable, and that will likely be put into place.

Health Insurance Exchange Qualified Health Plans

According to the law, by 2014, all states and the District of Columbia are required to establish HIEs and to offer state approved qualified health plans that offer a minimum set of benefits (CMS, 2013c; Committee, 2010; Congress, 2010; DHHS, 2012a, 2012b). The PPACA mandates that state HIEs must offer health insurance that is available and affordable to all eligible individuals through state approved qualified health plans

(DHHS, 2012a). A qualified health plan offered through the new Exchange must provide a set of minimum essential health benefits (CMS, 2013c; Corlette, Lucia, & Levin, 2013). There are ten categories of essential health benefits that will go into effect for new plans both inside and outside of the Exchange effective January 1, 2014. The minimum essential health benefits categories mandated to be a part of those plans are presented in Table 2-11. Additionally, HIEs must also offer a catastrophic health plan for purchase by young healthy adults, as well as four tiers of private health plan coverage – Bronze, Silver, Gold and Platinum - based on actuarial values.

In addition to the approved HIE health insurance plans, essential health benefits are expected to be included in health plans that will cover of up to 68 million U.S. citizens by 2016 (Corlette, et al., 2013). Plans participating in Exchanges must be accredited for quality, and must present their benefit options in a standardized manner for easy comparison based on DHHS guidance. Additionally, all Exchanges will use one, simple enrollment form (CMS, 2012). These and other requirements associated with state approved qualified health plans could simplify the choice of a state approved health insurance plan for vulnerable and at-risk/vulnerable groups particularly those with literacy, educational, and cultural barriers.

In addition to the approved HIE health insurance plans, essential health benefits are expected to be included in health plans that will cover of up to 68 million U.S. citizens by 2016 (Corlette, et al., 2013). Plans participating in Exchanges must be accredited for quality, and must present their benefit options in a standardized manner for easy comparison based on DHHS guidance. Additionally, all Exchanges will use one,

simple enrollment form (CMS, 2012). These and other requirements associated with state approved qualified health plans could simplify the choice of a state approved health insurance plan for vulnerable and at-risk/vulnerable groups, particularly those with literacy, educational, and cultural barriers.

The DHHS has put in place stringent requirements for the participation of insurance issuers who want to sell state approved qualified health plans through HIEs. Issuers must meet certification standards in ten standards areas, each with a minimum set of criteria to be met. Table 2-12 list the Certification Standards that must be met by all insurers when offering health plans through state HIEs.

Table 2-10: Summary of Select Mandated Health Insurance Exchange Functions

| <i>Functional Category</i> | <i>Functional Activity</i> |
|---|--|
| Administration: Administer a system of qualified health plans | <ul style="list-style-type: none"> • Certify plans that are qualified to participate in the HIE • Rate plans based on their quality and price • Review plans' premium increases |
| Consumer Support: Support enrollment in health plans and assist consumers | <ul style="list-style-type: none"> • Facilitate initial, annual, and special open enrollment periods for individuals • Facilitate participation by small businesses in a separate Small Business Health Options Program (SHOP) Exchange or a single unified Exchange • Maintain a website that provides standardized information on the price and quality of health plans • Operate a toll-free telephone assistance line • Establish a system of Navigators, entities that will conduct consumer education activities and facilitate enrollment in qualified health plans |
| Assistance Determination: Determine eligibility for assistance in obtaining health insurance | <ul style="list-style-type: none"> • Determine which participants are eligible for premium tax credits and cost-sharing subsidies • Assure that eligible applicants are enrolled in the appropriate public health program or private plan; Certify exemptions from the requirement for individuals to maintain health insurance coverage and from the penalty for failing to meet the requirement |
| Community Engagement: Consult with relevant stakeholders with regard to carrying out these activities. | <ul style="list-style-type: none"> • Develop and implement a stakeholder consultation plan • Provide culturally and linguistically appropriate outreach, educational materials to the public, including auxiliary aids and services for people with disabilities • Maintain an outreach plan for stakeholder populations including: individuals, entities with experience in facilitating enrollment such as agents/brokers, small businesses and their employees, employer groups, health care providers, community-based organizations, Federally-recognized Tribal communities, advocates for hard-to-reach populations, and other relevant populations as outlined in 45 CFR § 155.130. |

Source: (DHHS, et al., 2012d; Goodwin, 2010; Martin, 2013; Van de Water & Nathan 2011)

**Table 2-11: Categories of Essential Health Benefits for Health Plans Effective
January 1, 2014**

| | <i>Benefit Category</i> |
|------------|---|
| 1. | Ambulatory patient services |
| 2. | Emergency services |
| 3. | Hospitalization |
| 4. | Maternity and newborn care |
| 5. | Mental health and substance use disorder services including behavioral health treatment |
| 6. | Rehabilitative and habilitative services and devices |
| 7. | Prescription drugs; |
| 8. | Laboratory services |
| 9. | Preventive and wellness services and chronic disease management |
| 10. | Pediatric services, including oral and vision care |

Source: (CMS, 2013c; Corlette, et al., 2013)

Table 2-12: Qualified Health Plan Certification Standards

| To participate in an Exchange, a health insurance issuer must meet the following minimum criteria: | |
|---|---|
| Licensure | Licensed and in good standing in each State in which it intends to offer QHPs |
| Solvency | Meets State financial and solvency standards. |
| Marketing | Complies with all applicable State law governing marketing of health plans. |
| Benefit designs | Does not employ benefit designs discouraging enrollment by higher-need consumers. |
| Rate and benefit reporting | Provides information on rates and covered benefits, and submits a justification for any rate increases. |
| Network adequacy | Maintains provider networks that are sufficient in number and types of providers to assure that all services will be accessible without unreasonable delay. |
| Accreditation | Receives accreditation for QHPs within a timeframe specified by the Exchange. |
| Essential community providers | Includes in the provider network essential community providers, that serve low-income and medically-underserved populations. |
| Service area | QHP issuers cannot establish service areas that are discriminatory. |
| General Process | Complies with any additional standards and processes established by an Exchange. |

Source: <http://www.cms.gov/CCIIO/Resources/Files/Downloads/hie-overview-presentation.pdf>. (CMS, 2012)

2.2.2 The European Health Insurance Marketplace

HIEs are not a new concept in the provision of affordable health coverage. Several European countries have successfully integrated HIEs into their national health insurance programs, the result being that almost 100% of citizens, including identified at-risk/vulnerable populations have health coverage (Enthoven & van de Ven, 2007; R. Kreier, Zweifel, Peter, 2010; Reinhardt, 2004; Van Ginneken & Swartz, 2012; Van Ginneken, et al., 2013). However, a near universal program offering affordable health insurance coverage on a national level for all U.S. citizens represents a new chapter in this country's quest to reform its health care system. Understanding how HIE marketplaces have operated in European health care markets and acknowledging lessons to be learned could inform decisions on their function and operation in the U.S. on a national level.

European countries that have regulated HIEs or elements of Exchange marketplaces include: Belgium, the Czech Republic, Germany, the Netherlands, Slovakia and Switzerland (Van Ginneken, et al., 2013). The Exchange markets in these countries operate risk-bearing, sickness funds that allow individual citizens to periodically choose their health plan (Van Ginneken, et al., 2013). However, researchers have reported that the Swiss and Netherland models are similar in offering many of the components that are required by the PPACA, including the establishment of HIEs and risk adjustment programs (Enthoven & van de Ven, 2007; R. Kreier, Zweifel, Peter, 2010; Reinhardt, 2004; Van Ginneken & Swartz, 2012; Van Ginneken, et al., 2013). Both countries rely heavily on private insurers to create managed competition in their

insurance markets. Similar to the mandates of the PPACA, both of these European countries have: 1) a mandate for citizens to purchase insurance; 2) require their insurance markets to have standardized benefit plans including a basic health plan; 3) provide premium subsidies for low income citizens; and 4) have markets where citizens have a choice of insurers. In the Swiss market, basic health plans cannot reject an applicant for coverage, thus ensuring coverage of all individuals regardless of ability to pay. Similarly, in the Dutch market, insurers cannot reject an applicant, and in addition, the government covers all health costs incurred by children. (Enthoven & van de Ven, 2007; Reinhardt, 2004; Van Ginneken & Swartz, 2012; Van Ginneken, et al., 2013). In both markets, risk adjustment to offset the costs associated with high risk enrollees is managed through a central fund which reimburses insurance companies based on the risk profiles of enrollees (R. Kreier & Zweifel, 2010-2011; Van Ginneken, et al., 2013). This is an important concept as the U.S. struggles with the issue of adverse selection and how to develop risk adjustment compensation models to equalize costs incurred by insurers who could enroll a higher number of at-risk individuals with medical conditions that have gone untreated due to a lack of insurance.

Health reforms such as those mentioned above were implemented in 1996 in Switzerland and in 2006 in the Netherlands allowing sufficient time for lessons from both health systems to be reported. With respect to both markets, researchers offer the following five key lessons from the European market as the U.S. considers the operation of its Exchanges (Van Ginneken & Swartz, 2012; Van Ginneken, et al., 2013):

- Risk adjustment models must be continually revised with the addition of risk adjustment factors that have been tested over time;
- Determine why individuals do not enroll, or enroll and default on premiums, and implement policies to avoid an increase in the number of uninsured;
- Premium subsidies should be simple to administer, use a simple application process, and be difficult to abuse. This lesson is important for the U.S. in order to prevent “churning”, a phenomenon that occurs when the eligibility status of recipients of publicly funded health programs changes due to income levels, family size or other eligibility requirements, causing gaps in coverage;
- Guide insurers through price increases to insure continued quality of services. To address this lesson, the PPACA mandates that premium increases be justified by insurers and approved by the DHHS; and,
- Availability of useful, reliable information on provider’s costs and quality of care. The U.S. still struggles with providing information that is transparent enough for the public to compare provider costs and quality of care. Attempts to provide this type of provider information through U.S. HIEs may take time.

2.2.3 Early State Health Reform Efforts in the U.S.

Massachusetts, Vermont, and Utah have all implemented elements of health reform at the state level over the last two decades, with Massachusetts being the most comprehensive, and Vermont being the oldest.

The Massachusetts Health Reform Initiative of 2006 also provides lessons for health reform on the national level. Massachusetts is the only state with a mandate for individual health coverage, mandated employer health insurance coverage for employees, subsidized health premiums for individuals up to 300% of the federal poverty level (FPL), and a HIE to manage health plan options for subsidized and unsubsidized premium funding programs (Gruber, 2008; Steinbrook, 2006). Presently, Massachusetts stands as the only U.S. state that has reformed health care to expand coverage to uninsured and at-risk/vulnerable populations through the use of subsidized private health plans. Thus, the Massachusetts health reform initiative has served as the model for the PPACA.

By comparison however, both Vermont and Utah have had health reforms in place for several years. Over the last 20 years the State of Vermont has implemented health reforms that have improved the health of Vermonters. Vermont reforms have included making health coverage available through programs such as Dr. Dynasaur, Catamount Health and Vermont Health Access Program (VHAP). Reforms have included efforts to prevent denial of health insurance for pre-existing conditions, and implementing community rating so that all Vermonters, regardless of their age, gender or geographic location can get health insurance (Department of Vermont Health Vermont, 2013).

Utah created a state HIE for small businesses that allowed employees to receive a specified contribution in order that they could purchase health insurance on their own through a marketplace offering choices and options for coverage. However, the Utah

plan did not contain an individual or employer mandate, had no provision for subsidized care, and had very limited regulatory authority (Growth, 2012).

Under the PPACA covering at-risk/vulnerable populations and uninsured individuals, through health plans offered by HIEs will be accomplished through the use of subsidies. Using subsidies to support the purchase of health insurance has made a significant difference in the number of at-risk individuals who are now covered by health insurance in Massachusetts. The state's Commonwealth Health Insurance Connector, functions as a HIE, and was created to serve as a central purchasing pool for the sale of insurance at rates lower than non-group plans offered through the private market (Gruber, 2008, 2011). In Massachusetts, the availability of subsidies through the HIE for families with incomes up to 300% of the FPL has made insurance affordable. Even for the working poor, with incomes above the 300% FPL a limited coverage plan could be purchased at a cost of approximately \$200.00 per month for individuals (Gruber, 2008). The success of the Commonwealth Health Insurance Connector in providing subsidized care to at-risk/vulnerable populations and uninsured residents provides evidence that subsidized premiums can make a significant difference in the ability of at-risk/ vulnerable populations to afford health insurance coverage.

The PPACA goes beyond the Massachusetts subsidy limit, and provides subsidies for people earning between 133% and 400% of the FPL. Under the law, people earning below that amount will qualify for Medicaid (Bloombreg, 2012). In addition, states will have the flexibility to establish basic health plans for non-Medicaid eligible, lower-income individuals. For vulnerable and uninsured individuals who meet eligibility

requirements, this means that government subsidizes could provide all, or a significant portion of their health insurance premiums through the Exchange.

2.2.4 Key Design Issues and Barriers

A near universal program offering affordable health insurance coverage on a national level for all U.S. citizens represents a new chapter in this country's quest to reform its health care system. Health reform in the U.S. is in its infancy and there is no quantitative or qualitative research that unequivocally measures the success or failure of different components. However, the design elements and barriers that could impede universal coverage, especially for at-risk/vulnerable and uninsured populations, must be explored. Several researchers have attempted to connect the dots and provide insight into design issues and barriers that could impact the system based mostly on the experiences of the State of Massachusetts and the European market.

Kingsdale and Bertko (2010) present six design issues for states to consider. They assert that on the issue of organization and governance, Exchanges should be "insulated from political influence, and have access to the business expertise [they] need. Additionally, tax financed subsidies require that Exchanges be publicly accountable" (Kingsdale & Bertko, 2010). They posit that these requirements are most conducive to a "semi-independent government authority", governed by a board with relevant experience, appointed by elected officials (Kingsdale & Bertko, 2010). Rating rules based on factors such as age, family make up, risk activities (i.e. tobacco use), and where a person lives could automatically generate insurance pricing. These features could make comparison shopping through the HIE easy to accomplish. Additionally, design issues such as risk

adjustment, the number of approved health plans that should be offered through an Exchange, the selection process for plan issuers to participate in the Exchange, and ways to increase administrative efficiencies are design issues that could become barriers without the appropriate level of management and control (Kingsdale & Bertko, 2010).

The design of navigator programs and the assurance that entities receiving navigator grants have demonstrated expertise in developing relationships with at-risk/vulnerable populations is cited by Zemel, et al. (2012) as a critical element in the design of HIE's (Zemel, Arons, Miller, & Gauthier, 2012). The authors also point to the importance of designing a web portal that is user-friendly for consumers, and easy to incorporate mandated functionality such as eligibility determination across all public programs as being essential for a HIE to reach its goal of enrolling eligible individuals. Additionally, as early as February of 2012, Zemel, et al. (2012) pointed to the importance of marketing the Exchange, and the problems that poor marketing can have on the PPACA goal of reaching eligible individuals to inform and educate them in advance of open enrollment timeframes (Zemel, et al., 2012). Recent news reports show that ineffective use of this design element is beginning to severely impact outreach and education, particularly in states that have defaulted to Federally Funded Exchanges (Robert. Pear, 2013).

The importance of identifying design issues and barriers is clearly delineated by Jost (2013) in his report entitled *HIEs and the Affordable Care Act: Eight Difficult Issues* (Jost, 2013). In it, he identifies "eight difficult issues" that states and the federal government must address in implementing HIEs. He also examines how those issues

should be handled, and provides recommendations for their resolution. A summary of issues and his recommendations for resolution are presented in Table 2-13.

Table 2-13: Summary of HIE Implementation Issues and Recommendations for Resolution

| | <i>Issue</i> | <i>Resolution</i> |
|----|--|---|
| 1. | Governance of the Exchanges | <ul style="list-style-type: none"> • Exchanges should be independent agencies • Exempt from requirements of state administrative law or government operations requirements • Governing board composition should include stakeholders, state agencies with working relationships and persons with relevant experience • Management should be apolitical and professional • Outsource services where competitive markets exist, and performance can be monitored |
| 2. | Avoidance of adverse selection | <ul style="list-style-type: none"> • State regulation of markets outside Exchange should be identical to corresponding regulation inside the Exchange • DHHS design of as sophisticated but practical risk- adjustment system to discourage adverse selection against and within the Exchange |
| 3. | Making self-funded plans compatible with Exchanges | <ul style="list-style-type: none"> • Define self-funded status to clarify that substantial risk for cost of health care must be present to qualify as self-funded • Consider extending requirements of ACA to large and grandfathered plans that qualify for Exchange coverage |
| 4. | Making Exchanges attractive to employers | <ul style="list-style-type: none"> • Offer option of an aggregated bill covering the premiums of all employees • Assume the task of allocating premiums among insurers and plans chosen by individual |

| | <i>Issue</i> | <i>Resolution</i> |
|----|---|---|
| | | <p>employees</p> <ul style="list-style-type: none"> • Allow a fixed percentage of premium payment option or premium share based on category and richness of coverage • Employers could offer greater support to low-income employees |
| 5. | Use of regulatory authority by Exchanges | <ul style="list-style-type: none"> • Use certification power to ensure health plans comply with statutory requirements • Give Exchanges option of being active purchasers of health plans offered on the Exchange • Allow inclusive or exclusive approach to insurer participation based on state and local market conditions • Allow Exchanges to lower prices to the extent that competitive market conditions allow • Standardize and limit range of plan choices to stimulate competition based on price and value |
| 6. | Determining information that must be made available to consumers and employers | <ul style="list-style-type: none"> • Make information on benefits and limitations of plans readily and easily accessible • Contractually bind plans to the information they disclose on their Web sites • Develop rating systems for comparison of plans and satisfaction survey programs to solicit plan members opinions |
| 7. | Role of Exchange in making eligibility determinations for premium tax credits and cost-sharing reduction payments | <ul style="list-style-type: none"> • Clarify statutes to permit individuals to apply to the Exchange or to a publicly financed program such as Medicaid or SCHIP upon initial application • Facilitate electronic applications without need for paper documentation • Provide interim assistance when eligibility cannot be readily determined • Ensure continued enrollment of eligible |

| | <i>Issue</i> | <i>Resolution</i> |
|-----------|-------------------------------|--|
| | | individuals as a responsibility of the Exchange |
| 8. | Reducing administrative costs | <ul style="list-style-type: none"> • Develop revenue sources to fund the work of the Exchange (possible assessment on all insurers in the market) • Lower administrative costs for insurers and employers • Agent and broker commissions should be rational and similar regardless of plan being sold whether inside or outside of the Exchange |

Source: (Jost, 2013)

It is conceivable that in the three years since this report some of these recommendations or similar resolutions may have been implemented. However, a determination to that affect would require significant research and, where a recommendation is specific to state’s operations it would require a review of each state HIE agency. What is noteworthy however is that many of the issues that are being raised today mirror those identified by Jost (2013).

In short, design issues can easily become barriers to the operational effectiveness of HIEs. Recognizing and controlling for such barriers is essential for developing a HIE that can function as intended by federal law.

2.2.5 Business Model and Governance Structure

Jost (2013) delineates issues associated with the governance of HIEs that are significant when considering how state agencies with mandated federal functions that are not controlled by the state, will operate (Jost, 2013). On the issue of whether an

Exchange's business model should be a state entity or a private, non-profit organization, Jost (2013) and Van de Water and Nathan (2011) urge states to think about the legal considerations based on their state constitution since federal options of a new state agency, existing state agency, or non-profit may be bound by state constitutionality (Jost, 2013; Van de Water & Nathan 2011). Jost (2013), Merlis (2009), Van de Water and Nathan (2011), and Zemel, et.al (2012) all make the case for a governing board that represents a variety of interests, within and outside of the health and insurance industries. Additionally, all advise on the benefit of a "consumer" board member who can represent varying consumer interests (Jost, 2013; Merlis, 2009; Van de Water & Nathan 2011; Zemel, et al., 2012).

Van de Water and Nathan (2011) also point to the fact that the size of the board can present challenges, with multi-member boards providing more opportunity for diverse expertise and experiences but potentially impeding accountability and timely decision making; and smaller member boards, while being more efficient, lacking the depth and breadth of expertise needed for the issues to be considered (Van de Water & Nathan 2011). The need for HIE's not to be bound by state administrative laws or government rules and regulations and for management to be free of political ties is shared by all of these researchers as a valid concern. In addition, Merlis (2009) and Van de Water and Nathan (2011) raise the issue of the extent to which an Exchange might be subject to executive or federal oversight; and, whether the Exchange will need to seek annual appropriations from the state legislature, a consideration that could be problematic

once the federal government no longer has a presence in states that defaulted to Federally Facilitated Exchanges (Merlis, 2009; Zemel, et al., 2012).

Business models and governance structure present multi-faceted issues for which states will need to be clear of the consequences of their decisions. As Van de Water and Nathan (2011) point out,

“Governance” encompasses questions such as the following: Where is the Exchange located [within the state]? Who are the policy-making and administrative officials of the Exchange, and how are they chosen? How is the Exchange funded? What kinds of policy decisions is the Exchange empowered or required to make? What flexibility does the Exchange have with regard to personnel, procurement and other administrative matters?” (Van de Water & Nathan 2011)

Decisions made today, could serve as baseline against which states can evaluate the effectiveness of their governance structure after the first year of full operation. An evaluation could lead to re-tooling, if needed, HIE governance decisions to better serve citizens, but most importantly at-risk/vulnerable and uninsured populations.

2.2.6 Systemic Risk and the Health Insurance Exchange Environment

The establishment, governance and structure of HIE marketplaces are new to U.S. states and that unchartered territory produces what Carboni and Milward term systemic risk (Carboni & Milward, 2012). Systemic risk occurs when failure on the part of any agency in a highly contracted network of interdependent agencies occurs. Referring to networked governance arrangements, Carboni and Milward (2012) address the myriad of

issues that arise when government agencies rely on complex arrangements of independent service providers or contractors to carry out legislatively mandated services. The authors assert that while becoming more necessary in fiscally challenged environments including governments at all levels, networked privatized service arrangements challenge the government's ability to control both the contractors involved and the governance of such arrangements (Carboni & Milward, 2012). The result is systemic risk which occurs when one or more of the interdependent players fail, or a series of failures occur simultaneously, placing the organization and the government at risk of not being able to deliver promised services. Thus, systemic risk can have far reaching consequences when contracted services are aimed at at-risk/vulnerable populations (Carboni & Milward, 2012).

In the case of HIEs systemic risk can have far reaching consequences when contracted services are aimed at at-risk/vulnerable populations. Therefore, systemic risk is potentially greatest in the area of navigation services. Disruption of navigator programs due to internal and external issues that impact the HIE agency can cause a breakdown in the delivery of services to populations most in need of guidance and facilitation. For example, if HIE's have to work through issues associated with the basis for payment of services, service area designations, and the availability of funds to make payment to navigator agencies for services rendered, these issues will present opportunities for system failure. In particular, in the case of existing government HIE agencies and quasi-government HIE agencies that are a part the myriad of administrative rules and policies associated with procurement of outside services, the political processes

for enacting change in a timely manner can produce systemic risk. In the case of HIEs internal or external failures that produce systemic risk could jeopardize the ability of the HIE and its other agencies to function, and the failure of any one entity could have negative implications for the full HIE agency.

2.2.7 Section Summary

The most far reaching component of the PPACA is the establishment of HIEs. They serve as a cornerstone of the PPACA, providing an entrée for millions of at-risk/vulnerable groups and uninsured individuals into the health insurance market. This is particularly important for at-risk/vulnerable populations who have not had access to the care and services needed to improve their health status due to either an inability to afford health insurance coverage, or ineligibility to participate in publicly funded healthcare programs. For the first time ever in this country's history a government entity will be tasked with guaranteeing health insurance coverage for millions of uninsured and vulnerable individuals. The establishment, design, governance and management of HIEs are critical to their ability to carry out federally mandated functions. Likewise, design issues can become barriers to the effectiveness of HIE operations if not identified and resolved. In both instances, lessons can be learned from both the State of Massachusetts and the European market to inform U.S. decisions on the HIE marketplace.

2.3 Manuscript 2 Literature Review Section

Section 2.3 of this literature review will focus on Manuscript 2. First, it will examine the concept of at-risk/vulnerable populations, the risk factors that lead to their vulnerability, and the barriers they face in accessing quality, affordable health care. It

will explore The Vulnerability Model, as put forth by Shi and Stevens (Shi & Stevens, 2010) which synthesizes elements of earlier vulnerability models and includes “access-to-care” and “quality of care” as risk factors that lead to vulnerability.

Secondly, it will explore the long history of using traditional patient navigator programs in health services delivery. It will examine how those programs have served as facilitative tools in helping at-risk/vulnerable populations to access health care services. Health Insurance Exchange (HIE) navigator programs are expected to carry out many of the federally mandated functions that are directed towards reaching uninsured and at-risk/vulnerable groups. The use of navigator programs to carry out those functions will also be examined. Lastly, strategies proven to be successful in reaching at-risk/vulnerable populations using traditional navigator programs will be identified. These findings are expected to aid in building a case for why these strategies should be considered by HIEs to carry out the mandated function of outreach, education and enrollment of at-risk/vulnerable populations.

2.3.1 Definition of At-Risk/Vulnerable Populations

Achieving health coverage through HIEs is critical to meeting the unmet medical needs of uninsured and at-risk/vulnerable populations. Because of the Patient Protection and Affordable Care Act (PPACA), for the first time in the history of the U.S. a government agency will be tasked by law to provide health insurance coverage for millions of individuals whose health care needs have gone unmet for decades, and for some a lifetime. However, in order to understand the significance and far reaching impact of this health reform mandate, it is important to understand what individuals

constitute at-risk/vulnerable populations, the risk factors that have contributed to their medical vulnerability, and the implications of these vulnerabilities on their personal health and the health of the nation.

The definition of at-risk/vulnerable populations is viewed differently depending on the research discipline, (e.g. health care, sociology, psychology, criminal justice, emergency preparedness, etc.), and can include any number of at-risk/vulnerable groups (Shi & Stevens, 2010) . Shi and Stevens (2010), in their book *Vulnerable Populations in the United States* note that common practice is to partition at-risk/vulnerable populations into distinct subpopulations (Shi & Stevens, 2010). In the case of health care as a discipline, they identify those subpopulations as racial or ethnic minorities, the uninsured, children, the elderly, the poor, the disabled or handicapped, those with chronic medical conditions, individuals with no English or limited English proficiency, and those with literacy problems (Shi & Stevens, 2010). The Department of Health and Human Services (DHHS) does not provide a formal definition for at-risk/vulnerable populations in any of the guidance it has prepared on HIEs or navigator programs. However, the Centers for Disease Control and Prevention (CDC), an agency within the DHHS, defines at-risk/vulnerable populations as being “...defined by socio-economic status, geography, gender, age, disability status, risk status related to sex and gender, and among other populations identified to be at-risk for health disparities” (CDC, 2013). The literature reviewed for this research will center on those individuals or groups noted in the CDC definition with the exception of geography and disability status. Thus, this research will focus on low-income, racial and ethnic minority groups, culturally diverse

groups with limited English proficiency, and groups whose medical circumstances render their receipt of care especially burdensome without support and advocacy. Additionally, the working poor who are generally employed individuals unable to afford the cost of health plan premiums offered through an employer, will also be considered an at-risk group because of their economic circumstances. Because they are generally covered by Medicare, Medicaid, or State Children's Health Insurance Programs (SCHIP), elderly individuals and children will not be included in the definition of at-risk/vulnerable populations for this research.

Note: From the perspective of vulnerability, many researchers use the terms vulnerable populations and at-risk populations interchangeably. When citing an article or report, the term used by the author will be applied. However, in broadly referring to either group the term at-risk/vulnerable population(s) will be used. The majority of data and statistics on uninsured populations exclude children and the elderly. Data typically focuses on individuals in the age range of 19-64. Therefore, unless it is indicated that data relates specifically to uninsured working adults, data and statistics on uninsured populations presented in this research will be inclusive of at-risk/vulnerable populations.

2.3.2 Risk Factors Contributing to Vulnerability

Studies show that the single most long term contributor to poor health is socioeconomic status (Baker, Metzler, & Galea, 2005; Cutler & Lleras-Muney, 2007; Mechanic & Tanner, 2007). Individuals are vulnerable for a variety of reasons, including ones that are beyond their immediate and long-term control. As individual risk factors, these contributors to vulnerability are generally social, economic, financial, and

medical in nature. Additional risk factors are directly related to care delivery systems and include barriers that impede timely access to care, affordability of care, and the quality of care that is provided. As a result the health needs of at-risk/vulnerable populations are impacted by conditions that are internally and externally outside of their control. The socio-economic status indicators that generally define at-risk/vulnerable populations such as age, race, poverty, education, unemployment, environmental infrastructure, literacy, cultural experiences are generally the same social and economic factors that underlie the social determinants of their health (Biedrzycki, 2012).

An abundance of literature exists that investigates the association between social, economic, cultural and medical conditions as risk factors, and vulnerability and being uninsured (Baker, et al., 2005; Kaiser Family H. J. K. F. Foundation, 2012a; Mechanic & Tanner, 2007; Rogers, 1997). In addition to the literature, many models have been developed to study why at-risk/vulnerable groups tend to have poorer access to care and poorer health status. While most models focus on a one-dimensional explanation Shi and Stevens (2010) present a model for the interconnectivity between all risk factors and vulnerability. In their model, vulnerability is presented as being cyclical in nature with overlapping risk factors that recycle through generations of vulnerable families (Shi & Stevens, 2010). That model is shown as Figure 2-2 (Shi & Stevens, 2010). Additionally, Shi and Stevens (2010) offer a “new conceptual framework” for studying at-risk/vulnerable populations. Their framework not only presents the connection between ecological and individual risk factors but adds “access to care risk factors”,

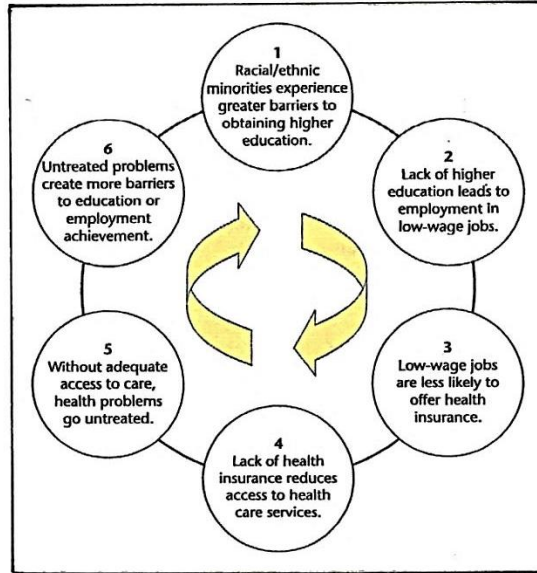
recognizing that together risk factors and access add to the vulnerability of individuals and the community as a whole (Shi & Stevens, 2010).

Socio Economic Risk Factors

Research has shown that race, ethnicity, age, gender, poverty, unemployment, lack of education, literacy and cultural experiences serve as the main socio-economic risk factors that play a significant role in creating vulnerability to health care. These risk factors can place low income, minority individuals at a disadvantage when seeking health services, and as a result contribute to disparities in health outcomes. Additionally, the presence of one risk factor increases the probability of having other risk factors, and the cumulative effect increases the vulnerability for a lack of health insurance leading to poor health outcomes (Shi & Stevens, 2010). Studies have shown that these risk factors are greatest for low-income and minority populations, and generally result in delayed access to health care services including mental health and dental health, high out of pocket costs, and a decreased ability to afford prescription medications and specialty care services when warranted (Schoen et al., 2013; Shi & Stevens, 2010). Additionally, persons with low socio-economic status have been found to be at greater risk for heart disease, certain cancers, obesity, arthritis, chronic diseases, and other health related illnesses (CDC, 2009b; Schoen, et al., 2013).

Figure ___ : Simplified Interconnections between ‘Risk Factors and the Cycling of Vulnerability

(Source: Shi & Stevens, *Vulnerable Populations in the United States*, 2nd Ed., 2010 pg. 86)



Source: Shi & Stevens (2010)

Figure 2-2: Interconnection Between Risk Factors and the Cycling of Vulnerability

Race, ethnicity and poverty as risk factors. Race and ethnicity are considered characteristics of vulnerability that impact health because certain at-risk/vulnerable groups have higher rates of morbidity and mortality when compared to non-Hispanic Whites (Rogers, 1997; Shi & Stevens, 2010). Included in these groups are African Americans, Hispanics, American Indians, Native Alaskans, Asians and immigrant groups

from African and Southeast Asian countries. In general, African Americans have a higher rate of mortality from preventable illness than any other racial group (E. Nolte & McKee, 2008; Schoen, et al., 2013; S. C. Schoenbaum, et al., 2011a; Shi & Stevens, 2010).

Often, the terms low income and poverty are used as proxies for one another. Both produce individuals who are economically disadvantaged. Studies have shown that low SES groups lack the financial resources needed to access systems of care and to maintain their personal health. According to Shi & Stevens (2010), “Poverty compounds the problems that minorities face in securing a regular source of health care” (Shi & Stevens, 2010). When comparing race/ethnicity, insurance coverage and regular source of care by poverty status, they found that Hispanics with incomes less than 100% of the poverty level were almost twice as likely (47%) to not have a regular source of health care when compared to non-Hispanic Blacks (27%), and non-Hispanic Whites (25%) (Shi & Stevens, 2010). Even at income levels 200% or higher than federal poverty levels, the Hispanic rate of 24% was twice the rate of non-Hispanic Whites at 12% and almost twice the rate of non-Hispanic Blacks at 14% (Shi & Stevens, 2010). These rates confirm the relationship between race, poverty and lack of insurance, indicating that multiple risk factors can increase individual vulnerability and have a negative effect on access to care.

Education as a risk factor. Through much research, education has been identified as a significant risk factor for poor health outcomes (Cutler & Lleras-Muney, 2007; Mechanic & Tanner, 2007; Rogers, 1997; Schoen, et al., 2013). Shi and Stevens (2010) report that educational level is a strong predictor of health status, morbidity and mortality (Shi &

Stevens, 2010). Individuals with higher levels of education are better able to navigate the health delivery system, improving their ability to seek preventive health services thereby maintaining optimal levels of health (Rogers, 1997). Additionally, Rogers (1997) notes that women who are more educated are more likely to receive the level of prenatal care that is associated with healthier pregnancy outcomes (Rogers, 1997). In its study of education as a risk factor for health outcomes, The National Center on Poverty tested the relationship between health and education using data from the National Health Insurance Survey (NHIS). Their analysis showed the following:

- Better educated people have lower morbidity rates from the most common acute and chronic diseases, independent of basic demographic and labor market factors.
- Life expectancy is increasing for everyone in the United States, yet differences in life expectancy have grown over time between those with and without a college education.
- Health behaviors alone cannot account for health status differences between those who are less educated and those who have more years of education.
- The mechanisms by which education influences health are complex and are likely to include (but are not limited to) interrelationships between demographic and family background indicators, effects of poor health in childhood, greater resources associated with higher levels of education, a

learned appreciation for the importance of good health behaviors, and one's social networks (Cutler & Lleras-Muney, 2007).

Cutler and Lleras-Muney (2007) further report that: "More education reduces the risk of heart disease by 2.2 percentage points (relative to a base of 31 percent) and the risk of diabetes by 1.3 percentage points (relative to a base of 7 percent). The authors found that an additional four more years of schooling lowers the probability of reporting being in fair or poor health by 6 percentage points (the mean is 12 percent), and reduces lost days of work to sickness by 2.3 days each year (relative to 5.2 on average)". (Cutler & Lleras-Muney, 2007)

Employment as a risk factor. Employment is strongly tied to education and income. Individuals with higher levels of education are generally more able to obtain higher paying jobs, and higher paying jobs generally result in higher incomes. Higher paying jobs are often managerial or professional in nature and in 2009 jobs in this category had an unemployment rate of 1.6% (Shi & Stevens, 2010). In general, minorities are most likely to be employed in service industry or blue-collar type jobs which offer lower wages and have higher unemployment rates at 5.3% and 6.3% respectively (Shi & Stevens, 2010). When comparing health insurance coverage between these two job categories, Shi and Stevens (2010) report that health coverage offered in service and blue-collar jobs will tend to be "much less comprehensive, [with] employees having to pay a greater share of the cost". Additionally, rates of unemployment have been shown to be higher among minority groups than among Whites. In 2009, rates of unemployment among African Americans and Hispanics were 15.3% and 12.4% respectively, and were

significantly higher than the 8.7% unemployment rate for Whites (Shi & Stevens, 2010). The only minority groups reported to have an unemployment rate lower than Whites were Asian and Pacific Islanders at 7.5% (Shi & Stevens, 2010).

Financial Risk Factors

Lack of insurance coverage: A lack of insurance impacts a person's ability to access needed medical services and, when accessed, unpaid medical bills can affect their long term financial security (Kaiser Family H. J. K. F. Foundation, 2012a). Trust for America's Health (2008) reports that in 2008, the rate of uninsurance among white Americans was 13% while the rate for African Americans was 22%. Among the Hispanic population, that rate was reported to be 36% (Trust, 2008).

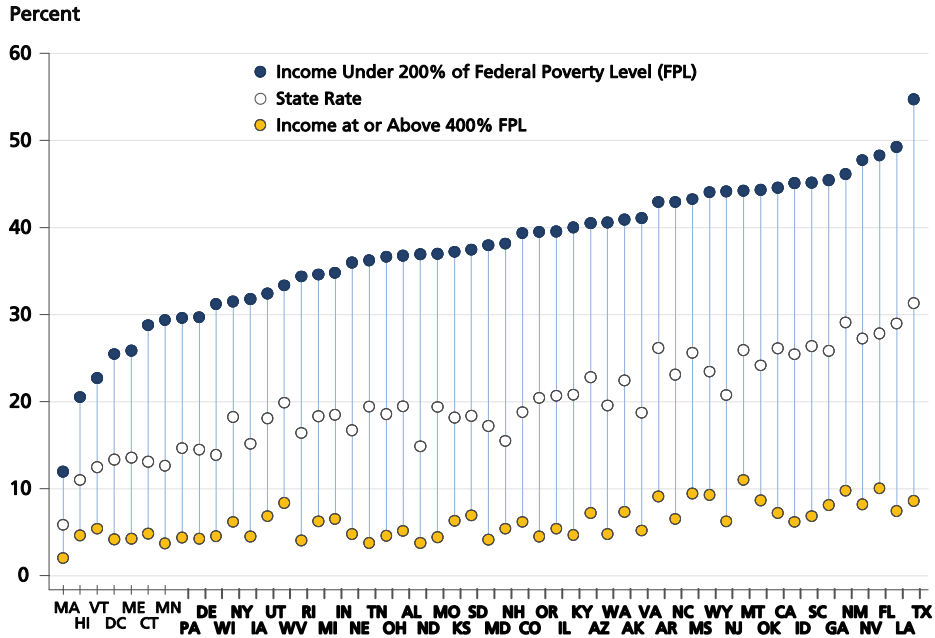
The success of the Massachusetts Commonwealth Health Insurance Connector in providing subsidized care to uninsured and vulnerable individuals provides evidence that subsidized premiums can make a difference in the ability of vulnerability populations to afford health insurance coverage. Since implementation of its health reform initiative, the State of Massachusetts has the lowest rate of uninsured individuals in the nation. Reports indicate that over 97% of Massachusetts citizens have health care coverage, either through employer sponsored group health plans, or through the subsidized and unsubsidized non-group plans offered through the state's HIE (Bigby, 2009; Mulvaney-Day, Alegria, Nillni, & Gonzalez, 2012). In a 2011 review of uninsured adults, aged 19-64 for all states, Massachusetts was found to have the lowest rates of uninsured adults in three categories: income at or above 400% of the FPL, the State rate, and income under 200% of the FPL (Schoen, et al., 2013). Texas had the highest rates of uninsured in all

categories. Below, Graph 2-1 provides a comparison of the State of Massachusetts and other U.S. states. These and other positive results of the Massachusetts Health Reform Initiative offer evidence for efforts at the national level through HIEs for the provision of health insurance coverage to uninsured adults and at-risk/vulnerable populations.

An added financial burden for uninsured populations is their struggle to pay medical bills or resolve medical debt. Exhibit 2-1 shows the results of a 2012 Commonwealth Fund (CWF) Biennial Health Insurance Survey of adults and the problems they reported with paying medical bills or medical debt. The survey showed that two out of five adults or 41% of respondents (75 million people) reported at least one of the problems listed in Exhibit 2-1 (S. R. Collins, Robertson, R., Garber, T., Doty, M.M., 2013).

The burden of medical bills and unresolved medical debt can cause uninsured individuals to not seek care or to forego needed medications. The CWF reports that this was more acute with low to moderate income adults and adults with chronic conditions (see Exhibit 2-2) (S. R. Collins, Robertson, R., Garber, T., Doty, M.M., 2013).

UNINSURED ADULTS AGES 19-64, 2010-11



Data: 2011-12 Current Population Survey.
Source: Commonwealth Fund Scorecard on State Health System Performance for Low-Income Populations, 2013.

Source: CWF (2013)

Graph 2-1: Comparison of Rates of Uninsured Adults Aged 19-64 for 50 U.S. States

| Percent of adults ages 19–64 | 2005 | 2010 | 2012 |
|--|---------------------------------|---------------------------------|---------------------------------|
| In the past 12 months: | | | |
| Had problems paying or unable to pay medical bills | 23% 39 million | 29% 53 million | 30% 55 million |
| Contacted by a collection agency about medical bills* | 21% 36 million | 23% 42 million | 22% 41 million |
| Contacted by collection agency for unpaid medical bills | 13% 22 million | 16% 30 million | 18% 32 million |
| Contacted by a collection agency because of billing mistake | 7% 11 million | 5% 9 million | 4% 7 million |
| Had to change way of life to pay bills | 14% 24 million | 17% 31 million | 16% 29 million |
| <i>Any of three bill problems (does not include billing mistake)</i> | 28% 48 million | 34% 62 million | 34% 63 million |
| Medical bills being paid off over time | 21% 37 million | 24% 44 million | 26% 48 million |
| <i>Any of three bill problems or medical debt</i> | 34% 58 million | 40% 73 million | 41% 75 million |
| * Subtotals may not sum to total: respondents who answered “don’t know” refused are included in the distribution but not reported. | | | |
| Source: The CWF Biennial Health Insurance Surveys (2005, 2010, and 2012). | | | |

Source: CWF (2013)

Exhibit 2-1: Millions of Adults Continue to Report Problems Paying Medical Bills or Medical Debt

Medical Risk Factors

Chronic Disease: The incidence and prevalence of chronic diseases among at-risk/vulnerable populations has been on a steady rise. The CDC (2009) reports that chronic diseases include such medical illnesses as heart disease and stroke, certain cancers, diabetes, arthritis, obesity, and respiratory diseases (CDC, 2009b). The report found that:

- among Americans, 7 out of 10 deaths each year are from chronic diseases;
- In 2005, almost one out of every two adults had at least one chronic illness;
- Health disparities in chronic disease incidence and mortality are widespread among members of racial and ethnic minority populations; and
- When compared to whites, African Americans have a higher rate of death from heart disease; and American Indians and Alaska Natives have substantially higher rates of diabetes (CDC, 2009b).

The CDC (2009) reports that more than 75 percent of the nation's health care spending is on people with chronic conditions (CDC, 2009b). Between FY2000 and FY2009 more than \$755 billion dollars was spend on chronic disease conditions known to disproportionately impact the health of at-risk/vulnerable populations (CDC, 2009b). Cunningham (2010) reports that "Almost 40% of uninsured people eligible to receive subsidies through the exchanges have chronic conditions or report fair or poor health..." (Cunningham, 2010). Clearly, the medical risk factors for at-risk/vulnerable populations exceed those of other population sub-groups, making them more vulnerable to conditions that increase morbidity and mortality. Given the disproportionate impact of chronic

disease on uninsured and at-risk/vulnerable populations, at-risk individuals will benefit most from the PPACA mandate that prohibits insurance issuers from denying health plan coverage based on pre-existing conditions. Table 2-14 presents the most prevalent chronic diseases and the vulnerable subgroups most impacted.

| Percent of adults ages 19–64 | 2003 | 2005 | 2010 | 2012 |
|--|---------------------------------|---------------------------------|---------------------------------|---------------------------------|
| In the past 12 months: | | | | |
| Had a medical problem, did not visit doctor or clinic | 22% 38 million | 24% 41 million | 26% 49 million | 29% 53 million |
| Did not fill a prescription | 23% 39 million | 25% 43 million | 26% 48 million | 27% 50 million |
| Skipped recommended test, treatment, or follow-up | 19% 32 million | 20% 34 million | 25% 47 million | 27% 49 million |
| Did not get needed specialist care | 13% 22 million | 17% 30 million | 18% 34 million | 20% 37 million |
| <i>Any of the above access problems</i> | 37% 63 million | 37% 64 million | 41% 75 million | 43% 80 million |
| Source: The CWF Biennial Health Insurance Surveys (2003, 2005, 2010, and 2012). | | | | |

Source: CWF (2013)

Exhibit 2-2: Number of Adults Reporting Cost-Related Problems Getting Needed Care Increased, 2003–2012

2.3.3 Barriers Contributing to Vulnerability

Many of the risk factors presented above also serve as barriers to care. For the four risk factors of race/ethnicity, low income, health insurance and no regular source of

care, Shi and Stevens (2010) report that Blacks have the highest rates of delayed needs in all categories with the exception of mental health care (Shi & Stevens, 2010). As a risk factor, being low income results in rates almost two times higher than higher income groups in all unmet needs categories. Also, being uninsured has a rate almost five to six times that of publicly insured individuals in all categories of unmet needs. However, unmet needs are not just impacted by individual risk factors, but are also impacted by system barriers.

Table 2-14: Chronic Diseases and the At-risk/vulnerable Populations Disproportionately Impacted

| <i>Chronic Disease</i> | <i>At-Risk Population Disproportionately Impacted</i> |
|--|--|
| Heart Disease and Stroke ¹ | Death rates in 2005 <ul style="list-style-type: none"> • Age adjusted stroke: 31% higher for African Americans than for whites • Heart disease: 23% higher for African Americans than for whites |
| Cancer ¹ | African Americans more likely to die of cancer than people of any other racial or ethnic group |
| Diabetes ¹ | American Indians and Alaska Native adults 2x's as likely as white adults to have diabetes |
| Arthritis ¹ | Higher proportion of African Americans report severe pain and activity and work limitations due to arthritis |
| Obesity ^{1,2} | Non-Hispanic black adults have the highest age-adjusted rates of obesity compared to other races (49.5%) Non-Hispanic black adolescent boys aged 12-19 have the highest prevalence compared to boys of other races at 19% Non-Hispanic black adolescent girls aged 2-19 have the |

| | |
|-----------------------------|--|
| | highest prevalence compared to girls of other races at 28% |
| Smoking ³ | Cigarette Smoking Rates: American Indians/Native Alaskans 31.5% Blacks (non Hispanic) 19.4% Hispanics 12.9% |

Source: (CDC, 2009b)¹; (CDC, 2012)²; (CDC, 2011)³

System barriers to vulnerability include factors such as access to health care facilities, the availability of quality services, geographic location, transportation, the availability of needed specialty services, and the cost of medical tests and prescription drugs. These barriers, while not under the control of individuals, nonetheless impact a vulnerable person’s ability to have health care experiences that could result in positive health outcomes.

2.3.4 Health Disparities, Health Status, and Health Outcomes

The health of its citizens is a reflection of the health of a nation. This is most evident in the fact that the U.S. ranks 37th in the world for overall health, and 16 out of 16 for amenable mortality among 16 Organization for Economic Co-Operation and Development (OECD) member countries. Despite the wealth of our nation, and the billions of dollars spent on healthcare, studies continue to show that the physical health and social welfare of the most at-risk/vulnerable populations in the U.S. continue to be at risk (CDC, 2004; E. Nolte & McKee, 2011; S. C. Schoenbaum, C. Schoen, J. L. Nicholson, & J. C. Cantor, 2011b). In combination the social determinants of health

along with disparities in the delivery of health care services have a negative impact on the health outcomes of at-risk/vulnerable populations (CDC, 2004; S. C. Schoenbaum, et al., 2011b; Shi & Stevens, 2010).

It is estimated that in America more than 100,000 deaths occur each year from conditions that are preventable and treatable with access to timely, affordable and available health services (E. Nolte & McKee, 2008, 2011). The CDC reports that many of the conditions that significantly impact the health status and health outcomes of at-risk/vulnerable populations are preventable and highly associated with amenable mortality (CDC, 2004, 2009b). These include diabetes, hypertensive disease, tuberculosis, treatable cancers, certain cardiovascular diseases, maternal death, perinatal deaths, selected childhood infections, and kidney diseases, to name a few (CDC, 2004; DeLuca, 2006; E. Nolte & McKee, 2011). It is widely reported that at-risk/vulnerable populations are disproportionately affected by these health conditions (CDC, 2004, 2009b; H. J. K. F. Foundation, 2012a; E. Nolte & McKee, 2008). In addition, for at-risk/vulnerable groups, premature death is greatest in the areas of breast cancer, HIV/TB, cardiovascular disease, infant mortality, diabetes, and hypertensive disease. (CDC, 2004; CMS, 2008; DeLuca, 2006; E. Nolte & McKee, 2011). Collectively, these chronic conditions account for some of the highest rates of amenable mortality and disproportionately impact populations with low SES and high burdens of illness (E. Nolte & McKee, 2011; S. C. Schoenbaum, Schoen, C., Nicholson, J.L., Cantor, J.C., 2011).

In fact, several studies have shown that poverty, race, health disparities and amenable mortality are factors in the overall health of at-risk/vulnerable populations that

are linked at the state level (CDC, 2004; Kaiser, 2009; E. Nolte, McKee, M., 2008; S. C. Schoenbaum, Schoen, C., Nicholson, J.L., Cantor, J.C., 2011; Woolf, 2009). For example angina, a common form of heart disease often leading to fatal heart attacks, is one of the leading causes of premature death in the United States (CDC, 2004). It is widely accepted from a clinical perspective, that angina is highly preventable with a healthy diet, medication for contributing factors such as diabetes, cholesterol and high blood pressure, and lifestyle changes such as increased exercise (CDC, 2009b). Yet, in 2004, the CDC reported that in the U.S. disparities in premature death from heart disease, “varied by state, and was high[est] among blacks, American Indians/Alaska Natives, Asian /Pacific Islanders, and Hispanics” (CDC, 2004).

Research on rates of amenable mortality by states has shown that amenable mortality is a factor in the overall health of at-risk/vulnerable populations with a disproportionate share of premature deaths suffered by those living in southern states, and the District of Columbia (S. C. Schoenbaum, et al., 2011a). Much like the CDC, in 2004-2005, Schoenbaum, et al. found that eight of the nine southern most states (NC, SC, GA, AL, MS, LA, TN, KY) experienced death rates of 108 to 142 deaths per 100,000 population, placing them in the bottom quartile of amenable deaths by state (S. C. Schoenbaum, et al., 2011b). Only the District of Columbia had a higher amenable mortality rate at 158 deaths per 100,000 population (S. C. Schoenbaum, et al., 2011a). Further evidence that poverty is greatest in these same states and the District of Columbia was presented by The Kaiser Family Foundation in its *Facts on Health Reform Report*. (Kaiser, 2009) Kaiser found that seven of the eight states plus the District of Columbia

accounted for more than 50 percent of the states with non-elderly uninsured individuals with income levels \leq 133% of the FPL (Kaiser, 2009).

In addition to CDC findings, further evidence that a link between poverty, race, and amenable mortality exists at the state level has been reported by Schoenbaum, Schoen, Nicholson, & Cantor (2011). Their 2011 study showed “a more than twofold variation in amenable mortality rates across the country... [that] was strongly associated with the percentage of state populations that were poor or black” (S. C. Schoenbaum, et al., 2011a). Using CDC Multiple Cause-of-Death data files, and U.S. Census population data, the authors noted that rates of amenable mortality ranged from a low of 63.9 deaths per 100,000 people under the age of 75 in Minnesota, to highs of 142.0 in Mississippi, and 158.3 in the District of Columbia. In addition, the CDC found strong correlations between state rates of uninsured and lower rates of preventive care.

Most recently in a September 2013 report on Health Care in the Two Americas, the CWF reported that:

- Where you live matters: For low-income populations, there are wide differences across states in access, quality and safety, and health outcomes; and
- Income-related health care disparities exist within states and across all areas of health system performance. (Schoen, et al., 2013)

Finally, seven years ago the *2006 National Healthcare Disparities Report* issued by the Agency for Healthcare Research and Quality (AHRQ) noted that many minorities are “...more likely than others to be diagnosed with late-stage breast and colorectal cancers, are disproportionately affected by diabetes and heart disease, and are more likely

to die from HIV”, further noting that “disparities related to race, ethnicity, and socioeconomic status still pervade the American health care system” (E. Nolte & McKee, 2008).

2.3.5 Health Coverage under the PPACA Programs

Traditional programs such as Medicare, Medicaid and the State Children’s Health Insurance Plan (SCHIP) have provided health insurance coverage for decades that has positively impacted the health of the at-risk/vulnerable populations they were created to serve. Numerous studies have shown that while it has taken many years, these programs have improved the health outcomes of the elderly, low-income, and at-risk children. By extension, the potential for health reform programs such as subsidized health plans offered through HIEs and the expansion of Medicaid to improve the health of millions of uninsured and vulnerable individuals seems reasonable.

While publicly funded programs have provided health coverage for certain at-risk subgroups, state eligibility rules have excluded millions of others from participation. Additionally, the high cost of health insurance premiums through employer benefit plans, has left both businesses and their employees without affordable options for health insurance coverage. At a minimum, through an essential health benefits plan, and subsidized premiums HIEs can make health insurance coverage affordable for millions of U.S. citizens. However, implementation of Federally Facilitated HIE’s has experienced set-backs that could make it difficult to reach and enroll the at-risk/vulnerable populations and uninsured individuals the PPACA was created to serve.

As reported on September 17, 2013 by *The New York Times*, Florida, Ohio, Missouri, and Georgia are states which have made conscious decisions to obstruct the implementation of federally facilitated HIEs in their states (Alvarez & Pear, 2013). According to the authors, “...[each has complicated] enrollment efforts and have [limited the dissemination of] information about the new program” (Alvarez & Pear, 2013). Table 2-15 presents a list of obstacles put forth to date by each of these states to impede any progress related to outreach, education and enrollment of uninsured and at-risk/vulnerable populations into approved health plans.

2.3.6 Potential for a Reduction in Vulnerability

Reforms under the PPACA will have the combined effect of creating a more improved health care environment for access to quality, affordable health care. However, the reform feature that bans the denial of health insurance coverage for pre-existing conditions will be especially important for vulnerable individuals with medical conditions for which they have never sought care. In a survey of uninsured adults, 40% of whom will be eligible for subsidized premiums, Cunningham (2010) reports that over a one year period, 65.7% did not get, or delayed getting, needed medical care, generally for chronic medical conditions such as diabetes, hypertension, heart disease, and cancer. Additionally, 57% reported problems paying medical bills (Cunningham, 2010). Thus, removing the previous ban on health coverage for pre-existing conditions reduces vulnerability by ensuring that uninsured and at-risk/vulnerable groups will be able to get care for medical problems that have impacted their overall health status for many years. Under the PPACA, uninsured and at-risk/vulnerable populations could be eligible for

health insurance coverage through two programs, Medicaid Expansion and state approved health plans with subsidized premiums through HIEs.

Medicaid Expansion:

One option provided under the PPACA to offer uninsured and at-risk/vulnerable populations health insurance coverage is the expansion of state Medicaid Programs. Medicaid expansion would allow individuals with income up to 138% of the FPL to be eligible for coverage under the Medicaid program (CWF, 2010; H. J. K. F. Foundation, 2013e). As an incentive to implement Medicaid expansion the federal government offered funding commitments that guaranteed payment of 100% of costs for newly eligible individuals from 2014 through 2016. From 2017 through 2019 the federal contribution decreases gradually and then remains in place at 90% from 2020 forward (DHHS, 2013c).

However, in June 2012, the Supreme Court of the United States ruled that the federal government could not mandate states to expand their Medicaid program. This ruling opened the door for the bitter partisan divide on the constitutionality of the PPACA to continue, and allowed states to opt out of one of the major programs identified for ensuring coverage to at-risk/vulnerable groups. In opting out, each state's decision on whether to participate in the Medicaid Expansion program was left to state governors and legislators. In the initial months following that ruling, only democratically controlled states moved forward with Medicaid Expansion plans, with most Republican controlled states citing increased costs in a fiscally challenged environment as their reason for opting not to expand Medicaid. In an effort to exemplify party unity, Republican

Table 2-15: The Potential Impact of State Obstructionist Efforts on the Effectiveness of Health Insurance Exchange Federally Mandated Activities

| <i>State</i> | <i>Obstruction Effort</i> | <i>Potential Impact</i> |
|-----------------|--|--|
| Florida | <ul style="list-style-type: none"> passed legislation taking away the state insurance commissioner’s ability to approve insurance rates for new health plans for the next two years ordered county health departments to bar navigators from providing outreach, education, and enrollment services to patients in county facilities prohibited all outside groups from using county health property to conduct non-state business. | <ul style="list-style-type: none"> Inability to approve affordable health plans will mean that residents will not have the benefit of lower cost health plans Health departments serve at-risk/vulnerable populations who potentially will not be offered education and enrollment in HIEs |
| Missouri | <ul style="list-style-type: none"> Adopted a law that restricts navigator activities and requires navigators to be licensed | <ul style="list-style-type: none"> Navigators will be unable to “provide advice concerning the benefits, terms and features of a particular health plan, or advise consumers about which health plan to choose.” |
| Ohio | <ul style="list-style-type: none"> Adopted a law prohibiting navigators from recommending a health plan or offering advice about a particular plan’s benefits Navigators can distribute certain information but not all information | <ul style="list-style-type: none"> Consumers, particularly those at risk for literacy or educational barriers, will not have the benefit of information presented at a literacy level or in terms that they understand |
| Georgia | <ul style="list-style-type: none"> Mandates that health insurance counselors be licensed to become navigators Requires fingerprinting and criminal background checks of all applicants | <ul style="list-style-type: none"> This mandate could significantly limit the pool of individuals that are uniquely qualified by racial, ethnic, educational, cultural, or community concordance to serve consumers |

Source: (Alvarez & Pear, 2013)

governors expressed staunch opposition to support any element of the PPACA. While some Republican governors have reversed their decisions, reasons for moving forward have been tempered with strong language about reversal of their decision to expand Medicaid should the federal government not follow through on its funding commitments (The Advisory Board Company, 2013).

To date, ten Republican governors have pushed for legislation to implement Medicaid Expansion programs (The Advisory Board Company, 2013). As of September 17, 2013 the following Republican led states have passed legislation authorizing expansion of their state Medicaid program: Arizona, Florida, Iowa, Michigan, Nevada, New Jersey, New Mexico, North Dakota, Ohio, and Pennsylvania (The Advisory Board Company, 2013; H. J. K. F. Foundation, 2013e). Through Medicaid expansion, these ten Republican led states will provide health insurance coverage to almost 3.8 million uninsured and vulnerable adults (Center for Budget and Policy Priorities, 2013). Along with nineteen Democratic states plus the District of Columbia, this brings the total number of states that have committed to implementation of a Medicaid Expansion program to thirty. Combined, the total number of uninsured adults that could be enrolled in a Medicaid expansion program in these thirty participating states would be close to 9.5 million individuals. Appendix Table A2.2 shows the status of each state with respect to expanding their Medicaid program as of September 17, 2013 and the number of uninsured and at-risk/vulnerable adults who would be newly eligible in each state. It is important to note that state decisions on Medicaid Expansion are still fluid and could change.

Under the PPACA, adults with incomes between 133 percent and 139 percent of the FPL would be eligible for health coverage through expansion of Medicaid programs (H. J. K. F. Foundation, 2012a). Estimates are that if fully implemented in all 50 states and the District of Columbia, the number of uninsured and vulnerable individuals that could be covered through Medicaid Expansion would be just over 15 million (The Advisory Board Company, 2013). Thus, Medicaid Expansion covering uninsured adults could provide health coverage to almost one half of the total number of uninsured individuals that are expected to benefit from the PPACA.

HIE Affordable Health Plans

The availability of subsidized premiums has the potential to make health insurance affordable for millions of uninsured individuals especially the working poor. Depending on income, HIEs will make insurance coverage available to individuals and families with incomes from 100% to 400% of the FPL (H. J. K. F. Foundation, 2012a). It is estimated that by 2019 through HIEs and subsidized premiums, more than 24 million uninsured and vulnerable individuals will have affordable health insurance coverage (H. J. K. F. Foundation, 2011a).

One of the largest and fastest growing at-risk/vulnerable groups that could benefit from the availability of affordable health plans through HIEs are young uninsured adults, ages 19 to 29. In 2009, the number of uninsured adults in this age range was estimated to be 14.8 million. That represented an increase of almost one million individuals over the number reported for 2008 (S. R. Collins & Nicholson, 2010). With an additional five million young adults who work but have high out-of-pocket health costs, the number of

uninsured and underinsured young adults reaches almost 20 million people. Under the PPACA, Collins and Nicholson (2010) estimate that as many as 12.1 million uninsured young adults could gain subsidized coverage, 7.2 million from health plans offered through the HIE, and 4.9 million through Medicaid Expansion (S. R. Collins & Nicholson, 2010).

Under the PPACA, uninsured and at-risk/vulnerable populations have a tremendous opportunity to obtain health insurance coverage and reduce their vulnerability to unmet medical needs. By the year 2019 the estimated number of uninsured and vulnerable individuals that could be covered through Medicaid expansion and HIE subsidized premium health plans could reach almost 40 million by 2019 (H. J. K. F. Foundation, 2011a).

2.3.7 Navigator Programs in Health Care Service Delivery

Researchers generally agree that there is no one single definition for what a navigator program is, or for what it does. However, for this research the author will make a distinction between what are known as patient navigator programs and navigator programs established under HIEs. HIE navigator programs will be defined as a federal mandate for the facilitation of outreach, education, and enrollment of at-risk/vulnerable populations into qualified health insurance plans. For this research, those programs that assist patients in facilitating the delivery of clinical health services will be referred to as traditional navigator programs.

The use of traditional navigator programs to facilitate and guide patients through complex health care environments and medical treatment protocols is not a new concept

in the delivery of health care services. These programs have been shown to be most successful with at-risk/vulnerable populations, whose social, economic, cultural or medical conditions have kept them from seeking needed health care services (Christie et al., 2008; Dohan & Schrag, 2005; Donelan et al., 2011; Dudley et al.; Duggan et al., 2012; Ferrante, Chen, & Kim, 2008; Ferrante, Wu, & Diccico-Bloom, 2011; H.P. Freeman, 2006; Garza et al., 2005; Green et al., 2008; Hansen et al., 2005; Hook, Ware, Siler, & Packard, 2012; Hunter et al., 2004; Jandorf, Gutierrez, Lopez, Christie, & S.H., 2005; Larkey, Gonzalez, Mar, & Glantz, 2009; Lasser et al., 2009; Nguyen & Kagawa-Singer, 2008; Nguyen, Tran, Kagawa-Singer, & Foo, 2011; Petereit et al., 2008; Reinschmidt et al., 2006; Schlueter, Thompson, Mason, Rayton M., & Arriola, 2010). In fact, the use of navigator programs to ensure the delivery of care for illnesses such as cancers, where studies have shown disparities in preventive services, treatment, and care has been a longstanding practice.

The use of navigators in health care service delivery is not new. Literature reveals that navigators have been used to support the delivery of medical services to at-risk/vulnerable populations for almost 40 years, with the first navigator program being implemented, with funding from the American Cancer Society, in New York's Harlem community in 1990 to facilitate breast cancer treatment in minority women (H.P. Freeman, 2004, 2006). Prior to the implementation of the Harlem Hospital Center Breast Cancer Screening and Patient Navigation Program, from 1964 to 1986, 606 patients, 94% (570) of whom were African American were treated for breast cancer at Harlem Hospital Center (H.P. Freeman, 2004). The majority of patients were low SES, with almost 50%

having no health insurance coverage. Nearly half of patients presenting were Stage 3 and 4 and incurable at diagnosis, with only 6% diagnosed as Stage 1 or early breast cancer. Compared to a five year survival rate of nearly 60% at the time for White American women, the survival rate for these patients was determined to be 39%. This made clear the fact that “Late diagnosis and treatment at an incurable stage of the disease is [a] principal cause of death” (H.P. Freeman, 2004). With the implementation of the patient navigator program to support access to screening and assistance in navigating the health care environment, in 5 years from 1995 to 2000, the five year rate of survival for this at-risk group was estimated to be 70% (H.P. Freeman, 2004). The “Harlem Experience” provided proof that navigator programs were effective in reaching hard to reach populations for health services and for improving health outcomes.

Studies have shown that significant disparities continue to exist in cancer prevention, treatment and follow-up care for at-risk/vulnerable populations, particularly for breast and cervical cancers in African American women, Hispanic women, American Indians, Alaska Natives, and Asian and Pacific Islander women (Moy & Chabner, 2011; Steinberg et al., 2006; Wolff et al., 2003). In addition, cancers have been reported to be the leading cause of death for Asian American men and women (Nguyen & Kagawa-Singer, 2008). Hispanic women are reported to have the highest incidence of cervical cancer, with an age adjusted incidence of 12.5 cases per 100,000 women. This compares to an incidence of 7.0 per 100,000 for non-Hispanic Whites. Also, mortality associated with cervical cancer among Hispanics is 2.9 per 100,000 versus 2.1 per 100,000 for non-Hispanic Whites. In addition, African American males have been found

to be at greater risk for prostate cancer, having a mortality rate as much as 2.4 times greater than their white counterparts (Nonzee et al., 2012). However, the largest disparities in cancer have been found among American Indians. In the Northern Plains area of South Dakota the cancer mortality rate among this subgroup is 40% higher than that of the overall U.S. population. The age adjusted cancer mortality for this same American Indian population stands at 232 per 100,000 as compared to 166 per 100,000 for the general population (Petereit, et al., 2008). For all of the referenced subgroups these disparities have led to increased mortality, due mainly to an inability to access quality, affordable care in a timely manner (Battaglia, Roloff, Posner, & Freund, 2007). Patient navigator programs have been found to help reduce the incidence of cancer in these groups and to reduce mortality by facilitating early detection and prevention services, and assisting in the delivery of timely care and treatment.

Barriers Addressed by Navigator Programs

Studies have shown that navigator programs are successful in addressing a number of barriers that impede a patient's ability to access and navigate a care system. Many of these barriers are logistic, cultural, educational, financial, and communication in nature. To address these barriers, patient navigators (PNs) receive training in the most effective way to advocate for patients and to facilitate their movement through delivery systems that oftentimes are new to them (Percac-Lima et al., 2009). Table 2-16 lists the most common barriers that navigator programs aim to remove. These include: patients being uninsured, low levels of health literacy, cultural beliefs that lead to mistrust of the health system, and logistical barriers such as transportation and day care needs.

Table 2-16: Barriers Addressed by Navigator Programs to Facilitate Care

| <i>Barrier</i> | |
|----------------|---|
| 1. | Being uninsured or under insured through publicly funded insurance programs such as Medicaid |
| 2. | Lower levels of health literacy or education that contribute to fears associated with screening and or diagnosis |
| 3. | Cultural orientations that contribute to a lack of trust in medical institutions or fatalism regarding an illness |
| 4. | Logistical barriers associated with transportation child-care, clinic schedules, work schedules, rural residence, and geographic location of medical facilities |
| 5. | Difficulties negotiating relationships with providers or healthcare organizations due to language or cultural differences |

Source: (Dohan & Schrag, 2005; Wolff, et al., 2003)

Patient Navigator Programs for Cancer

Breast Cancer. There has been an overall decline in the rate of mortality from breast cancer over the last 20 years. This decline has been due mainly to improvements in early screening and detection and to advances in treatment and care (Schlueter, et al., 2010). However, studies have shown that not all women have benefited equally from these improvements. It has been shown that while White women are diagnosed at a higher rate than minority women, African American women have a higher rate of mortality due to late stage diagnosis (Schlueter, et al., 2010).

In an evaluation of the Avon Foundation Community Education and Outreach Initiative (CEOI) Patient Navigation Program, Schlueter et al. (2010) found that using

PNs who were breast cancer survivors to help navigate newly diagnosed breast cancer patients was highly successful (Schlueter, et al., 2010). In a study of 18 low SES minority breast cancer patients, participants reported the strengths of the program to be: 1) the educational guidance provided by the PN; 2) the emotional and spiritual support from someone who had experienced their illness; and 3) the consistent availability of their PN to answer questions, attend treatment sessions, and guide them through tasks such as making appointments, arranging transportation, providing follow-up calls, and assisting with questions from providers. The authors noted that a weakness of the program was the enrollment process. Patients reported having confusing experiences and were not able to recall when or whether they were officially enrolled in the program (Schlueter, et al., 2010). While the most positive aspect of the program was the PN/patient relationship that developed, the program's administrative problems with the enrollment process are something that should be considered when designing HIE enrollment processes. Despite a noted weakness in the enrollment process, this study provides evidence that the use of PNs to help patients navigate medical services and administrative barriers to facilitate care and treatment can have a positive impact on health experiences.

Hook et al. (2012) studied the use of a nurse navigator model in a rural community setting. In a survey of 103 newly diagnosed patients with breast cancer who used nurse navigation services over a two-year period researchers found that overall, patients were "highly satisfied" with the use of a nurse navigator (Hook, et al., 2012). Using a 14 question, Likert Scaled survey tool, results in four major areas of support –

educational needs, emotional needs, user-friendliness, and overall satisfaction - showed that 72% of survey participants selected “strongly agree” for each survey question regarding the benefits of a nurse navigator. While the majority of participants in this navigator program were White (82%), rural communities can experience some of the same health service barriers that low income minority populations experience in large urban settings. Thus, the use of navigator services in rural environments is important to determining the overall effectiveness of such programs beyond the urban setting.

Nguyen and Kagawa-Singer (2008) reported on the barriers faced by participants in the REACH 2010-Promoting Access to Health for Southeast Asian and Pacific Islander Women (PATH for Women) project which focused on reducing disparities in breast and cervical cancer in women of Cambodian, Chamorro, Laotian, Samoan, Thai, Tongan and Vietnamese decent in Los Angeles and Orange County, CA (Nguyen & Kagawa-Singer, 2008). The barriers cited in their report are the same barriers identified in Table 2-16 above. The PATH program uses health education materials that are linguistically and culturally tailored to the needs of the communities, along with community health education provider trainings, and patient navigation services using community health outreach navigators (Nguyen & Kagawa-Singer, 2008). Through tailored interventions including mass media, door-to-door, and phone campaigns, community health navigators have linked thousands of Asian American Pacific Islander women to needed health services.

Other patient navigator programs have shown improvement in health outcomes. In a study of delays in follow-up after abnormal breast cancer screening results for a

racially diverse group of inner-city women, Battaglia et al. (2007) report that using a PN for intervention services resulted in 78% of patients having timely follow-up versus 64% of patients with no intervention. Findings from adjusted analysis were found to be significant for older age ($p = .0003$); having private insurance ($p = .006$), having an abnormal mammogram ($p = .0001$) and being referred from a hospital based practice versus a community health center ($p = .003$). The authors found that PNs contributed positively to reducing the delay in breast cancer follow-up and care for poor and minority patients (Battaglia, et al., 2007).

Other health related navigator programs. The value of patient navigator programs and the services they provide has been recognized beyond their traditional use in cancer programs. Similar studies have shown the same level of effectiveness in facilitating patients through care and treatment services resulting in an improvement in health outcomes and high levels of patient satisfaction with navigator services.

Lasser, et al. (2009) found that in combination with correspondence from primary care providers, a PN based intervention resulted in 31% of intervention patients being screened for colorectal cancer at six months, versus only 9% of control patients (Lasser, et al., 2009). Jandorf et al. (2005) also report successful use of patient navigators in increasing colorectal cancer screening among a minority population of low SES. In a study group of 78 men and women, the researchers found that within six months of a physician recommendation to obtain a colorectal cancer screening, 15.8% of patients who received navigator services obtained the screening as compared to 5% of patients with no patient navigator intervention. The group receiving patient navigator services

also showed a higher rate of fecal occult blood test completion, at 42.1% compared to 25% for the control group (Jandorf, et al., 2005).

Similar positive findings relative to health outcomes were reported by Percac-Lima, et al. (2009) for a colorectal screening program using multilingual PNs to address the barriers encountered by a low income, ethnically diverse population in an urban setting in the Boston area (Percac-Lima, et al., 2009). The Boston area is known to be ethnically diverse, with large numbers of immigrants from African, Central America, and middle European countries (Percac-Lima, et al., 2009). The diversity of the patient population was evident by the many languages that PNs spoke in addition to English and Spanish, including Arabic, Farsi, Portuguese, Russian, Serbo-Croatian and Somali (Percac-Lima, et al., 2009). Study results showed that participants in an intervention group who received a letter of introduction, educational material, and in-person or phone contact with a language concordant navigator were 27% more likely to receive colorectal screening. This compared to a screening rate of 12% for the non-intervention group. Completion of a colonoscopy by the intervention group was reported to be 21%, resulting in the identification of 10.5 polyps per 100 patients. By contrast, the colonoscopy completion rate for the control group was 10% with identification of 6.8 polyps per 100 patients. The study authors concluded that the use of a multilingual PN program that is culturally tailored and designed to address barriers to care, can improve colorectal cancer screening and colonoscopy rates for patients who are low income, and ethnically and linguistically diverse.

Patient Navigator programs have also been used successfully with American Indian communities. Native American Indians have significantly higher cancer related health disparities than any other minority population. Age adjusted cancer mortality for this group is 232 per 100,000. That compares to 166 per 100,000 for the general U.S. population (Petereit, et al., 2008). Navigator programs have proven successful for American Indian cancer patients in the Northern Plains of South Dakota, and at the Rapid City Regional Hospital in Rapid City. In both studies, patient navigator programs proved successful in addressing the barriers faced by both communities. In the Northern Plains, American Indians receiving navigator services during radiation treatment had an average of 3 fewer days of treatment interruptions when compared to patients who did not receive navigator services (Petereit, et al., 2008). Fifty-two patients receiving treatment at the Rapid City Regional Hospital participated in a culturally tailored PN program. When surveyed relative to their satisfaction with care, patients who received PN services showed improvement in their levels of satisfaction with their health care (Guadagnolo, Cina, Koop, Brunette, & Petereit, 2011).

Patient navigator programs have proven successful across a continuum of prevention, treatment and follow-up care activities. In addition, the use of PNs to successfully facilitate care activities for at-risk/vulnerable populations was shown to be effective across all studies presented. In the reported studies, patients faced the same barriers regardless of race, ethnicity, or cultural background. Likewise, in these studies strategies used by PN to remove those barriers were proven to be successful in navigating service delivery environments and facilitating care regardless of the medical

illness. Additionally, a consistent set of strategies were used by navigators to achieve maximum results. These included strategies in the areas of advocacy, communication, literacy and culture, education, emotional support, and consistent availability to serve patients. Additionally the value of racial and ethnic concordance were shown to be significant factors in building trust, as was the use of navigators who had actually experienced the same illness as the patients they served. Translating the use of navigator services from health care delivery to HIE functions of outreach, education, and enrollment of uninsured and at-risk/vulnerable populations into health insurance plans has the potential to produce the same successful results.

2.3.8 Health Insurance Exchange Navigator Programs

Whether State Based, State Partnerships, or Federally Facilitated, Exchange navigator programs are tasked with conducting outreach, education, and health plan enrollment activities to facilitate the enrollment of at-risk/vulnerable populations and otherwise eligible individuals. State-based exchanges that design their own navigator programs will maintain full control over selecting organizations to carry out navigator activities. They have been able to set the requirements of their navigator programs and delineate those requirements in their request for proposals for navigator services. For states electing to default to a federally facilitated exchange, the federal government will make the final decision on which agencies or organizations within the state will carry out navigator activities and how those activities will be implemented.

The use of navigator programs to carryout mandated activities of outreach, education and enrollment of uninsured and at-risk/vulnerable groups is required. Using

strategies found to be successful in traditional navigator programs for reaching the same at-risk/vulnerable groups has the potential to create successful HIE navigator program. HIE navigator programs will guide the same at-risk/vulnerable populations and assist in providing many of the same duties that traditional navigators provide including education on available health plans, and information on resources within the health system that can serve their needs beyond enrollment. Providing these services will require navigators to be racially and ethnically concordant with the enrollees they serve, to be aware of the barriers that these same at-risk/vulnerable populations have faced as of result of being uninsured, to build trust and a supportive working relationship, and to be able to communicate in a linguistically and culturally appropriate manner. Traditional navigator programs have proven that these activities are not only possible, but can result in successful HIE navigator programs. Absent the use of these successful strategies, it is likely that HIEs will not reach their goal of providing health insurance to millions of uninsured and at-risk/vulnerable populations.

2.3.9 Section Summary

This literature review has shown the relationship between risk factors as vulnerabilities, being uninsured, and the negative health outcomes that can result. At-risk/vulnerable populations have higher incidences and rates of mortality for many illnesses that are amenable to health with access to preventive and timely health care services. Traditional navigator programs have been successful in improving the health outcomes of at-risk/vulnerable groups for chronic diseases that severely impact the health of at-risk subgroups including African Americans, Hispanics, Asian American and

Pacific Islanders, and American Indians who suffer the highest incidences and rates of mortality for cancers.

Research has presented a myriad of evidence that at-risk/vulnerable populations continue to experience risk factors that contribute to wide disparities in health care. Providing health insurance coverage to these populations could significantly improve their general health and their health outcomes for medical illnesses that they are most vulnerable for. The PPACA, through its provision of health insurance coverage for at-risk/vulnerable populations, has the potential to improve health outcomes and amenable mortality rates for the U.S. as a whole.

HIEs have been tasked with ensuring the enrollment of uninsured and at-risk/vulnerable populations in approved health plans, the first time in the history of the nation that such a task has been mandated to a government agency. HIE navigator programs have an opportunity to provide successful outreach, education and enrollment activities to uninsured and at-risk/vulnerable groups using the same proven strategies that have worked for traditional navigator programs. In doing so, HIEs will likely be able to reach their goal of enrolling millions of individuals in approved health plans, thus reaching the PPACA goal of near universal health coverage for all Americans.

CHAPTER 3

AN ASSESSMENT OF STATE BASED HEALTH INSURANCE EXCHANGE BUSINESS MODELS AND GOVERNANCE STRUCTURES ¹

¹ Waldrop, Reinetta T., Lee, J., Hou, SU-I, Harris, C., Murray, D. (2013).
To be submitted to Health Affairs

3.0 Abstract

On October 1, 2013, states began to enroll uninsured and otherwise eligible individuals into qualified health plans through Health Insurance Exchanges (HIEs). These exchanges are mandated by the Patient Protection and Affordable Care Act of 2010. Therefore, all HIE business models and governance structures have become operational. The purpose of this study was to examine the establishment and implementation of State Based HIE business models and governance structures. All sixteen State Based HIEs and the District of Columbia were reviewed. HIEs are new to the U.S. insurance market and are therefore in their infancy. Thus, no quantitative or operational data was available on the most effective business model or governance structure.

A literature search yielded numerous articles on the HIE created by the State of Massachusetts, the European HIE Market, and reports on the establishment of HIEs including legislative actions and governance. A review of the literature found that ten states (59%) enacted HIEs as quasi-governmental business entities. Governing authority bodies ranged from five member boards to 19 member boards, with one state establishing five regional councils that seated a total of 180 members. Several design issues were identified that had the potential to impact the effectiveness of HIEs. They included 1) lack of a risk adjustment model to address adverse selection, 2) administrative rules and policies relative to internal management activities, 3) board appointment and composition restrictions, 4) funding mechanisms for operating revenue beyond 2014, 5) an inability to attract large numbers of healthy young adults to spread

risk, and 6) the unavailability of sufficient plans to promote competition. Also, a federal mandate to contract with external agencies to provide navigator services has the potential for systemic risk in a highly networked environment. Thus, HIEs will need to closely monitor contracted arrangements that could impact the delivery of navigator services and ultimately the goals of the PPACA. Additional issues and barriers were identified and are presented in this report.

Key words: Health Insurance Exchange, PPACA, ACA, governance structure, systemic risk, State Based HIE, exchange marketplace.

3.1 Introduction

The Patient Protection and Affordable Care Act of 2010 (PPACA) represents the first major health reform effort at the national level since the passage of Medicare and Medicaid in 1965. The underlying tenet of the Act is to provide near universal coverage to all eligible U.S. citizens. The Act, which was signed into law on March 23, 2010 by President Barack Obama has three main aims: (1) to expand health coverage; (2) to ensure access to quality, affordable health care; and (3) to contain the growth of health care costs (CMS, 2012; Congress, 2010). A critical factor in achieving these aims is the establishment of HIEs in all states and the District of Columbia. According to the Department of Health and Human Services (DHHS) (DHHS, 2012b), the purpose of a HIE is to serve as: "... a competitive organized marketplace to help consumers and small businesses buy health insurance in a way that permits easy comparison of available plan options based on price, benefits, and quality" (DHHS, 2012b). In keeping with this purpose, HIEs are tasked with conducting federally mandated activities that will

facilitate the enrollment of uninsured, eligible individuals into state qualified health insurance plans. It is estimated that HIEs will provide health insurance coverage to more than 40 million uninsured individuals by the year 2019 (Elmendorf, 2010). Key to reaching this goal is the establishment of HIEs in all states. By law, all states and the District of Columbia are required to establish two types of exchanges, Individual HIEs for enrollment of eligible individuals into individual health plans, and Small Business Health Option Exchanges (SHOP) for purchase of affordable health plans by small businesses for their employees. However, in July 2013, implementation of SHOP Exchanges was postponed for one year. Thus, this research will focus solely on individual HIE models. This research seeks to answer the following questions:

- Do business model and governance structure along with governing authority composition impact the effectiveness of State Based HIE agencies?

Health Insurance Exchange Models

States were given the option of establishing one of three HIE models: a State Based Exchange, a State Partnership Exchange, or defaulting to a Federally Facilitated Exchange.

State Based Exchange: By establishing State Based HIEs, states have the opportunity to impact insurance affordability, access to care, and the provision of services to their vulnerable and uninsured populations. Choosing to create their own Exchange gives states flexibility in the type of business model, governance structure, and management framework under which their Exchange will operate. It also allows states the flexibility

they need in designing programs to address the unique needs of their at-risk/vulnerable populations. While DHHS has provided guidance on the kinds of activities that HIEs must carry out and the stakeholder involvement that should be included (DHHS, 2012b), states electing to implement State Based HIE's are able to maintain control of processes for identifying and selecting community based organizations (CBOs), non-profit agencies, and consumer advocacy agencies to carry out certain mandated functions.

State-Partnership Exchange: State Partnership Exchanges represent a hybrid Exchange model. They are based on Federally Facilitated Exchange models where states have accepted responsibility for particular components of the Exchange, leaving other components to the federal government for development and implementation (Kaiser Family H. J. K. F. Foundation, 2013a). In its guidance on the establishment of State Partnership Exchanges (CMS, 2013a), the DHHS outlined various options that states have to provide input on the establishment of their Partnership Exchanges. As a result a variety of partnership options have evolved. One of the first hybrid models to be approved by the DHHS was for the State of Utah. Under its Exchange model, Utah has requested to be allowed to operate its SHOP Exchange, while turning over its Individual Exchange to the federal government (Norman, 2013). Other states have elected to turn over their information technology mandated components to the federal government for implementation. This was mainly due to resource and capacity constraints associated with making eligibility requirements across all government programs available through a web portal (H. J. K. F. Foundation, 2013a). Researchers agree that DHHS acceptance of this model for implementing an Exchange is representative of their willingness to

cooperate fully with those states that have limitations in implementing all of the functional aspects of an Exchange. DHHS further views State Partnership Exchanges as stepping stones to the establishment of State Based Exchanges when and if state resources and capabilities permit (CMS, 2013a).

Federally Facilitated Exchange: The PPACA provides for the federal government to operate a Federally Facilitated Insurance Exchange in any state choosing not to establish a State Based Exchange (Congress, 2010; DHHS, 2012b). For states choosing to default to a Federally Facilitated Exchange, the DHHS has indicated a willingness to structure the Exchange so that state knowledge and expertise can be integrated into the Exchange to the greatest extent possible. Under Federally Facilitated Exchanges, states will continue to maintain responsibility for approving qualified state health plans to be offered through their exchanges. (DHHS, et al., 2012d).

However, by choosing not to establish their own State Based Exchange, states with Federally Facilitated Exchanges relinquish much of their control over Exchange operating functions to the federal government. This includes the kinds of agencies and organizations chosen to support navigator functions, and how certain other mandated contractual activities will be carried out and managed.

Due to the wide range of scenarios emerging for the sharing of exchange responsibilities under the State Partnership model, this model will not be considered in this research. Also, because the DHHS will operate Federally Facilitated Exchanges with varying degrees of support and cooperation from state governments, these Exchanges will not be included in this research.

Establishment of State Based Health Insurance Exchanges

The DHHS has made almost \$3.6 billion dollars in grant funding available over the past 3 years to support the establishment of HIEs (DHHS, et al., 2012d). Level One funding was made available to support planning, establishment, and implementation of Exchanges and focused on nine core areas: 1) Background Research; 2) Stakeholder Involvement; 3) Governance; 4) Program Integration; 5) Regulatory/Legislative Actions; 6) Technical Infrastructure; 7) Finance; 8) Resources and Capabilities; and 9) Business Operations. Level One Establishment grants were made to 48 states and the District of Columbia. Level Two Establishment funding was available only to those states choosing to implement a State Based Exchange and focused on outreach and marketing activities. Level Two also provided funds to support HIE operations through December 2014 (DHHS, et al., 2012d). Level One funding to State Based HIEs has totaled \$973 million dollars since 2010. Level Two funding has totaled \$2 billion dollars to these same HIEs in the same timeframe (DHHS, et al., 2012d). A breakdown of Level One and Level Two funding to State Based HIEs is shown in Appendix Table A3-1.

HIE Mandated Functions.

Whether State Based, Federally Facilitated, or State Partnership, the DHHS has handed down specific functions that all HIEs are required to comply with. Many of these functions are aimed at creating competition among insurance carriers, and increasing consumer choice through the number of plans and benefits offered. Additional aims include ensuring transparency on plan cost and quality, and ensuring the availability of enrollment, eligibility determination, and other information to consumers

(DHHS, et al., 2012d). A summary of mandated HIE functions is shown in Appendix Table A3-2.

DHHS guidance allows for many of these functions to be contracted out (CMS, 2012). Thus, state control over the type of business model and the design of its exchange, its governance structure, and the management of its operations is critical to managing the contractual arrangements that are allowable, and that will likely be put into place.

Business Model, Governance Structure, and Management of State Based HIEs

State based models will develop different approaches to meet the PPACA requirements for creation of their HIEs. To date, 13 states and the District of Columbia have established State Based HIEs through legislative action. Those states are: California (CA), Colorado (CO), Connecticut (CT), Hawaii (HI), Idaho (ID), Maryland (MD), Massachusetts (MA), Minnesota (MN), Nevada (NV), New Mexico (NM), Oregon (OR), Vermont (VT), and Washington (WA). Three states, Kentucky (KY), New York (NY), and Rhode Island (RI) have used executive orders. Thus, differences in the business model chosen, governance structure, management, and design of HIE agencies could make a difference in the ability of an Exchange to effectively carry out mandated functions.

Through their legislative bodies all state-based HIEs have determined their business model as well as their governance structure. For State-Based Exchanges, states were given the choice of creating one of three business entities: create Exchanges as new government entities or as entities within existing state agencies, as non-profit

organizations, or as multi-state regional agencies (DHHS, 2012a). The DHHS has also provided guidance on governing authority composition and conflict of interest considerations (DHHS, 2012c).

Sixteen states and the District of Columbia have implemented State Based HIEs. Examining the initial business entities and governance structures that were enacted could reveal a legislative preference for a particular model. Recognizing preferences could help to determine if a certain model will emerge as being the best HIE business option. Also, reviewing how governing authority composition and membership appointments were apportioned could give insight into how much freedom HIEs will have from political ties. Lack of autonomy to carry out business operations and an inability to be apolitical in its decision making are design elements that could have an impact on the effectiveness of HIEs. Therefore, assessing design and governance at baseline and identifying issues and barriers is critical to future evaluations. Findings from the Massachusetts, Swiss, and Dutch HIE markets regarding design issues and barriers can inform these assessments.

3.2 Literature Review

HIE design issues, barriers, and governance structure are informed by lessons learned from the Massachusetts Health Reform Initiative of 2006, and the establishment of HIEs in the Swiss and Dutch European markets. Massachusetts set up a HIE on the state level and it was this model that served as the basis for HIEs under the PPACA. In the European market both Switzerland and the Netherlands have experience with HIEs at both the state (Swiss cantons) and the national levels (Van Ginneken, et al., 2013). The

lessons learned from an analysis of HIE design and governance at both the state and national levels could have significance for federally mandated HIEs under the PPACA.

Key Design Issues and Barriers

A near universal health coverage program offering affordable health insurance on a national level for all U.S. citizens represents a new chapter in this country's quest to reform its health care system. Universal coverage through health reform is in its infancy and there is no quantitative or qualitative research that unequivocally measures the success or failure of this goal. However, understanding how certain design elements and barriers could impede achieving universal coverage should be explored. Several researchers have connected the dots and provided insight into design issues and barriers that could impact HIE effectiveness based on the experiences of the State of Massachusetts and the European market.

Lessons from the Massachusetts HIE Experience. The Massachusetts HIE, known as the Massachusetts Health Connector has been in operation since 2006. It manages two coverage programs, one for subsidized coverage called Commonwealth Care which serves individuals with incomes below 300% of the federal poverty level, and a second called Commonwealth Choice, for unsubsidized coverage available to individuals who do not qualify for publicly funded health programs or subsidized premiums under Commonwealth Care. Established in 2006 as a part of the state-wide Massachusetts Health Reform Initiative, Massachusetts Health Connector already existed as a quasi-governmental entity that was independent of any state agency or executive office when the PPACA became law (H. J. K. F. Foundation, 2013d). In 2012 legislation was

enacted by the Massachusetts General Assembly which authorized the entity to become the State Based Exchange under the PPACA. The exchange is governed by an 11 member board and provides for representation of consumer and small business interests on the board. By statute board members are appointed by the Governor and the Attorney General of the state. No board members are appointed by members of the legislative body.

The Massachusetts HIE has been very successful in reaching its intended population. By 2008, through targeted marketing and outreach campaigns, the Commonwealth Connector had reduced the number of uninsured and at-risk/vulnerable populations without insurance coverage from 715,000 in 2004, two years prior to implementation of health reform to 263,000 in 2008, two years after implementation (A. Smith, 2009; Steinbrook, 2006). Today, the Massachusetts Health Connector is financially self sustaining, using a financing strategy legislatively authorized that permits it to apply a surcharge to all health plans that are offered through the HIE (H. J. K. F. Foundation, 2013d). It must be noted however, that the Massachusetts HIE market has always included the participation of the business community. Thus, the high rate of employment, and high percentage of employer sponsored group health plans adds to the low levels of uninsured individuals in the state and positively contributes to the health plan surcharge strategy that finances the administrative and operational costs of the Exchange (Steinbrook, 2006).

Lessons from the European HIE Experience. Switzerland and The Netherlands are generally assumed to have HIE Marketplaces that are very similar to the U.S. HIE

marketplaces mandated by the PPACA. The Swiss HIE marketplace is referred to as the Market for Compulsory Health Insurance (Reinhardt, 2004). The Swiss HIE has been designed to facilitate price transparency and comparison shopping through commercial websites. These features eliminate barriers to knowing the cost of premiums before choosing a health plan (R. Kreier, Zweifel, Peter, 2010). Swiss HIEs are administered by cantons, which are functionally equivalent to U.S. states. Unlike the U.S., the Swiss insurance market is characterized by heavy national government regulation in many parts of the system, but most especially in its private insurance market (Reinhardt, 2004). However, even though the Swiss private insurance market is heavily regulated at the national level, issues posed by regulation could inform design and participation barriers by private insurers in U.S. State Based HIEs.

The Dutch HIE has also focused on ensuring that information sharing with consumers is a high priority. Additionally, they recognized that governance structure and policies within the HIE for price competition needed to be significant elements in its design (Enthoven & van de Ven, 2007). Equalizing risk among insurers to lessen adverse selection however, is still a problem. Much like Switzerland, private insurers in the Dutch system are highly regulated by the government. However, efforts are underway to gradually relax regulatory requirements and allow a more competitive market to evolve (Enthoven & van de Ven, 2007).

Design Issues and Barriers for State Based HIEs

In considering HIEs under the PPACA, Kingsdale and Bertko (2010) present six design issues that can act as barriers for states to consider: 1) governance and

organization for autonomy; 2) rating rules for easy on-line shopping; 3) risk adjustment strategies; 4) the range of plans and benefit options to be offered; 5) processes for insurance carrier bidding and selection; and 6) protecting the public. On the issues of organization and governance, they advise that Exchanges should be “insulated from political influence, and have access to the business expertise [they] need... [and as] tax financed subsidies be publicly accountable”. Kingsdale and Bertko (2010) further posit that these requirements are most conducive to a “semi-independent government authority”, governed by a board with relevant experience, appointed by elected officials (Kingsdale & Bertko, 2010). They suggest that rating rules based on factors such as age, family make up, risk activities such as tobacco use, and geographic location could automatically generate insurance pricing, thus making on-line comparison shopping easy to accomplish. Also, design issues such as risk adjustment strategies to address adverse selection, the availability of sufficient health plans and benefit options to promote competition, fairness in the bidding and selection process for plan issuers operating in the Exchange, and increased administrative efficiencies and transparency are design issues that could become barriers if not adequately managed and controlled during implementation and operation (Kingsdale & Bertko, 2010).

Zemel, et al. (2012) include the design of navigator programs and the need for entities receiving navigator grants to have “demonstrated” expertise in developing relationships with at-risk/vulnerable populations as potential design issues (Zemel, et al., 2012). They point to these as critical elements in HIE design which, if not present, can impede the goal of enrolling intended populations (Zemel, et al., 2012). They also point

to the importance of designing a web portal that is user-friendly for consumers and that can easily incorporate mandated as well as changing functionality.

As early as February of 2012, a full 20 months before HIE's were scheduled to begin their operations, Zemel, et al. (2012) pointed to marketing as a crucial design element. Inadequate marketing can create a barrier to outreach, education and enrollment of at-risk/vulnerable populations and the uninsured into qualified health plans. The authors recommended that education regarding the purpose of the exchanges, and outreach and marketing campaigns begin early. They also recommend that marketing efforts be comprehensive and include information on all programs available through the exchange. This includes the fact that applying for Medicaid, SCHIP and Medicaid Expansion can occur through HIEs. (Zemel, et al., 2012). Consumer education about the intent and use of exchanges to purchase health insurance plans cannot be done effectively without assistive tools such as navigators and in-person assisters, and resource tool kits such as user friendly web portals, and educational materials (Zemel, et al., 2012). None of the awareness and educational elements so necessary to the success of HIEs in reaching intended populations can occur without effective marketing. Recent news reports show that ineffective marketing along with the enactment of obstructionist laws and policies are beginning to severely impact outreach and education, particularly in states that have defaulted to Federally Funded Exchanges (Keith, Lucia, & Monahan, 2013; Kennedy, 2013; Robert. Pear, 2013).

The importance of identifying design issues and barriers is the subject of Jost's report entitled *HIEs and the Affordable Care Act: Eight Difficult Issues* (Jost, 2013). In

it he identifies “eight difficult issues” that states and the federal government must address in implementing HIEs. He also examines how those issues should be handled and identifies potential resolutions. Many of these issues are the same as those identified by researchers such as Zemel, et.al. (2012), Kingsdale and Bertko (2010) in examining the U.S. HIE market, and by researchers in the Swiss and Dutch European HIE markets. Thus, these can be considered the major design issues and barriers that states must be concerned with when designing and implementing state based HIEs. Jost (20123) has identified the same design issues reported by other researchers but has provided what he believes are recommendations for their resolution (Jost, 2013). Appendix Table A3-3 presents a synopsis of the design issues and barriers along with recommendations for resolution as identified by Jost (2013).

HIEs have been established by federal statute. However, design issues and barriers arise mainly at the state level and can be the result of legislative actions or implementation activities. Nonetheless, design issues can easily become barriers to the effectiveness of HIEs if not managed properly using evidence based characteristics from a best fit theory of management. Recognizing and controlling for such barriers is essential for developing a HIE that can function as intended by federal law.

Business Model and Governance Structure

Issues associated with the governance of HIEs can be significant when considering how agencies created by state legislative action and tasked with carrying out federally mandated functions (not controlled by the state) will operate (Jost, 2013). On the issue of whether an Exchange’s business model should be a state entity or a private,

non-profit organization, Jost (2013) and Van de Water & Nathan (2011) point out that decisions on a model may be informed by legal considerations and by state constitutions (Jost, 2013; Van de Water & Nathan 2011). Jost (2013), Merlis (2009), Van de Water & Nathan (2011), and Zemel et al. (2012) all make the case for a governing board that represents a variety of interests, within and outside of the health and insurance industries. They also advise on the benefit of a “consumer” board member who can represent consumer interests (Jost, 2013; Merlis, 2009; Van de Water & Nathan 2011; Zemel, et al., 2012). Van de Water points to the fact that the size of the board can present challenges. While multi-member boards provide more opportunity for diverse expertise and experiences they can potentially impede accountability and timely decision making. Smaller boards, on the other hand, while being more efficient, can lack the depth and breadth of expertise needed for the myriad of state and federal issues to be considered (Van de Water & Nathan 2011). All agree that HIEs should not to be bound by state administrative laws or government rules and regulations regarding internal management functions such as human resources and procurement. Additionally, HIEs should be free of political ties that inhibit their effective functioning. Merlis (2009) and Van de Water & Nathan (2011) raise the issue of the extent to which an Exchange might be subject to continued executive or federal oversight, and whether the Exchange will need to seek annual appropriations from the state legislature to finance its operations. Both of these issues could become problematic once the federal government no longer has a presence in states that initially defaulted to Federally Facilitated Exchanges and later switch to State Based or State Partnership Exchanges (Merlis, 2009; Zemel, et al., 2012).

Van de Water & Nathan (2011) note that independent of the type of governance that is legislated by states, the same issues will have to be considered by all HIEs. These are: 1) the political independence and accountability of the exchange; 2) the prevention of conflicts of interest; 3) subjection to administrative rules and regulations that could impede operations; and 4) financial concerns such as methods for and continuity of operating funds, financial reporting requirements, and oversight, monitoring, and auditing of finances based on government or non-profit accounting principles (Van de Water & Nathan 2011). They further suggest that governance of exchanges must be concerned with five key *who*, *what*, *where*, and *how* questions:

- 1) ***Who*** are the policy-making and administrative officials of the Exchange, and how are they chosen?
- 2) ***What*** kinds of policy decisions are the Exchange empowered or required to make?
- 3) ***What*** flexibility does the Exchange have with regard to personnel, procurement and other administrative matters?
- 4) ***Where*** is the Exchange located [within the state]?
- 5) ***How*** is the Exchange funded? (Van de Water & Nathan 2011).

Systemic Risk and the HIE Environment

The establishment, governance and structure of HIE marketplaces are new to states and that unchartered territory produces what Carboni and Milward term systemic risk (Carboni & Milward, 2012). Referring to networked governance arrangements, Carboni and Milward address the myriad of issues that arise when government agencies rely on complex arrangements of independent service providers or contractors to carry

out legislatively mandated services. The authors assert that while becoming more necessary in fiscally challenged environments including government at all levels, networked privatized service arrangements challenge the government's ability to control both the contractors involved and the governance of such arrangements (Carboni & Milward, 2012). The result is systemic risk which occurs when one or more of the interdependent players fail, or a series of failures occur simultaneously, placing the organization and the government at risk of not being able to deliver promised services (Carboni & Milward, 2012). In the case of HIEs systemic risk can have far reaching consequences when contracted services are aimed at at-risk/vulnerable populations. Consideration of the possibility of systemic risk is particularly important because HIEs, as government entities, will rely heavily on external contracted organizations to accomplish certain federally mandated activities.

Studies show that HIE's will need to avoid political and financial pitfalls that could potentially impact their ability to carry out federally mandated activities through contractual arrangements (Jost, 2013; Van de Water & Nathan 2011). Thus, governance structure is important not only to a HIEs ability to function independently, but to its ability to proactively assess and correct for networked arrangements that could produce systemic risk (Carboni & Milward, 2012; Kingsdale & Bertko, 2010; Merlis, 2009; Van de Water & Nathan 2011).

3.3 Methodology

Study Design and Scope

This study used a qualitative methodology to conduct a synthesis of data, information, and empirical research findings that have informed practice in organizational governance and the establishment and operation of HIEs. Because HIEs are in the beginning stages of implementation, there was no quantitative data or information available that reported on the impact of business model or governance structure on HIE effectiveness. Public use datasets providing statistics on uninsured populations and information on the legislative enactment and current status of state HIE efforts were accessed from secured state and federal government websites. Datasets were used where possible to synthesize data pertinent to this research and to generate descriptive statistics. This study examined findings from peer reviewed journal articles and from reports published by federal and state governments as well as health policy research agencies, foundations and organizations between 2004 and 2013. A total of 63 items were found using four search engines: Google Scholar, Galileo, PubMed, and JSTOR and the websites of several health research organizations. Twenty-nine of those items were selected for use in this research. Sixteen State Based HIEs and the District of Columbia were examined. For purposes of this research, the District of Columbia will be reported as a State Based Exchange Therefore, all references to 17 states will include the District of Columbia.

Synthesis of the Literature

This research assessed the business models and governance structures enacted by law for State Based Exchanges. A review of state legislation was conducted to determine the preferred business model. Using literature review findings, business models were assessed in four areas: 1) the level of independence generally associated with the model, 2) the potential for government oversight in the operations of the entity based on business model, 3) the potential for political influence that could adversely impact the mission of the agency, and 4) the financial and decision making authority associated with each type of business model. A continuum of business model independence was developed from this assessment with each business type assessed from least to greatest independence along the continuum.

Governance structure was also examined. That review sought to assess the impact of governing authority type and composition, apportionment, appointment authority, and restrictions placed on governing body membership on HIE governance. These elements of governance structure were compared with literature review findings that inform the characteristics of effective governance. An assessment of all State Based HIE business models combined with a review of their governance structure, was expected to show which models were most frequently enacted and which governing structures have been viewed as most applicable to HIE agencies. In addition, funding associated with the establishment of State Based Exchanges and sustainability funding were also reviewed. Laws establishing those Exchanges were reviewed to determine if funding strategies for long term financing of the Exchanges were legislatively defined.

Other Relevant Literature. To aid in these assessments, information from state websites, specifically HIE and legislative websites was reviewed. Also, state information available through DHHS and CMS websites, as well as data collected and published by DHHS from planning and implementation grant funding and other reporting mechanisms was used in this research. Specific sections of the PPACA as signed into law were also researched along with rules and regulations published by the DHHS in the Federal Register. Journal articles and reports on reform of the U.S. health system, and the role and responsibilities of health insurance marketplaces were also examined. In addition, reports and subject briefs published by highly respected health policy and research organizations such as The Robert Wood Johnson Foundation, The Commonwealth Fund, The Henry J. Kaiser Family Foundation, The Trust for America's Health, and others were also reviewed.

3.4 Results

This work sought to answer the following research question: Do business model and governance structure along with governing authority composition impact the effectiveness of State Based HIE agencies? Findings suggest that how a HIE is designed, its legislatively enacted governance structure, and governing authority apportionment, appointment and composition can impact the effectiveness of HIE organizations. While findings are empirical only, there is significant experience from the State of Massachusetts Commonwealth Connector HIE and European HIE marketplaces to conclude that HIEs can be impacted by these elements. Research findings also produced evidence that HIE funding can also impact effectiveness.

State Based HIE Business Model

A review of the business entities created for State Based HIEs showed that states legislatively enacted three different business models. These were: 1) entities operated by new or existing state agencies; 2) quasi-governmental entities; and 3) non-profit entities. Entities operated directly by the state were placed within existing state agencies. Five states (29%) enacted business models to be operated by the state. They were Kentucky, Minnesota, New York, Rhode Island, and Vermont. Kentucky placed its HIE Office in the Cabinet for Health and Family Services; Minnesota elected to create its HIE as an agency within the Executive Branch; New York created its HIE as a division within its Department of Health; Rhode Island set up its HIE as a division in the Executive Branch; and Vermont's HIE operates as a division of the Department of Vermont Health Access. Ten states (59%) – California, Colorado, Connecticut, the District of Columbia, Idaho, Maryland, Massachusetts, Nevada, Oregon, and Washington enacted quasi-governmental business entities. These quasi governmental entities are described in general as independent public entities that are not affiliated with any agency or department of the state government (H. J. K. F. Foundation, 2013c). Two states (12%) – Hawaii and New Mexico created HIEs that would function as public non-profit corporations.

HIE Governance Structure

A review of governance structure showed that for 16 states, the number of board appointments ranged from five to 19 board members. The mean number of individuals serving on a board was 11 members. Idaho had the largest member board at 19

individuals, while the smallest boards were found in Vermont and California, both with five members. The State of Kentucky's board is advisory in nature rather than a governing board. The New York HIE is governed by five Regional Advisory Committees comprised of a total of 180 members (H. J. K. F. Foundation, 2013c). Appendix Table A3-4 presents a summary of the type of business model and the number of members serving on authority boards by state for the State Based Exchanges.

Governing board composition was reviewed for all State Based Exchanges. Board composition and the apportionment of board member appointments were defined by legislative action or executive order when the HIEs were created. The literature review on board composition stressed the importance of ensuring that a representative number of stakeholders including consumers hold governing board seats. Research findings revealed wide variations in board composition across all 17 states. Nine states legislatively require consumer and small business representation on the board, seven states (CA, CO, HI, ID, MD, NV, VT, WA) did not legislatively require such representation. New Mexico legislatively required consumer representation on the board but not small business representation. In five states (DC, HI, MN, OR, WA) have boards are appointed by the Governor or Mayor with the consent of the legislative body. In Vermont, the Chair and all members of the Board were found to be state employees. Additionally, the apportionment of board appointments between governors, legislators, and other entities varied across states, as did board membership restrictions. Appendix Table A3-5 presents a summary matrix of governing board composition, appointment, apportionment, and membership restrictions.

HIE Establishment Funding and Sustainability Financing

Funding provided through DHHS establishment grants allowed HIEs to support planning, establishment, and implementation of Exchanges. Findings show that the 17 State Based Exchanges received Level One funding ranging from a low of \$6.2 million dollars for Rhode Island to a high of \$236.8 million dollars for the State of California. Level One funding averaged \$57.2 million dollars for the 17 State-Based Exchanges. Level Two funding was made available only to State-Based Exchanges and ranged from a low of \$14.2 million dollars for Vermont to a high of \$674 million dollars for California. The average Level Two funding was \$114 million dollars and provided funding for marketing activities including the development of outreach and education campaigns, and for the first year of HIE operations through December 2014.

Federal funding for HIE operations will end in 2014. Therefore, state HIEs must have a plan for becoming financially self-sustaining before January, 2015. A review of state exchange profiles showed that HIE legislation for 14 states addressed strategies for sustaining HIEs beyond federal funding by assessing user fees on health plans or on premiums for plans sold on the exchange (H. J. K. F. Foundation, 2013c). These states also gave HIEs the authority to assess and collect their user fees. In some states, those user fees will extend to insurers who are selling health plans outside of the exchange. At this time three states, Idaho, New York and Vermont have not indicated what options they will consider. Only the California legislature has approved an annual state appropriation for financing their HIE to ensure sustainability beyond December 2014.

Empirical findings from this research suggest that to be effective, HIEs must have business models and governance structures that adhere to critical design and governance elements. Effectiveness measures based on design and governance and identified by researchers are presented in Table A3-1 (financing strategies), Table A3-3 (design issues and barriers), and Table A3-5 (governance). Seven elements were consistently identified by the major researchers referenced in this work as being important to the functioning and sustainability of HIEs. Of those seven measures two pertain to governance, and five pertain to business model design. Those seven measures of effectiveness are listed in Table A3-6. The majority of State Based HIEs studied in this research met these design and governance criteria. The seventeen states met five of the seven criteria presented for effectiveness 50% of the time or more. The first exception was the measure regarding governing board composition, specifically the appointment of both consumer and small business representatives on the board. This measure was met by only 47% of states. The second exception was the measure related to a mix of apportionment between the governor and the legislature, which was met by only 35% of states. Given the infancy of the HIE marketplace, those that do not meet some of these basic measures will have the opportunity to re-tool their design and governance decisions as markets mature and functionality, rules and regulations change. Table A3-6 presents the seven effectiveness measures and the percentage of HIE's meeting each measure.

Systemic Risk

Because HIEs will engage in a number of external contractual arrangements it is hypothesized that systemic risk could have far reaching consequences for contracted services aimed at at-risk/vulnerable populations. Systemic risk could potentially be greatest in the area of navigation services. Disruption of navigator programs due to internal or external issues that impact the HIE agency can cause a breakdown in the delivery of services to populations most in need of guidance and facilitation. For example, if HIE's have to work through issues associated with the payment of services, service area designations, and the availability of funds to make payment to navigator agencies for services rendered, these issues could present opportunities for system risk and potential failure within the networked structured.

In the case of quasi-governmental HIEs and HIEs that are operated as a division of a state department, the myriad of administrative rules and policies associated with administrative responsibilities can produce systemic risk. In areas like human resources, procurement of goods and services, and the political processes that must be followed for enacting change in a timely manner, the potential for systemic risk due to internal requirements is great. The effects of systemic risk can occur when failure on the part of any agency, internal or external, in a highly contracted network of interdependent agencies occurs. HIE internal or external failures that produce systemic risk could jeopardize the ability of the agency and its contracted partners to function, and the failure of any one entity could have negative implications for the full HIE agency.

3.5 Conclusion

Establishment of HIEs in all 50 states and the District of Columbia continues to be essential to the PPACA goal of providing near universal health care to all U.S. citizens. Sixteen states and the District of Columbia elected to implement State Based HIEs. All HIEs, whether State Based, State Partnerships, or Federally Facilitated will be required to carry out a set of federally mandated functions. Creating state based HIEs that can accomplish those activities is a state responsibility. Key to that responsibility is their business model and governance structure both of which are legislatively defined. HIE design and governance structures can also create barriers to effective operation.

Along a continuum of business model independence with the least independent being HIE agencies created as part of existing state departments or offices, and the greatest independence being public non-profit organizations with no governmental ties, quasi governmental agencies would likely fall midway on the scale. Ten states (59%) created quasi governmental agencies representing the majority of business entities enacted by state legislatures. This broadly popular model could likely represent a compromise on the part of legislators between no control, and too much control at the executive level. Thus, ongoing monitoring of the effectiveness of the other two models will need to occur to ensure that HIE goals and functions are not compromised.

This study sought to answer the research question: Do business model and governance structure design including governing authority composition impact the effectiveness of State Based HIE agencies? Study findings on HIE business model design, governance structure, and governing authority composition suggest that their

design model and governance structure can impact their effectiveness. To be most effective, HIEs must be apolitical agencies, be able to operate without being subject to administrative rules and regulations, and have legislatively defined strategies for sustainability funding along with the authority to collect those funds. Given that the HIE marketplace is in its initial stages, it will likely be a year or more before sufficient data is available to quantitatively measure their effectiveness.

Dependence on contractual arrangements that are essential to providing mandated services, no matter the population to be served, can create systemic risks. Such risks if proactively and timely managed and controlled can prevent failure of essential components, loss of consumer services and any potential for failure of the HIE agency.

The value of this study is that a synthesis of information on business model and governance structure designs as well as governing board composition of HIEs at their inception has been collected and will be available for future comparative evaluation of State Based HIEs. Using findings from this research as baseline provides an opportunity for re-tooling HIE design decisions as this critical component of health reform matures. Such evaluations can assist in moving towards a best practice business model and governance design that ensures continued health insurance coverage for at-risk/vulnerable populations. These research findings can also inform the federal role of state-based HIE marketplaces in moving the nation towards near universal health insurance coverage for all eligible U.S. citizens.

A limitation of this research is that it only looked at State Based HIEs. The business model and governance structure designs and governing board composition of

State Partnership and Federally Facilitated Exchanges should also be examined. Such a review could result in findings that inform business and governance designs that are unique to these particular models. Thus, a review of these models is recommended as future research. For those states that move to State Based HIE marketplaces in the near future, these research findings could be of value.

3.6 Summary

While HIEs have been established in all states and the District of Columbia not all states chose to create the same HIE model. Understanding limitations imposed by legislative design and governance decision at inception is critical to being able to evaluate HE performance in the future. Quasi-governmental entities that are apolitical, have a separate funding stream from state appropriations, have the participation of consumer and small business representatives on their governing board, and have control over administrative activities, among other measures will likely be the best positioned for effectiveness. States that have created State Based Exchanges can learn from each other how to prevent and manage risk, create and implement financing strategies for long term funding and sustainability, and learn best ways to work with CBOs and other external agencies to help achieve enrollment goals and thus the goals of the PPACA. HIE's have a major role in making health insurance coverage available and affordable for millions of U.S. citizens, and there is no other agency tasked with such an enormous responsibility and their success or failure rests with the state agencies that created their existence.

3.7 References

- Carboni, J. L., & Milward, H. B. (2012). Governance, Privatization, and Systemic Risk in the Disarticulated State. [Article]. *Public Administration Review*, 72, S36-S44.
doi: 10.1111/j.1540-6210.2012.02670.x
- CMS. (2012). *Affordable Insurance Exchanges*. Washington, DC: DHHS Retrieved from <http://www.cms.gov/CCIIO/Resources/Files/Downloads/hie-overview-presentation.pdf>.
- CMS. (2013a). Affordable Insurance Exchanges Guidance, Guidance on the State Partnership Exchange In D. o. H. a. H. Services (Ed.), *Guidance on the State Partnership Exchange* (pp. 23). Washington,DC.
- The Patient Protection and Affordable Care Act, US Government Printing Office, Pub. L. No. 111-148 906 (2010 March 23, 2010).
- DHHS. (2012a). *Patient Protection and Affordable Care Act; Establishment of Exchanges and Qualified Health Plans; Exchange Standards for Employers. Final Rules*. (CMS 9989-F). Washington, DC: United States GPO Retrieved from <http://exchange.nv.gov/uploadedFiles/exchangenvgov/Content/Resources/CMS-9989-F.pdf>.
- DHHS. (2012b). HHS Issues Final Rule to Implement Health Insurance Exchange Markets. [Article]. *Managing Benefits Plans*, 14(4), 1-3.
- DHHS. (2012c). *Federal Register / Vol. 77, No. 59 / Tuesday, March 27, 2012 / Rules and Regulations*. Washington, D.C.: Government Printing Office.

DHHS, CMS, & CCIIO. (2012d). *Cooperative Agreement to Support Establishment of the Affordable Care Act's Health Insurance Exchanges*. (FOA Number: IE-HBE-12-001

CFDA: 93.525). Washington, DC: Retrieved from

<http://www.cms.gov/CCIIO/Resources/Funding->

[Opportunities/Downloads/amended-spring-2012-establishment-foa.pdf](http://www.cms.gov/CCIIO/Resources/Funding-Opportunities/Downloads/amended-spring-2012-establishment-foa.pdf).

Elmendorf, D. W. (2010, May 20, 2010). [Congressional Budget Office Cost Estimate of H.R. 4872, Reconciliation Act of 2010].

Enthoven, A. C., & van de Ven, W. P. M. M. (2007). Going Dutch -- Managed-Competition Health Insurance in the Netherlands. *The New England Journal of Medicine*, 357(24), 2421-2423. doi: <http://dx.doi.org/10.1056/NEJMp078199>

Goodwin, W. (2010). Federal health care reform legislation establishes consumer protections, health insurance exchanges. *North Carolina Medical Journal*, 71(3), 239-242.

Henry J. Kaiser Family Foundation, K. F. (2013a). Establishing Health Insurance Marketplaces: An Overview of State Efforts Retrieved May 14, 2013, 2013A, from <http://kff.org/health-reform/issue-brief/esrtablishing-health-insurance-marketplaces>

Henry J. Kaiser Family Foundation, K. F. (2013c). State Health Insurance Marketplace Profiles Retrieved June 24, 2013, 2013, from <http://kff.org/state-health-exchange-profiles/>

- Henry J. Kaiser Family Foundation, K. F. (2013d). State Health Exchange Marketplace Profiles: Massachusetts *Health Reform*. Menlo Park, CA.
- Jost, T. S. (2013, July 15, 2010). Health Insurance Exchanges Under the Affordable Care Act: Key Policy Issues. Retrieved from <http://www.commonwealthfund.org/blog/Jul/Health-Insurance-Exchanges.aspx>
- Keith, K., Lucia, K. W., & Monahan, C. (2013, July 1, 2013). Will New Laws in States with Federally Run Health Insurance Marketplaces Hinder Outreach? Retrieved from <http://www.commonwealthfund.org/Blog/2013/Jul/Will-State-Laws-Hinder-Federal-Marketplaces-Outreach>
- Kennedy, K. (2013). Florida bans navigators from county health offices Retrieved September 13, 2013, 2013, from <http://www.lifehealthpro.com/2013/09/12/florida-bans-navigators-from-county-health-offices>
- Kingsdale, J., & Bertko, J. (2010). Insurance Exchanges Under Health Reform: Six Design Issues For The States. *Health Affairs*, 29(6), 1158-1163.
- Kreier, R., Zweifel, Peter. (2010). Health Insurance in Switzerland: A Closer Look at a System Often Offered as a Model for the United States *Hofstra Law Review*, 39(1), 23.
- Martin, A. (2013). 10 Things to Know About State Health Insurance Exchanges (pp. 10). LifeHealthPro.com: Summit Business Media.
- Merlis, M. (2009). A Health Insurance Exchange: Prototypes and Design Issues (pp. 27). Washington, DC.

- Pear, R. (2013, August 2, 2013). Missouri Citizens Face Obstacles to Coverage, *The New York Times*, p. 4. Retrieved from http://www.nytimes.com/2013/08/03/us/missouri-citizens-face-obstacles-to-coverage.html?nl=todaysheadlines&emc=edit_th_20130803&pagewanted=print
- Reinhardt, U. E. (2004). The Swiss Health System: Regulated Competition Without Managed Care. *JAMA*, 292(10), 1227-1231.
- Smith, A. (2009). Massachusetts leads health coverage - Census: Census Bureau reports that Massachusetts had the lowest 2008 rates of uninsured, while Texas had the highest. *SDpecial Report: Fixing Heathcare* Retrieved November 5, 2013, from http://money.cnn.com/2009/09/21/news/economy/census_health_insurance/
- Steinbrook, R., MD. (2006). Health Care Reform in Massachusetts - A Work in Progress. *New England Journal of Medicine*, 354(20), 4.
- Van de Water, P. N., & Nathan , R. P. (2011). Governance Issues for Health Insurance Exchanges *Health Policy Brief* (Vol. 1, pp. 12). Washington, DC: National Academy of Social Insurance.
- Van Ginneken, E., Swartz, K., & Van Der Wees, P. (2013). Health Insurance Exchanges In Switzerland And The Netherlands Offer Five Key Lessons For The Operations Of US Exchanges. [Article]. *Health Affairs*, 32(4), 744-752. doi: 10.1377/hlthaff.2012.0948
- Zemel, S., Arons, A., Miller, C., & Gauthier, A. (2012). Building a Consumer-Oriented Health Insurance Exchange: Key Issues (pp. 29). Washington, DC: National Academy for State Health Policy.

3.8 Appendix

List of Tables

Table A3-1: State Based Health Insurance Exchange Establishment
Funding By State

Table A3-2: A Summary of Select DHHS Mandated Health Insurance
Exchange Functions

Table A3-3: A Summary of Health Insurance Exchange Design Issues and
Barriers with Identified Resolutions

Table A3-4: State Based Health Insurance Exchange Business Model and
Governance Board Size by State

Table A3-5: Matrix of State Based Health Insurance Exchange Governance
Board Composition, Appointment, Apportionment, and Member
Restrictions

Table A3-6: Measures for Effective State Based Health Insurance Exchange
Business Model and Governance Structure Design

Appendix Table A3-1: State Based Health Insurance Exchange Establishment

Funding and Financing Strategies for Self Funding in 2015 By State

| <i>State (Political Leadership)</i> | <i>HIE Marketplace</i> | <i>Establishment Grant Funding as of July, 2013</i> | | <i>HIE Financing strategies for self funding in 2015</i> |
|-------------------------------------|-------------------------------------|---|-------------------------------|---|
| | | <i>Level One ¹</i> | <i>Level Two ²</i> | |
| California (D) | Covered California | \$236.8 M | \$674 M | Annual state appropriation |
| Colorado (D) | Connect for Health Colorado (C4HCO) | \$62.4 M | \$116.2 M | Fee assessments on premiums; other options under consideration |
| Connecticut (D) | Access Health CT | \$9.8 M | \$107.3 M | Fee assessment for HIE insurers |
| District of Columbia (D) | DC Health Link | \$9.2 M | \$73 M | User and licensing fees; assessments on insurers inside and outside of HIE |
| Hawaii (D) | Hawaii Health Connector | \$77.2 M | Not indicated | Assessments and fees for participating insurers; possible state appropriation |
| Idaho (R) | The Exchange Project | \$21.3 M | Not indicated | Not indicated |
| Kentucky (D) | kynect, Kentucky Health Connector | \$70.9 M | \$182.7 M | Assessments of insurers inside and outside of HIE; no state appropriation |
| Maryland (D) | Maryland Health Connection | \$34.2 M | \$123 M | Fees or assessments on HIE participating insurers |
| Massachusetts (D) | Commonwealth Connector | \$54.3 M | \$81.3 M | Initial state appropriation; now financially self-sustaining; |

| <i>State (Political Leadership)</i> | <i>HIE Marketplace</i> | <i>Establishment Grant Funding as of July, 2013</i> | | <i>HIE Financing strategies for self funding in 2015</i> |
|--|-------------------------------------|---|-------------------------------|---|
| | | <i>Level One ¹</i> | <i>Level Two ²</i> | |
| | | | | authorized to apply a surcharge to participating plans |
| Minnesota (D) | The Minnesota Insurance Marketplace | \$112.7 M | Not indicated | User fee assessed on plans sold on the exchange |
| Nevada (D) | Nevada Health Link | \$24.7 M | \$50 M | Monthly fee to insurers for each member enrolled in insurer's plan |
| New Mexico (D) | NM Health Connections | \$36 M | Not indicated | Assessments of insurers inside and outside of HIE; no state appropriation |
| New York (R) | New York State of Health | \$155.2 M | \$185.2 | Not indicated |
| Oregon (D) | Cover Oregon | \$16.7 M | \$226.4 M | Administrative fee assessed on insurer selling plans on HIE |
| Rhode Island (I) | RI Health Benefits Exchange | \$6.2 M | \$58.5 M | Receives funds from insurers or other entities |
| Vermont (I) | Vermont Health Connect | \$21.2 M | \$14.2 M | Options being considered |
| Washington (D) | Washington Health Plan Finder | \$24 M | \$127.8 | Premium tax on all plan premiums |
| ¹ Level One Funding includes \$1M in Planning Grant Funding to all states in Sept, 2010 | | | | |
| ² Level Two Funding is for outreach and marketing activities | | | | |

Source: (Kaiser Family H. J. K. F. Foundation, 2013c)

Appendix Table A3-2: A Summary of Select DHHS Mandated Health Insurance

Exchange Functions

| <i>Function Category</i> | <i>Functional Activity</i> |
|---|--|
| Administration: Administer a system of qualified health plans | <ul style="list-style-type: none"> • Certify plans that are qualified to participate in the Exchange • Rate plans based on their quality and price • Review plans' premium increases |
| Consumer Support: Support enrollment in health plans and assist consumers | <ul style="list-style-type: none"> • Facilitate initial, annual, and special open enrollment periods for individuals • Facilitate participation by small businesses in a separate Small Business Health Options Program (SHOP) Exchange or a single unified Exchange • Maintain a website that provides standardized information on the price and quality of health plans • Operate a toll-free telephone assistance line • Establish a system of Navigators, entities that will conduct consumer education activities and facilitate enrollment in qualified health plans |
| Assistance Determination: Determine eligibility for assistance in obtaining health insurance | <ul style="list-style-type: none"> • Determine which participants in the Exchange are eligible for advance premium tax credits and cost-sharing subsidies, subject to appeal of decisions to the Secretary of Health and Human Services (HHS) • Assure that eligible applicants are enrolled in the appropriate health program (Medicaid, CHIP, basic health, or Exchange subsidies) and health insurance plan • Administer the system of employee free-choice vouchers • Certify exemptions from the requirement for individuals to maintain health insurance coverage and from the penalty for failing to meet the requirement |
| Community Engagement: Consult with relevant stakeholders with regard to carrying out these activities. | <ul style="list-style-type: none"> • Develop and implement a stakeholder consultation plan • Provide culturally and linguistically appropriate outreach and educational materials to the public, including auxiliary aids and services for people with disabilities • Maintain an outreach plan for stakeholder populations including: individuals, entities with experience in |

| <i>Function Category</i> | <i>Functional Activity</i> |
|--------------------------|--|
| | facilitating enrollment such as agents/brokers, small businesses and their employees, employer groups, health care providers, community-based organizations, Federally-recognized Tribal communities, advocates for hard-to-reach populations, and other relevant populations as outlined in 45 CFR § 155.130. |

Source: (DHHS, et al., 2012d; Goodwin, 2010; Martin, 2013; Van de Water & Nathan 2011)

**Appendix Table A3-3: A Summary of Health Insurance Exchange Design Issues
and Barriers with Identified Resolutions**

| | <i>Issue</i> | <i>Resolution</i> |
|-----------|--|---|
| 1. | Governance of the Exchanges ^{1,2} | <ul style="list-style-type: none"> • Exchanges should be independent agencies • Exempt from requirements of state administrative law or government operations requirements • Governing board composition should include stakeholders, state agencies with working relationships and persons with relevant experience • Management should be apolitical and professional • Outsource services where competitive markets exist, and performance can be monitored |
| 2. | Avoidance of adverse selection through risk adjustment strategies ^{1,2} | <ul style="list-style-type: none"> • State regulation of markets outside Exchange should be identical to corresponding regulation inside the Exchange • Design a practical risk- adjustment system to discourage adverse selection against and within the Exchange |
| 3. | Making self-funded plans compatible with Exchanges ¹ | <ul style="list-style-type: none"> • Define self-funded status to clarify that substantial risk for cost of health care must be present to qualify as self-funded • Consider extending requirements of ACA to large and grandfathered plans that qualify for Exchange coverage |
| 4. | Making Exchanges attractive to employers ¹ | <ul style="list-style-type: none"> • Offer option of an aggregated bill covering the premiums of all employees • Assume the task of allocating premiums among insurers and plans chosen by individual employees • Allow a fixed percentage of premium payment option or premium share based on category and richness of coverage • Employers could offer greater support to low-income employees |
| 5. | Use of regulatory authority by Exchanges ¹ | <ul style="list-style-type: none"> • Use certification power to ensure health plans comply with statutory requirements • Give Exchanges option of being active purchasers of health plans offered on the Exchange |

| | <i>Issue</i> | <i>Resolution</i> |
|-----|---|--|
| | | <ul style="list-style-type: none"> • Allow Exchanges to lower prices to the extent that competitive market conditions allow • Standardize and limit range of plan choices to stimulate competition based on price and value |
| 6. | Determine information to be made available to consumers and employers, including range of plans and benefits to be offered ^{1,2} | <ul style="list-style-type: none"> • Make information on number of plans offered, benefits, and limitations of plans readily and easily accessible • Contractually bind plans to the information they disclose on their Web sites |
| 7. | Role of Exchange in making eligibility determinations for premium tax credits and cost-sharing reduction payments ¹ | <ul style="list-style-type: none"> • Facilitate electronic applications without need for paper documentation • Provide interim assistance when eligibility cannot be readily determined • Ensure continued enrollment of eligible individuals as a responsibility of the Exchange |
| 8. | Reduce administrative costs and ensure transparency ^{1,2} | <ul style="list-style-type: none"> • Develop revenue sources to fund the work of the Exchange (possible assessment on all insurers in the market) • Lower administrative costs for insurers and employers • Agent and broker commissions should be rational and similar regardless of plan being sold whether inside or outside of the Exchange |
| 9. | Plan Bidding and Selection ² | <ul style="list-style-type: none"> • Establish bidding processes that provide consumers with broad access to choice of providers, including wide geographic coverage • Establish processes for plan selection based on value • Establish processes that ensure fair and impartial selection of participating plans • Ensure buyers' and sellers' perceptions of fairness, value and efficiency |
| 10. | Funding of Exchange Entities | <ul style="list-style-type: none"> • Examine all strategies for funding of HIEs including: <ul style="list-style-type: none"> ○ Annual state appropriations ○ Fees levied on insurance issuers participating in the Exchange |

| | <i>Issue</i> | <i>Resolution</i> |
|------------|--|--|
| | | <ul style="list-style-type: none"> ○ Pooled administrative fee levied on all insurers approved for business in the state |
| 11. | Marketing , education and outreach campaigns ³ | <ul style="list-style-type: none"> ● Develop early marketing campaigns that: <ul style="list-style-type: none"> ○ Inform consumers and stakeholders of establish- ment and purpose of exchange marketplaces ○ Include stakeholders in consumer outreach aimed at the their specific eligible populations ○ Develop campaign and educational materials to inform at-risk/vulnerable populations at an appropriate literacy level and in culturally appropriate languages |
| 12. | Navigator selection and expertise with at-risk/vulnerable populations ³ | <ul style="list-style-type: none"> ● Contract with organizations that have demonstrated expertise in establishing relationships with at-risk/vulnerable populations |
| 13. | Web-Portal Design ³ | <ul style="list-style-type: none"> ● Create web portals that allow for easy on line shopping ● Present information that is easy to understand, and allows consumers to easily compare plans and benefits ● Portals should allow for easy updating of functionality and changing information in order to keep information current |

Source: (Jost, 2013)¹ ; (Kingsdale & Bertko, 2010)² ; (Zemel, et al., 2012)³

Appendix Table A3-4: State Based Health Insurance Exchange Business Model and Governance Board Size by State

| <i>State (Political Leadership)</i> | <i>HIE Marketplace Name</i> | <i>HIE Design</i> | |
|-------------------------------------|-----------------------------------|--|---|
| | | <i>Business Model</i> | <i>Board Size</i> |
| California (D) | Covered California | Quasi-governmental | 5-member board |
| Colorado (D) | Connect for Health Colorado | Quasi-governmental | 12-member board |
| Connecticut (D) | Access Health CT | Quasi-governmental | 14-member board |
| District of Columbia (D) | DC Health Link | Quasi-governmental | 11-member board |
| Hawaii (D) | Hawaii Health Connector | Non-profit | 15-member board |
| Idaho (D) | The Exchange Project | Quasi-governmental | 19-member board |
| Kentucky (D) | kynect, Kentucky Health Connector | Operated by State Office in cabinet for Health & Family Services | 19-member Advisory Board |
| Maryland (D) | Maryland Health Connection | Quasi-governmental | 9-member board |
| Massachusetts (D) | Massachusetts Health Connector | Quasi-governmental | 11-member board |
| Minnesota (D) | The Minnesota Marketplace | Operated by State Agency within Executive Br | 7-member board |
| Nevada (D) | Nevada Health Link | Quasi-governmental | 10-member board |
| New Mexico (R) | NM Health Connections | Non-profit public corporation | 13-member board |
| New York (R) | New York State of Health | Operated by State Division in Dept of Health | 5 Regional Advisory Committees ¹ |
| Oregon (D) | Cover Oregon | Quasi-governmental | 9-member board |
| Rhode Island (I) | RI Health Benefits Exchange | Operated by State Division in Executive Branch | 13-member board |
| Vermont (D) | Vermont Health | Operated by State | 5-member |

| <i>State (Political Leadership)</i> | <i>HIE Marketplace Name</i> | <i>HIE Design</i> | |
|-------------------------------------|-------------------------------|---|---|
| | | <i>Business Model</i> | <i>Board Size</i> |
| | Connect | Division in Dept of VT Health Access | board |
| Washington (D) | Washington Health Plan Finder | Quasi-governmental | 11-member board |
| | | Quasi-governmental (n=10) Operated by State (n=5) Non-Profit (n=2) | Mean = 10.93 ¹ Excluded based on size |

Source: (H. J. K. F. Foundation, 2013c)

Appendix Table A3-5: Matrix of State Based Health Insurance Exchange Governance Board Composition, Appointment Apportionment, and Member Restrictions

| <i>State</i> | <i>Board Size</i> | | | <i>Apportioned Appointments</i> | | | <i>Legislatively Required Appointments</i> | | <i>Board Composition Restrictions</i> |
|--------------|--------------------|---------------|-------------------|---------------------------------|--------------------|--------------|--|--------------------------------|---|
| | <i>Total Board</i> | <i>Voting</i> | <i>Non-Voting</i> | <i>Governor</i> | <i>Legislature</i> | <i>Other</i> | <i>Consumer Interest</i> | <i>Small Business Interest</i> | |
| CA | 5 | 5 | - | 2 | 2 | 1 | No | No | <ul style="list-style-type: none"> - Expertise in key subject areas loosely defined - Restrictions on affiliations while on the board - Four key stakeholder advisory groups created including a Tribal Group |
| CO | 12 | 9 | 3 | 5 | 4 | 3 | No | No | <ul style="list-style-type: none"> - Expertise in key subject areas loosely defined - Restrictions loosely defined |
| CT | 14 | 12 | 2 | 2 | 6 | 6 | Yes | Yes | <ul style="list-style-type: none"> - Expertise in key areas specifically defined - Consumer groups concerned re: board member affiliations with insurance industry and under representation of consumer and small businesses - Restrictions on affiliations while on the board |
| DC | 11 | 7 | 4 | 7 | - | 4 | Yes | Yes | <ul style="list-style-type: none"> - Appointments by Mayor with confirmation by Council - Broad range of expertise required and specifically defined |
| HI | 15 | 11 | 4 | 15 | - | - | No | No | <ul style="list-style-type: none"> - All board members appointed by Governor with consent of Senate |

| <i>State</i> | <i>Board Size</i> | | | <i>Apportioned Appointments</i> | | | <i>Legislatively Required Appointments</i> | | <i>Board Composition Restrictions</i> |
|--------------|--------------------|---------------|-------------------|---------------------------------|--------------------|--------------|--|--------------------------------|--|
| | <i>Total Board</i> | <i>Voting</i> | <i>Non-Voting</i> | <i>Governor</i> | <i>Legislature</i> | <i>Other</i> | <i>Consumer Interest</i> | <i>Small Business Interest</i> | |
| ID | 19 | 17 | 2 | 14 | 3 | 2 | No | No | - Expertise in broad areas of health |
| KY | 19 | 19 | - | 16 | - | 3 | 3 | 1 | - Board is Advisory with broad expertise in areas of health - Commissioner of Department of Insurance serves as Chair of Board - Strong consumer representation on board |
| MD | 9 | 9 | - | 6 | - | 3 | No | No | - Expertise in broad areas of health, not specifically defined - Restrictions on affiliations while on board |
| MA | 11 | 11 | - | 4 | - | 7 | Yes | Yes | - Appointments apportioned by legislative action - Restrictions on employment and affiliations in health & insurance markets |
| MN | 7 | 7 | - | 6 | - | 1 | 2 | 1 | - Board members appointed by Governor with consent of Senate - Restrictions on employment and affiliations in health & insurance markets |
| NV | 10 | 9 | 3 | 7 | 2 | 3 | Yes | Yes | - Broad range of expertise required and specifically defined - Restrictions on affiliations while on board |
| NM | 15 | 13 | 2 | 6 | 6 | 3 | Yes | No | - Legislation requires representation of state's Native American population - Conflict of interest provisions are legislatively not very |

| <i>State</i> | <i>Board Size</i> | | | <i>Apportioned Appointments</i> | | | <i>Legislatively Required Appointments</i> | | <i>Board Composition Restrictions</i> |
|--------------|--------------------|---------------|-------------------|---------------------------------|--------------------|--------------|--|--------------------------------|---|
| | <i>Total Board</i> | <i>Voting</i> | <i>Non-Voting</i> | <i>Governor</i> | <i>Legislature</i> | <i>Other</i> | <i>Consumer Interest</i> | <i>Small Business Interest</i> | |
| | | | | | | | | | restrictive |
| NY* | - | - | - | - | - | - | Yes | Yes | - Range of expertise very general and broad in the area of health - Governance by 5 Regional Advisory Committees with 180 members |
| OR | 9 | 9 | - | 7 | - | 2 | Yes | Yes | - Board members appointed by Governor with consent of Senate - Board range of expertise is broad and specifically defined - Restrictions on employment, consulting delineated |
| RI | 13 | 13 | - | 9 | - | 4 | 2 | 2 | - Broad range of expertise required and specifically defined - Restrictions on employment and affiliations while on board |
| VT | 5 | 5 | - | 5 | - | - | No | No | - Chair and all members of the Board are state employees |
| WA | 11 | 9 | 2 | 9 | - | 2 | No | No | - Governor's appointments from list of nominees from 2 largest caucuses in House and Senate - Governor appoints Chair |

Source: Kaiser State HIE Profiles (2013)

**Table 3-6: Measures for Effective State Based Health Insurance
Exchange Business Model and Governance Structure Design**

| | <i>Design Measure ¹</i> | <i>Percent (#) of HIEs</i> |
|--|--|--------------------------------|
| Business model | 1. Be independent of legislative or state administrative requirements, rules or regulations for their operation (quasi-governmental or non-profit) | 71% (12) |
| Business model | 2. Be apolitical and free of the influence of elected officials. | 59% (10) |
| Governance | 3. Have governing board appointments that legislatively require both consumer and small business representation. | 47% (8) |
| Business model /financing | 4. Have financing strategies for sustainability that are legislatively defined. | 82% (14) |
| Business model /financing | 5. Have the authority to implement sustainability strategies. | 82% (14) |
| Business model | 6. Have the flexibility to develop external relationships that allow it to meet its goals in a timely manner with no political interference. | 71% (12) |
| Governance | 7. Apportionment of board member selection is a mix of executive and legislative branch power. | 35% (6) |
| | | |
| ¹ Measures are based on findings reported by researchers whose work is presented in this study. | | |

CHAPTER 4

THE IDENTIFICATION OF TRADITIONAL NAVIGATOR PROGRAM STRATEGIES TO INFORM HEALTH INSURANCE EXCHANGE NAVIGATOR PROGRAMS FOR OUTREACH, EDUCATION AND ENROLLMENT OF VULNERABLE POPULATIONS IN APPROVED HEALTH PLANS²

² Waldrop, Reinetta T., Lee, J., Hou, SU-I, Harris, C., Murray, D. (2013).
To be submitted to the Journal of Health Care for the Poor and Underserved

4.0 Abstract

Health Insurance Exchanges (HIEs) were created under the Patient Protection and Affordable Care Act of 2010 to serve as public marketplaces for the purchase of health insurance coverage by uninsured U.S. citizens. To identify and serve eligible individuals, HIEs were mandated by federal statute to establish navigator programs that would provide outreach, education and enrollment of uninsured and at-risk/vulnerable populations into affordable health plans. HIE navigator programs are designed to assist consumers in understanding the wide variety of health plan options available and to help guide them in selecting health plans that meet their needs. To carry out these mandated functions, HIEs are required to contract with community based organizations, consumer advocacy agencies, and other social service agencies to serve as navigator programs. For decades, patient navigator programs have successfully facilitated the delivery of clinical health services to at-risk/vulnerable populations. Their use of certain strategies to guide vulnerable individuals through complex health systems to receive the care and services they need has proven successful. It is theorized that to guide the same at-risk/vulnerable groups through a complex public health insurance market and enroll them in qualified health insurance plans, identification and application of the same successful navigation strategies is necessary. This research examined the kinds of vulnerable populations served by navigator programs, the personal and professional characteristics needed in a navigator to successfully carry out their role, and identified the strategies used by traditional navigator programs to support patients and facilitate care. This research resulted in the development of a typology of those successful strategies.

Findings showed that programs which used strategies such as advocacy, education, logistical support, and other facilitative approaches, along with racial, ethnic, and cultural concordance were successful in increasing patient compliance, treatment and care, and health outcomes. Also, using navigators who had experienced the same illness added trust to the navigation process and to the ability of patients to engage in a supportive relationship. Because HIE's will engage in providing navigator services these findings will inform their use of strategies that will prove successful in reaching, educating and enrolling the same at-risk/vulnerable populations into affordable health insurance plans that will provide access to care and improve their health outcomes.

Keywords: patient navigation programs, navigator services, navigator strategies, vulnerable populations, at-risk populations, access to care, medically underserved, health disparities.

4.1 Introduction

Estimates are that there are over 40 million uninsured individuals in the U.S. (S. R. Collins, Robertson, R., Garber, T., Doty, M.M., 2013; Cunningham, 2010). This includes vulnerable and at-risk/vulnerable populations who have traditionally been excluded from the health insurance market. Their exclusion has generally been due to socio-economic, financial, and medical conditions that have precluded their ability to afford health coverage. Serving as public marketplaces for the purchase of affordable health insurance, HIEs are key factors in enrolling these individuals into qualified non group health plans.

To reach uninsured and at-risk/vulnerable populations, the law requires HIEs to establish navigator programs. HIEs will use community based organizations, consumer advocacy agencies and social service organizations to serve in this role. As navigator programs, they will be responsible for facilitating outreach, education, and enrollment of eligible individuals into health plans offered through the exchange.

Despite the fact that navigator programs have been used for decades to facilitate the delivery of clinical health services, researchers generally agree that there is no one single definition for what a navigator program is, or for what it does ((Darnell, 2007; Dohan & Schrag, 2005). However, for this research patient navigator programs that have traditionally facilitated the delivery of clinical care services will be defined as traditional navigator programs. HIE navigator programs will be defined as federally mandated programs for the facilitation of outreach, education, and enrollment of at-risk/vulnerable populations into qualified health insurance plans.

The use of traditional navigator programs to assist in the receipt of health services is not a new concept in health service delivery. In fact, the use of these programs to ensure the delivery of clinical care for illnesses such as cancers where research has documented disparities in treatment and care has been a longstanding practice (Dohan & Schrag, 2005; Dudley et al.; Duggan, et al., 2012; Ferrante, et al., 2008). These traditional programs have been most effective in serving the needs of at-risk/vulnerable populations. In particular, they have facilitated treatment and care for breast and cervical cancers in racial and ethnic minority women, prostate cancer in men, and colorectal cancer in minority populations, and have helped to improve cancer screening, cancer outcomes,

and mortality rates of these at-risk/vulnerable groups (H.P. Freeman, 2006; Garza, et al., 2005; Hansen, et al., 2005; Jandorf, et al., 2005; Lasser, et al., 2009). The at-risk/vulnerable populations served by traditional navigator programs are the same at-risk/vulnerable populations that HIEs are tasked with enrolling into qualified health plans. They include low income and uninsured individuals, African Americans, Hispanics, Asian women, Native U.S. citizens, HIV/AIDS patients, and rural populations. For these populations, the socio-economic status (SES) indicators that generally define them as vulnerable such as age, race, ethnicity, poverty, education levels, limited English proficiency, cultural experiences, and unemployment, are generally the same social and socio-economic factors that underlie the social determinants of their health. Thus, using strategies to guide patients through care systems that are fragmented, confusing, and inexperienced in serving at-risk/vulnerable populations is essential to ensuring that vulnerable individuals receive the health care services they need. The literature on this topic is extensive and a set of clear consistent strategies has evolved.

While not officially termed navigator programs, public and private organizations like the American Association of Retired Persons, officially sanctioned union organizations, and certain group purchasing insurance plans have used the concept of navigation in their outreach efforts. While more passive than active in their engagement of specific populations, their efforts generally involve the use of passive techniques such as marketing activities to enroll targeted groups of individuals into group insurance plans. While not an active technique involving direct one-on-one engagement, the use of navigator like programs outside the field of health service delivery aimed at enrolling

individuals into insurance programs has been a long standing practice. Also, the individuals targeted through these programs are generally already insured such that the aim is to get individuals to change over to new plans. Thus, the strategies they use would most likely not be successful with uninsured, at-risk/vulnerable populations.

Navigator programs in HIE marketplaces, while not delivering patients to a point of service for the provision of care, will nonetheless guide and facilitate the same kinds of socially, culturally and medically vulnerable individuals to enroll in health insurance plans. To be successful it is theorized that HIE navigator programs would need to implement many of the characteristics and strategies successfully used to facilitate vulnerable individuals into programs of clinical care. HIE navigator programs will be responsible for guiding vulnerable individuals through an insurance market with which they are unfamiliar. As is the case with traditional navigators that guide patients through their choice of treatment and care options, HIE navigators will educate and guide at-risk individuals through a choice of health plan options.

Estimates are that millions of uninsured and vulnerable individuals will be eligible for various health plan options offered through the HIE marketplace (S. R. Collins, Robertson, R., Garber, T., Doty, M.M., 2013; Cunningham, 2010). Thus, they will need to be guided through the maze that will characterize exchange marketplaces and through the multiple health plan options that will exist. Traditional navigator programs have successfully engaged individuals who have never had access to treatment and care for their illness, and whose education, literacy levels, and cultural diversity have made it difficult for them to navigate health care systems. Similarly, HIE navigator programs

will need to be successful in engaging individuals who have never had insurance coverage, and whose education, literacy levels, and cultural and linguistic diversity require decision making support. Following the strategies that have been used by traditional navigator programs could ensure the success of HIE navigator programs.

This research will explore the long history of using navigator programs in health services delivery. It will look at how traditional navigator program have served as facilitative tools in helping individuals to access health care, and it will examine the strategies used to successfully serve those individuals. It will also explore the kinds of personal and professional characteristics required of patient navigators to make them successful in one-on-one patient engagement.

This research also seeks to answer the question: Do traditional navigator programs that facilitate health service delivery to at-risk/vulnerable populations provide evidence of proven strategies that can be used by State Based HIE navigator programs for outreach, education and enrollment of at-risk/vulnerable individuals into qualified health plans? Study findings will inform the development of a typology of successful navigator strategies that are expected to aid in building a case for why those strategies should be considered by HIEs when carrying out their mandate for outreach, education and enrollment of at-risk/vulnerable populations.

4.2 Literature Review

The use of HIE navigator programs to facilitate health insurance coverage is critical to meeting the unmet medical needs of uninsured and at-risk/vulnerable populations. Because of the Patient Protection and Affordable Care Act (PPACA) for the

first time in this country's history, a government agency will be tasked by federal law to provide health insurance coverage for millions of at-risk individuals whose health care needs have gone unmet for decades, and for some a lifetime. However, in order to understand the significance of this health reform mandate, it is important to understand what makes millions of individuals vulnerable. Understanding the risk factors that have contributed to their vulnerability, the barriers they face in accessing quality, affordable health care services and the implications of those vulnerabilities on their personal health are critical to HIEs successfully enrolling millions of uninsured individuals into health insurance plans.

Definition of At-Risk/Vulnerable Populations

The Department of Health and Human Services (DHHS) does not provide a formal definition for at-risk/vulnerable populations in any of the guidance it has prepared for establishment of HIE navigator programs. This research will therefore use the CDC definition for at-risk/vulnerable populations, that being "...[populations] defined by socio-economic status, geography, gender, age, disability status, risk status related to sex and gender, and among other populations identified to be at-risk for health disparities" (CDC, 2013). For this study, and as used in the CDC definition, the terms at-risk populations and vulnerable populations are used interchangeably, and refer to those individuals or groups noted in the CDC definition with the exception of geography and disability status. When citing an article or report, the term used by the author will be applied. However, in broadly referring to either group the term at-risk/vulnerable population(s) will be used. Also, because elderly individuals and children are generally

covered by Medicare, Medicaid, or State Children's Health Insurance Programs they will not be included in the definition of at-risk/vulnerable populations used for this research. Thus, this research will focus on uninsured individuals 19-64 years of age, and low-income, racial and ethnic minority groups, culturally diverse groups with limited English proficiency, and groups with chronic medical conditions that render their receipt of care especially burdensome without support and advocacy.

Risk Factors Characteristic of At-Risk/Vulnerable populations

At-risk/vulnerable populations in the U.S. have always been at greater risk for poor health outcomes. On a continuum from poor to excellent, studies show that the single most long term contributor to individual health is socio-economic status (H.P. Freeman, 2004; Steinberg, et al., 2006; Vargas, Ryan, Jackson, Rodriguez, & Freeman, 2008) The socio-economic indicators that generally define at-risk/vulnerable populations such as age, race, poverty, education, unemployment, environmental infrastructure, low literacy, and cultural experiences are the same social and socio-economic factors that underlie the social determinants of their health (Biedrzycki, 2012). Additional risk factors are directly related to care delivery systems and include barriers that impede timely access to care, affordability of care, and the quality of care provided. Thus, individuals who are vulnerable for poor health are vulnerable for a variety of reasons, including ones that are beyond their immediate and long-term control.

An abundance of literature exists that investigates the association between SES risk factors, and vulnerability and being uninsured (Baker, et al., 2005; H. J. K. F. Foundation, 2012a; Mechanic & Tanner, 2007; Rogers, 1997). In addition, models have

been developed to study why at-risk/vulnerable groups tend to have poorer access to care and poorer health status. Most models focus on a one-dimensional explanation, i.e. risk factors only. Shi and Stevens (2010), however, have developed a model that considers the interconnectivity between all risk factors, personal and system, and vulnerability (Shi & Stevens, 2010). Additionally, they offer a conceptual framework that adds “access to care risk factors” thereby recognizing that together SES and access add to the vulnerability of individuals and the community as a whole (Shi & Stevens, 2010). Their conceptual framework adapted to this research is presented in the Appendix as Figure A4-1.

Race, ethnicity, age, gender, poverty, unemployment, lack of education, low literacy and cultural experiences are common socio-economic risk factors that play a role in creating vulnerability to health care. These risk factors place individuals at a disadvantage when seeking health services, and as a result contribute to disparities in health outcomes. Also, the presence of one risk factor increases the probability of having other risk factors, and the cumulative effect increases vulnerability and leads to poor health outcomes (Shi & Stevens, 2010). Studies have shown that these risk factors are greatest for low-income and minority populations, and generally result in delayed access to health care services (Schoen, et al., 2013; Shi & Stevens, 2010). Persons with low socio-economic status have been found to be at greater risk for heart disease, certain cancers, obesity, arthritis, chronic diseases, and other health related illnesses (CDC, 2009b; Schoen, et al., 2013).

Race, Ethnicity, and Poverty as Risk Factors. Race and ethnicity are considered characteristics of vulnerability that impact health because certain racial and ethnic groups have higher rates of morbidity and mortality. Included in these groups are African Americans, Hispanics, American Indians, Native Alaskans, and immigrant groups from African and Southeast Asian countries (CDC, 2009b). In general, rates of amenable mortality, i.e. death from illness that is preventable given timely access to prevention and treatment, are higher among African Americans than any other racial group (E. Nolte & McKee, 2008; Schoen, et al., 2013; S. C. Schoenbaum, et al., 2011a; Shi & Stevens, 2010).

As a risk factor, poverty results in a lack of financial resources needed to access systems of care and to maintain personal health. According to Shi & Stevens (2010), “Poverty compounds the problems that minorities face in securing a regular source of health care” (Shi & Stevens, 2010). When comparing race/ethnicity, insurance coverage and regular source of care by poverty status, Shi and Stevens (2010) found that Hispanics with incomes less than 100% of the poverty level were 47% more likely to *not* have a regular source of health care. This compared to 27% for non-Hispanic Blacks, and 25% for non-Hispanic Whites. Even at income levels 200% or higher than federal poverty levels, the Hispanic rate of 24% was twice the rate of non-Hispanic Whites (12%) and almost twice the rate of non-Hispanic Blacks (12%) (Shi & Stevens, 2010). These rates confirm the relationship between race, poverty and lack of insurance, indicating that multiple risk factors can increase individual vulnerability and have a negative effect on access to care.

Education as a Risk Factor. Education has been identified as a significant risk factor for poor health outcomes (Cutler & Lleras-Muney, 2007; Mechanic & Tanner, 2007; Rogers, 1997; Schoen, et al., 2013). Shi and Stevens (2010) report that educational level is a strong predictor of health status, morbidity and mortality (Shi & Stevens, 2010). Individuals with higher levels of education are better able to navigate the health delivery system, improving their ability to seek preventive health services, thus maintaining optimal levels of health (Rogers, 1997). In its study of education as a risk factor for health outcomes The National Center on Poverty tested the relationship between health and education using data from the National Health Insurance Survey (NHIS). Study results showed that:

- Better educated people have lower morbidity rates from the most common acute and chronic diseases, independent of basic demographic and labor market factors.
- Life expectancy is increasing for everyone in the United States, yet differences in life expectancy have grown over time between those with and without a college education.
- Health behaviors alone cannot account for health status differences between those who are less educated and those who have more years of education.
- The mechanisms by which education influences health are complex and are likely to include (but are not limited to) interrelationships between demographic and family background

indicators, effects of poor health in childhood, greater resources associated with higher levels of education, a learned appreciation for the importance of good health behaviors, and one's social networks (Cutler & Lleras-Muney, 2007).

Cutler and Lleras-Muney further report that: "More education reduces the risk of heart disease by 2.2 percentage points (relative to a base of 31%) and the risk of diabetes by 1.3 percentage points (relative to a base of 7%). An additional four more years of schooling lowers the probability of reporting being in fair or poor health by 6 percentage points (the mean is 12%), and reduces lost days of work to sickness by 2.3 days each year (relative to 5.2 on average)" (Cutler & Lleras-Muney, 2007). *Unemployment as a risk factor*. Employment is strongly tied to education and income. Individuals with higher levels of education are generally more able to obtain higher paying jobs, which generally result in higher incomes. Higher paying jobs are often managerial or professional in nature and in 2009 jobs in this category had an unemployment rate of 1.6% (Shi & Stevens, 2010). In general, minorities are most likely to be employed in service industry or blue-collar type jobs which offer lower wages and have higher unemployment rates (5.3% and 6.3% respectively) (Shi & Stevens, 2010). When comparing health insurance coverage between these job categories, Shi and Stevens report that health coverage offered in service and blue-collar jobs will tend to be "much less comprehensive, [with] employees having to pay a greater share of the cost" (Shi & Stevens, 2010). Additionally, rates of unemployment have been shown to be higher among minority groups than Whites. In 2009, rates of unemployment among African Americans at 15.3%

and Hispanics at 12.4% were significantly higher than rates for Whites at 8.7%. The only minority groups reported to have an unemployment rate lower than Whites were Asian and Pacific Islanders at 7.5%.

System and Financial Barriers Contributing to Vulnerability. Unmet needs are not just impacted by individual risk factors, but are also impacted by system barriers. System barriers to vulnerability include factors such as access to health care facilities, the availability of quality services, geographic location, transportation, the availability of needed specialty services, and the cost of medical tests and prescription drugs. These barriers greatly impact a vulnerable person's ability to have health care experiences that result in positive health outcomes.

Financially, while publicly funded programs have been in place to provide health coverage for certain at-risk/vulnerable groups, eligibility rules have excluded millions of others from participation. Additionally, the high cost of health insurance premiums through employer benefit plans, has left both businesses and their employees without affordable options for health insurance coverage. A lack of insurance impacts a person's ability to access needed medical services and when accessed, unpaid medical bills can affect their long term financial security (H. J. K. F. Foundation, 2012a). Trust for America's Health reports that in 2008, the rate of uninsurance among white U.S. citizens was 13% while the rate for African Americans was 22%. Among the Hispanic population, that rate was reported to be 36% (Trust, 2008). The burden of medical bills and unresolved medical debt can cause uninsured individuals to not seek care or to forego needed medications.

Medical Risk Factors: The incidence and prevalence of chronic diseases among at-risk/vulnerable populations has been on a steady rise. The CDC reports that chronic diseases include medical illnesses such as heart disease and stroke, certain cancers, diabetes, arthritis, obesity, and respiratory diseases such as asthma (CDC, 2009b). The 2009 CDC report found that:

- among U.S. citizens, seven out of ten deaths each year are from chronic diseases;
- In 2005, almost one out of every two adults had at least one chronic illness;
- Health disparities in chronic disease incidence and mortality are widespread among members of racial and ethnic minority populations; and
- When compared to whites, African Americans have a higher rate of death from heart disease; and American Indians and Alaska Natives have substantially higher rates of diabetes (CDC, 2009b).

The CDC reports that more than 75 percent of the nation's health care spending is related to chronic conditions (CDC, 2009b). A 2009 report showed that between FY2000 and FY2009 more than \$755 billion dollars was spend on chronic disease conditions known to disproportionately impact the health of at-risk/vulnerable populations (CDC, 2009b). Cunningham reports that "Almost 40% of uninsured people eligible to receive subsidizes through the exchanges have chronic conditions or report fair or poor health..." (Cunningham, 2010). Clearly, the medical risk factors for at-risk/vulnerable populations exceed those of other population sub-groups, making them more vulnerable to conditions that increase morbidity and mortality. Given the disproportionate impact of chronic

disease on uninsured and at-risk/vulnerable populations, at-risk individuals will benefit most from the PPACA mandate that prohibits insurance carriers from denying health insurance coverage based on pre-existing conditions.

Health Coverage under the PPACA Programs

Traditional programs such as Medicare, Medicaid and the State Children's Health Insurance Plan (SCHIP) have provided health insurance coverage for decades that has positively impacted the health of the at-risk/vulnerable populations they are intended to serve.

Two years after its passage, Medicare covered 19.5 million enrollees; in 2009, that number had increased to 46.3 million (Shi & Singh, 2012). In 2009 Medicaid served 60 million low-income women and children (Shi & Singh, 2012). It provides a minimum set of services mandated by the federal government and required for receipt of federal fund matching. In 1996, one year prior to passage of the SCHIP, it was estimated that there were 10.1 million uninsured children in the U.S (Shi & Singh, 2012). According to the Children's Defense Fund that number was reduced to 7.2 million uninsured children in 2011 (Buist, 2012). The Defense Fund expects that with the removal of bureaucratic barriers, 95% of all children will be eligible for health insurance coverage under the PPACA (Buist, 2012).

Research has shown that these programs have reduced morbidity and mortality and improved the health outcomes of the elderly, low-income, and at-risk children. By extension, the potential for health insurance coverage through HIE subsidized health

plans to improve the health of millions of uninsured and vulnerable individuals seems reasonable.

Potential for a Reduction in Vulnerability

Reforms under the PPACA will have the combined effect of creating a more improved health care environment for access to quality, affordable health care. However, the reform feature that bans the denial of health insurance coverage for pre-existing conditions will be especially important for vulnerable individuals with medical conditions for which they have never sought care. In a survey of uninsured adults, 40% of whom will be eligible for subsidized premiums, Cunningham (2010) reports that over a one year period, 65.7% did not get, or delayed getting, needed medical care, generally for chronic medical conditions such as diabetes, hypertension, heart disease, and cancer. Additionally, 57% reported problems paying medical bills, preventing them from seeking care for existing illnesses (Cunningham, 2010). Thus, removing the ban on health insurance coverage for pre-existing conditions reduces vulnerability by ensuring that uninsured and at-risk/vulnerable groups will be able to get care for medical problems that have impacted their overall health status for many years.

Under the PPACA health coverage for all U.S. citizens is mandated. However it will be up to HIE navigator programs to identify at-risk/vulnerable populations and perform the outreach, education and enrollment activities mandated by the law.

Traditional Navigator Programs in Health Care Service Delivery

For decades, patient navigator programs have been viewed as a necessary approach to reducing racial, ethnic, and cultural barriers to health service delivery and to disparities in health outcomes (Darnell, 2007; H.P. Freeman, 2004; Petereit, et al., 2008; Steinberg, et al., 2006; Vargas, et al., 2008; Wolff, et al., 2003). The need for such programs, particularly around the issue of cancer and its disparate outcomes, has been widely acknowledged by presidential administrations and non-profit organizations.

Recognition at the federal level started in 1971 with President Richard Nixon's War on Cancer, and his signing of the National Cancer Act (Harold P. Freeman & Rodriguez, 2011). Later, the American Cancer Society published its 1989 *Report to the Nation on Cancer in the Poor in 1989*, citing issues and barriers to care in response to testimony from poor U.S. citizens who had been diagnosed with cancer (H.P. Freeman, 2004). Later, through passage of the Patient Navigator Outreach and Chronic Disease Prevention Act of 2005 (P.L. 109-18) President George W. Bush made \$25 million dollars available for patient navigator demonstration programs aimed at improving the health outcomes of underserved communities (Darnell, 2007). At the time, this act was viewed as the largest single coordinated commitment at the federal level to patient navigation (Darnell, 2007). Today, through the PPACA signed by President Barack Obama in 2010, \$3.5 million dollars was allotted for fiscal year 2010, and additional authorization continues through 2015 for the extension of patient navigator programs (U.S. Congress, 2010). For decades recognition at the federal level of the value of patient navigator programs with funding for their implementation has continued.

Decades of funding have given rise to numerous articles addressing the use of navigator programs to support at-risk/vulnerable groups. Studies show that effective strategies must embrace concepts such as cultural competency, ethnic concordance, coordination of services, advocacy, building trust, knowledge management of services and resources, easy accessibility for clients, counseling, communication skills, appropriate literacy levels, competency testing, specialized training, continuing education, access to technology and electronic resources, the use of individuals who can connect with and positively relate to the populations being served, and the ability of navigators to educate individuals on a level that they understand (Brooks & Kendall, 2012; Dohan & Schrag, 2005; Edlin, 2013; Ferrante, et al., 2008; Ferrante, et al., 2011; Fillion et al., 2012; Fischer, Sauaia, & Kutner, 2007; H.P. Freeman, 2004; Harold P. Freeman & Rodriguez, 2011; Garza, et al., 2005; Hook, et al., 2012; Hunter, et al., 2004; Institute, 2005; Jandorf, et al., 2005; Nonzee, et al., 2012; Saly, 2013; Wujcik, 2011). These concepts are also viewed as characteristics that patient navigators must personally be able to exemplify in order to successfully carry out their duties and responsibilities and engage patients in a supportive relationship. Researchers found that navigators who consistently exhibited these characteristics were more likely to develop engaging and long lasting relationships with patients, These relationship generally resulted in improved compliance with scheduled and recommended treatments, increase adherence to treatment and medication protocols, improved health outcomes, and high levels of patient satisfaction with navigators and the services they provided (Brooks & Kendall, 2012; Dohan & Schrag, 2005; Ferrante, et al., 2011; Fischer, et al., 2007). In each study,

connecting with the populations to be served by understanding who they were and the circumstances that contributed to their vulnerability increased the success of the navigator program.

The first navigator program, as we know it today, was implemented with funding from the American Cancer Society, in New York's Harlem community in 1990 to facilitate breast cancer treatment in minority women (H.P. Freeman, 2004, 2006). Prior to the implementation of the Harlem Hospital Center Breast Cancer Screening and Patient Navigation Program, from 1964 to 1986, 606 patients, 94% (570) of whom were African American were treated for breast cancer at Harlem Hospital Center (H.P. Freeman, 2004). The majority of patients were low SES, with almost 50% having no health insurance coverage. Nearly half of patients presented with late Stage 3 and Stage 4 breast cancer, incurable at diagnosis, with only 6% diagnosed as Stage 1 or early breast cancer. Compared to a five year survival rate of nearly 60% at the time for White American women, the survival rate for these patients was determined to be 39% (H.P. Freeman, 2004). This made clear the fact that "Late diagnosis and treatment at an incurable stage of the disease is [a] principal cause of death" (H.P. Freeman, 2004).

With implementation of the patient navigator program to support access to screening and assistance in navigating the health care system, in five years from 1995 to 2000, the five year rate of survival for this at-risk group was estimated to be 70% (H.P. Freeman, 2004). Assisting in removing financial, communication, information, emotional, and medical barriers, as well as addressing issues of fear and distrust were key elements of the Harlem navigator program (Harold P. Freeman & Rodriguez, 2011).

The “Harlem Experience” provided proof that navigator programs were effective in reaching hard to reach populations to facilitate the delivery of health services and for improving health outcomes.

Studies have shown that significant disparities continue to exist in cancer prevention, treatment and follow-up care for at-risk/vulnerable populations, particularly for breast and cervical cancers in African American women, Hispanic women, American Indians, Alaska Natives, and Asian and Pacific Islander women (Moy & Chabner, 2011; Steinberg, et al., 2006; Wolff, et al., 2003). In addition, cancers have been reported to be the leading cause of death for Asian American men and women (Nguyen & Kagawa-Singer, 2008). Hispanic women are reported to have the highest incidence of cervical cancer, with an age adjusted incidence of 12.5 cases per 100,000 women (Duggan, et al., 2012). This compares to an incidence of 7.0 per 100,000 for non-Hispanic Whites. Also, mortality associated with cervical cancer among Hispanics is 2.9 per 100,000 versus 2.1 per 100,000 for non-Hispanic Whites (Duggan, et al., 2012). In addition, African American males have been found to be at greater risk for prostate cancer, having a mortality rate as much as 2.4 times greater than their white counterparts (Nonzee, et al., 2012). However, the largest disparities in cancer have been found among American Indians (AI).

In the Northern Plains area of South Dakota the cancer mortality rate among this subgroup is 40% higher than that of the overall U.S. population. Also, the age adjusted cancer mortality for this same AI population stands at 232 per 100,000 as compared to 166 per 100,00 for the general population (Petereit, et al., 2008). For all of these

referenced subgroups disparities have led to increased mortality, due mainly to an inability to access quality, affordable care in a timely manner (Battaglia, et al., 2007).

Barriers Addressed by Navigator Programs

Studies have shown that navigator programs are successful in removing a number of barriers that impede a patient's ability to access and navigate a care system. Many of these barriers are logistic, cultural, educational, financial, and communicative in nature. To address these barriers, patient navigators (PNs) receive training in the most effective way to advocate for patients and to facilitate their movement through delivery systems that oftentimes are new to them (Percac-Lima, et al., 2009). Table 4-1 describes the most common barriers that navigator programs aim to remove as identified by Dohan and Schrag (2005) and Wolff, et al. (2003).

Patient Navigator Programs for Cancer

Breast Cancer. The good news is that there has been an overall decline in the rate of mortality from breast cancer over the last 20 years. This decline has been due mainly to improvements in early screening and detection and to advances in treatment and care (Schlueter, et al., 2010). The bad news however, is that these same studies show that not all women have benefited equally from these improvements. It has been shown that while White women are diagnosed at a higher rate than minority women, African American women have a higher rate of mortality due to late stage diagnosis (Schlueter, et al., 2010).

Table 4-1: Barriers Addressed by Navigator Programs to Facilitate Care

| <i>Barriers</i> |
|--|
| 1. Financial concerns including not being able to afford treatments as a result of being uninsured or under insured through publicly funded insurance programs such as Medicaid |
| 2. Lower levels of health literacy or education that contribute to fears associated with screening and or diagnosis |
| 3. Cultural orientations that contribute to a distrust of medical institutions and medical providers |
| 4. Fear emanating from the presence of multiple medical conditions or fatalism regarding a particular illness |
| 5. Logistical barriers associated with transportation child-care, clinic schedules, work schedules, rural residence, and geographic location of medical facilities |
| 6. Difficulties negotiating relationships with providers or healthcare organizations due to language or cultural differences |

Source: (Dohan & Schrag, 2005; Wolff, et al., 2003)

In an evaluation of the Avon Foundation Community Education and Outreach Initiative (CEOI) Patient Navigation Program, Schlueter et al. (2010) found that using PNs who were breast cancer survivors to help navigate newly diagnosed breast cancer patients was highly successful (Schlueter, et al., 2010). In a study of 18 low SES minority breast cancer patients, participants reported the strengths of the program to be: 1) the educational guidance provided by the PN; 2) the emotional and spiritual support from someone who had experienced their illness; and 3) the consistent availability of their PN to answer questions, attend treatment sessions, and guide them through tasks such as making appointments, arranging transportation, providing follow-up calls, and

assist with questions from providers (Schlueter, et al., 2010). The authors noted that a weakness of the program was the enrollment process. Patients reported having confusing experiences and were not able to recall when or whether they were officially enrolled in the program (Schlueter, et al., 2010). While the most positive aspect of the program was the PN/patient relationship that developed, the program's administrative problems with the enrollment process are something that should be considered when designing HIE enrollment processes. Despite the weakness noted in the enrollment process, this study provides evidence that the use of PNs to help patients navigate medical services and administrative barriers to facilitate care and treatment can have a positive impact on health experiences.

Hook et al. (2012) studied the use of a nurse navigator model in a rural community setting. In a survey of 103 newly diagnosed patients with breast cancer who used nurse navigation services over a two-year period researchers found that overall, patients were "highly satisfied" with the use of a nurse navigator (Hook, et al., 2012). Using a 14 question, Likert scaled survey tool, results in four major areas of support - educational needs, emotional needs, user-friendliness, and overall satisfaction - showed that 72% of survey participants selected "strongly agree" for each survey question regarding the benefits of a nurse navigator. While the majority of participants in this navigator program were White (82%), rural communities can experience some of the same health service barriers that low income minority populations experience in large urban settings. Thus, the use of navigator services in rural environments is important to determining the overall effectiveness of such programs beyond the urban setting.

Nguyen and Kagawa-Singer (2008) reported on the barriers faced by participants in the Reach 2010 Promoting Access to Health for Pacific Islander and Southeast Asian Women (PATH for Women) program which focuses on reducing disparities in breast and cervical cancer in women of Cambodian, Chamorro, Laotian, Samoan, Thai, Tongan and Vietnamese descent in Los Angeles and Orange County, CA. Many of the barriers cited in their report are the same barriers identified in Table 4-1. The PATH program uses health education materials that are linguistically and culturally tailored to the needs of the communities, along with community health education provider trainings, and patient navigation services using community health outreach navigators. Through tailored interventions including mass media, door-to-door, and phone campaigns, community health navigators have linked thousands of Asian American Pacific Islander women to needed health services (Nguyen & Kagawa-Singer, 2008).

Other patient navigator programs have shown improvement in health outcomes. In a study of delays in follow-up after abnormal breast cancer screening results for a racially diverse group of inner-city women, Battaglia et al. (2007) report that using a PN for intervention services resulted in 78% of patients having timely follow-up versus 64% of patients with no intervention. Findings from adjusted analysis were found to be significant for older age ($p = .0003$); having private insurance ($p = .006$), having an abnormal mammogram ($p = .0001$) and being referred from a hospital based practice versus a community health center ($p = .003$). The authors found that PNs contributed positively to reducing the delay in breast cancer follow-up and care for poor and minority patients (Battaglia, et al., 2007).

Other health related navigator programs. The value of patient navigator programs and the services they provide has been recognized beyond their traditional use in breast cancer programs. Similar studies have shown the same level of effectiveness in facilitating patients through care and treatment services resulting in an improvement in health outcomes and high levels of patient satisfaction with navigator services.

Lasser, et al. (2009) found that in combination with correspondence from primary care providers, a patient navigator based intervention resulted in 31% of intervention patients being screened for colorectal cancer at six months, versus only 9% of control patients (Lasser, et al., 2009). Jandorf, et al. (2005) also report successful use of PNs in increasing colorectal cancer screening among a minority population of low SES. In a study group of 78 men and women, the researchers found that within six months of a physician recommendation to obtain a colorectal cancer screening, 15.8% of patients who received navigator services obtained the screening as compared to 5% of patients with no PN intervention. The group receiving PN services also showed a higher rate of fecal occult blood test completion, at 42.1% compared to 25% for the control group (Jandorf, et al., 2005).

Similar positive findings related to health outcomes were reported by Percac-Lima, et al. (2009) for a colorectal screening program using multilingual PNs to address the barriers encountered by a low income, ethnically diverse population in an urban setting in the Boston area (Percac-Lima, et al., 2009). The Boston area is known to be ethnically diverse, with large numbers of immigrants from African, Central America, and middle European countries (Percac-Lima, et al., 2009). The diversity of the patient

population was evident by the many languages that patient navigators spoke in addition to English and Spanish, including Arabic, Farsi, Portuguese, Russian, Serbo-Croatian and Somali (Percac-Lima, et al., 2009). Study results showed that participants in an intervention group who received a letter of introduction, educational material, and in-person or phone contact with a language concordant navigator were 27% more likely to receive colorectal screening. This compared to a screening rate of 12% for the non-intervention group. Completion of a colonoscopy by the intervention group was reported to be 21%, resulting in the identification of 10.5 polyps per 100 patients. By contrast, the colonoscopy completion rate for the control group was 10% with identification of 6.8 polyps per 100 patients (Percac-Lima, et al., 2009). The study authors concluded that the use of a multilingual PN program that is culturally tailored and designed to address barriers to care, can improve colorectal cancer screening and colonoscopy rates for patients who are low income, and ethnically and linguistically diverse.

Patient navigator programs have also been used successfully with American Indian communities. Native American Indians have significantly higher cancer related health disparities than any other minority population. Age adjusted cancer mortality for this group is 232 per 100,000; that compares to 166 per 100,000 for the general U.S. population (Petereit, et al., 2008). Navigator programs have proven successful for American Indian cancer patients in the Northern Plains of South Dakota, and at the Rapid City Regional Hospital in Rapid City, SD. In both studies, PN programs proved successful in addressing the barriers faced by both communities. In the Northern Plains, American Indians receiving navigator services during radiation treatment had an average

of 3 fewer days of treatment interruptions when compared to patients who did not receive navigator services (Petereit, et al., 2008). Fifty-two patients receiving treatment at the Rapid City Regional Hospital participated in a culturally tailored PN program. When surveyed relative to their satisfaction with care, patients who received PN services showed improvement in their levels of satisfaction with their health care (Guadagnolo, et al., 2011).

Patient navigator programs have proven successful across a continuum of prevention, treatment and follow-up care activities. In all instances, the barriers faced by patients have been the same, regardless of race, ethnicity, or cultural background. Likewise, strategies used by patient navigators to remove those barriers have proven successful in navigating service delivery environments and facilitating care regardless of the medical illness. Translating the use of navigator services from health care delivery to HIE functions of outreach, education, and enrollment of uninsured and at-risk/vulnerable populations into health insurance coverage has the potential to produce the same successful results.

Navigator Programs in the HIE Marketplace

Whether State Based, State Partnerships, or Federally Facilitated, exchange navigator programs are tasked with conducting outreach, education, and health plan enrollment activities to facilitate the enrollment of at-risk/vulnerable populations and otherwise eligible individuals. State-based exchanges that design their own navigator programs will maintain full control over selecting organizations to carry out navigator activities. They have been able to set the requirements of their navigator programs and

delineate those requirements in their request for proposals for navigator services. Part of that delineation is the decision on using navigators or in-person assisters. For most states, decisions are funding driven, as federal funds can be used to support the use of in-person assisters, while they cannot be used to hire HIE navigators (CMS, 2013b; Norman, 2013). Thus, state-based HIEs are expected to differ in their approach to providing navigator services.

The State of Washington's Health Benefit Exchange through a Request for Proposals (RFPs) process sought agencies whose demonstrated work with at-risk/vulnerable populations could leverage the development of navigator networks. Taking a lead role, selected agencies would be responsible for coordinating mandated outreach and education efforts, training navigators, monitoring performance and service quality, addressing individual complaints, submitting required data and reports, and issuing grant dollars to network organizations for services performed (Edlin, 2013). State representatives anticipate that by 2015 Washington's Exchange navigator program will be fully functional. In the interim, it will rely on existing social service staff to serve as in-person assisters to perform the role of navigators.

By contrast, the Connecticut HIE adopted an approach to its navigator program that includes contracting with as many as 300 community based organizations (Edlin, 2013). Their effort to identify and select qualified organizations is expected to extend into the first quarter of 2014. The Exchange is targeting organizations who have established relationships with employers and consumers. The Exchange itself plans to carry out performance monitoring and quality of service assessments by polling

exchange participants on several metrics. These include an understanding of: 1) exchange operation, 2) the enrollment process, 3) the availability of qualified health plans, including government programs such as Medicaid, and 4) several other measures aimed at monitoring the performance of navigator programs (Edlin, 2013).

The states of Washington and Connecticut represent different approaches in the establishment of State Based HIE navigator programs, and most State Based navigator programs will likely fall somewhere in the middle. Because of its size, diversity, and the linguistic complexity of its population, the State of California will implement a statewide Assisters Program and will use both navigators and existing social service agency personnel as in-person assisters. Their program will be implemented using non-profit organizations, community clinics, labor unions, and County Social Services offices (H. J. K. F. Foundation, 2013c). The District of Columbia will recruit and hire in-person assisters using federal funding to carry out navigator activities. They will concentrate on reaching members of the Lesbian, Gay, Bi-Sexual and Transgender community, individuals with limited English proficiency, and populations without easy access to the Internet (H. J. K. F. Foundation, 2013c). In Minnesota, Navigator and In-Person Assister programs will be implemented in January 2015. Until then, navigator activities will be carried out by existing outreach workers, in the Department of Human Services (H. J. K. F. Foundation, 2013c).

The design and implementation of navigator and in-person assister programs varies from state to state. A general review of HIE websites shows that most have issued RFPs or RFIs to seek responses from external agencies interested in providing navigator

program services. Both Washington and Connecticut have elected to use existing agencies that serve at-risk/vulnerable populations until their navigator programs are fully up and running. However, by law in-person assisters can be used to provide navigator services. Federal regulations require states to develop training standards for navigators and recommend the 30 hour training program that DHHS has developed. States however, can require more training as well as certification for navigators. However, the major difference between in-person assisters and navigators is in funding. In-person assisters can be funded using establishment grant funds, navigators cannot (Napel & Eckel, 2013; Norman, 2013). Several states have indicated their intent to apply for additional establishment grant funds to operate in-person assister programs until they can determine how to fund navigator programs through their HIEs. Going forward, states will have to determine how they will fund their navigator programs.

4.3 Methodology

Study Design and Scope

A qualitative research methodology was used to collect information on traditional navigator program strategies and consistent themes used to facilitate clinical care services to the vulnerable populations that they serve. A review of the literature identified descriptive reports, non-experimental observational studies, quasi-experimental cohort studies and randomized control trials that reported on navigator program goals, strategies, outcomes, the type of at-risk population being served and the desired characteristics of patient navigators for engaging study populations. Peer reviewed journal articles and reports published by federal and state governments as well as health policy research

agencies, foundations and organizations between 2002 and 2013 on the topics of vulnerable populations and navigator programs were reviewed. A total of 103 items were found using four search engines: Google Scholar, Galileo, PubMed, and JSTOR and the websites of health research organizations. Fifty-six of those items were used in this research. Studies were analyzed to determine whether outcomes in care coordination and treatment compliance improved and whether those improvements were attributed to the use of specific strategies.

Mandated HIE navigator duties and characteristics and the duties and characteristics of traditional patient navigators were also examined. A comparative analysis was conducted between the duties of traditional navigators, navigator duties as defined by the DHHS and a set of navigator core competencies to determine if they were similar in scope and responsibility.

A typology of navigator strategies was developed using five categories of service identified by the author. Categories were viewed as overarching service support functions and strategies were found to be closely aligned with a particular category of service. The five categories of service developed and used in this study were: advocacy, counseling, education, facilitative, and personal concordance. Strategies were placed in a category of service based on the type of support they provided. These five categories were established for this research and were not delineated in any of the articles reviewed

Synthesis of the Literature

Vulnerable populations. Literature on the risk factors that characterize at-risk/vulnerable individuals was collected using peer reviewed journal articles, textbooks, and various

reports. Barriers to care were identified as personal or system related, and disparities in care, health outcomes, and mortality for at-risk/vulnerable groups were examined. A General Vulnerability Framework was constructed based on vulnerabilities that act on the risk factors identified. An adapted framework was developed using navigator programs and HIE access to quality, affordable health plan options as interventions on those risk factors. It is theorized that the at-risk/vulnerable populations served by traditional navigators programs are the same populations with the same need for interventions that will be served by HIE navigator programs.

Patient Navigator Programs. The literature on traditional patient navigator programs is extensive. Fifty six studies on patient navigator programs that served populations at risk for disparities in treatment and care for a variety of health related illnesses were identified. These included low income and uninsured individuals, racial and ethnic minorities, rural communities, culturally and linguistically challenged populations, and populations with specific medical conditions. Peer reviewed articles on traditional programs were analyzed for consistency in program approach and strategies for reaching and guiding at-risk/vulnerable populations.

Other relevant literature

Literature reviewed for this study also included information from the DHHS and state websites. Journal articles and reports on health reform, health insurance under the PPACA, uninsured and at-risk/vulnerable populations, health insurance marketplaces, and navigator programs for at-risk/vulnerable populations were examined. Reports and briefs published by highly respected health policy and research organizations such as The

Robert Wood Johnson Foundation, The Commonwealth Fund, The Henry J. Kaiser Family Foundation, The Trust for America's Health on the topic of HIE navigator programs were also reviewed.

Evaluative Criteria:

Strategies determined to positively contribute to improved outcomes as measured by study goals, were considered successful, as were strategies that were consistent across all patient navigator programs. Additionally, concepts that informed each category of service were based on an evaluation of the strategy and the desired characteristics of navigators. The evaluation resulted in a typology of strategies determined to be successful based on study goals, objectives, and findings.

4.4 Results

A review of the literature found that uninsured and at-risk/vulnerable populations have always been at greater risk for poor health outcomes, decreased life expectancy, and higher rates of mortality for preventable illnesses. Uninsured and at-risk/vulnerable populations are disproportionately impacted by chronic disease; African Americans, Hispanics, and Asians have rates of breast, cervical, prostate, and colorectal cancers higher than their white counterparts; and all subgroups experience unequal treatment and disparate care leading to poorer health outcomes and premature death. Passage of the Patient Protection and Affordable Care Act of 2010, and its mandate of health insurance coverage for all U.S. citizens have the potential to change decades of disparate and unequal care. Just as health coverage under Medicare, Medicaid and SCHIP has improved the health outcomes of millions of elderly and low income adults and children,

HIEs have the opportunity to improve the health of millions of at-risk/vulnerable populations by providing quality affordable health coverage.

The Shi & Stevens General Conceptual Framework for Vulnerability, which combines risk factors identified in this research with access to care is presented in the Appendix as Figure A4-1. Figure A4-1 shows how ecological and individual risk factors when impacted by system vulnerabilities can result in negative health outcomes. For this research, a second conceptual framework was developed to theorize the impact of health insurance coverage and navigator programs as interventions. Appendix Figure A4-2 modifies the General Framework to show the impact of HIE health insurance coverage and navigator program strategies on those same ecological and individual risk factors. The result is theorized to be improved health outcomes at the individual, community, and national levels. Taking the Shi & Stevens Conceptual Framework for Vulnerability one step further seemed appropriate given the PPACA aim to improve access to care and expand health coverage to uninsured and at-risk/vulnerable populations to improve their health status.

Findings on Successful Strategies for Patient Navigator Programs

The use of navigator programs to successfully facilitate prevention, treatment and care activities for at-risk/vulnerable populations has been shown to be effective. Various strategies in the areas of advocacy, communication, and logistical support, as well as education, emotional support, and consistent availability to serve patients were shown to be successful in improving health outcomes. Additionally the value of racial and ethnic concordance, and cultural competency was shown to be significant in building trust, as

was the use of navigators who had actually experienced the same illness as the patients they served.

Across all studies reviewed, six strategies emerged that were pivotal in achieving maximum results. These included 1) removal of barriers to care, 2) knowledge management of services and resources, 3) counseling and educating individuals on a level that they understood, 4) communicating at appropriate literacy levels, 5) specialized training and continuing education, and 6) the use of individuals who could connect with and positively relate to the populations being served. Findings showed that these strategies were consistent and recurring across navigator programs regardless of illness, and did not differ based on the populations served. The same strategies found to be successful for African Americans were also successful for Hispanic, Asian and American Indian populations. Successful strategies were also found to be independent of gender and community/location of services.

A review of more than fifty articles on navigator programs revealed that saturation was reached with the identification of the same five to six strategies for each of the five evaluative categories listed in the methodology: Advocacy, Counseling, Education, Facilitative, and Personal Concordance. A summary matrix presenting a typology those successful strategies is presented in Appendix Table A4-1.

Harold Freeman established the nation's first patient navigator program in Harlem in 1990 ((H.P. Freeman, 2006). The "Harlem Experience" provided proof that navigator programs could be effective in reaching hard to reach populations to facilitate clinical health services that could improve health outcomes. Considered a pioneer in patient

navigator programs, he developed a set of principles that have become standards for patient navigation and embraced by all navigator programs. Those principals were found to be incorporated in many of the strategies used by the navigator programs reviewed. His nine principals and their focus in the provision of navigator services are presented in Appendix Table A4-2.

Findings on Duties and Responsibilities of Navigators

The DHHS released guidelines on the use of navigators in outreach, education and enrollment activities aimed at at-risk/vulnerable populations. Key to that guidance is the duties and responsibilities of navigators in carrying out those activities. Likewise, studies on the use of navigators to facilitate the delivery of services also reported essential characteristics required of navigators to be successful in their roles. Those characteristics were delineated in the typology matrix (see Appendix Table A4-1). The roles and responsibilities of HIE navigators as outlined by the DHHS were cross referenced to a set of core competencies developed by Brooks and Kendall (2012) at the Georgetown University Health Policy Institute, and to the roles and responsibilities of traditional navigators. Findings presented in Appendix Table A4-3 show that several duties and responsibilities were found to be consistent in each of four domains created for functional comparison: Information Services and Knowledge Management, Communication Skills, Facilitative Services, and Community and Personal Engagement/Concordance.

Use of Traditional Navigator Program Strategies by HIE Navigator Programs

Using strategies found to be successful in traditional navigator programs for reaching the same at-risk/vulnerable groups has the potential to create successful HIE navigator programs. HIE navigator programs will guide the same at-risk/vulnerable populations, with the same risk factors, barriers to care and need for assistance in navigating an unfamiliar system of public health insurance. As such, they will need to provide many of the same services that traditional navigator programs provide including education, advocacy, counseling, knowledge management on resources and services, and facilitative support. As with traditional navigator programs racial, ethnic and cultural concordance will be important in developing trust.

However, using successful strategies to guide vulnerable individuals requires employees who possess certain personal characteristics and skill sets. Findings indicate that to be effective navigators must be advocates, be empathetic, be compassionate, be supportive, be culturally competent, be trainable, and be problem solvers. It is these characteristics that navigator programs must rely on to be able to engage patients in trusting and supportive relationships. A list of the characteristics and skill sets that navigators should possess based on program strategies is also presented in Table A4-1.

4.5 Conclusion

This research sought to answer the question as to whether traditional navigator programs that facilitate health service delivery to at-risk/vulnerable populations could provide evidence of proven strategies that can be used by State Based HIE navigator

programs for outreach, education and enrollment of at-risk/vulnerable individuals into qualified health plans.

Research findings show that traditional navigator programs have successfully reached, educated and served the same at-risk/vulnerable populations that HIE marketplaces will serve. Therefore, the successful strategies used by traditional navigator programs for guiding at-risk individuals through clinical care and treatment services, represent a cadre of evidence based activities that have improved health outcomes, increased compliance with recommended treatment protocols, guided patients through complex health delivery system environments, and facilitated the removal of personal and system barriers to care. As such, they provide evidence of proven strategies that can be used by State Based HIE navigator programs.

These same evidence based strategies will need to be used by HIE navigator programs to successfully reach, educate and guide consumers to health plans that can improve their access to care and their health outcomes. The populations HIEs will serve are the same populations served by traditional navigator programs. The majority of patients served by traditional navigator programs were low income minorities and uninsured individuals. Traditional navigator program strategies were successful independent of patient age, gender, race, ethnicity, or medical illness. HIEs will serve the same uninsured and at/risk vulnerable individuals. Successfully facilitating their enrollment into health plans through a public insurance marketplace must be independent of their age, gender, race, ethnicity or medical illness. The use of successful evidence based navigator strategies will accomplish this.

Research Limitations

It is important to note a few limitations of this research. First, this study reports only on the establishment of navigator programs in State Based HIEs. It is possible that in Federally Facilitated and State Partnership HIEs there are differences in approach that were not considered in this research. Thus, generalizability to all states relative to the establishment of navigator programs may not be possible. However, some generalizability can be afforded on two issues: the at-risk/vulnerable populations to be served and the use of successful evidence based navigator strategies. Empirical evidence found that the strategies used by navigator programs were successful across racial and ethnic groups, gender, illness and other risk factors for poor health outcomes. Since every HIE program will serve these same populations, the evidence based strategies used by traditional navigator programs could be used by all HIE navigator programs.

4.6 Summary

This study has shown that a myriad of evidence exists to show that without health insurance coverage, at-risk/vulnerable populations will continue to experience risk factors that contribute to wide disparities in health care. HIE's can make a difference in the health status of at-risk/vulnerable populations who currently have no health insurance coverage. Research findings show that well developed navigator programs have used evidence based strategies to improve the health outcomes of at-risk/vulnerable populations. As is the case with traditional navigator programs that guide patients through their choice of treatment and care options, HIE navigator programs will guide at-risk individuals through a choice of health plan options. Therefore, HIE navigator

programs can use those same evidence based strategies to successfully reach, and educate at-risk/vulnerable populations and facilitate their enrollment into qualified health plans. In addition, there is significant similarity in the roles and responsibilities of HIE navigators and the duties and responsibilities of traditional navigators. Thus, findings build a case for HIEs to use the same evidence based strategies and navigator duties and responsibilities to carry out mandated navigator functions.

For the first time in U.S. history a government agency has been tasked with ensuring the enrollment of uninsured and at-risk/vulnerable populations into approved health plans. HIE navigator programs have an opportunity to use proven strategies that have worked for decades. In doing so, HIEs will be able to reach their goal of enrolling millions of individuals in approved health plans, thus reaching the PPACA goal of near universal health coverage for all U.S. citizens.

4.7 References

- Baker, E. A., Metzler, M. M., & Galea, S. (2005). Addressing Social Determinants of Health Inequities: Learning From Doing. [Editorial]. *American Journal of Public Health, 95*(4), 3.
- Battaglia, T. A., Roloff, K., Posner, M. A., & Freund, K. M. (2007). Improving follow-up to abnormal breast cancer screening in an urban population. *Cancer, 109*(S2), 359-367. doi: 10.1002/cncr.22354
- Biedrzycki, P. A., Koltun, R. (2012). Integration of Social Determinants of Community Preparedness and Resiliency in 21st Century Emergency Management Planning. *Journal of Homeland Security Affairs, 8*(14).
- Brooks, T., & Kendall, J. (2012). Designing Navigator Programs to Meet the Needs of Consumers: Duties and Competencies (pp. 8). Washington, D.C.: Georgetown University Health Policy Institute.
- Buist, A. (2012, 2012). Children's Health. *Policy Priorities* Retrieved October 14, 2013, 2013, from <http://www.childrensdefense.org/policy-priorities/childrens-health/>
- CDC. (2009). The Power of Prevention: Chronic disease...the public health challenge of the 21st century (N. C. f. C. D. P. a. H. Promotion, Trans.) (pp. 18). Atlanta, GA: Centers For Disease Control and Prevention.
- CDC. (2013, November 11, 2011). Office of Minority Health and Health Equity (AMHHE) Home Page Retrieved September 7, 2013, 2013, from <http://www.cdc.gov/minorityhealth/populations.html>

- CMS. (2013b). *In-Person Assistance in the Health Insurance Marketplace* Washington, DC: DHHS Retrieved from <http://www.cms.gov/CCIIO/Programs-and-Initiatives/Health-Insurance-Marketplaces/assistance.html>.
- Collins, S. R., Robertson, R., Garber, T., Doty, M.M. (2013). *Insuring the Future: Current Trends in Health Coverage and the Effects of Implementing the Affordable Care Act Biennial Health Insurance Survey 2012* (pp. 41). Washington, DC: The Commonwealth Fund.
- The Patient Protection and Affordable Care Act, US Government Printing Office, Pub. L. No. 111-148 906 (2010 March 23, 2010).
- Cunningham, P. (2010). *Who Are the Uninsured Eligible for Premium Subsidies in the Health Insurance Exchanges?* (pp. 8). Washington, DC: Center for Studying Health System Change.
- Cutler, D., & Lleras-Muney, A. (2007). *Education and Health* (9 ed., pp. 4): Gerald R. Ford School of Public Policy, University of Michigan.
- Darnell, J. S. (2007). Patient navigation: a call to action. *Social Work*, 52(1), 81-84.
- DHHS. (2013a). *Cooperative Agreement to Support Navigators in Federally-facilitated and State Partnership Exchanges*. (CA-NAV-13-001). Washington, DC: DHHS.
- Dohan, D., & Schrag, D. (2005). Using navigators to improve care of underserved patients. *Cancer*, 104(4), 848-855. doi: 10.1002/cncr.21214
- Dudley, D. J., Drake, J., Quinlan, J., Holden, A., Saegert, P., Karnad, A., & Ramirez, A. *Beneficial Effects of a Combined Navigator/Promotora Approach for Hispanic Women Diagnosed with Breast Abnormalities*.

Duggan, C., Coronado, G., Martinez, J., Byrd, T. L., Carosso, E., Lopez, C., . . .

Thompson, B. (2012). Cervical cancer screening and adherence to follow-up among Hispanic women study protocol: a randomized controlled trial to increase the uptake of cervical cancer screening in Hispanic women. *BMC Cancer, 12*, 170.

Edlin, M. (2013). NAVIGATORS Play a lead role. [Article]. *Managed Healthcare Executive, 23*(2), 38-40.

Ferrante, J. M., Chen, P.-H., & Kim, S. (2008). The effect of patient navigation on time to diagnosis, anxiety, and satisfaction in urban minority women with abnormal mammograms: a randomized controlled trial. *Journal Of Urban Health: Bulletin Of The New York Academy Of Medicine, 85*(1), 114-124.

Ferrante, J. M., Wu, J., & Diccico-Bloom, B. (2011). Strategies used and challenges faced by a breast cancer patient navigator in an urban underserved community. *Journal of the National Medical Association, 103*(8), 729-734.

Fillion, L., Cook, S., Veillette, A.-M., Aubin, M., de Serres, M., Rainville, F., . . . Doll, R. (2012). Professional Navigation Framework: Elaboration and Validation in a Canadian Context. [Article]. *Oncology Nursing Forum, 39*(1), E58-E69.

Fischer, S. M., Sauaia, A., & Kutner, J. S. (2007). Patient Navigation: A Culturally Competent Strategy to Address Disparities in Palliative Care. [Article]. *Journal of Palliative Medicine, 10*(5), 1023-1028. doi: 10.1089/jpm.2007.0070

Foundation, H. J. K. F. (2012a). THE UNINSURED A PRIMER *Kaiser Commission on Medicaid and the Uninsured* (pp. 46). Menlo Park, CA.

- Freeman, H. P. (2004). A Model Patient Navigation Program. *Oncology Issues*, 19, 4.
- Freeman, H. P. (2006). Patient Navigation: A community based strategy to reduce cancer disparities. *Journal of Urban Health*, 83(2), 139.
- Freeman, H. P., & Rodriguez, R. L. (2011). History and principles of patient navigation. *Cancer*, 117(S15), 3537-3540. doi: 10.1002/cncr.26262
- Garza, M. A., Jingyu, L., Blinka, M., Farabee-Lee, I., Neuhaus, C. E., Zabora, J. R., & Ford, J. G. (2005). A Culturally Targeted Intervention to Promote Breast Cancer Screening Among Low-Income Women in East Baltimore, Maryland. *Cancer Control*, 12(2), 8.
- Guadagnolo, B. A., Cina, K., Koop, D., Brunette, D., & Petereit, D. G. (2011). A Pre-post Survey Analysis of Satisfaction with Health Care and Medical Mistrust after Patient Navigation for American Indian Cancer Patients. *Journal of Health Care for the Poor and Underserved*, 22(4), 13.
- Hansen, L. K., Fleigl, P., Modiano, M. R., Lopez, J. A., Escobedo, S., Moinpour, C. M., . . . Meyskens, F. L. (2005). An educational program to increase cervical and breast cancer screening in Hispanic women: A Southwest Oncology Group Study. *Cancer nursing*, 28(1), 47.
- Henry J. Kaiser Family Foundation, K. F. (2013c). State Health Insurance Marketplace Profiles Retrieved June 24, 2013, 2013, from <http://kff.org/state-health-exchange-profiles/>

- Hook, A., Ware, L., Siler, B., & Packard, A. (2012). Breast Cancer Navigation and Patient Satisfaction: Exploring a Community-Based Patient Navigation Model in a Rural Setting. [Article]. *Oncology Nursing Forum*, 39(4), 379-385.
- Hunter, J. B., de Zapien, J. G., Papenfuss, M., Fernandez, M. L., Meister, J., & Giuliano, A. R. (2004). The impact of a promotora on increasing routine chronic disease prevention among women aged 40 and older at the U.S.-Mexico border. *Health Education & Behavior*, 31(4), 18S.
- Institute, N. C. (2005). *NCI's Patient Navigator Research Program: Fact Sheet*. Washington, DC: Retrieved from <http://crchd.cancer.gov/>.
- Jandorf, L., Gutierrez, Y., Lopez, J., Christie, J., & S.H., I. (2005). Use of a patient navigator to increase colorectal cancer screening in an urban neighborhood health clinic. *Journal of urban health*, 82(2), 216.
- Lasser, K. E., Murillo, J., Medlin, E., Lisboa, S., Valley-Shah, L., Fletcher, R. H., . . . Ayanian, J. Z. (2009). A multilevel intervention to promote colorectal cancer screening among community health center patients: results of a pilot study. [Article]. *BMC Family Practice*, 10, 1-7. doi: 10.1186/1471-2296-10-37
- Mechanic, D., & Tanner, J. (2007). Vulnerable People, Groups, And Populations: Societal View. *Health Affairs*, 26(5), 11.
- Moy, B., & Chabner, B. A. (2011). Patient Navigator Programs, Cancer Disparities, and the Patient Protection and the Affordable Care Act. *The Oncologist*, 16, 5.

- Napel, S. T., & Eckel, D. (2013). Navigators and In-Person Assistors: State Policy and Program Design Considerations (pp. 11). Princeton, NJ: State Health Reform Assistance Network.
- Nguyen, T.-U. N., & Kagawa-Singer, M. (2008). Overcoming Barriers to Cancer Care Through Health Navigation Programs. *Seminars in Oncology Nursing*, 24(4), 270-278. doi: <http://dx.doi.org/10.1016/j.soncn.2008.08.007>
- Nolte, E., & McKee, C. M. (2008). Measuring The Health Of Nations: Updating An Earlier Analysis. *Health Affairs*, 27(1), 14.
- Nonzee, N. J., McKoy, J. M., Rademaker, A. W., Byer, P., Luu, T. H., Liu, D. C., . . . Simon, M. A. (2012). Design of a prostate cancer patient navigation intervention for a Veterans Affairs hospital. *BMC Cancer*, 12, 340.
- Norman, J. (2013). Navigators of State Health Insurance Exchanges Prepare to Help Applicants. *Washington Health Policy Week in Review* Retrieved May 20, 2013, 2-13, from <http://www.commonwealthfund.org/Newsletters/Washington-Health-Policy-in-Review/2013/May/May-20-2013/Navigators-of-State-Health-Insurance-Exchanges.aspx?view>
- Percac-Lima, S., Grant, R. W., Green, A. R., Ashburner, J. M., Gamba, G., Oo, S., . . . Atlas, S. J. (2009). A culturally tailored navigator program for colorectal cancer screening in a community health center: a randomized, controlled trial. *Journal Of General Internal Medicine*, 24(2), 211-217. doi: 10.1007/s11606-008-0864-x
- Petereit, D. G., Molloy, K., Reiner, M. L., Helbig, P., Cina, K., Miner, R., . . . Roberts, C. R. (2008). Establishing a Patient Navigator Program to Reduce Cancer Disparities

- in the American Indian Communities of Western South Dakota: Initial Observations and Results. *Cancer Control*, 15(3), 6.
- Rogers, A. C. (1997). Vulnerability, health and health care. *Journal of Advanced Nursing*, 27, 8.
- Saly, E. (2013). Help Wanted: Preparing Navigators and Other Assistants To Meet New Consumer Needs (pp. 32). Chicago, IL: Illinois Health Matters.org.
- Schlueter, D. F., Thompson, W. W., Mason, T. A., Rayton M., & Arriola, K. J. (2010). A Qualitative Evaluation of the Avon Foundation Community Education and Outreach Initiative Patient Navigation Program. *Journal of Cancer Education* 25(4), 7.
- Schoen, C., Radley, D., Riley, P., Lippa, J., Berenson, J., Dermody, C., & Shih, A. (2013). Health Care in the Two Americas. Washington, DC: The Commonwealth Fund.
- Schoenbaum, S. C., Schoen, C., Nicholson, J. L., & Cantor, J. C. (2011). Mortality Amenable to Health Care in the United States: The Roles of Demographics and Health Systems Performance. *Journal of Public Health Policy*, 32(4), 23.
- Shi, L., & Singh, D. A. (2012). *Delivering Health Care in America: A Systems Approach* (5th ed.). Burlington, MA: Jones & Bartlett.
- Shi, L., & Stevens, G. D. (2010). *Vulnerable Populations in the United States* (2nd ed.). San Francisco, CA: Jossey-Bass.
- Steinberg, M. L., Fremont, A., Khan, D. C., Huang, D., Knapp, H., Karaman, D., . . . Streeter, O. E. (2006). Lay patient navigator program implementation for equal

access to cancer care and clinical trials. *Cancer*, 107(11), 2669-2677. doi:
10.1002/cncr.22319

Trust. (2008). Improving the Health of Low-Income and Minority Communities (D. o. G. Relations, Trans.) *A Healthier America: 10 Top Priorities For Prevention. Preventing Epidemics. Protecting People* (pp. 28). Washington, DC: Turst For America's Health.

Vargas, R. B., Ryan, G. W., Jackson, C. A., Rodriguez, R., & Freeman, H. P. (2008). Characteristics of the original patient navigation programs to reduce disparities in the diagnosis and treatment of breast cancer. *Cancer*, 113(2), 426-433. doi:
10.1002/cncr.23547

Wolff, M., Baates, T., Beck, B., Young, S., Ahmed, S., & Maurana, C. (2003). Cancer Prevention in Underserved African American Communities: Barriers and Effective Strategies - A Review of the Literature. *Wisconsin Medical Kpirma*, 102(5), 6.

Wujcik, D. M. (2011). The Evolution of Patient Navigation. [Article]. *ONS Connect*, 26(10), 5-5.

4.8 Appendix

Appendix List of Figures

Figure A4-1: Conceptual Framework for Vulnerability: Impact of SES and Access to Care Risk Factors on Health Outcomes

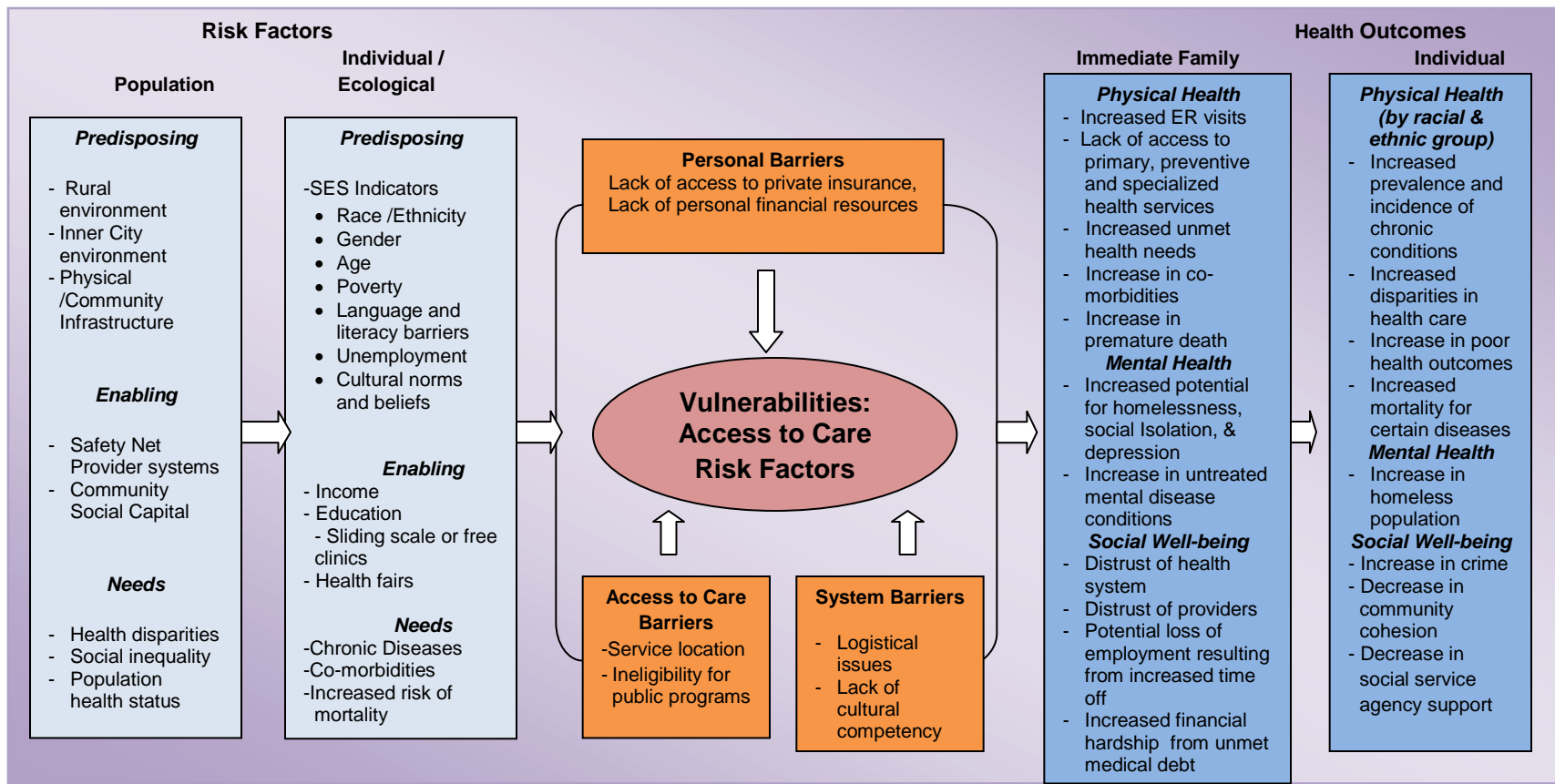
Figure A4-2: Conceptual Framework for Intervention: Impact of SES Risk Factors and Health Insurance Coverage and Navigator Programs as Interventions under the PPACA on Health Outcomes

Appendix List of Tables

Table A4-1: Typology of Successful Traditional Navigator Program Strategies

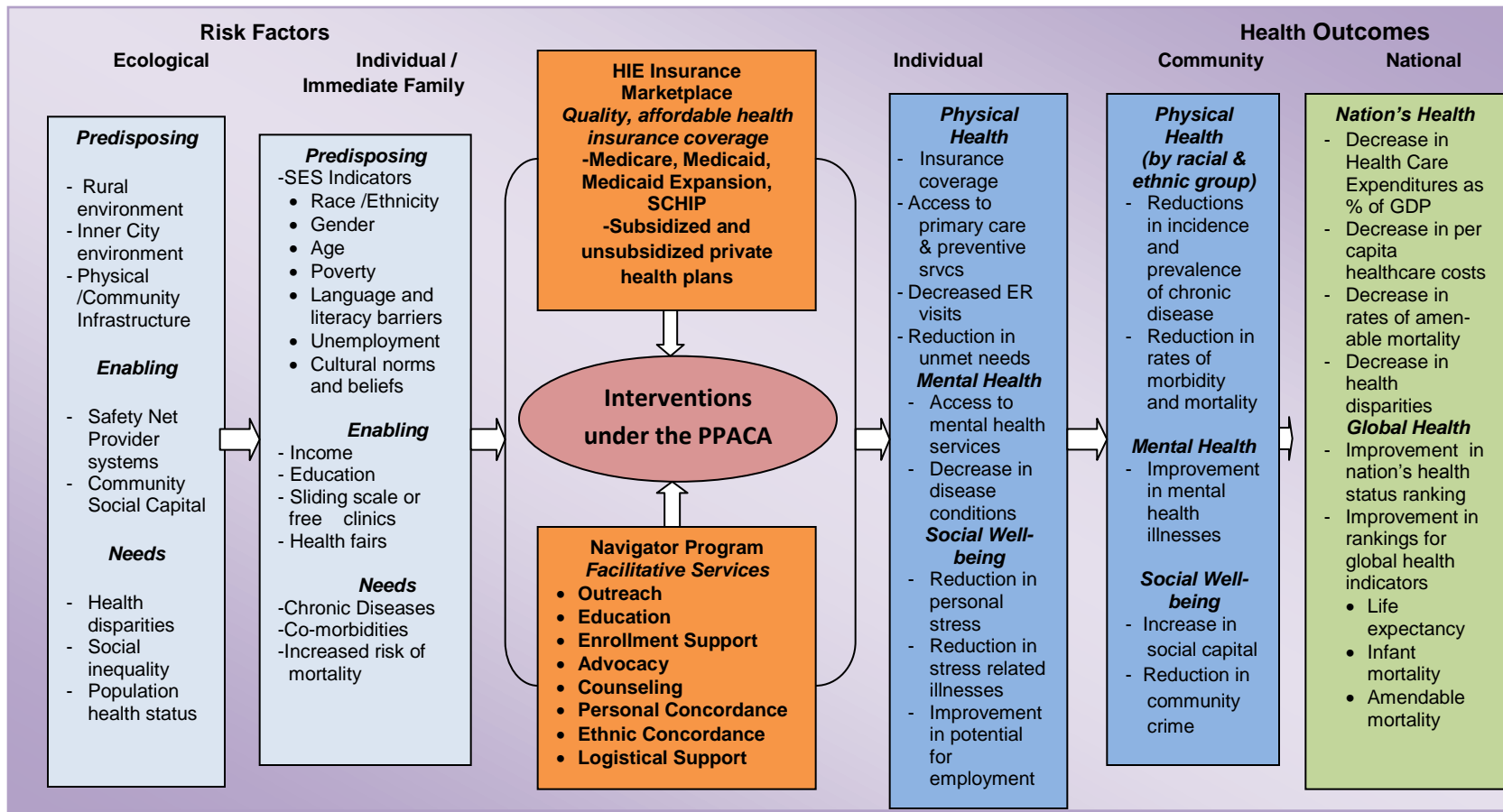
Table A4-2: Freeman's Nine Principles of Patient Navigation

Table A4-3: Analysis of Navigator Roles and Responsibilities by Process and Function



Source: Shi & Stevens (2010)

Figure A4-1: Conceptual Framework for Vulnerability: Impact of SES Risk Factors and Access to Care Risk Factors on Health Outcomes



Source: Adapted from Shi & Stevens (2010)

Figure A4-2: Conceptual Framework for Intervention: Impact on SES Risk Factors of Health Insurance Coverage and Navigator Programs as Interventions under the PPACA on Health Outcomes

Table A4-1: Typology of Successful Traditional Navigator Program Strategies¹

| # | <i>Category of Service</i> | <i>Navigator Characteristics and Skill Sets</i> | <i>Successful Strategies</i> |
|----|----------------------------|--|---|
| 1. | Advocacy | <ul style="list-style-type: none"> • Engage in social networking • Have institutional knowledge of specific illnesses • Have knowledge of agencies that engage in policy making, including legislative advocacy | <ul style="list-style-type: none"> • Collaborate with social institutions and networks that advocate for specific illnesses or diseases • Engage with and inform institutions and government agencies on the issues surrounding specific illnesses or diseases • Serve as a liaison on behalf of patients • Understand the policies relevant to the area of navigation • Identify personnel within a service setting that are involved in the care of patients and develop relationships that permit advocacy on behalf of patient |
| 2. | Counseling | <ul style="list-style-type: none"> • Understand the importance of outreach • Be a compassionate communicator • Empathize with the patient’s situation • Exhibit strength of conviction | <ul style="list-style-type: none"> • Conduct ongoing support sessions • Counsel patients through financial, care delivery, logistical and system barriers • Provide emotional support through active, empathetic listening • Promote self-determination on the part of the patient by helping them to own their illness and their journey through recovery • Be easily accessible for counseling on support and care services • Communicate and interact with patients on a level that promotes comfort |
| 3. | Education | <ul style="list-style-type: none"> • Be competent in all areas of service and resource knowledge management | <ul style="list-style-type: none"> • Educate patients on the services and resources available to support their healing • Be educated about and provide education to patients on the illness they have |

| # | <i>Category of Service</i> | <i>Navigator Characteristics and Skill Sets</i> | <i>Successful Strategies</i> |
|----|-----------------------------|---|--|
| | | <ul style="list-style-type: none"> • Be culturally competent | <ul style="list-style-type: none"> • Require continued education and training • Require cultural competency training • Educate navigators on methods for engaging patients at an educational level that is both appropriate and respectful |
| 4. | Facilitative | <ul style="list-style-type: none"> • Understand the kinds of barriers that patients face • Learn how to effectively remove barriers to care • Be supportive in Coordinating services • Intervene in logistical issues | <ul style="list-style-type: none"> • Connect patients with community and social support services • Guide patients through complicated processes in a timely manner • Involve CBOs in care services to increase the types of services available to patients • Become “highly wired connectors” • Understand the personal and system barriers faced by the population • Problem solve and create solutions to patient problems |
| 5. | Personal Concordance | <ul style="list-style-type: none"> • Be culturally relevant • Be racially and ethnically appropriate • Learn how to build trust • Learn how to build personal connectedness | <ul style="list-style-type: none"> • Chose individuals who are members of the community they serve • Chose navigators who are culturally relevant when matching navigators with patients • Use navigators whose racial and ethnic concordance is in line with patients being served whenever possible • Establish rapport to build connected relationships • Meet patients “where they are” • Employ the use of patient navigators who have overcome the same illness as a means of improving the counseling role. Navigator is then viewed as someone who has been through similar experiences and therefore gives guidance based on that experience. |

¹Source: Compiled from multiple sources listed in Reference Section.

Table A4-2: Freeman’s Nine Principles of Patient Navigation

| # | <i>Principle</i> | <i>Navigation Focus</i> |
|----|--|--|
| 1. | Patient navigation is a patient-centric healthcare service delivery model. | The focus is to promote the timely movement of an individual patient through an often complex healthcare continuum, beginning in the patient’s neighborhood... from detection, to diagnosis, to treatment ... a journey that continues from rehabilitation and survivorship to the end of life. |
| 2. | Patient navigation serves to integrate a fragmented healthcare system for the patient. | Patient navigation has the potential of creating a seamless flow for patients as they journey through the care continuum...serving as [a] guiding force... through a complex system of care. |
| 3. | The core function of patient navigation is the elimination of barriers to timely care across all segments of the healthcare continuum. | This function is most effectively carried out through a one-on-one relationship between the navigator and the patient. |
| 4. | Patient navigation should be defined with a clear scope of practice that distinguishes the role and responsibilities of the navigator from that of all other providers. | Navigators should be integrated into the health care team to promote maximum benefit for the individual patient. |
| 5. | Delivery of patient navigation services should be cost-effective and commensurate with the training and skills necessary to navigate an individual through a particular phase of the care continuum. | |
| 6. | The determination of who should navigate should be determined by the level of skills required at a given phase of navigation. | There is a spectrum of navigation extending from services that may be provided by trained lay navigators to services that require navigators who are professionals, such as nurses and social workers. |
| 7. | In a given system of care there is the need to define the point at which navigation begins and the point at which navigation ends. | |
| 8. | There is a need to navigate patients across disconnected systems of care, like primary and tertiary care sites. | Patient navigation can serve as the process that connects disconnected healthcare systems. |
| 9. | Patient Navigation systems require coordination. | In larger systems of patient care coordination is best carried out by assigning a navigation coordinator or champion who is responsible for overseeing all phases of navigation activity within a given healthcare site or system. It is important to distinguish a system of patient navigation from the patient navigator(s) who work within the system. |

Source: (Harold P. Freeman & Rodriguez, 2011)

Table A4-3: Comparative Analysis of Navigator Roles and Responsibilities by Process and Function

| | <i>Roles and Responsibilities , Core Competencies, and Navigator Duties by</i> | | |
|--|---|--|--|
| Functional Domains | <i>Required Navigator Duties (DHHS, 2013a)</i> | <i>Core Competencies of HIE Navigators (Brooks & Kendall, 2012)</i> | <i>Traditional Navigator Programs – Navigator Duties¹</i> |
| Information Services and Knowledge Management | <ul style="list-style-type: none"> • Maintain expertise in eligibility, enrollment and program specifications | <ul style="list-style-type: none"> • Knowledge of current public coverage programs, including Medicaid and CHIP • Familiarity with health insurance, including benefits, cost-sharing requirements, and how managed care works | <ul style="list-style-type: none"> • Institutional knowledge of specific illnesses • Service and resource knowledge management • Knowledge of agencies that engage in policy making, including legislative advocacy |
| Communication Skills <ul style="list-style-type: none"> • Education • Advocacy • Counseling | <ul style="list-style-type: none"> • Conduct public education activities to raise awareness about available quality health plans • Provide information and services in a fair, accurate and impartial manner • Provide referrals to applicable offices or any enrollee with a grievance, complaint, or question regarding their health plan, coverage or eligibility determination | <ul style="list-style-type: none"> • Experience conducting outreach and application assistance to low-income consumers in establishing financial eligibility for public programs • Ability to translate complex policy and insurance jargon into plain language • Aptitude to learn and communicate how advanced premium tax credits (APTC) work, as well as the financial implications of tax credit reconciliation; | <ul style="list-style-type: none"> • Competency testing and training • Specialized training • Continuing education and training |

| | <i>Roles and Responsibilities , Core Competencies, and Navigator Duties by</i> | | |
|---|---|--|--|
| Functional Domains | <i>Required Navigator Duties (DHHS, 2013a)</i> | <i>Core Competencies of HIE Navigators (Brooks & Kendall, 2012)</i> | <i>Traditional Navigator Programs – Navigator Duties</i> ¹ |
| Facilitative Services | <ul style="list-style-type: none"> • Distribute fair and impartial information • Facilitate selection of a Qualified Health Plan | <ul style="list-style-type: none"> • Knowledge of local resources such as community health centers, health and human services, and immigrant-related resources. | <ul style="list-style-type: none"> • Removal of barriers to care • Coordination of services • Access to technology and electronic resources |
| Community and Personal Engagement /Concordance | <ul style="list-style-type: none"> • Provide information in a manner that is culturally and linguistically appropriate to the needs of the population being served by the Exchange | <ul style="list-style-type: none"> • Ability to serve consumers with limited English proficiency, low literacy, and limited experience with insurance • Expertise and accessibility aids to assist people with disabilities; | <ul style="list-style-type: none"> • Cultural relevance • Racial and ethnical concordance • Building trust • Personal connectedness • Accessibility |

¹Source: Compiled from multiple sources listed in Reference Section.

CHAPTER 5

CONCLUSION

5.0 Overview

The final chapter of this dissertation will connect the empirical findings and concepts presented in Chapters One through Four. It will address the two research questions and discuss the study findings relevant to each. It will also discuss the interdependence of HIEs and navigator programs in ensuring quality, affordable health care coverage to vulnerable populations under the PPACA. Sustainability of both of these components is vital to near universal coverage, and frameworks for sustainability are presented.

This chapter will also discuss the potential for health reform to change the health status of at-risk groups and to improve the global standing of the U.S. as a nation based on the establishment of HIEs and the development of navigator programs. Research also revealed that the U.S. is facing a global “health disadvantage” when compared to high income peer nations. This newest challenge to the global health status of the U.S. is important because it does not involve at-risk/vulnerable populations. This new kind of disparate health outcome impacts a higher income, higher socio-economic group, and has the potential to result in lower global health status rankings. This new challenge suggests that there are potentially two populations in the U.S. at opposite ends of the economic spectrum facing disparate health outcomes. Thus, the potential for health

reform to improve the health not only of at-risk/populations but a growing higher income, higher socio-economic group based on its attention to preventive services can impact national and international U.S. health rankings. This chapter will briefly discuss how health reform could impact this new challenge.

Lastly, in considering opportunities for future research several recommendations are presented that address challenges which could impact the sustainability of HIEs and navigator programs. As these two components of health reform continue to evolve eliminating these challenges will be important to ensuring their survival. Finally, the limitations of this research and its implications for public health will be discussed.

5.1 Research Questions and Research Findings

This study sought to answer two research questions:

- *Research Question 1:* Do business model and governance structure design including governing authority composition impact the effectiveness of State Based HIE agencies?
- *Research Question 2:* Do traditional navigator programs that facilitate health service delivery to at-risk/vulnerable populations provide evidence of proven strategies that can be used by State Based HIE navigator programs for outreach, education and enrollment of at-risk/vulnerable individuals into qualified health plans?

Findings for Research Question 1

Relative to business model and governance structure, in particular governing authority composition, and their impact on the effectiveness of HIEs, the following conclusions are drawn:

- Findings suggest that how a HIE is designed, its legislatively enacted governance structure, and governing authority apportionment, appointment and composition can impact the effectiveness.
- The most effective HIE's are semi-independent business entities with quasi-governmental business models being preferred; are apolitical and free of political influence, are not subject to administrative rules and regulations; and have autonomy to implement revenue generating strategies for sustainability in the future. HIEs must be able to function independently attending to business operations that involve oversight of health plans offered through the exchange, developing necessary external contracts, and managing a public marketplace expected to serve millions of individuals.
- Governing board apportionment, appointment, and composition are critical. Governing boards must be free of political influence. Apportionment of board members must be balanced between the executive and legislative branches of state government, appointment composition must include consumer and small business representation, with appropriate restrictions to ensure that no conflict of interest exists between board members and the business they must carry out. A mix of voting and non-voting members should be appointed. Board size should

be sufficient to have representation from all stakeholders involved in the business and community elements of the HIE.

While findings are empirical only, there is experience from the State of Massachusetts Commonwealth Connector HIE and European HIE marketplaces to conclude that absent these design element HIE's may not have the independence and flexibility they require to effectively carry out mandated functions. Based on findings, it can be concluded that business model and governance structure design including governing authority composition can impact the effectiveness of State Based HIE agencies.

Findings for Research Question 2

Relative to the use of traditional navigator program (TNP) strategies for facilitating the delivery of health services to vulnerable populations, and the use of their successful strategies by HIE navigator programs to facilitate the outreach, education and enrollment of those same at-risk/populations into approved health plans, the following conclusions are drawn:

- TNP have facilitated at-risk/vulnerable populations with SES, financial, personal and system barriers through unfamiliar and complex health delivery systems;
- TNP have used strategies that have proven to be successful in improving compliance with treatment and care, and improving health outcomes;
- Program strategies were successful independent of patient age, gender, race, ethnicity, or medical illness;

- HIE navigator programs will guide the same at-risk/vulnerable populations, with the same risk factors, barriers to care and need for assistance in navigating an unfamiliar system of public health insurance;
- They will provide many of the same services that traditional navigator programs provide including education, advocacy, counseling, knowledge management on resources and services, and facilitative support;
- Elements of personal concordance relative to race and ethnicity and cultural experience that are necessary for navigator/ patient engagement in TNP will also be necessary for HIE navigator / consumer engagement.

While empirical in nature, these findings are evidence based across more than fifty studies on traditional navigator programs. Thus, it can be concluded that TNPs provide evidence of proven strategies that can be used by State Based HIE navigator programs for outreach, education and enrollment of at-risk/vulnerable individuals into qualified health plans.

Interdependence of HIE's and HIE Navigator Programs

As noted, HIEs and HIE navigator programs have major roles to play in providing health insurance for uninsured and vulnerable populations. Their ability to work in concert is key to the PPACA reaching its goal of near universal coverage. By doing so, HIEs and navigator programs have the potential to ensure health insurance coverage for millions of uninsured and vulnerable populations. Collins, Schoen and Davis note that if the PPACA were fully implemented in 2011, “almost 90% of uninsured individuals who are legal residents would gain insurance either through

Medicaid or through subsidized premiums for private health plans sold on the Exchange” (S. R. Collins, Schoen, & Davis, 2011).

HIEs are a vital component in making insurance available and affordable for all Americans. To do so, they must make available for purchase a wide range of health plans. A mandated function of HIE navigator programs is to conduct outreach and education activities that result in uninsured and vulnerable individuals enrolling into the health plans offered through the Exchange. Thus, the interdependence and interconnectedness of these two components is apparent. Figure A4-2 which presented an adapted Conceptual Framework for Vulnerability, showed how access to HIE health plans combined with navigator activities can, through the PPACA, serve as interventions that that lead to improved health outcomes at the individual, community, and the national level.

Federal funding for HIEs and in-person assisters is not guaranteed beyond 2014. Therefore, HIE’s will need to find ways to ensure an ongoing stream of revenue for their continued operation. This includes the need to continue to fund navigator agencies to provide mandated functions. As reported earlier, sustained funding for HIEs can occur in a number of ways – legislative appropriations, user fees, premium assessments – and can involve insurers participate in the HIE marketplace or the full complement of insurers licensed to operate in the state. Absent annual legislative appropriations, HIE’s will need to have the authority to collect revenues to ensure their viability and continued contracting with community agencies for navigator services required by the law.

5.2 Reform of the U.S. Health System: Concluding Thoughts

The U.S. journey towards a reformed system of health care and health service delivery may finally be at hand. For the last one hundred years, this country has made numerous overtures towards a national health care system. However, only three major reform efforts have taken serious hold. The Social Security Act (SSA) of 1935 was a social reform that provided retirement benefits to the elderly population and eventually included health care services for the disabled and for individuals with renal failure. In 1965 the signing of the Medicare and Medicaid Acts, both titles under the SSA provided health insurance coverage to the elderly and to low income adults and children, respectively. In March, 2010, the Patient Protection and Affordable Care Act was signed into law by President Barack Obama with a major goal of expanding health coverage to all U.S. citizens.

Key to this goal was the establishment of HIEs in each state and the District of Columbia where individuals could apply for, enroll in, and purchase an affordable health plan approved by the state. Making health care coverage affordable for uninsured and vulnerable populations has the potential to remove personal and system barriers that have kept these at-risk groups from seeking needed health care services. System and personal barriers to receiving health care have led to unequal access and inequalities in outcomes. Forged mainly by socio economic risk factors and the presence of medical conditions that render individuals unable to seek care without advocacy and assistance, research has shown that racial and ethnic minorities have poorer health outcomes for illnesses that are treatable and preventable with access to quality medical services.

America's health status ranking of 37th in the world has not changed in more than a decade (Murray & Frenk, 2010; WHO, 2000). We continue to be outranked on major global health indicators by other major industrialized nations, particularly those in the European market with whom we are generally compared (WHO, 2012, 2013). Despite being number 1 for health care spending per capita in 2006, U.S. rankings were 39th for infant mortality, 43rd for adult female mortality, 42nd for adult male mortality and 36th for life expectancy (Murray & Frenk, 2010). Relative to amenable mortality which disproportionately impacts the at-risk vulnerable populations which have been the subject of this research, the U.S. ranks 19th out of 19 industrialized countries (S. C. Schoenbaum, et al., 2011a). Given the wealth of our nation, health care resources beyond measure, increasing investments in health technology, and the availability of publicly funded health programs such as Medicare, Medicaid, and SCHIP, most researchers attribute our poor performance on the global stage to the lack of a national comprehensive health insurance program (Muennig & Glied, 2010; S. C. Schoenbaum, et al., 2011a). Moving to a near universal system of health care has the potential to improve the health outcomes of millions of individuals who have never had access to health care due to socio-economic reasons or medical conditions that have rendered them unable to afford quality health care. However, while years of research suggests that removing barriers to access and care can improve the health status of at-risk groups, there is growing evidence that America's poor health status may not be attributable solely to the disparities, inequities and social determinants of health suffered by vulnerable populations.

In a 2011 National Research Council report, attention was drawn to a rising international “mortality gap” between American adults age 50 and over when compared to counterparts in developed high income countries (National Research Council (US) & Medicine, 2013). In a follow-up 2013 report the National Research Council (NRC) and the Institute of Medicine (IOM) suggest this “health disadvantage” exists among highly advantaged Americans (National Research Council (US) & Medicine, 2013). When compared to sixteen high income countries they found that “...Americans with healthy behaviors or those who are White, insured, college-educated, or in upper-income groups appear to be in worse health than similar groups in comparison countries” (National Research Council (US) & Medicine, 2013). They report that individual behaviors such as high calorie consumption per capita, prescription and illicit drug abuse, alcohol related traffic fatalities, firearm ownership at a higher rate than peers in other countries, and early sexual debut by U.S. adolescents have resulted in Americans with “high socioeconomic status” experiencing poorer health and a higher mortality rate among individuals 50 years and older than their peers in comparable high income countries (National Research Council (US) & Medicine, 2013). In addition to individual behaviors, also noted were issues relative to systems of care (fragmented delivery systems, lack of affordable care, access issues) and factors influenced by physical and social environments (built environments that discourage physical activity, family violence, pollution) in U.S. communities.

The importance of this research is timely. First, it has significance given the low U.S. rankings on several international measures of health status. Second, it sheds light

on the fact that this new “health disadvantage” transcends socio-economic status. High income, well educated Americans placed in a competitive ‘health disadvantage’ could benefit from some of the same health related interventions and infrastructure improvements offered through health reform. The NCR & IOM report cites that “In countries with the most favorable health outcomes, resource investment and infrastructure often reflect a strong societal commitment to the health and welfare of the *entire* population” (National Research Council (US) & Medicine, 2013). Through health reform the U.S. has finally begun to make the kinds of investments needed to catch up with the personal health advances that other countries made decades ago. Thus, it is made clearer through the NRC & IOM report that these investments will not only serve uninsured and vulnerable populations, but could benefit high income, socio-economically “advantaged” groups when compared to their peers in comparable high income countries. The PPACA will change the health status of vulnerable populations, but more importantly it can change the health status of the U.S. as a nation on several international measures of health that involve the entire U.S. population. Given this, the interdependent roles of HIEs and navigator programs become all the more important.

5.3 Proposed Frameworks for Sustainability

Sustainability Framework for HIEs

Central to the success of state-based HIE marketplaces are their business operating model, governance structure, decision making authority, funding and management framework. Also important are the alternatives available for each of these elements because they can directly impact a HIEs ability to effectively carry out its

mission. To be as effective as possible, HIE's should be independent of any legislative or governmental oversight, be independent of the influences of politics, and operate without adherence to governmental rules and regulations. Their governing bodies should include individuals who understand the health issues and needs of consumers in general and uninsured and vulnerable populations in particular. They should also have knowledge of the problems faced by small business employers in acquiring and maintaining health insurance coverage that is affordable for small businesses who generally lack sufficient employees to spread risks. Also, having board representation experienced in the insurance industry can ensure an understanding of the need to maintain a balance between the public marketplace created by the exchange and the private insurance market. This expertise is essential to maintaining a balanced market economy between insurers who participate in the HIE marketplace, and those who choose not to participate. Likewise, having expertise on the board in insurance and financial market matters can be valuable for those HIEs with the authority to impose user fees as a source of ongoing revenue to finance operations beyond 2014. These alternatives in any combination are likely to help create a HIE that can sustain itself. However, absent any of these elements, a HIE may not be able to withstand the uncertainty of the public marketplace and any potential shifts in the health care economy.

HIEs will contract with numerous community organizations to provide navigator activities as evidenced by the State of Connecticut's intent to contract with as many as 300 CBOs to perform navigator functions. A network of 300 agencies has significant

potential for systemic risk. Synergy among HIE networked agencies must remain high and intact for maximum effectiveness. Thus, HIE's will need to guard against the failure of any networked agency in order to safeguard against failure of the entire HIE operation. Because of the large numbers of CBOs that could participate as navigator agencies, systemic risk in the HIE marketplace has the greatest potential to occur with contracted navigator programs, and thus to impact services to vulnerable populations.

Sustainability Framework for HIE Navigator Programs

Reaching, educating and serving millions of individuals who have not had the education, resources, or finances to navigate the health care system will require an organization with established community ties and a record of community service. A sustainable framework for such an organization would need to have four major elements: 1) an organizational history of meeting the needs of vulnerable populations; 2) a management approach that adapts quickly to changes in contractual relationships, service requirements, and rules for program management and reporting; 3) knowledge of strategies proven to be successful in reaching clients and engaging them in services; and 4) a staff that understands the challenges faced by at-risk individuals and who have experience in using the strategies identified to facilitate their enrollment into health plans. Additionally, the ability to tailor strategies proven to be effective in reaching at-risk populations and engaging and earning their trust is critical to program success. Navigator programs will also need to ensure an opportunity for staff knowledge management by providing ongoing training on rules and regulations regarding HIEs, navigator program responsibilities, and health plan eligibility. Also, employing

individuals who understand how to navigate personal and system barriers faced by the clients they will serve is critical. HIE navigator programs will need to adopt the strategies of traditional navigator programs to be effective, successful, and most of all sustainable. Two earlier Appendix Tables in Chapter 4 (Table A-1 and Table A-3) provided a list of successful navigator strategies and a listing of navigator roles and core competencies, respectively. Because both lists are extensive, they will not be delineated in the framework presented. However, because their content is critical to a framework for the sustainability of a navigator program they are incorporated by reference.

Proposed frameworks for sustainable HIEs and HIE navigator programs are presented in Exhibits 5.1 and 5.2, respectively.

Exhibit 5.1: Proposed Framework for a Sustainable State Based Health Insurance Exchange *

| <i>Design Element</i> | <i>Recommended Alternative</i> | <i>Rational</i> |
|---|---|--|
| HIE Structure /Business Operating Model | Quasi-governmental | Widely recognized legislatively as an independent public entity not affiliated with any agency or department. |
| Governance Appointment | Balance of appointments by the Governor and the Legislature | Appointments from both the executive and legislative branches of state government could prevent any allegiance. The law should spell out the number and types of appointments that can be made by each branch. |
| Governance Structure | Board of Directors | The Board, its representatives and its size should be sufficient to include the level of expertise needed to make decisions on HIE related business topics. State ethics rules on Conflict of Interest as well as guidelines published by the DHHS in the Federal Register, Vol. 77, No. 59 dated March 27, 2012 should be enforced. |
| Governance Composition | <i>Voting Representation:</i> Consumer Small Business Insurance Industry Finance Industry Other community leader and business appointments <i>Ad Hoc Representation:</i> Select state agencies with a functional stake in the operations and outcomes of the HIE | Board member’s credentials should reflect the range of expertise needed to govern the business activities of the Exchange. The decision on voting and non-voting ad hoc representation should be contained in the law which established the exchange. The types of business appointments should be contained in the law along with names of state agencies that have been agreed upon to serve in ad hoc capacities. |
| Funding | User fees, per enrollee assessment, or premium assessment | HIEs will need a source of revenue to support its operations, including ongoing contractual arrangements with agencies providing navigator services. |
| <p>* This recommended framework is based on empirical findings from this research and is not endorsed by any specific article or report. It is the opinion of the author of this dissertation.</p> | | |

Exhibit 5.2: Proposed Framework for Sustainability of HIE Navigator Programs *

| | <i>Elements for Program Sustainability</i> | |
|--|--|---|
| 1. | Ongoing Program Management | <ul style="list-style-type: none"> • Continue development of relationships with vulnerable populations • Implement programs for training, continuing education and competency testing for staff to ensure workers are informed of changes in federal and state rules and regulations related to their functions, program expectations, and eligibility and enrollment requirements into HIE health plans • Have the ability to quickly adapt to changing rules and regulations • Maintain technology resources that support staff knowledge management • Employ community lay workers or similar individuals as navigators who have the skills and expertise required to carry out navigator duties • Meet on a regularly scheduled basis with management staff of the HIE • Ensure reports and deliverables are timely and meet reporting requirements • Maintain data systems that collect data, generate required reports, and perform data mining functions on all available variables. |
| 2. | Strategies for Engagement of Vulnerable Populations | See Chapter 4 – Appendix Table A-1 |
| 3. | Navigator Characteristics | See Chapter 4 – Appendix Table A-3 |
| <p>* This recommended framework is based on empirical findings from this research and is not endorsed by any specific article or report. It is the opinion of the author of this dissertation.</p> | | |

5.4 Challenges and Recommendations for Future Research

The central role of HIEs as the public marketplace for the purchase of health insurance was demonstrated when millions of visitors to the federal website on its first day of operation were unable access information or applications to apply for coverage. The majority of issues were information technology related and caused the site to crash. This site serves as the hub for more than thirty HIEs in states that elected the Federally Facilitated Exchange model and some states that implemented State-Partnership models (R. Pear & Goodnough, 2013). News reports indicate that fewer technical problems were being experienced by State Based HIEs that elected to develop and operate their own State Based websites generally because they can react more quickly to problems, something not necessarily possible due to the complexity of the federal Exchange.

Since opening, State Based HIEs have been able to demonstrate a need for affordable health insurance which is very likely generalizable across the nation. Seven days after debut, Kentucky's health insurance website "kynect" was found to be "working betterthan in most states" (Cross, 2013). By October 25th, Kentucky Governor Steve Beshear noted: "People who say the Affordable Care Act doesn't work need look no further than Kentucky...The fact that so many Kentuckians are actively seeking health coverage...tells us that kynect is meeting a gaping need in our state. At long last, every Kentuckian can finally find affordable health insurance" (The Lane Report, 2013). As of October 25, 2013, statistics out of Kentucky showed:

- ◆ 305,949 unique visitors to the website, viewing 7.2 million web pages

- ◆ 267,938 people conducted preliminary screenings to determine qualifications for subsidies, discounts or programs like Medicaid
- ◆ 51,482 applications started
- ◆ 26,174 enrolled in new health coverage, including Medicaid and private insurance
- ◆ 1,607 standalone dental plans enrolled
- ◆ Enrollment composite: 21,342 have enrolled in Medicaid and 4,832 have enrolled in a qualified health plan, and
- ◆ 10,443 have been found eligible for a subsidy to purchase a qualified health plan, but some have not yet chosen a plan (The Lane Report, 2013).

Kentucky's experience with "...a less-flashy but more efficient website...[that is] very straightforward in allowing consumers to browse plans without first creating an account" (Cross, 2013) is likely the reason for its quick success.

While other states have experienced some technical problems, they have nonetheless, made progress in enrollment. The Nevada Review Journal reports that despite early technical issues, as of October 8, the Silver State Exchange showed 89,687 unique visitors; had 21,864 accounts created; and had 3,644 applications filed (Robison, 2013). USA Today reported that nearly 174,000 New Yorkers had applied through the state's HIE, with 37,000 signing up for coverage (Spector, 2013). Of the 37,000 enrollees, almost two-thirds (24,600) found that because of their income levels, they were eligible for the state's Medicaid program. The remaining 13,000 new enrollees chose private insurance. It was also reported that since its October 1 launch, more than 77,000 individuals had been served by the state's customer service center (Spector, 2013). Other success stories reported by the New York Times within one week of launch

include: The State of Washington with 9,700 individuals signing up for coverage; the State of Connecticut processing 1,175 applications; and the State of California completing more than 16,000 applications in the first five days of operation (R. Pear & Goodnough, 2013). Analysts and consultants are attributing the success of state run exchanges to straightforward, easy to navigate, clear language websites (R. Pear & Goodnough, 2013).

The federal website healthcare.gov is complex, requires users to first create an account before they can peruse the website, and must connect each user with a website portal that provides information on approved health plans in their state. Both the Kentucky and State of Washington websites do not require a user to first create an account (R. Pear & Goodnough, 2013; Report, 2013). This change should be a consideration as the federal site is overhauled to improve performance and enhance the user experience.

Even in the face of immediate technical issues the PPACA continues to face challenges that could derail its ability to improve the health of individuals and the nation as a hold. Despite benefits such as keeping college students on parental insurance policies until the age of 26, removing the ban pre-existing conditions for children, and removing the caps on lifetime insurance benefits that have gone into effect in the past two years, most Americans continue to have a negative view of the law. Most notable of these challenges is educating the American public on health reform, what it is, what it means, what it has to offer, and the importance of health coverage for all Americans, not just those who can afford it. This requires better marketing and advertising, something

that appears to have been the missing link for better public acceptance of the law. A June, 2013, Kaiser Health Tracking Poll reported that differences in how the law is “branded” are resulting in differences in how it is perceived. When referred to as “Obamacare” versus the “health reform law”, 47% of respondents expressed an unfavorable view of the law, while 42% expressed a favorable view (Kaiser Family H. J. K. F. Foundation, 2013). This suggests that marketing health reform has been slow and ineffective, and a more aggressive, non-branded, positive marketing campaign is needed.

The rules and regulations under which HIEs are currently operating were established by the DHHS over the last three years. Establishment of one of three federally defined HIE models, state created HIE business entities carrying out federally mandated functions potentially without the benefit of federal funding after 2014, and HIE mandated contracts with potentially hundreds of agencies carrying out navigator functions, in combination present an ongoing opportunity for complex environments with confusing federal, state, and contractual relationships. Likewise the field for HIE navigator agencies and independent navigators is crowded. Currently, it is comprised of CBOs, consumer advocacy agencies, community health centers, social service agencies, and in some instances individuals. As will likely be the case with the State of Connecticut which anticipates contracting with as many as 300 agencies for navigator services (Edlin, 2013), large numbers present a potential challenge for the control of information dissemination, ongoing training on qualified health plans and public program eligibility rules, and service and accountability for enrollment outcomes. As initial mandates and service requirements go into effect opportunities will likely arise for

ongoing changes in federal and state rules and regulations regarding exchanges and the roles and responsibilities of navigator programs (Van de Water & Nathan 2011). Thus, ongoing monitoring and evaluation of these two interdependent components is essential.

In addition to challenges presented during the initial implementation of insurance exchanges, additional challenges could impact the sustainability of HIEs and navigator programs and lessen their ability to meet the needs of uninsured and vulnerable populations. The recommendations for future research that follow represent an opportunity to be proactive in anticipating challenges and developing solutions before issues arise.

Recommendation One: Ensure ongoing evaluation and monitoring of approved health plan options to ensure compliance with DHHS criteria for participation in HIEs.

Rational: Health plans operating within the Exchange have a very stringent set of requirements to gain entry into the Exchange marketplace. HIEs will need to ensure that all state and federal requirements for initial entry into the public marketplace are met. By federal statute, approved health plans must offer a set of minimum essential benefits (MEBs). HIEs will need to maintain an ongoing working relationship with state insurance offices to monitoring any changes in services and benefits offered by HIE health plans to ensure that MEBs are not compromised. Additional, HIEs should consider routinely surveying plan participants to ensure that services and benefits offered by a plan carrier are in fact provided and that premium charges are preserved for the indicated contract term.

Recommendation Two: Develop risk adjustment models that correct for adverse selection using understandable and uncomplicated formulas (Kingsdale & Bertko, 2010; Van Ginneken & Swartz, 2012). *Rational:* In a free market adverse selection will occur and risk adjustment formulas that fairly address this issue are critical to keeping carriers and competition in the HIE marketplace. The law is clear that individuals applying for health insurance coverage through the Exchange cannot be turned down by plans that are participating in the public marketplace. Likewise, participating plans must set premiums that are community rated. The result is that certain plan carriers could serve a disproportionate share of individuals with costly medical conditions compared to other carriers. There must be an easy mechanism to adjust for risk associated with adverse selection. Policies that address this issue must be clear regarding how those risk pools are funded, including any formulas used to determine the level of contribution from insurance carriers, and how distributions from risk pools are made.

Recommendation Three: Mandate and monitor continuing education for navigators on rules and regulations affecting health plan services and benefits, premium subsidies, deductibles and co-payments, and changing eligibility rules for SCHIP and Medicaid including Medicaid Expansion to control for churning in order to prevent gaps in insurance coverage for eligible populations (Buettgens, Nichols, & Dorn, 2012; Hayes & Schoen, 2013). *Rational:* Navigator organizations must ensure that staff is trained on all federal and state rules and regulations for enrollee participation in publicly funded and premium subsidized health plans. Navigators are responsible for distributing “fair and impartial information” on qualified health plans, and guiding individuals to plans that

best fit their needs. Continuing education that supports knowledge management in these areas is crucial.

Recommendation Four: Monitor approved health plans for the inclusion of essential community providers as a part of their preferred provider networks. This would include such providers as public health departments, community health centers, public hospitals, and other safety net providers from which vulnerable populations have traditionally sought service. *Rational:* The implications of exclusion from provider networks on the financial and economic viability of safety net providers could be serious. Reform will result in more individuals being enrolled in insurance plans that use preferred provider networks in which safety net providers do not participate. The need for safety net organizations will continue. They will continue to serve those without insurance, as well as large immigrant populations that are not eligible to acquire health insurance coverage under the reform act. Thus, they must continue to have a population of paying patients to ensure their viability. Use of the DHHS Non-Exhaustive List of Essential Community Providers (DHHS, 2012) by HIEs to ensure participation of safety net provider organizations in health plan networks will need to be monitored and enforced.

Recommendation Five: Marketing and outreach to increase participation and enrollment of healthy 18 to 30 year olds into HIE health plans is essential. *Rational:* The success of health reform requires that all Americans have health insurance coverage. This includes healthy young adults who are currently uninsured because they either cannot afford health insurance or because they do not believe that they need health insurance (Kaiser Family H. J. K. F. Foundation, 2013). Enrolling this healthy population is necessary to

offset the number of individuals who will enter the health care market with costly medical conditions. Premiums paid by healthy users less likely to access the system for chronic or other long term medical conditions, provides the financial leverage necessary to contain costs and make healthcare affordable. Mechanisms to ensure the enrollment of this healthy adult population will need to be developed, implemented, monitored and evaluated on an ongoing basis to ensure the financial viability of the health reform system.

Recommendation Six: Identify mechanisms for developing a stream of revenue to support HIE future operations. (Jost, 2013). *Rational:* Establishment Grant funding for HIE operations ends in December 2014. States will need to have mechanisms in place that provide ongoing funding for HIEs. Legislative approval of funding mechanisms including insurance carrier assessment or per enrollee fees with authority given to HIEs to impose and collect all fee revenue is needed. In addition, a determination of whether fees will extend to all insurers doing business in the state or just to those participating in the HIE will have to be made.

Recommendation Seven: Ongoing monitoring of the economic implications of the HIE public marketplace on private insurers who do not participate in the HIE must be monitored to identify any possibilities for negative impact. (Bayly, 2012; Fera, 2013). *Rational:* This is required to maintain a balanced relationship between those insurers participating in the HIE and those insurers choosing not to offer health plans through the public market. All payers in the state will face new business risks, cost challenges, and an environment of economic uncertainty, and States Insurance Commissions will need to

ensure level economic playing fields for all carriers. This will be especially important if insurers choosing not to sell plans through the exchange are assessed a fee to support the operations of an exchange in which they do not participate. Economic concerns could result in some insurers choosing to exit the state's private market, which could impact the ability of employers to offer options for large group plans and reduce competition in the private market.

Recommendation Eight: Create state HIE websites that are easy to maintain, easy to update, easy to understand, and have user friendly portal features. ***Rational:*** Events of the last few weeks underscore the importance of designing websites that are straightforward and easy to use. Website design, colors used, and the size of text and pictures should be visually appealing. Moving users through the site should involve as few screens as possible, and the use of links to access new information or another website should be easy to detect. Decisions on which languages websites should be made available in should be based on the second languages most prevalent within the state. Instructions for accessing information in other languages should be available.

5.5 Research Limitations

While there are three HIE models that have been implemented among the 50 states and the District of Columbia, this research is limited to state based HIEs. State Partnership and Federally Facilitated Exchanges were excluded from this study. Thus, findings relative to HIE design, business operating model, and governance structure are specific to State Based Exchanges and may not be generalizable to other Exchange models. However, given that all Exchanges are mandated to contract with external

organizations to carry out navigator functions, findings relative to the management framework and the concerns regarding systemic risk could be considered by all Exchange models. Also, since all Exchanges will focus on the same uninsured and vulnerable populations the typology of successful navigator strategies could be generalizable to both State Partnership and Federally Facilitated Exchanges.

5.6 Implications for Public Health

Health reform will impact public health both positively and negatively. For decades, public health has been the champion of uninsured, underserved, and vulnerable populations. Health reform will improve the health status of eligible Americans who have been most at risk for health outcomes that have become public health concerns. Improvements in the incidence of public health problems such as chronic illnesses, obesity, smoking, and other conditions that lead to increased rates of morbidity and mortality in certain at-risk populations are likely to occur. The entry of vulnerable populations into the care delivery system will, over time, likely have a positive impact on eliminating many conditions that have risen to the status of public health epidemics.

However, throughout the health care debate and the implementation of health reform, little has been penned about the impact of reform on the more than 16 million undocumented immigrants. Exclusion of this group from health reform means that there will continue to be a segment of the population who are disproportionately impacted by chronic diseases and other illnesses that are preventable given timely access to care. Without the benefits that health reform makes available to eligible Americans, the undocumented immigrant population will likely become the new face of amenable

mortality in the U.S. The health status of this population is a matter of public health concern and the need for safety net services for this group will continue to exist.

Rosemary Stevens, a health care historian notes that America has a history of providing protection for health needs to groups that have been “identified as worthy of care” (Sheehan, 2010). Health care for the military and veterans came about in the 1950’s; Medicare for the elderly and Medicaid for poor women and children were established in 1965; the Indian Health Care Improvement Act of 1976 sought to improve the health of American Indians and Alaska Natives; and SCHIP was implemented in 1997 to expand health coverage for a growing number of uninsured children. Inclusion of undocumented immigrants into the health reform movement could occur if passage of an immigration law addresses the personal and public health implications of a lack of access to quality affordable care for this at-risk group.

According to the National Association of County & City Health Officials (NACCHO), the PPACA’s commitment to public health is evidenced by the mandatory provision of \$15 billion dollars over the next decade through the Prevention and Public Health Fund. The Fund provides “enhanced support for individual and community-based interventions known to promote healthy behavior, create healthy environments, reduce health disparities, or reduce the incidence of chronic and infectious diseases” (NACCHO, 2011).

The PPACA places emphasis on preventive care and the provision of certain free prevention services. It also results in improved access to care through preferred provider networks and Accountable Care Organizations. This means that public health will need

to guard against any belief at local funding levels that public health services can be significantly reduced as a result of health reform. With the possible exception of rural communities, public health may need to reconsider its provision of personal health services and direct its efforts more towards population based health care. NACCHO asserts that the implementation of health reform has presented new partnership opportunities for public health and in particular, local health departments. Those opportunities are presented below in Table 5-3.

Table 5-3: Opportunities for Public Health Engagement in Health Reform

| # | New Opportunities for Public Health Consideration under Health Reform |
|---|--|
| 1 | Convene partnerships for population-based prevention, including the engagement of new partners in policy development for communities |
| 2 | Transition clinical services to community partners such as FQHCs and focus LHD resources on population-based functions |
| 3 | Convene and coordinate population health and HIT activities among community partners including healthcare providers and community-based organizations |
| 4 | Promoting a framework for understanding and measuring health inequities in order to impact both the medical and social determinants of health |
| 5 | Overseeing the planning, development, and implementation of healthcare reform locally |
| 6 | Evaluating changes in the health environment, on a local and regional basis |
| 7 | Monitoring health status of vulnerable populations, including uninsured and immigrant communities, and gaps in health insurance coverage |
| 8 | Working with individual states to apply for grant opportunities that align with state and local priorities and leverage the work of community and local stakeholders |
| 9 | Educating community residents and community-based organizations about the choices available under the ACA |

Source: (NACCHO, 2011)

5.7 Summary

Despite America's long and storied history of millions of uninsured and vulnerable individuals, combined with decades of inequality in treatment and disparate health outcomes, the PPACA and in particular, HIE and HIE navigator programs have the potential to make health care a right and not a privilege. In attempting to level the playing field, two important and highly dependent components will need to share the responsibility for reaching, educating, and enrolling millions of individuals into quality, affordable health plans. HIEs need navigator programs to perform the duties that will result in eligible individuals being identified, educated, and counseled on which health plan options best fit their needs. Navigator programs need HIE marketplaces to serve as the public available outlet for purchase of those health plan. While their duties and roles are distinctly different, together, they will serve as the primary vehicles by which uninsured and vulnerable populations will finally gain entry into the health insurance market. On October 1, 2013, the need for a marketplace to provide insurance to millions of vulnerable and uninsured Americans and to give insured individuals more financially reasonable options was demonstrated when almost 7.7 million individuals attempted to access the healthcare.gov website on its first day of operation. This number increases substantially if the millions of individuals who directly accessed State-Based HIE websites are included.

As health reform continues to unfold, challenges and opportunities for improvement of HIEs and navigator programs will present themselves. Thus, this research is expected to add to an emerging body of knowledge about both of these two

important components. First, the analysis of early state-based HIE agency operating model, governance structure and management framework based on established theory, can be used to inform future research leading to a best practice model for HIEs. Second, the identification of navigator strategies used successfully by traditional navigator programs to reach at-risk populations could inform the design, and implementation of HIE navigator program strategies in the future. Third, recommended frameworks for the sustainability of HIE agencies and navigator programs are based on empirical findings from this research and could lead to a best practice model for use by State Based Exchange programs going forward, as well as State Partnership and Federally Facilitated Exchanges that move to State Based models in the future. It has taken almost a century to achieve, but today health care in America is no longer a privilege. As of March 23, 2010 it is a right that all citizens will be able to enjoy.

REFERENCES

- Altman, L. K., M.D. (1990, February 27, 1990). DOCTOR'S WORLD; C.D.C.'s New Chief Has an Unusual Resume, *The New York Times*. Retrieved from <http://www.nytimes.com/1990/02/27/science/doctor-s-world-cdc-s-new-chief-has-an-unusual-resume.html?pagewanted=all&src=pm>
- Alvarez, L., & Pear, R. (2013, September 17, 2013). Florida Among States Undercutting Health Care Enrollment, *The New York Times*. Retrieved from http://www.nytimes.com/2013/09/18/us/florida-among-states-undercutting-health-care-enrollment.html?ref=health&_r=0
- Anderson, G. F., & Frogner, B. K. (2008). Health spending in OECD countries: obtaining value per dollar. *Health Affairs (Project Hope)*, 27(6), 1718-1727. doi: 10.1377/hlthaff.27.6.1718
- Baker, E. A., Metzler, M. M., & Galea, S. (2005). Addressing Social Determinants of Health Inequities: Learning From Doing. [Editorial]. *American Journal of Public Health*, 95(4), 3.
- Battaglia, T. A., Roloff, K., Posner, M. A., & Freund, K. M. (2007). Improving follow-up to abnormal breast cancer screening in an urban population. *Cancer*, 109(S2), 359-367. doi: 10.1002/cncr.22354
- Bayly, E. (2012). AMERICAN HEALTH BENEFIT EXCHANGES: STATE REGULATORS MUST ENCOURAGE PRIVATE MARKET

- PARTICIPATION. [Article]. *Journal of Health Care Law & Policy*, 15(1), 197-226.
- Biedrzycki, P. A., Koltun, R. (2012). Integration of Social Determinants of Community Preparedness and Resiliency in 21st Century Emergency Management Planning. *Journal of Homeland Security Affairs*, 8(14).
- Bigby, J. A. (2009). Controlling Health Care Costs in Massachusetts After Health Care Reform: There is No Silver Bullet. *Journal of the American Medical Association*, 169(20), 3.
- Blavin, F., Blumberg, L. J., Buettgens, M., Holahan, J., & McMorrow, S. (2012). How choices in exchange design for states could affect insurance premiums and levels of coverage. *Health Affairs*, 31(2), 290-298.
- Bloombreg, B. (2012). HHS Issues Final Rule to Implement Health Insurance Exchange Markets (Vol. 14-04 MBP 1, pp. 4). Arlington, VA: Bureau of National Affairs.
- Blumenthal, D., & Morone, J. (Eds.). (2010). *The Heart of Power: Health and Politics in the Oval Office*. Berkley, CA: University of California Press.
- Brooks, T., & Kendall, J. (2012). Designing Navigator Programs to Meet the Needs of Consumers: Duties and Competencies (pp. 8). Washington, D.C.: Georgetown University Health Policy Institute.
- Buettgens, M., Nichols, A., & Dorn, S. (2012). Churning Under the ACA and State Policy Options for Mitigation *Timely Analysis of Immediate Health Policy Issues* (pp. 12). Washington, DC: Urban Institute.

- Buist, A. (2012, 2012). Children's Health. *Policy Priorities* Retrieved October 14, 2013, 2013, from <http://www.childrensdefense.org/policy-priorities/childrens-health/>
- Carboni, J. L., & Milward, H. B. (2012). Governance, Privatization, and Systemic Risk in the Disarticulated State. [Article]. *Public Administration Review*, 72, S36-S44. doi: 10.1111/j.1540-6210.2012.02670.x
- CDC. (2004). *Disparities in Premature Deaths from Heart Disease --- 50 States and the District of Columbia, 2001*. Atlanta: Centers for Disease Control and Prevention Retrieved from www.cdc.gov/mmwr/preview/mmwrhtml/mm5306a2.htm.
- CDC. (2009a). *Centers for Disease Control and Prevention, FY 2010 Budget, May 14, 2009*. Atlanta, GA: Centers for Disease Control and Prevention Retrieved from www.cdccoalition.org/.../FY%202010%20Budget-APHA%20presentatio...
- CDC. (2009b). The Power of Prevention: Chronic disease...the public health challenge of the 21st century (N. C. f. C. D. P. a. H. Promotion, Trans.) (pp. 18). Atlanta, GA: Centers For Disease Control and Prevention.
- CDC. (2013, November 11, 2011). Office of Minority Health and Health Equity (AMHHE) Home Page Retrieved September 7, 2013, 2013, from <http://www.cdc.gov/minorityhealth/populations.html>
- Christie, J., Itzkowitz, S., Lihau-Nkanza, I., Castillo, A., Redd, W., & Jandorf, L. (2008). A randomized controlled trial using patient navigation to increase colonoscopy screening among low-income minorities. *Journal of the National Medical Association*, 100(3), 278-284.

- CMS. (2008). *National Health Expenditure Projections 2010-2020*. Washington, DC: U.S. Government Retrieved from <https://www.cms.gov/NationalHealthExpendData/downloads/proj2010.pdf>.
- CMS. (2011). *National Health Expenditures 2011 Highlights*. Washington, DC: Centers for Medicare and Medicaid Services Retrieved from <http://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/NationalHealthExpendData/downloads/highlights.pdf>.
- CMS. (2012). *Affordable Insurance Exchanges*. Washington, DC: DHHS Retrieved from <http://www.cms.gov/CCIIO/Resources/Files/Downloads/hie-overview-presentation.pdf>.
- CMS. (2013a). Affordable Insurance Exchanges Guidance, Guidance on the State Partnership Exchange In D. o. H. a. H. Services (Ed.), *Guidance on the State Partnership Exchange* (pp. 23). Washington,DC.
- CMS. (2013b). *In-Person Assistance in the Health Insurance Marketplace* Washington, DC: DHHS Retrieved from <http://www.cms.gov/CCIIO/Programs-and-Initiatives/Health-Insurance-Marketplaces/assistance.html>.
- CMS. (2013c). *Essential Health Benefits, Actuarial Value & Accreditation Standards*. Washington, DC: DHHS Retrieved from <http://www.cms.gov/CCIIO/Resources/Files/Downloads/ehb-av-accred-final-2-25-2013v2.pdf>.

- CMS. (2013d, October 1, 2013). State Health Insurance Marketplaces Retrieved October 28, 2013, 2013, from <http://www.cms.gov/CCIIO/Resources/Fact-Sheets-and-FAQs/state-marketplaces.html>
- Collins, S. R., & Nicholson, J. L. (2010). Realizing Health Reform's Potential: Young Adults and the Affordable Care Act of 2010 *Health Reform* (Vol. 101). Washington, DC: The Commonwealth Fund.
- Collins, S. R., Robertson, R., Garber, T., Doty, M.M. (2013). Insuring the Future: Current Trends in Health Coverage and the Effects of Implementing the Affordable Care Act *Biennial Health Insurance Survey 2012* (pp. 41). Washington, DC: The Commonwealth Fund.
- Collins, S. R., Schoen, C., & Davis, K. (2011, November 10, 2011). New Census Poverty Measure Shows Medical Expenses Push 10 Million More Americans into Poverty. Retrieved from <http://www.commonwealthfund.org/Blog/2011/Nov/New-Census-Poverty-Measure.aspx?..>
- Committee, D. P. (2008). *Soaring Health Care Costs are Unsustainable for Families and Individuals, Businesses, and All Levels of Government* Washington, DC: Retrieved from <http://www.dpc.senate.gov/docs/sr-111-1-82.html>.
- Committee, D. P. (2010, September 17, 2010). The Patient Protection and Affordable Care Act: Detailed Summary. *Responsible Reform for the Middle Class*, from <http://www.dpc.senate.gov/healthreformbill/healthbill04.pdf>
- Company, A. B. (2013). The Daily Briefing: Where each state stands on ACA's Medicaid expansion (pp. 7): The Advisory Board Company.

- The Patient Protection and Affordable Care Act, US Government Printing Office, Pub. L. No. 111-148 906 (2010 March 23, 2010).
- Corlette, S., Lucia, K. W., & Levin, M. (2013). Implementing the Affordable Care Act: Choosing an Essential Health Benefits Benchmark Plan *Realizing Health Reform's Potential* (Vol. 15, pp. 14). Washington, D.C>: Commonwealth Fund.
- Cross, A. (2013, October 7, 2013). Ky. health insurance exchange working better than elsewhere., *Kentucky Health News*, p. 2. Retrieved from www.lanereport.com
- Cunningham, P. (2010). Who Are the Uninsured Eligible for Premium Subsidies in the Health Insurance Exchanges? (pp. 8). Washington, DC: Center for Studying Health System Change.
- Cutler, D., & Lleras-Muney, A. (2007). Education and Health (9 ed., pp. 4): Gerald R. Ford School of Public Policy, University of Michigan.
- CWF. (2010). What Will Happen Under Health Reform- and What's Next? *Columbia Journalism Review*(May/June), 12.
- Darnell, J. S. (2007). Patient navigation: a call to action. *Social Work*, 52(1), 81-84.
- Davis, P. (2009). *Medicare: History of Part A Trust Fund Insolvency Projections* (RS2096). Washington. DC: CRS Retrieved from <http://www.aging.senate.gov/crs/medicare14.pdf>.
- DeLuca, N. (2006). *Stop TB in the African-American Community* Division of Tuberculosis Elimination. Centers for Disease Control and Prevention. Atlanta. Retrieved from www.cdc.gov/hiv/topics/aa/resources/.../pdf/Comorbidities_TB

- DHHS. (2012). Non-Exhaustive List of Essential Community Providers (pp. 13,890 entries). Washington, DC: Department of Health and Human Services.
- DHHS. (2012a). *Patient Protection and Affordable Care Act; Establishment of Exchanges and Qualified Health Plans; Exchange Standards for Employers. Final Rules.* (CMS 9989-F). Washington, DC: United States GPO Retrieved from <http://exchange.nv.gov/uploadedFiles/exchangenvgov/Content/Resources/CMS-9989-F.pdf>.
- DHHS. (2012b). HHS Issues Final Rule to Implement Health Insurance Exchange Markets. [Article]. *Managing Benefits Plans*, 14(4), 1-3.
- DHHS. (2012c). *Federal Register / Vol. 77, No. 59 / Tuesday, March 27, 2012 / Rules and Regulations.* Washington, D.C.: Government Printing Office.
- DHHS. (2013a). *Cooperative Agreement to Support Navigators in Federally-facilitated and State Partnership Exchanges.* (CA-NAV-13-001). Washington, DC: DHHS.
- DHHS (Producer). (2013c, September 21, 2010). HHS finalizes rule guaranteeing 100 percent funding for new Medicaid beneficiaries. [Press Release] Retrieved from <http://www.hhs.gov/news/press/2013pres/03/20130329a.html>
- DHHS, CMS, & CCIIO. (2012d). *Cooperative Agreement to Support Establishment of the Affordable Care Act's Health Insurance Exchanges.* (FOA Number: IE-HBE-12-001
CFDA: 93.525). Washington, DC: Retrieved from <http://www.cms.gov/CCIIO/Resources/Funding-Opportunities/Downloads/amended-spring-2012-establishment-foa.pdf>.

- Dohan, D., & Schrag, D. (2005). Using navigators to improve care of underserved patients. *Cancer, 104*(4), 848-855. doi: 10.1002/cncr.21214
- Donelan, K., Mailhot, J. R., Dutwin, D., Barnicle, K., Oo, S., Hobrecker, K., . . . Chabner, B. A. (2011). Patient Perspectives of Clinical Care and Patient Navigation in Follow-up of Abnormal Mammography. [Article]. *JGIM: Journal of General Internal Medicine, 26*(2), 116-122. doi: 10.1007/s11606-010-1436-4
- Dudley, D. J., Drake, J., Quinlan, J., Holden, A., Saegert, P., Karnad, A., & Ramirez, A. Beneficial Effects of a Combined Navigator/Promotora Approach for Hispanic Women Diagnosed with Breast Abnormalities.
- Beneficial Effects of a Combined Navigator/Promotora Approach for Hispanic Women Diagnosed with Breast Abnormalities.*
- Duggan, C., Coronado, G., Martinez, J., Byrd, T. L., Carosso, E., Lopez, C., . . . Thompson, B. (2012). Cervical cancer screening and adherence to follow-up among Hispanic women study protocol: a randomized controlled trial to increase the uptake of cervical cancer screening in Hispanic women. *BMC Cancer, 12*, 170.
- Edlin, M. (2013). NAVIGATORS Play a lead role. [Article]. *Managed Healthcare Executive, 23*(2), 38-40.
- Elmendorf, D. W. (2010, May 20, 2010). [Congressional Budget Office Cost Estimate of H.R. 4872, Reconciliation Act of 2010].

- Enthoven, A. C., & van de Ven, W. P. M. M. (2007). Going Dutch -- Managed-Competition Health Insurance in the Netherlands. *The New England Journal of Medicine*, 357(24), 2421-2423. doi: <http://dx.doi.org/10.1056/NEJMp078199>
- Ericson, K. M. M., & Starc, A. (2012). Designing and Regulating Health Insurance Exchanges: Lessons from Massachusetts. [Article]. *Inquiry (00469580)*, 49(4), 327-338.
- Fera, B. (2013). How Are Insurance Companies Preparing for Health Insurance Exchanges? [Article]. *Financial Executive*, 29(1), 24-26.
- Ferrante, J. M., Chen, P.-H., & Kim, S. (2008). The effect of patient navigation on time to diagnosis, anxiety, and satisfaction in urban minority women with abnormal mammograms: a randomized controlled trial. *Journal Of Urban Health: Bulletin Of The New York Academy Of Medicine*, 85(1), 114-124.
- Ferrante, J. M., Wu, J., & Diccico-Bloom, B. (2011). Strategies used and challenges faced by a breast cancer patient navigator in an urban underserved community. *Journal of the National Medical Association*, 103(8), 729-734.
- Fillion, L., Cook, S., Veillette, A.-M., Aubin, M., de Serres, M., Rainville, F., . . . Doll, R. (2012). Professional Navigation Framework: Elaboration and Validation in a Canadian Context. [Article]. *Oncology Nursing Forum*, 39(1), E58-E69.
- Fischer, S. M., Sauaia, A., & Kutner, J. S. (2007). Patient Navigation: A Culturally Competent Strategy to Address Disparities in Palliative Care. [Article]. *Journal of Palliative Medicine*, 10(5), 1023-1028. doi: 10.1089/jpm.2007.0070

Foundation, H. J. K. F. (2011a). A Profile of Health Insurance Exchange Enrollees *Focus on Health Reform* (pp. 18). Washington, DC: The Kaiser Family Foundation.

Foundation, H. J. K. F. (2012a). THE UNINSURED A PRIMER *Kaiser Commission on Medicaid and the Uninsured* (pp. 46). Menlo Park, CA.

Foundation, H. J. K. F. (2013). Kaiser Health Tracking Poll: June 2013 (pp. 9). Washington, DC: Kaiser Family Foundation.

Foundation, H. J. K. F. (2013a). Establishing Health Insurance Marketplaces: An Overview of State Efforts Retrieved May 14, 2013, 2013A, from <http://kff.org/health-reform/issue-brief/esrtablishing-health-insurance-marketplaces>

Foundation, H. J. K. F. (2013b). State Decisions on Health Insurance Exchanges and the Medicaid Expansion, as of June 20, 2013. In K. F. Foundation (Ed.), *Health Reform*. Washington, DC: Henry J Kaiser Family Foundation.

Foundation, H. J. K. F. (2013c). State Health Insurance Marketplace Profiles Retrieved June 24, 2013, 2013, from <http://kff.org/state-health-exchange-profiles/>

Foundation, H. J. K. F. (2013d). State Health Exchange Marketplace Profiles: Massachusetts *Health Reform*. Menlo Park, CA.

Foundation, H. J. K. F. (2013e, September 17, 2013). Status of State Action on the Medicaid Expansion Decision, as of September 16, 2013

change indicator *State Health Facts* Retrieved September 20, 2013, 2013, from <http://kff.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act/#map>

- Foundation, H. J. K. F. (2013f). The Coverage Gap: Uninsured Poor Adults in States that Do Not Expand Medicaid *Health Reform Issue Brief* (pp. 8). Washington, DC.
- Foundation, K. F. (2009). Timeline: History of Health Reform Efforts in the U.S. Washington, DC: The Henry J Kaiser Foundation.
- Freeman, H. P. (2004). A Model Patient Navigation Program. *Oncology Issues*, 19, 4.
- Freeman, H. P. (2006). Patient Navigation: A community based strategy to reduce cancer disparities. *Journal of Urban Health*, 83(2), 139.
- Freeman, H. P., & Rodriguez, R. L. (2011). History and principles of patient navigation. *Cancer*, 117(S15), 3537-3540. doi: 10.1002/cncr.26262
- Garza, M. A., Jingyu, L., Blinka, M., Farabee-Lee, I., Neuhaus, C. E., Zabora, J. R., & Ford, J. G. (2005). A Culturally Targeted Intervention to Promote Breast Cancer Screening Among Low-Income Women in East Baltimore, Maryland. *Cancer Control*, 12(2), 8.
- Ginsburg, P. B. (2008). High and Rising Health Care Costs: Demystifying U.S. Health Care Spending. In L. Shi & D. A. Singh (Eds.), *The Nation's Health* (8th ed., pp. 375-387). Sudbury, MA: Jones & Bartlett.
- Goodwin, W. (2010). Federal health care reform legislation establishes consumer protections, health insurance exchanges. *North Carolina Medical Journal*, 71(3), 239-242.
- Green, A. R., Peters-Lewis, A., Percac-Lima, S., Betancourt, J. R., Richter, J. M., Janairo, M.-P. R., . . . Atlas, S. J. (2008). Barriers to screening colonoscopy for low-

income Latino and white patients in an urban community health center. *Journal Of General Internal Medicine*, 23(6), 834-840. doi: 10.1007/s11606-008-0572-6

Growth, C. f. (2012). 2012 Presidential White Paper #6: Former Utah Governor Jon Huntsman

Presidential White Papers Retrieved September 16, 2013, from

<http://www.clubforgrowth.org/whitepapers/?subsec=137&id=911>

Gruber, J. (2008). Massachusetts Health Care Reform: The View From One Year Out.

[Article]. *Risk Management & Insurance Review*, 11(1), 51-63. doi:

10.1111/j.1540-6296.2008.00129.x

Gruber, J. (2011). Massachusetts points the way to successful health care reform.

[Article]. *Journal of Policy Analysis & Management*, 30(1), 184-192. doi:

10.1002/pam.20551

Guadagnolo, B. A., Cina, K., Koop, D., Brunette, D., & Petereit, D. G. (2011). A Pre-post

Survey Analysis of Satisfaction with Health Care and Medical Mistrust after

Patient Navigation for American Indian Cancer Patients. *Journal of Health Care*

for the Poor and Underserved. , 22(4), 13.

Hansen, L. K., Fleigl, P., Modiano, M. R., Lopez, J. A., Escobedo, S., Moinpour, C. M., .

. . Meyskens, F. L. (2005). An educational program to increase cervical and breast

cancer screening in Hispanic women: A Southwest Oncology Group Study.

Cancer nursing, 28(1), 47.

- Hayes, S., & Schoen, C. (2013, July 10, 2013). Stop the Churn: Preventing Gaps in Health Insurance Coverage. Retrieved from <http://www.commonwealthfund.org/Blog/2013/Jul/Stop-the-churn>
- Holtz-Eakin, D. (2011). Does Massachusetts Health Care Reform Point to Success with National Reform. *Journal of Policy Analysis & Management*, 30(1), 18.
- Hook, A., Ware, L., Siler, B., & Packard, A. (2012). Breast Cancer Navigation and Patient Satisfaction: Exploring a Community-Based Patient Navigation Model in a Rural Setting. [Article]. *Oncology Nursing Forum*, 39(4), 379-385.
- Hunter, J. B., de Zapien, J. G., Papenfuss, M., Fernandez, M. L., Meister, J., & Giuliano, A. R. (2004). The impact of a promotora on increasing routine chronic disease prevention among women aged 40 and older at the U.S.-Mexico border. *Health Education & Behavior*, 31(4), 18S.
- Institute, N. C. (2005). *NCI's Patient Navigator Research Program: Fact Sheet*. Washington, DC: Retrieved from <http://crchd.cancer.gov/>.
- Jandorf, L., Gutierrez, Y., Lopez, J., Christie, J., & S.H., I. (2005). Use of a patient navigator to increase colorectal cancer screening in an urban neighborhood health clinic. *Journal of urban health*, 82(2), 216.
- Jost, T. S. (2013, July 15, 2010). Health Insurance Exchanges Under the Affordable Care Act: Key Policy Issues. Retrieved from <http://www.commonwealthfund.org/blog/Jul/Health-Insurance-Exchanges.aspx>

- Kaiser. (2009). Facts on Health Reform. In C. Marks, Schwartz, T., Donaldson, L. (Ed.), *Kaiser Commission on Medicaid and the Uninsured* (pp. 23). Washington, DC: The Henry J. Kaiser Family Foundation.
- Keehan, S. P., Sisko, A. M., Truffer, C. J., Poisal, J. A., Cuckler, G. A., Madison, A. J., . . . Smith, S. D. (2011). National Health Spending Projections Through 2020: Economic Recovery And Reform Drive Faster Spending Growth. *Health Affairs*, 30(8), 1594-1605.
- Keith, K., Lucia, K. W., & Monahan, C. (2013, July 1, 2013). Will New Laws in States with Federally Run Health Insurance Marketplaces Hinder Outreach? Retrieved from <http://www.commonwealthfund.org/Blog/2013/Jul/Will-State-Laws-Hinder-Federal-Marketplaces-Outreach>
- Kennedy, K. (2013). Florida bans navigators from county health offices Retrieved September 13, 2013, 2013, from <http://www.lifehealthpro.com/2013/09/12/florida-bans-navigators-from-county-health-offices>
- Kingsdale, J. (2012). How small-business health exchanges can offer value to their future customers - and why they must. *Health Affairs*, 31(2), 275-283.
- Kingsdale, J., & Bertko, J. (2010). Insurance Exchanges Under Health Reform: Six Design Issues For The States. *Health Affairs*, 29(6), 1158-1163.
- Kreier, R., & Zweifel, P. (2010-2011). Health Insurance in Switzerland: A closer look at a system often offered as a model for the United States. *Hofstra Law Review*, 39, 22.

- Kreier, R., Zweifel, Peter. (2010). Health Insurance in Switzerland: A Closer Look at a System Often Offered as a Model for the United States *Hofstra Law Review*, 39(1), 23.
- Larkey, L. K., Gonzalez, J. A., Mar, L. E., & Glantz, N. (2009). Latina recruitment for cancer prevention education via Community Based Participatory Research strategies. *Contemporary Clinical Trials*, 30(1), 47-54. doi: <http://dx.doi.org/10.1016/j.cct.2008.08.003>
- Lasser, K. E., Murillo, J., Medlin, E., Lisboa, S., Valley-Shah, L., Fletcher, R. H., . . . Ayanian, J. Z. (2009). A multilevel intervention to promote colorectal cancer screening among community health center patients: results of a pilot study. [Article]. *BMC Family Practice*, 10, 1-7. doi: 10.1186/1471-2296-10-37
- Long, S. K., Stockley, K., & Dahlen, H. (2011). National Reform: What Can We Learn from Evaluations of Massachusetts? *SHARE - State Health Access Reform Evaluation* (pp. 7): Robert Wood Johnson Foundation.
- Martin, A. (2013). 10 Things to Know About State Health Insurance Exchanges (pp. 10). LifeHealthPro.com: Summit Business Media.
- AN ACT PROVIDING ACCESS TO AFFORDABLE, QUALITY, ACCOUNTABLE HEALTH CARE.(see House, No. 4479, amended) Chapter 58 C.F.R. (2006).
- Mechanic, D., & Tanner, J. (2007). Vulnerable People, Groups, And Populations: Societal View. *Health Affairs*, 26(5), 11.
- Merlis, M. (2009). A Health Insurance Exchange: Prototypes and Design Issues (pp. 27). Washington, DC.

- Moy, B., & Chabner, B. A. (2011). Patient Navigator Programs, Cancer Disparities, and the Patient Protection and the Affordable Care Act. *The Oncologist, 16*, 5.
- Muennig, P. A., & Glied, S. A. (2010). What Changes in Survival Rates Tell Us About US Health Care. *Health Affairs, 29*(11), 9.
- Mulvaney-Day, N., Alegria, M., Nillni, A., & Gonzalez, S. (2012). Implementation of Massachusetts Health Insurance Reform with Vulnerable Populations in a Safety-Net Setting. *Journal of Health Care for the Poor and Underserved., 23*, 19.
- Murray, C. J. L., & Frenk, J. (2010). Ranking 37th — Measuring the Performance of the U.S. Health Care System. *New England Journal of Medicine, 362*(2), 98-99. doi: doi:10.1056/NEJMp0910064
- NACCHO. (2011). Implementation of the Patient Protection and Affordable Care Act: A White Paper (pp. 3). Washington, DC: NACCHO.
- Napel, S. T., & Eckel, D. (2013). Navigators and In-Person Assistors: State Policy and Program Design Considerations (pp. 11). Princeton, NJ: State Health Reform Assistance Network.
- National Research Council (US), & Medicine, I. o. (2013). U.S. Health in International Perspective: Shorter Lives, Poorer Health. S. H. Woolf, . & L. Aron (Eds.), Retrieved from <http://www.ncbi.nlm.nih.gov/books/NBK115854/>
- Nguyen, T. N., & Kagawa-Singer, M. (2008). Overcoming Barriers to Cancer Care Through Health Navigation Programs. *Seminars in Oncology Nursing, 24*(4), 270-278. doi: <http://dx.doi.org/10.1016/j.soncn.2008.08.007>

- Nguyen, T. N., Tran, J. H., Kagawa-Singer, M., & Foo, M. A. (2011). A qualitative assessment of community-based breast health navigation services for Southeast Asian women in Southern California: recommendations for developing a navigator training curriculum. *American Journal of Public Health, 101*(1), 87-93.
- Nolte, E., & McKee, C. M. (2008). Measuring The Health Of Nations: Updating An Earlier Analysis. *Health Affairs, 27*(1), 14.
- Nolte, E., & McKee, C. M. (2011). Variations in Amenable Mortality - Trends in 16 High-Income Nations. *Health Policy*.
- Nolte, E., McKee, M. (2008). Measuring the Health of Nations: Updating an Earlier Analysis. *Journal of Health Affairs, 27*(1), 58-71.
- Nonzee, N. J., McKoy, J. M., Rademaker, A. W., Byer, P., Luu, T. H., Liu, D. C., . . . Simon, M. A. (2012). Design of a prostate cancer patient navigation intervention for a Veterans Affairs hospital. *BMC Cancer, 12*, 340.
- Norman, J. (2013). Navigators of State Health Insurance Exchanges Prepare to Help Applicants. *Washington Health Policy Week in Review* Retrieved May 20, 2013, 2-13, from <http://www.commonwealthfund.org/Newsletters/Washington-Health-Policy-in-Review/2013/May/May-20-2013/Navigators-of-State-Health-Insurance-Exchanges.aspx?view>
- O'Sullivan, J. (1998). *Medicare: Financing the Part A Hospital Insurance Program*. Washington, DC: CRS, Library of Congress Retrieved from http://www.law.umaryland.edu/marshall/crsreports/crsdocuments/98-457_EPW.pdf.

OECD. (2013). OECD Health Data 2013 *OECD Health Data*. Paris, France: The Organisation for Economic Co-operation and Development (OECD).

Pear, R. (2013, August 2, 2013). Missouri Citizens Face Obstacles to Coverage, *The New York Times*, p. 4. Retrieved from http://www.nytimes.com/2013/08/03/us/missouri-citizens-face-obstacles-to-coverage.html?nl=todaysheadlines&emc=edit_th_20130803&pagewanted=print

Pear, R., & Goodnough, A. (2013, October 8, 2013). Uninsured Find More Success via Health Exchanges Run by States, *The New York Times*. Retrieved from http://www.nytimes.com/2013/10/09/us/politics/uninsured-find-more-success-via-health-exchanges-run-by-states.html?_r=0&pagewanted=print

Percac-Lima, S., Grant, R. W., Green, A. R., Ashburner, J. M., Gamba, G., Oo, S., . . .

Atlas, S. J. (2009). A culturally tailored navigator program for colorectal cancer screening in a community health center: a randomized, controlled trial. *Journal Of General Internal Medicine*, 24(2), 211-217. doi: 10.1007/s11606-008-0864-x

Petereit, D. G., Molloy, K., Reiner, M. L., Helbig, P., Cina, K., Miner, R., . . . Roberts, C. R. (2008). Establishing a Patient Navigator Program to Reduce Cancer Disparities in the American Indian Communities of Western South

Dakota: Initial Observations and Results. *Cancer Control*, 15(3), 6.

Priorities, C. o. B. P. (2013). Status of the ACA Medicaid Expansion after Supreme Court Ruling (pp. 4). Washington, DC: Center on Budget & Policy Priorities.

Reinhardt, U. E. (2004). The Swiss Health System: Regulated Competition Without Managed Care. *JAMA*, 292(10), 1227-1231.

- Reinschmidt, K. M., Hunter, J. B., Fernandez, M. L., Lacy-Martinez, C. R., Guernsey de Zapien, J., & Meister, J. (2006). Understanding the Success of Promotoras in Increasing Chronic Diseases Screening. *Journal of Health Care for the Poor and Underserved*, 17(2), 9.
- Report, T. L. (2013, October 25, 2013). More than 26,000 enrolled in health coverage through kynect, *The Lane REport*. Retrieved from <http://www.lanereport.com/25500/2013/10/more-than-26000-enrolled-in-health-coverage-through-kynect/>
- Robison, J. (2013, October 14, 2013). Technical glitches Snarl Silver State Health Insurance Exchange, *Las Vegas Review Journal*, p. 2. Retrieved from <http://www.reviewjournal.com/business/technical-glitches-snarl-silver-state-health-insurance-exchange>
- Rogers, A. C. (1997). Vulnerability, health and health care. *Journal of Advanced Nursing*, 27, 8.
- Ruof, M. C. Vulnerability, Vulnerable Populations, and Policy *Scope Note Series* (Vol. 44, pp. 14). Washington, D.C.: National Reference Center for Bioethics Literature. The Joseph and Rose Kennedy Institute of Ethics. Georgetown University.
- Saly, E. (2013). Help Wanted: Preparing Navigators and Other Assisters To Meet New Consumer Needs (pp. 32). Chicago, IL: Illinois Health Matters.org.
- Schlueter, D. F., Thompson, W. W., Mason, T. A., Rayton M., & Arriola, K. J. (2010). A Qualitative Evaluation of the Avon Foundation Community Education and

- Outreach Initiative Patient Navigation Program. *Journal of Cancer Education* 25(4), 7.
- Schoen, C., Radley, D., Riley, P., Lipka, J., Berenson, J., Dermody, C., & Shih, A. (2013). *Health Care in the Two Americas*. Washington, DC: The Commonwealth Fund.
- Schoenbaum, S. C., Schoen, C., Nicholson, J. L., & Cantor, J. C. (2011a). Mortality Amenable to Health Care in the United States: The Roles of Demographics and Health Systems Performance. *Journal of Public Health Policy*, 32(4), 23.
- Schoenbaum, S. C., Schoen, C., Nicholson, J. L., & Cantor, J. C. (2011b). Mortality amenable to health care in the United States: The roles of demographics and health systems performance. *J Public Health Policy*. doi: 10.1057/jphp.2011.42
- Schoenbaum, S. C., Schoen, C., Nicholson, J.L., Cantor, J.C. (2011). Mortality Amenable to Health Care in the United States: The Roles of Demographics and Health Systems Performance Retrieved September 26, 2011, from www.commonwealthfund.org/Publications/In-the-Literature/2011/Aug/Mortality
- Sheehan, H. (2010). Healthcare reform in the USA, 2010: the rocky road ahead? *Indian Journal of Medical Ethics* VII(3), 3.
- Shi, L., & Singh, D. A. (2012). *Delivering Health Care in America: A Systems Approach* (5th ed.). Burlington, MA: Jones & Bartlett.
- Shi, L., & Stevens, G. D. (2010). *Vulnerable Populations in the United States* (2nd ed.). San Francisco, CA: Jossey-Bass.

- Smith, A. (2009). Massachusetts leads health coverage - Census: Census Bureau reports that Massachusetts had the lowest 2008 rates of uninsured, while Texas had the highest. *SDpecial Report: Fixing Heathcare* Retrieved November 5, 2013, from http://money.cnn.com/2009/09/21/news/economy/census_health_insurance/
- Smith, D. G. (2008). *Covering Uninsured Children: The Impact of the August 17 SCHIP Directive* Washington, D.C.: Centers for Medicare and Medicaid Retrieved from <http://www.hhs.gov/asl/testify/2008/04/t20080409c.html>
- Spector, J. (2013, October 24, 2013). 37,000 enrolled in N.Y. health exchange so far, *USA Today*, p. 2. Retrieved from <http://www.usatoday.com/story/news/nation/2013/10/24/new-york-health-care-exchange/3177787/>
- Steinberg, M. L., Fremont, A., Khan, D. C., Huang, D., Knapp, H., Karaman, D., . . . Streeter, O. E. (2006). Lay patient navigator program implementation for equal access to cancer care and clinical trials. *Cancer*, *107*(11), 2669-2677. doi: 10.1002/cncr.22319
- Steinbrook, R., MD. (2006). Health Care Reform in Massachusetts - A Work in Progress. *New England Journal of Medicine*, *354*(20), 4.
- Stremikis, K., Berenson, J., Shih, A., & Riley, P. (2011). Health Care Opinion Leaders' Views on Vulnerable Populations in the U.S. Health System *COMMISSION ON A HIGH PERFORMANCE HEALTH SYSTEM* (Vol. 17, pp. 12). New York: The Commonwealth Fund.

- Trust. (2008). Improving the Health of Low-Income and Minority Communities (D. o. G. Relations, Trans.) *A Healthier America: 10 Top Priorities For Prevention. Preventing Epidemics. Protecting People* (pp. 28). Washington, DC: Turst For America's Health.
- Van de Water, P. N., & Nathan , R. P. (2011). Governance Issues for Health Insurance Exchanges *Health Policy Brief* (Vol. 1, pp. 12). Washington, DC: National Academy of Social Insurance.
- Van Ginneken, E., & Swartz, K. (2012). Implementing Insurance Exchanges -- Lessons from Europe. *The New England Journal of Medicine*, 367(8), 691-693.
- Van Ginneken, E., Swartz, K., & Van Der Wees, P. (2013). Health Insurance Exchanges In Switzerland And The Netherlands Offer Five Key Lessons For The Operations Of US Exchanges. [Article]. *Health Affairs*, 32(4), 744-752. doi: 10.1377/hlthaff.2012.0948
- Vargas, R. B., Ryan, G. W., Jackson, C. A., Rodriguez, R., & Freeman, H. P. (2008). Characteristics of the original patient navigation programs to reduce disparities in the diagnosis and treatment of breast cancer. *Cancer*, 113(2), 426-433. doi: 10.1002/cncr.23547
- Vermont. (2013). Vermont Health Connect Retrieved September 16, 2013, from http://healthconnect.vermont.gov/healthcare_reform/vermont_reforms
- WHO. (2000). World Health Report 2000. Health Systems: Improving Performance *World Health Report* (pp. 215). Geneva, Switzerland: World Health Organization.

- WHO. (2012). World Health Statistics 2012 (pp. 178). Geneva, Switzerland: World Health Organization.
- WHO. (2013). World Health Statistics 2013 (pp. 180). Geneva, Switzerland: World Health Organization.
- Wolff, M., Baates, T., Beck, B., Young, S., Ahmed, S., & Maurana, C. (2003). Cancer Prevention in Underserved African American Communities: Barriers and Effective Strategies - A Review of the Literature. *Wisconsin Medical Journal*, 102(5), 6.
- Woolf, S. H. (2009). Social Policy as Health Policy. *Journal of the American Medical Association*, 301(11), 1166 - 1169.
- Wujcik, D. M. (2011). The Evolution of Patient Navigation. [Article]. *ONS Connect*, 26(10), 5-5.
- Zemel, S., Arons, A., Miller, C., & Gauthier, A. (2012). Building a Consumer-Oriented Health Insurance Exchange: Key Issues (pp. 29). Washington, DC: National Academy for State Health Policy.

APPENDIX

Table A2.1: Status of State Action on the Medicaid Expansion Decision as of
September 16, 2013

Table A2.1: Status of State Action on Medicaid Expansion, as of September 16, 2013

| Note: Highlighted states have moved forward to implement Medicaid Expansion Programs. States highlighted in blue are headed by Democratic Governors; States highlighted in red are headed by Republican Governors; States with no highlight are in opposition to Medicaid Expansion at this time. Total = 51 (50 states plus the District of Columbia). | | | | |
|---|---|--|--|---|
| Location | Current Status of Medicaid Expansion Decision | Governor's Position | Key Legislative Activity | Newly eligible Uninsured Adults (in thousands) ⁵ |
| United States | 26 Moving Forward at this Time; 22 Not Moving Forward at this Time; 3 Debate Ongoing | 30 Supports; 16 Opposes; 5 Weighing Options | | (in thousands) ⁵ |
| | | | | 15,060 (U.S.) |
| Alabama | Not Moving Forward at this Time | Opposes | | 321 |
| Alaska | Not Moving Forward at this Time | Opposes | | 141 |
| Arizona | Moving Forward at this Time | Supports | Legislation authorizing the Medicaid expansion has been signed into law. | 89 |
| Arkansas ¹ | Moving Forward at this Time | Supports | Legislation authorizing the Medicaid expansion has been signed into law. | 218 |
| California | Moving Forward at this Time | Supports | Legislation authorizing the Medicaid expansion has been | 1873 |

| | | | | |
|----------------------|--|----------|---|------|
| | | | signed into law. | |
| Colorado | Moving Forward at this Time | Supports | Legislation authorizing the Medicaid expansion has been signed into law. | 225 |
| Connecticut | Moving Forward at this Time | Supports | Legislation authorizing the Medicaid expansion has been signed into law. | 88 |
| Delaware | Moving Forward at this Time | Supports | | 17 |
| District of Columbia | Moving Forward at this Time | Supports | | 9 |
| Florida ² | Moving Forward at this Time | Supports | Legislative session ended with no legislation authorizing the Medicaid expansion. | 1295 |
| Georgia | Not Moving Forward at this Time | Opposes | | 684 |
| Hawaii | Moving Forward at this Time | Supports | | 37 |
| Idaho | Not Moving Forward at this Time | Opposes | | 108 |
| Illinois | Moving Forward at this Time | Supports | Legislation authorizing the Medicaid expansion has been signed into law. | 522 |
| Indiana | Not Moving Forward at this Time ³ | Opposes | | 374 |
| Iowa ¹ | Moving Forward at this Time | Supports | Legislation authorizing the Medicaid expansion has been | 106 |

| | | | | |
|--------------------------|---------------------------------|------------------|---|-----|
| | | | signed into law. | |
| Kansas | Not Moving Forward at this Time | Weighing Options | | 141 |
| Kentucky | Moving Forward at this Time | Supports | | 288 |
| Louisiana | Not Moving Forward at this Time | Opposes | | 330 |
| Maine | Not Moving Forward at this Time | Weighing Options | Legislation authorizing the Medicaid expansion has been vetoed by the Governor. | 46 |
| Maryland | Moving Forward at this Time | Supports | Legislation authorizing the Medicaid expansion has been signed into law. | 167 |
| Massachusetts | Moving Forward at this Time | Supports | Legislation authorizing the Medicaid expansion has been signed into law. | 88 |
| Michigan ¹ | Moving Forward at this Time | Supports | Legislation authorizing the Medicaid expansion has been signed into law. | 564 |
| Minnesota | Moving Forward at this Time | Supports | Legislation authorizing the Medicaid expansion has been signed into law. | 130 |
| Mississippi ² | Not Moving Forward at this Time | Opposes | | 231 |
| Missouri | Not Moving Forward at this Time | Supports | A committee to further study the Medicaid expansion has been | 351 |

| | | | | |
|----------------------------|---------------------------------|----------|--|-----|
| | | | established. | |
| Montana ² | Not Moving Forward at this Time | Supports | | 59 |
| Nebraska | Not Moving Forward at this Time | Opposes | | 78 |
| Nevada | Moving Forward at this Time | Supports | | 163 |
| New Hampshire ² | Debate Ongoing | Supports | A committee to further study the Medicaid expansion has been established. | 51 |
| New Jersey | Moving Forward at this Time | Supports | Legislation authorizing the Medicaid expansion has been signed into law. ⁴ | 307 |
| New Mexico | Moving Forward at this Time | Supports | Legislation authorizing the Medicaid expansion has been signed into law. | 127 |
| New York | Moving Forward at this Time | Supports | Legislation authorizing the Medicaid expansion has been signed into law. | 170 |
| North Carolina | Not Moving Forward at this Time | Opposes | Passed Legislation prohibiting implementation of the Medicaid expansion without legislative approval | 587 |
| North Dakota | Moving Forward at this Time | Supports | Legislation authorizing the Medicaid expansion has been signed into law. | 24 |

| | | | | |
|---------------------------|---------------------------------|------------------|--|------|
| Ohio | Debate Ongoing | Supports | | 578 |
| Oklahoma | Not Moving Forward at this Time | Opposes | | 225 |
| Oregon | Moving Forward at this Time | Supports | | 252 |
| Pennsylvania ¹ | Moving Forward at this Time | Weighing Options | | 520 |
| Rhode Island | Moving Forward at this Time | Supports | Legislation authorizing the Medicaid expansion has been signed into law. | 38 |
| South Carolina | Not Moving Forward at this Time | Opposes | | 287 |
| South Dakota | Not Moving Forward at this Time | Opposes | A committee to further study the Medicaid expansion has been established. | 40 |
| Tennessee ¹ | Debate Ongoing | Weighing Options | | 361 |
| Texas | Not Moving Forward at this Time | Opposes | Passed Legislation prohibiting implementation of the Medicaid expansion without legislative approval | 1748 |
| Utah | Not Moving Forward at this Time | Weighing Options | Passed Legislation prohibiting implementation of the Medicaid expansion without legislative approval | 105 |
| Vermont | Moving Forward at this Time | Supports | | <1 |

| | | | | |
|---------------|---------------------------------|----------|--|-----|
| Virginia | Not Moving Forward at this Time | Opposes | A committee to further study the Medicaid expansion has been established. | 342 |
| Washington | Moving Forward at this Time | Supports | Legislation authorizing the Medicaid expansion has been signed into law. | 308 |
| West Virginia | Moving Forward at this Time | Supports | | 131 |
| Wisconsin | Not Moving Forward at this Time | Opposes | | 181 |
| Wyoming | Not Moving Forward at this Time | Opposes | Passed Legislation prohibiting implementation of the Medicaid expansion without legislative approval | 24 |

Footnotes

1. Exploring an approach to Medicaid expansion likely to require waiver approval.
2. Discussion of a special session being called on the Medicaid expansion.
3. On September 3, 2013, Indiana received a one-year extension for its existing 1115 waiver program, the Healthy Indiana Plan (HIP).
4. Governor signed into law budget legislation (S3000) which included authorization of the Medicaid expansion. The Governor separately vetoed a stand-alone bill that authorized the expansion (S2644).
5. Source: Center on Budget & Policy Priorities. <http://www.cbpp.org/files/status-of-the-ACA-medicaid-expansion-after-supreme-court-ruling.pdf>

Source: Kaiser Family Foundation. <http://kff.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act/#map>