

**THE INTERFACE BETWEEN COMMUNITIES AND THE PRIMARY CARE SYSTEM  
IN RURAL AND LOW-INCOME WEST VIRGINIA**

*HISTORICAL AND COUNTY-LEVEL EXPERIENCE TO INFORM THE FUTURE OF  
COMMUNITY HEALTH WORKERS (CHWS)*

by  
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A dissertation submitted to Johns Hopkins University in conformity with  
the requirements for the degree of Doctor of Public Health

Baltimore, Maryland  
March 2017

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## **Abstract**

West Virginia (WV) has been working to strengthen the interface between its communities and the primary care system for many decades. The uncertain future of the Affordable Care Act (ACA) and recent evidence of continued lags and declines in health outcomes and state and federal healthcare budgets have added to the urgency for further changes to primary care system functioning and community engagement. A dialogue about how to address these challenges is underway among a number of stakeholders in WV, which includes potential uses and strategies for Community Health Workers (CHWs).

This dissertation included a historical analysis to provide state-wide context of the community and primary care system interface since the New Deal Era in WV, and two county-level case studies to explore the nature of that interface at the local level. The historical analysis entailed archival document review and 12 oral histories, which were analyzed and organized into an historical argument synthesizing WV's experience. The county case study sites were selected to represent different contexts as well as population health status across the state. These cases provided frontline perspectives from the primary care workforce and communities. Methods for the county cases included document review and 35 in-depth interviews. The interviews were transcribed and coded, and two cases were developed using a framework analysis approach.

Historically, the state of WV has extensive experience with encouraging, supporting, or requiring community and primary care system interaction. This experience has been fragmented and inaccessible to current stakeholders, however, and has not led to a coherent strategy or program. Stakeholders and decision-makers can learn from

historical experience about how communities have engaged with primary care in order to develop such a program; the county case studies will reinforce and spotlight such learning opportunities. Mingo County, the first of the two county cases, has a short history of bringing multiple local partners together to create a shared vision for a healthier future. These partners are implementing an integrated set of initiatives, including a CHW cadre, to engage and support the community while providing services that reflect local priorities and values. In Pendleton County, several decades of experience with engaging the community to provide input and feedback to the primary care system has resulted in high quality clinical services and enduring relationships among local individuals and agencies. This county does not have a shared vision for the future of primary care or CHWs, with many local agencies working independently.

This study identified a number of recommendations for the future of CHW work in WV and beyond: 1) Develop local visions and strategies for CHWs and share these with other counties and state-level leadership in WV to help inform local and state plans and identify necessary resources. 2) Ensure that communities and the primary care system seek out, value, and support those individuals performing CHW tasks. 3) Keep CHW certification processes simple and be inclusive of diverse local models. 4) Invest time and resources in relationships among and between community members and the primary care system at local- and state-level. 5) Draw on community and primary care worker experiences in WV to identify relevant and inclusive metrics for measuring and tracking community engagement. 6) Continue to focus attention and support on primary care and community engagement, particularly when political and financial support is for these efforts is low.

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## **Acknowledgements**

I would like to first thank all of the respondents and mentors in West Virginia who shared their time, ideas, connections, and other resources with me. Although the WV context is familiar since I grew up in a rural county in the state, the depth of experience, caring, and dedication to improving health around the state have been deeply humbling to me. In particular, I would like to thank Arnie Hassen, Drema Mace, Cecil Pollard, Tom Sims, and Henry Taylor for their ongoing mentorship, networking help, and ceaseless encouragement.

In addition, the local teams in the counties where I conducted the two case studies were extremely generous and supportive. In Mingo County, the Williamson Health and Wellness team as well as the partners that they connected me with were extremely helpful and supportive of this work. In Pendleton County, the Pendleton Community Care leadership as well as the local health department were invaluable in providing a long history of their efforts and facilitating connection with other local representatives.

I would also like to thank all of the archives where I conducted research and the staff persons at the private document collections in particular. I have been so appreciative of the interest that they have taken in my research topic and their willingness to make numerous extra efforts to find, organize, copy, mail, and discuss materials that they thought could be helpful to me. I also sourced documents from several private collections including foundations, the WV Bureau for Public Health, and several individuals. In particular, I would like to thank Tom Light, Laura Boone, Kevin Fredette, Debra Basham, and Matt Dailey for all of their help with finding, organizing, and providing me with access to information.

Within the Johns Hopkins Bloomberg School of Public Health, I am grateful to a number of faculty, staff, and students. In particular, I would like to thank my advisor, David Peters, for his patience, thoughtfulness, and precise and demanding feedback. I have been very fortunate to learn from him, and appreciate his commitment to making time for me between his numerous responsibilities. A number of other faculty members including Pamela Surkan, Randall Packard, Katherine Smith, Henry Perry, Bill Brieger, Sara Bennett, Maria Merritt, and Peter Winch have also mentored me and shared their diverse perspectives on issues as I progressed from my coursework through selection of a dissertation topic through the process of completing my degree. The Center for Qualitative Studies in Health and Medicine (CQSHM) has also been a source of a dissertation enhancement award grant and a space for collegial feedback at several points during my studies. Fellow students, both those a year or a few years ahead of me as well as in my own cohort have been extremely helpful as well. They have offered their experiences, helpful literature, contacts, and comic relief in order to help all of us stay balanced and reach our goals. I hope I have been able to give back even a fraction of the solidarity and support that they have provided to me.

I would like to appreciate the team at Future Generations University, including my fellow faculty members, the students and alumni, and also our hardworking staff. Being able to work with this organization over the course of my data collection and dissertation writing has helped me balance building my research and teaching experience, and has given me another home in a different part of West Virginia than where I grew up.

A number of mentors in my home community in the Greenbrier Valley in WV have also contributed ideas, places to stay, helpful connections, and hugs, lunches,

Facebook likes, and myriad other encouragements among the way. In particular, I would like to thank Susan Burt and other High Rocks staff members, Gary and Bonnie Brown, and Rachel Tompkins. Susan has given me pep talks at several critical junctures, Gary and Bonnie have opened their home in Charleston, WV to me and introduced me to a number of my oral history respondents, and Rachel introduced me to Sandra Barney who has since become a friend and mentor. In addition, Susan Sanders jumped on-board in the last few weeks and provided a skilled and thorough perspective to my writing, helping me find typos and clarify language. She was amazing!

My family has been supportive and proud as well as impatient with me during this intense journey. Even when they did not always understand what I was doing or why certain steps took so long, they encouraged me to work hard to uphold my values and produce a final dissertation that I am proud of. My parents have spent many hours discussing my ideas, traveling to events, sending me news and inspirational examples of work others are doing around the world.

Finally, my partner, Saman Nezami, has been the most constant witness of the many early mornings and late nights of writing and re-writing, and the ups and downs of progress and delays. He has seen many tears and (hopefully) almost equally many moments of celebration. He has willingly given his energy, his printer, his cooking talents, his perspective on the world, and his unwavering belief in the importance of this work and my ability to excel at it. I am very grateful to him, and look forward to supporting him to complete his own doctoral studies in the next couple of years.

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## Abbreviations

ACA	Affordable Care Act
ACT	American College Testing
AFSC	American Friends Service Committee
AHEC	Area Health Education Center
AIDS	Acquired Immune Deficiency Syndrome
ANP	Advance Nurse Practitioner
APHA	American Public Health Association
ARC	Appalachian Regional Commission
ATV	All-Terrain Vehicle
AV	Appalachian Volunteers
BPH	Bureau for Public Health
CDC	Centers for Disease Control
CHIP	Child Health Insurance Program
CHERP	Community Health Education Resource Person
CHF	Chronic Heart Failure
CHW	Community Health Worker
CMS	Centers for Medicare and Medicaid Services
CNA	Certified Nursing Assistant
COE	Center of Excellence
CON	Certificate of Need
COPC	Community Oriented Primary Care
COPD	Chronic Obstructive Pulmonary Disease
DHHR	Department of Health and Human Resources
EMT	Emergency Medical Technician
EPA	Environmental Protection Agency
EZ/EC	Empowerment Zones/Enterprise Committees
FERA	Federal Emergency Relief Administration
FNS	Frontier Nursing Service
FQHC	Federally Qualified Health Center
FRC	Family Resource Council
FSA	Farm Security Administration
GDP	Gross Domestic Product
GENESIS	General Ethnographic Nursing Evaluation Studies
HA	Housekeeping Aide
HIPAA	Health Insurance Portability and Accountability Act
HIV	Human Immunodeficiency Virus
HMO	Health Maintenance Organization
HPSA	Health Professional Shortage Area
HRSA	Health Resources and Service Administration
IAPP	International Association for Public Participation
IDI	In-depth Interview
IOM	Institute of Medicine
IRB	Institutional Review Board

IT	Information Technology
JHSPH	Johns Hopkins School of Public Health
LMIC	Low- and Middle-Income Country
LPN	Licensed Practical Nurse
MCCP	Medical Care Cooperative Program
MIHOW	Maternal Infant Health Outreach Worker
MS	Microsoft
MUA	Medically Underserved Area
NHSC	National Health Service Corps
NP	Nurse Practitioner
OEO	Office of Economic Opportunity
PA	Physician Assistant
PCC	Pendleton Community Care
PCMH	Patient-Centered Medical Home
PHC	Primary Health Care
PHN	Public Health Nurse
PI	Principle Investigator
PTSD	Post Traumatic Stress Disorder
RHEP	Rural Health Education Partnership
RHI	Rural Health Initiative
RN	Registered Nurse
RWJF	Robert Wood Johnson Foundation
SHD	State Health Department
STDs	Sexually Transmitted Diseases
TB	Tuberculosis
UMWA	United Mine Workers of America
UNICEF	United Nations Children’s Fund
US	United States
USDHHS	United States Department of Health and Human Services
VA	Veteran’s Affairs
VISTA	Volunteers in Service to America
WHO	World Health Organization
WIC	Women Infants and Children
WPA	Works Project Administration
WV	West Virginia
WVHIC	West Virginia Health Innovation Collaborative
WVRHA	West Virginia Rural Health Association
WVSOM	West Virginia School of Osteopathic Medicine
WVSIM	West Virginia State Innovation Model
WVU	West Virginia University

## **I. Introduction**

This dissertation builds on previously conducted research and adds to discussions currently taking place in West Virginia (WV). These discussions are informing the future directions of policy, training opportunities, and stakeholder perceptions on how to improve primary care outcomes in WV's rural communities by using Community Health Workers (CHWs). (Crespo et al., 2015; Miller, 2015a, 2015b) The focus of this dissertation is to better understand the interface—including dialogue, relationship-building, joint planning, and collaborative project or program implementation and evaluation—between communities and the primary care system by analyzing underlying assumptions and risks involved in improving primary care outcomes. By analyzing this community and primary care system interface across time and different regions of the state, this study identifies opportunities for CHWs to facilitate the process and outcomes of that interface.

Particularly within the complex US primary care system—which consists of a combination of public, private, and corporate health services—the ability of diverse local actors to work effectively and efficiently together for positive change is critical. (Grumbach & Bodenheimer, 2004; Rittenhouse & Shortell, 2009) All of these interactions take place within a historical and cultural context—some background on WV to frame the rest of this dissertation is provided in this chapter.

WV is located completely within the Appalachian cultural region, a largely rural area in the eastern United States that covers parts of Mississippi and Alabama in the South up to New York State in the North following the Appalachian mountain range. WV is a land-locked, predominantly mountainous state. It was part of the original English

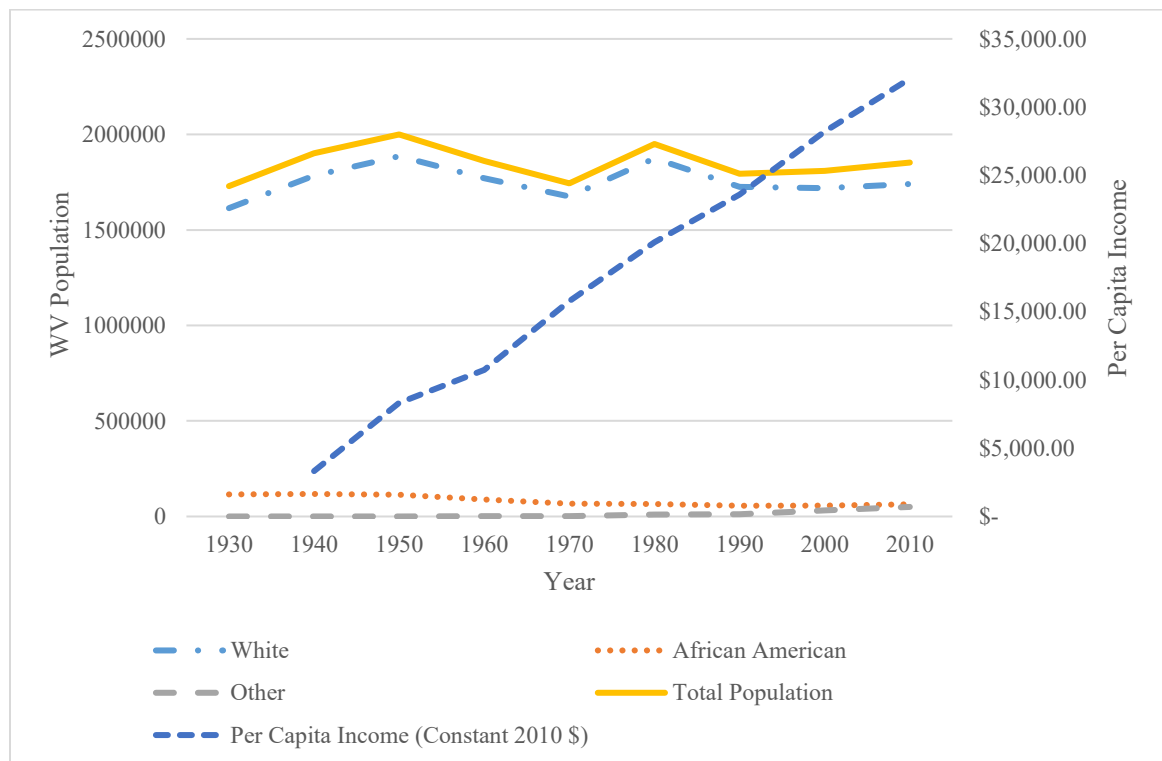
colony of Virginia, and then part of the state of Virginia until it separated from Virginia and joined the Union in 1863 as its own state during the civil war due to disagreements with Virginia over slavery.(US Commerce Department, 2012)

In the early settlement days in WV, which for most regions of the state was in the early 1800s, farmers from the East Coast moved into the area and established small farms on the remote and often steep land. By the late 1800s, out of state businessmen began to arrive in order to take advantage of the timber and coal reserves that had been discovered in the region. Many local farmers began working in one or both of those industries and the population of the coalfields grew substantially. In the early 1900s, when coal companies began laying off workers in large numbers, coal mining technologies were still very labor-intensive and economic slow-downs had not yet driven people back out of the region in search of another livelihood.(Duncan, 2014)

WV is often described as the second most rural state in the nation. According to the US Census Bureau, 60% of the population lives in counties classified as rural, although substantial investments in interstates and other infrastructure have increased access to some of these areas in recent years.(WVU, 2014, p. 31) There has been a steady shift of population from rural to urban areas. Over the past century, migration to urban living has resulted in a 30 percentage point decrease in the number of West Virginians living in rural populations—declining from 80% in 1910 to just over 50% in 2010.(US Commerce Department, 2012)

Over the past nearly a century, WV's population has ebbed and flowed in parallel with economic booms and busts and has shifted to an older population with fewer working-age individuals, but it has not seen dramatic changes in either overall population

size or ethnic composition (Figure 1).(WVU, 2014, p. 46) Per capita personal income has risen steadily since the New Deal Era, even in terms of constant dollars. Currently, WV’s per capita income is fourth from the lowest in the USA at 81% of national averages.(WVU, 2014) According to the 2010 census, WV has a population of 1,852,994 people.(WVU, 2014) The population is 94% non-Hispanic white, 3.8% non-Hispanic black, 1.2% Hispanic, and 1% other.(WVU, 2014)



**Figure 1: Historical Population by Ethnicity and Per Capita Income Trends in West Virginia<sup>1</sup>**

WV economy and job market have long been dominated by the coal industry, particularly in the southern half of the state. Mining jobs, while offering lucrative pay, carry high risks of injury or illness, and high rates of disability. Jobs are also not equally

<sup>1</sup> Data from U.S. Decennial Census, US Census Bureau, 2016. Retrieved from <http://www.census.gov/prod/www/decennial.html> and from the US Bureau of Economic Analysis. Retrieved from <https://www.bea.gov> Interactive Data tools. Per capita incomes were calculated in constant 2010 dollars using the US Census Bureau’s Consumer Price Index (CPI) available at <http://www.census.gov/topics/income-poverty/income/guidance/current-vs-constant-dollars.html>.



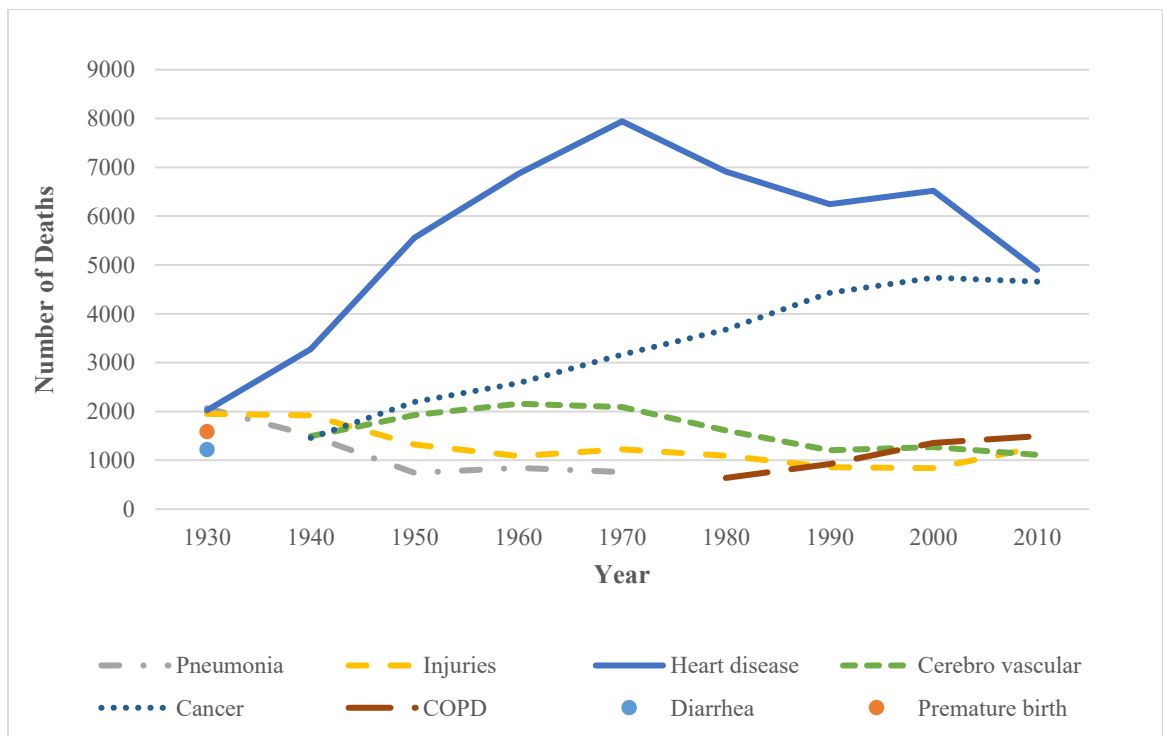
distributed among the population. People who have social ties to mining companies or are perceived to be coming from respectable families based on historical family behavior or political affiliations are more likely to get hired than those seen as coming from “bad” families, despite their individual qualifications or work ethic.(Duncan, 2014) Aside from mining jobs, employment options in many rural areas are slim aside from mining jobs, so many women and young people are competing for jobs in government services such as welfare offices, the local hospitals, or the few grocery stores, fast food restaurants, or malls that exist. Other people strike out on their own and do odd jobs or create their own businesses such as fixing equipment or hauling scrap metal.(Duncan, 2014)

Unemployment rates are high, particularly recently as the rate of coal mining layoffs have increased for an already shrunken workforce and the economic recession has impacted both public sector jobs as well as the economy overall. In some places, only 44% of men over sixteen were employed compared with the 65% national average.(Duncan, 2014, p. 71)

The mining and natural resources industry in WV skews the average hourly pay rates, and masks the wide range in salaries.(WVU, 2014, p. 17) As of 2013, 17.9% of West Virginians lived below the poverty line—2.5 percentage points higher than the national average.(US Census Bureau, 2013) What these summative measures mask is that those living below the poverty line may be living very far below it, and even those individuals managing to live above the poverty line may have very insecure and risk-laden work that could leave them jobless and/or disabled at any time.(Duncan, 2014)

Since 1930, WV’s burden of disease has changed substantially. Leading causes of mortality have shifted from predominantly communicable diseases in the 1930s to

predominantly chronic conditions today. Figure 2 shows the top five causes of mortality for WV for each decade since 1930—clearly demonstrating the changing crude mortality rates. Heart disease has been a leading cause of death across the decades, and decreases in mortality in recent decades are partly due to improved treatment options which have led to higher rates of morbidity as people live longer with the condition. Other diseases such as tuberculosis, chronic liver disease, mental illness leading to suicide, and Alzheimer’s disease have also contributed to population mortality rates. Cancer mortality has been steadily increasing over the decades, while COPD (Chronic Obstructive Pulmonary Disease) has only recently been increasing. Injuries, including motor vehicle as well as occupation-related injuries, have been a consistent issue throughout the time period of the study.



**Figure 2: Trends in Leading Causes of Mortality in WV between 1930 and 2010<sup>2</sup>**

<sup>2</sup> These data were obtained via the WV Department of Health and Human Resources, Bureau for Vital Statistics.

West Virginia has some of the poorest health indicators in the United States, including high rates of obesity, diabetes, cancer, and disabilities.(Miller, 2015b; US Census Bureau, 2013; WVU, 2014) WV is currently ranked 4<sup>th</sup> from the bottom in overall health rankings; the state's position has improved slightly in recent years, and the ranking varies from year to year.(WVU, 2014, p. 32) Prevalence of obesity is estimated at 32.4% of the population; WV is ranked 3<sup>rd</sup> from the worst in obesity rates in the nation with only Louisiana and Mississippi having higher rates.(WVU, 2014) Smoking and other unhealthy lifestyles as well as the chronic health conditions that they contribute to are leading causes of morbidity and mortality in WV. The state ranks 2<sup>nd</sup> to the worst out of all 50 states for smoking rates with 29% of the adult population indicating that they smoke tobacco daily.(WVU, 2014) Managing high blood pressure, increasing physical activity, reducing smoking, and improving nutrition could mitigate these health issues.(WVU, 2014) Addressing these problems, in turn, will require a reduction in inequities by race, gender, socioeconomic status, improvements in access to health services, the environment, and health policy reform. Therein lies part of the challenge: it is a complex and interconnected system, and all of these and other factors contribute to the current situation.(WVU, 2014, p. 46)

The poor health outcomes in WV are not solely a reflection of lack of overall spending on health care. In fact, WV ranks 12<sup>th</sup> in the nation for health care spending with a per capita health expenditure of \$7,667 per year.(Kaiser Family Foundation, 2014, 2015) This spending is paid for largely via insurance plans including those in

employment contracts, Medicaid and Medicare plans for low-income and elderly populations, other public and private insurance companies, and out of pocket payments for the 6% uninsured population and for services not covered fully or at all by insurance plans.(Kaiser Family Foundation, 2014, 2015) Historically, grants and federal funds that helped pay for health services have often been insufficient, unreliable, short term, and inflexible to address population needs—particularly to support local solutions, ownership, and ideas. With the recent expansion of Medicaid resulting from the Affordable Care Act (ACA), more low-income people have been eligible for health insurance often for the first time in their lives.(Kaiser Family Foundation, 2014) At the same time, state and federal budget cuts in WV are diminishing the resources available to provide care for the entire population.(Eyre, 2015) In addition, WV’s primary care service provision projects and programs have often been fragmented, which has led to inefficiency and lack of continuity in care. This fragmentation has taken the form of inconsistent and partial primary care approaches across the state.

Also contributing to WV’s population health status, recent reports show that the geographical distribution of health workers—including primary care providers—does not align with population needs. Primary care worker shortages in rural areas and for low-income populations persist despite decades of efforts to address them.(WVRHA, 2012, 2014)

As a whole, these complex dynamics have created a sense of dependency on limited and unreliable resources and on external solutions. Expectations for more resources, policy changes, and other fixes often have not been met or sustained, and at the

same time they have contributed to the lack of local ownership or motivation to improve health outcomes.

The work of reaching out to communities including health education, advocacy, and other community-based health activities has commonly been viewed as low prestige in WV, regardless of who has provided those services over time. Political and social pressures to overcome stereotypes of being in a backwards, lazy, uneducated region have increased pressure on government and payer entities to invest in high technology solutions or other high profile health infrastructure.(M. Walker, 2013) Secondly, WV has a history of dependency, exploitation by industry and politicians, and reliance on external resources and solutions,(Duncan, 2014; Glen, 1989) which has not yielded the desired health outcomes. Many payers and policy makers have also viewed health initiatives that focus on community engagement, preventive education, social support, and other advocacy services as a risky investment due to the unclear potential for direct or short-term results, and legal concerns regarding the appropriateness of the scope of work often performed by lay people who are well placed and willing to do it.<sup>3</sup> This work has also been viewed as a second class care option by many health workers, as well as by policy makers and funders across WV and the US—or as a placeholder strategy that would be replaced as soon as a more advanced system could be developed.

Recently, a state-wide initiative to incorporate a formal community health worker (CHW) cadre into WV's primary care system, particularly for rural and low-income populations, has been discussed.(Pollard, 2015; WVHIC, 2015) CHWs commonly do community outreach, health education, peer support, and advocacy.(RWJF, 2016; WHO,

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<sup>3</sup> This was a common theme identified across archival materials, oral history respondents, and interviewees.

2007) The ACA defines a CHW as a person who “promotes health or nutrition within the community in which the individual resides by serving as a liaison between communities and healthcare agencies.”(*Patient Protection and Affordable Care Act*, 2010) Roles, competencies, payment structures, and other details regarding the use of CHWs in the US and globally will be described further in Chapter IV.

Until now, the work of CHWs has been done by both professional primary care workers and by non-medical community members in WV, but no clear definition, tracking system, support structure, or regulatory framework exists at the state level. A number of pilot projects have also been implemented to work closely with communities by including outreach workers, peer counselors, or CHW-type workers in the health workforce in WV.(Miller, 2015a; Henry G. Taylor, 2013; Vanderbilt University, 2015)

An active inquiry into an appropriate definition and role for CHWs in WV is underway. Decision-makers at state and national levels recognize that changes in the structure and financing of primary care service delivery and of the primary care workforce are needed.(Bodenheimer & Pham, 2010; Kaiser Family Foundation, 2014; WVHIC, 2015) CHWs are showing promise as an approach in other US states and around the world to improve community engagement in local primary care systems and in ensuring appropriate access and utilization of services.(Crespo et al., 2015; Crigler et al., 2014; Henry Perry, Zulliger, & Rogers, 2014; RWJF, 2016) Different models for CHWs are used in different contexts throughout the state, though many were not formally called CHWs, and there are numerous ways that CHWs can be incorporated into the existing primary care system in rural and low-income WV.(Flieger, 2016)

The possibility of adding CHWs to the primary care workforce is the most recently proposed solution to address these outlined challenges. Developing funding and support strategies and increasing formal recognition for this work in WV could help address the historical challenges of supporting these workers, and improve their image and perceived value within the primary care system and in communities.

In terms of regulation and parameters for reimbursement or other funding for CHWs, WV Code does not define a role for CHWs or any equivalent interfacing role between communities and the rest of the health system. Chapter 18B: Higher Education, Article 16 defines the roles of primary care professionals including physicians, mid-level providers, and allied health professionals.(WV Legislature, 2014b) Articles 3-7E detail the powers and duties for licensing physicians, nurses, pharmacists, several kinds of technicians, dentists, and physician assistants (WV Legislature, 2014c). In Article 29H-9, the code related to pilot programs of patient-centered medical homes mentions the potential composition of community health teams; the composition or roles of such teams and the qualifications for potential additional cadres of workers such as CHWs are not mentioned (WV Legislature, 2014a).

This study provides a framework, built on WV's experiences, for how communities can interface with their local primary care systems, and how the nature of this interface influences levels of community engagement and utilization of primary care services. The entire conceptual framework is presented in Appendix 1; sub-components used in the analysis in this study are presented in Chapter II.

As current discussions CHW unfold in WV, several points are important to remember. Any discussion, planning, and pilot projects are not taking place in a vacuum,

and need to build on historical experience, of which this study will argue there is a vast amount—though not always in an accessible or coherent format—and will show how to continue building on it. The state-wide historical experience and findings will be presented in Chapter V.

Two county case studies will be analyzed in Chapters VIII and IX. Engaging those who have first-hand local experience and will be directly affected by any proposed changes—particularly rural communities and frontline primary care workers—to share their experience and contribute recommendations for action plans. These local stakeholders have not been systematically engaged in the state-level dialogue on CHWs until this point, and this study will help add their perspectives to the ongoing dialogue.

Finally, this dissertation compares and contrasts WV's experience of the community and primary care interface across time and place in Chapter X. This comparison leads to recommendations about what is needed to support the work of CHWs in WV in the future. Specifically, historical and contemporary experience points towards considerations for legislation, the work of the primary care system, and how communities can direct their energy and perspectives in order to contribute to the outcomes and impact towards which many stakeholders are working.



## II. Conceptual Framework

The conceptual framework in this dissertation is constructed in the form of a theory of change. Theories of change are often used to help describe how complex processes of change happen—or are proposed to happen—and may be used for project planning, monitoring, and evaluation. (IPAL-Keystone, 2009; Rogers, 2014; Taplin, Clark, Collins, & Colby, 2013; Vogel, 2012; Woolcock, 2013) While theories of change do not purport to explain “the truth,” they can help make explicit how change is believed to occur, and can provide evidence to attribute change to a specific project or program, or troubleshoot if desired changes do not manifest in the course of an intervention. (Taplin et al., 2013; Vogel, 2012)

This conceptual framework was developed by the researcher and faculty collaborators, based on the questions being pursued in the study and proposed mechanisms for how change occurs, as an overall framework for analysis of the interface between communities and the local primary system in WV. The research team used data from the study to establish the logic for how the overarching context of primary care provision, the explicitly stated underlying assumptions, risks, and stakeholder perspectives influenced the policies, projects, and programs that were planned, implemented and evaluated.

The conceptual framework in this dissertation is used to explain the current status of primary care outcomes and CHW roles in WV, which constitute the problem of interest (see Figure 3). The problems in the primary care system that are driving the recent dialogue about CHWs are articulated in the Introduction (Chapter I) of this

dissertation. Over the last century, many of the same problems have evolved in nature and magnitude, but remain challenges that must be overcome.

Underlying the kinds of interventions that have been implemented in WV to engage and empower communities to interface with the primary care system are a series of assumptions and risks. These assumptions and risks were identified based on the research questions and honed using the data collected during the fieldwork for this study. These assumptions and risks were then utilized to provide a systematic framework for the critical analysis of those data. In this study, the researcher focused on the role of communities in interfacing with the primary care system, and utilized the sub-set of assumptions and risks most directly related to the change pathway of interest.

Two kinds of assumptions are considered carefully in the conceptual framework. First, assumptions about the causal mechanism related to the change domain on community engagement and empowerment were reviewed and are described further in the literature review in Chapter IV. Secondly, assumptions about implementation are discussed in depth in the historical chapter as well as the county cases when looking at WV's experience in action. The assumptions included in this study are the availability of motivated and trained people to do the work of primary care, the willingness and ability of local stakeholders to share best practices and learn from each other, and whether communities are accepting of new approaches for primary care service provision.

Three stakeholder groups were identified to ensure that the needs and drivers of each group of actors were considered. For the historical objective, the perspectives came from policymakers, funders, and others in key leadership roles, often at the state level. For the county cases, both primary care professional and also community representative

perspectives were included and analyzed. This study distinguished between the formal or professional primary care system, and the communities that are served by that system and also have their own important roles in improving the primary care outcomes, and ultimately health status, of the community members. This distinction facilitates analysis of the interface between the two local stakeholder groups while ensuring that both are included in a deliberate and balanced way.

Although in public health the ultimate goal is often to show impacts on health status,(Rogers, 2014; Taplin et al., 2013) linkages to impact were not assessed directly in this study. Intermediate primary care outcomes were assessed to the degree possible, including levels of community engagement in primary care system planning, implementation, and evaluation, and how appropriate and equitable access to primary care services has been.

Finally, numerous external factors also contribute to health status, but are often outside of the control of the primary care provision system. These factors are described within both the state-wide historical chapter as well as the history and context of each county case study, but are not analyzed separately in detail.

In Figure 3, the components of the conceptual framework that were utilized only in the historical analysis, only in the county cases, and across the entire dissertation are color coded as follows:

- Green highlights indicate use in both the historical analysis and in the county-level case studies.
- Blue highlighted indicate use only in the historical chapter.
- Yellow highlights indicate use only in the county-level cases.

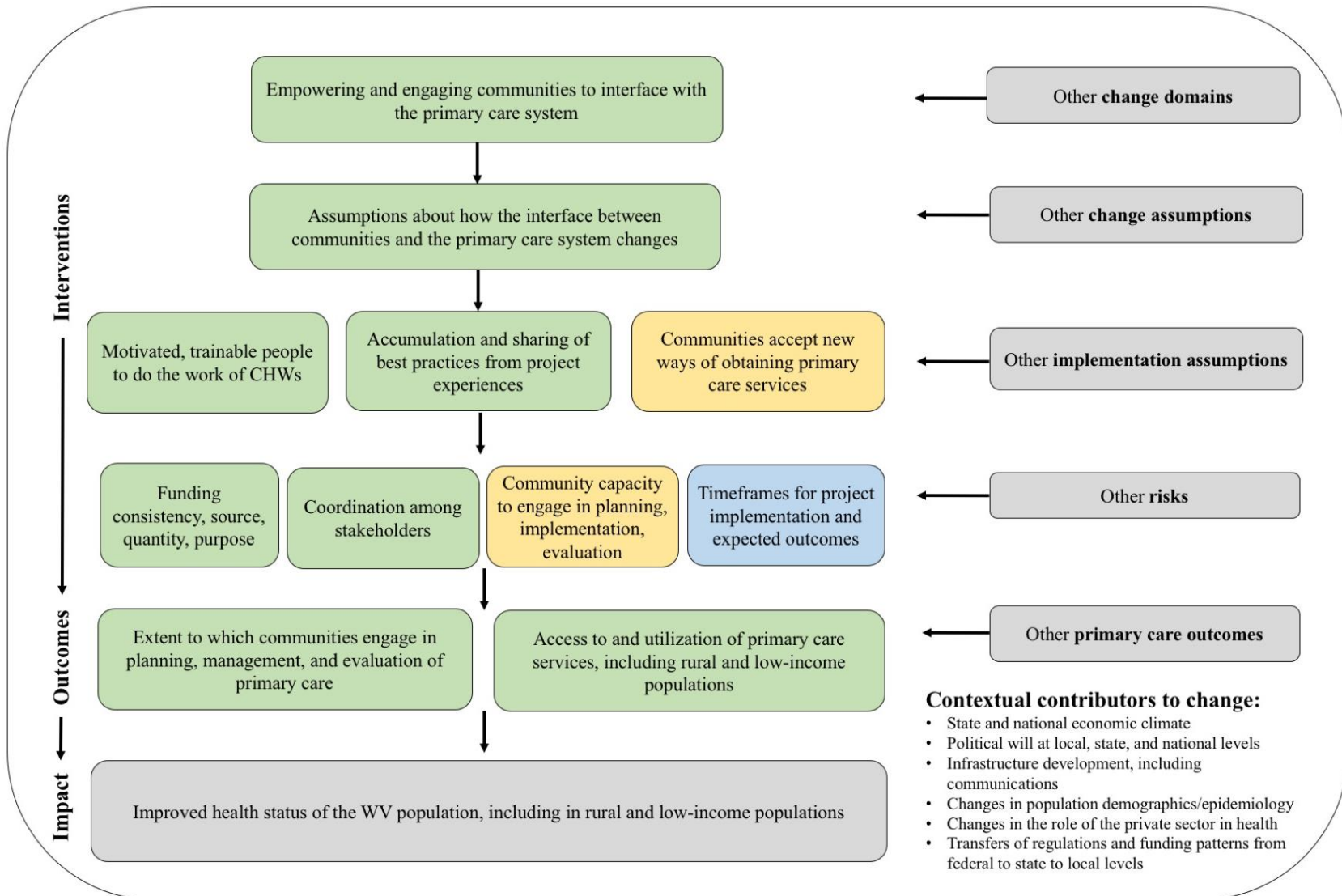


Figure 3: Conceptual Framework

### **III. Study Design and Research Questions**

#### **Study Design**

This study utilized a multiple case study research design (Yin, 2009) with a historical analysis serving as a contextual foundation. The state-wide historical analysis of efforts to invest in, study, and strengthen the interface between communities and primary care system in WV since 1930. The historical analysis focused on identifying and analyzing specific time periods between 1930 and the present day within which interventions related to engaging and empowering communities to interface with the primary care system took place. Lessons learned about the challenges and opportunities of engaging communities, which are often a focus of CHW work, are analyzed in relation to assumptions and risks in the conceptual framework.

Within the state, two county-level case studies of the local interface between communities and primary care systems were analyzed. The county-level cases explore contemporary dynamics between communities and the primary care system, overlaid on their historical context, in different regions of the state. The objective of the case study analysis was to explore diverse local models of the community and primary care interface that have developed in WV, to identify common features and differences across the models, and to make recommendations for how CHWs can facilitate and strengthen this interface in the future.

## **Research Questions**

### Historical Research Questions

- 1) Since 1930, how has the planning and implementation of funding strategies and regulatory changes affected the interface between communities and the primary care system in rural and low-income WV?
- 2) Since 1930, how have historical initiatives—that included workers in CHW roles—sought to strengthen the interface between communities and the primary care system in rural and low-income populations in WV?
  - a) What are the major challenges and opportunities to strengthening the interface and why?
  - b) How is the nature of the interface associated with improved primary care outcomes?

*Rationale:* The aim in answering these specific historical research questions was to systematically analyze the experience and outcomes of the interface between communities and the primary care system in rural and low-income populations in WV since 1930. The analysis of that experience led to identification of key lessons learned across the assumptions and risks in the conceptual framework that contribute to achievement of primary care outcomes.

The policy maker and funder stakeholder group whose perspective is the focus of the historical analysis includes state-level health insurance agency leaders, legislators and other government workers, Boards of Medicine leaders, and other state-level authorities and regulatory bodies. To this stakeholder group, the history of primary care and

community engagement and empowerment can be hard to piece together as it is scattered in many places, and documentation is often incomplete. Thus, the available evidence of historical experience and the achieved outcomes are often not consulted when designing new iterations of programs or new initiatives. The purpose of analyzing historical initiatives related to the interface between communities and the primary care system was that extensive documentation of the experience has been amassed in implementing related policies and programs in WV over nearly a century, but it is not in usable or accessible format to inform decisions about CHWs in the future. Although it was not the primary goal of this dissertation to produce a comprehensive catalog of this experience, hopefully the historical results highlight key findings related to the history of the community and primary care system interface in a form that can be understood, accessed, and built upon.

Recent dialogues about CHWs and necessary reforms to the primary care systems are not the first time in WV history that key actors have paused to consider new strategies to address challenges for the community and primary care system interface. This is also not the first time that national policy has dramatically changed the financing of health services or the options available to low-income populations and those with poor health outcomes, who are more likely to be living in rural areas in WV. The historical policy and programs developed over the past decades, since the passage of the New Deal in the 1930s, have had complex and often unintended consequences. New programs have replaced or have been built onto earlier efforts, all within a complex and constantly evolving political, economic, and social context.

Using multiple data sources, this study constructed a multi-perspective and context-rich history of strategies that have been implemented in WV and use the key findings to inform strategies and recommendations for the future of CHWs. Fortunately, in addition to written documentation in archives and private collections, many of the people who have been involved with state-level policies and programs related to the primary care workforce and CHW pilot projects over recent decades are still located in the state or region, and could be contacted to discuss their perspectives. Many have a long history of engagement in and observation of the primary care system, and have seen first-hand the ways in which communities around the state have been engaged over time. Oral history respondents were able to help tie various initiatives, policies, events, and individuals into a more coherent—and also more complex, political, and relationship-oriented—narrative.

#### County-level Case Study Research Questions

- 1) How has the local historical context and experience with community engagement and empowerment to interface with the primary care system shaped local stakeholder priorities and aspirations?
- 2) How does the nature of the current interface between the primary care system and the community it serves influence:
  - a) the extent to which community engagement and empowerment occurs, and
  - b) access to and utilization of primary care services?
- 3) How can a CHW facilitate this interface?



*Rationale:* These research questions cover both the historical experience and context as well as the nature of the current interface between communities and the primary care system at the local level. Building on the state-wide analysis conducted under the historical research questions, the county case studies were a way to analyze how diverse local interfaces between communities and the primary care system work at the level of project implementation, service provision, and the community's experience of engagement. A common feature of CHW work is to help ensure that appropriate and timely conversations are taking place between the primary care system and communities. CHWs can often serve as a bi-directional translator of knowledge and experience within those dialogs, which are often both structured as well as informal on an as-needed basis.(O\*Net Online, 2016; Rosenthal et al., 2015; USDHHS, 2007) The chapters answering these research questions analyzed existing and potential areas where the work of CHWs has been demonstrated value in supporting and strengthening this interface.

Community members—particularly low-income, rural, and less educated ones—sometimes do not feel able or welcome to bring their knowledge, capacity for action, priorities, or needs to discussion opportunities. Similarly, the primary care system and the larger regulatory system within which it functions sometimes does not know what to do to respond to population needs, or how to be most effective with limited resources and capacity. If respectful and proactive dialogue occurs between these local stakeholders, some of these limitations and stressors could be reduced or removed. If discussion does not occur, then opportunities that could facilitate better primary care outcomes and impact are more likely to be missed.

The health system in WV is complex, with many actors engaging in different ways to address different health issues from different perspectives in different parts of the state. At a local level (county or smaller), however, this complexity becomes more manageable. It can be managed because the locally-engaged actors are often fewer in number, and the representatives of different agencies and organizations can build relationships among themselves in ways that are more challenging to do at higher levels.

In this study, the local primary care workforce included physicians, nurse practitioners, physician assistants, other nurses, social workers, pharmacists, and other formally trained health professionals. Local health workers are able to more fully understand health issues in communities, including distribution of the burden of disease as well as social determinants of health. Thus far, however, they had not been asked in a systematic way about their perspectives, priorities, and experiences for increasing the ability of the primary care system to improve primary care outcomes in communities, and the potential for CHWs to contribute to achieving those aims.

This study defined community representatives as local leaders within a county area—elected officials, leaders of sub-populations, organizational representatives, and citizens, including those who do and do not use local health services. They were the non-health professional local actors with an interest in and potentially important role in improving the primary care outcomes of their county.

The historical experience of increasing local primary care workforce collaboration and integration in local cultures and contexts in the US has taken myriad forms to building relationships and partnerships with communities.(Grumbach & Bodenheimer, 2004; Mickan & Rodger, 2005; Yaffe, Dulka, & Kosberg, 2001) A separate literature has

delved deeply into the importance of increasing community capacity to improve the community's own health and the role of other actors in facilitating discussion and voicing their needs and priorities.(Newell, 1975; D. Taylor-Ide & Taylor, 2002) Each body of literature still tends to focus on either the primary care workforce or the community—only considering whether and how each should engage the other. Ultimately, this study examined how CHWs could facilitate the creation of a balanced and bi-directional flow of information about health needs, available resources, accountability mechanisms, and the regulations and social norms within which the interface between primary care systems and communities must function.

Finally, community stakeholders' priorities can be quite different than those of the primary care workforce. Communities often rank social determinants of health—such as water quality, agriculture, and the local economy—as even more important than health service provision.(Newell, 1975; WHO, 2008) These other determinants and the availability of primary care services are both essential to address in local contexts because they influence health status of populations. Further, communities' aspirations for local health services often focus on their perceptions skilled and personable providers, adequate facilities, and current practices, equipment, and technology.(C. E. Taylor, 2005) Balancing the needs and aspirations of all concerned local actors is a challenge that will be explored in the chapters outlining the county case study findings.

#### **IV. Literature Review:**

This chapter provides a brief orientation to the literature on the core topics and concepts studied in this dissertation. The organization of this chapter follows the conceptual framework described in Chapter II. This chapter traces the major change pathway of the interface between communities and the primary care system underpinning the historical and county case study analyses—from assumptions about how change occurs through to achieving the desired outcomes and impact. The first section of this chapter focuses on change mechanism assumptions related to the concepts of primary care system in the US (including WV), communities, and CHWs including the complexities related to defining each concept, and challenges and opportunities for how these can align and find opportunities for reinforcement and synergy. It also reviews definitions and complexities related to the concept of “community” and how communities can be engaged and empowered. The second section on implementation assumptions outlines the challenges and opportunities of how change happens during project and program implementation across the set of assumptions in the conceptual framework. In the third section of this chapter, risks for engaging and empowering communities, summarizes the literature on a set of forces that often put pressure on or limit the effort of primary care projects or programs and the work of CHWs. Finally, the last section of this chapter on achieving primary care outcomes and impact reviews the experience with measuring and achieving primary care outcomes, including levels of community engagement and changes in access to primary care services, which can ultimately contribute to equitable improvements in population health status.

## **Change Mechanism Assumptions**

### **Primary Care in the United States**

Dating back to the 1920s, the term “primary care” within the Dawson Report proposed a structure for health services that included a “primary health care center.”(Starfield, Shi, & Macinko, 2005) In 1996, primary care was defined in an Institute of Medicine (IOM) report as, “the provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community.”(IOM, 1996, p. 18) Primary care is also usually the first point of contact for patients and communities with the health care system and may be provided in private physician offices, local health departments, community health centers, emergency departments, and other venues.(Macinko, Starfield, & Shi, 2003)

The primary care “system” with its current infrastructure, standards, and financing mechanisms, did not formally develop in the US until the 1960s and afterwards when two major reports illuminated the need for some foundational structures and guidelines such as how to balance basic health service provision with the growing emphasis on specialized medicine and the importance for every individual living in the US to have a designated primary care physician.(Phillips, 2010) Before the 1960s, most primary care was provided by private physicians who set their own modest rates and often made deals and negotiated trades and accessible rates with low income and elderly individuals who

needed care.(Nettleman & Yanni, 2003) Many people continue to receive care in this manner in rural Appalachia.

Primary care has been the focus of a number of debates on access, quality, and cost of health care in the United States. The crux of the debate is that, despite the US's high expenditures on health services as a whole, health outcomes are poor compared with other high income countries.(Macinko et al., 2003) The lack of emphasis on and investment in primary care is often considered a major contributor to this phenomenon.(Bates, 2010; IOM, 1996) Evidence and arguments for the value of primary care also continue to expand because primary care is a space where patients can resolve many of their health concerns, build relationships with providers, access health information, access screening and preventive services, and link their individual care to the health of their families and communities.(IOM, 1996)

In recent decades, the number of diagnosed co-morbidities (patients with multiple diseases, oftentimes chronic conditions) has been increasing.(Starfield, 2011) This increase creates challenges and knowledge frontiers for primary care clinicians and all support staff in diagnosing, managing, and coordinating the care of patients who often require long-term medication and follow-up activities, including with specialized physicians. As financing models strive to ensure quality care while pushing for improved cost control strategies—particularly for specialist visits, tests, and medications—the need for more effective strategies will continue to increase.(Starfield, 2011)

The ACA has included several provisions to enhance support for primary care in the US, including increases in reimbursement rates for many primary care services.(Bates, 2010) Many argue, however, that the US healthcare system requires

more fundamental shifts in order to produce the dramatic changes needed to better manage managing costs and patient outcomes.(Bates, 2010) Although several experiments—including the Patient Centered Medical Home (PCMH) model described later in this chapter—are in progress, it is unclear whether the early positive findings that have been obtained are the extent of the impact that can be achieved. Standards and best practices are still being developed,(Starfield, 2010) and experimentation with additional approaches is needed.(Bates, 2010)

### **Defining the “Community”**

Although the concept seems simple, the word community is “one of the most contested in the social sciences.”(Jewkes & Murcott, 1996, p. 555) Based on studies of health promotion projects in the United Kingdom, communities are often defined by external actors who make assumptions about which groups of people share common characteristics, without understanding the views of the proposed membership of the community. Often, the community members themselves have substantially different perceptions of community boundaries, and to which communities they belong.(Jewkes & Murcott, 1996) Communities are often defined by geographical locations or by a sense of belonging or common needs and values.(Head, 2007; Zakus & Lysack, 1998) In addition, the definers often assume that these groups of people have a sense of shared ownership and can even act collectively.(Jewkes & Murcott, 1996; D. Taylor, Taylor, & Taylor, 2012)

Often, “community representatives” are the practical pathway for engaging with communities; the selection of these representatives also influences how the community is defined and which aspects of it are understood and emphasized.(Jewkes & Murcott, 1998;

Laverack & Wallerstein, 2001; Zakus & Lysack, 1998) The selected representatives are usually “obvious” choices due to being well known, well connected, and well informed about the community, yet without a personal “axe to grind” on issues faced by the community they represent.(Jewkes & Murcott, 1998) Even so, community representative perspectives, when compared among a group, often do not produce a coherent “community” perspective. Further, these representatives do not necessarily include the perspectives of marginalized groups.(Jewkes & Murcott, 1998) Oftentimes, published studies about working with communities do not detail whom in the community they interacted with or disaggregate perspectives by gender, income, or other common power and control differentials.(George, Mehra, Scott, & Sriram, 2015) Thus, although a “community” is often assumed, little is documented about how the definition of the community was conceived and whose perspectives within it were captured.

### **Engaging and Empowering Communities to Interface with Primary Care**

Community engagement, often used interchangeably with the term “community participation,” in the health sector is often associated with the 1970s and the policies and declarations of the World Health Organization (WHO) related to primary health care.(L. M. Morgan, 2001; Zakus & Lysack, 1998) Community engagement is defined as the process of individual community members, or a community as a whole, taking on increased responsibility for its wellbeing and future, as well as taking the ownership to identify and implement solutions, and evaluating these strategies as part of a sustainable process.(Zakus & Lysack, 1998) Community participation is an approach that, “provides people with the sense that they can solve their problems through careful reflection and collective action.”(Zakus & Lysack, 1998, p. 2) Participation has also been viewed in two



fundamental ways: as a utilitarian means to achieving health goals through voluntary or incentivized community participation, or as an empowerment approach that transfers control and responsibility to communities so that they can identify and address their own health priorities.(L. M. Morgan, 2001)

Not all participation is equal. The International Association for Public Participation (IAPP) utilizes a continuum of participation from information-sharing on one end to citizen control or empowerment on the other—with consultation, partnership, and delegated power in the middle.(Head, 2007)

The experience of using community participation has been disappointing to some because of its apparent failure to deliver on ambitious goals to solve complex health problems.(Rifkin, 1996; Zakus & Lysack, 1998) Instead, community participation can also be viewed as an “iterative learning process” that allows communities, local partners, and governance structures to learn and solve problems together while keeping realistic expectations about what can be achieved in a given timeframe and context.(L. M. Morgan, 2001; Rifkin, 1996)

In practice, community participation involves myriad challenges; key among these are how participation is defined, the level of complexity of the process utilized, and the diversity of primary care issues that community participation approaches can seek to address.(Zakus & Lysack, 1998) Studying these issues reveals varying kinds and degrees of success and limited scope for generalization of experience across diverse contexts and initiatives.(Head, 2007; Zakus & Lysack, 1998) The major challenge with community participation is the persistent lack of understanding of how it works. While many of the factors essential to it—such as commitment and active involvement of community

members—are clear, there is less clarity on how to nurture or find people who engage to this degree and how these people then catalyze the participation of others.(NIH, 2011; Zakus & Lysack, 1998)

Experience shows, however, that imposing or incentivizing a community participation agenda from the outside is unlikely to be effective in the long run.(NIH, 2011; Zakus & Lysack, 1998) This could be partly because effective engagement has been recognized as part science and part art form, and the latter of these requires consistent sensitivity to and extensive experience with the community of interest.(NIH, 2011) In addition, local power imbalances, despite efforts to minimize or rectify them, can also hamper the perpetuation of meaningful participation particularly if the priorities and efforts that communities are expected to participate in do not reflect the perceived needs of that community.(George et al., 2015; L. M. Morgan, 2001)

Individual and community empowerment often starts by people telling their stories so that they feel heard and understood.(Gibbon, Labonte, & Laverack, 2002; Wallerstein & Bernstein, 1994) The full impact of empowerment efforts may not be felt by a community at large until sometimes years after an intervention or event has taken place, although individual experience of empowerment may happen much more quickly.(Laverack & Wallerstein, 2001) Often, community empowerment can be a progression from individual empowerment that expands to include social groups, and then builds to include communities and its social and political connections.(Laverack & Wallerstein, 2001) Ultimately, community empowerment goes beyond engagement or participation and implies community ownership and control over the direction of the work.(Madhusudan, 2016) Though community participation in health programs—

particularly health promotion activities—is common, examples of true community leadership and direction of interventions are not extensively documented in the literature.(George et al., 2015; Madhusudan, 2016)

Empowerment has often been defined in terms of powerlessness. Individual and collective approaches have been used to understand subjective dimensions—including feelings of hopelessness and a sense that control is held externally by others.(Wallerstein, 1993; Wallerstein & Bernstein, 1994) A practice-based definition of empowerment proposed by Nina Wallerstein reads: “a social action process that promotes participation of people, who are in positions of perceived and actual powerlessness, towards goals of increased individual and community decision-making and control, equity of resources, and improved quality of life.”(Wallerstein, 1993, p. 219) Others have defined empowerment as both external and internal factors that result in “gaining control over one’s life circumstances, gaining power over resources and decision making, and overcoming structural barriers that prevent marginalized groups from exercising autonomy and self-determination.”(Madhusudan, 2016) Some scholars have argued that empowerment cannot be “bestowed” upon someone, but must be developed from within by an individual or community wishing to achieve it.(Laverack, 2006)

The process of empowerment, as referenced in the field of psychology, has been described and depicted in a number of ways.(Cattaneo & Chapman, 2010; Cobb, 1993) First, it is iterative and ongoing. Secondly, in an empowerment process, both individual and social aspects are at play. Within the process, a number of essential components beginning with setting meaningful goals through ensuring that the necessary self-efficacy, knowledge, competence, and resources needed for action are in place. Assessing

the results of action, the linkages to the desired outcome, and the action taken by the person or group is necessary to reinforce and perpetuate the empowerment process.(Cattaneo & Chapman, 2010)

From a social conflict mediation perspective, empowerment constitutes a process of each individual in a conflict becoming aware of his or her position, taking ownership of and articulating that perspective, and then working to meet their needs within that perspective.(Cobb, 1993) Communities as a whole can apply similar processes where disenfranchised groups are “legitimized through their own efforts to gain control over their lives.”(Cobb, 1993) Additionally, the community as a whole can develop norms for managing these negotiations, which often targets and removes barriers to a more inclusive self-governance process.(Cobb, 1993)

Empowering communities has practical implications for helping communities achieve improvements in health status.(Laverack, 2006) As communities, and groups within them, gain confidence and competence, they also increase their sense of power and control which often translates into behavior changes and positive influence on health status.(Laverack, 2006; Wallerstein, 1993) Deepa Narayan and colleagues at the World Bank have identified four elements of empowerment that must be present for effective progress and reforms in governance structures to occur. These elements include 1) individuals and communities being able to access information, 2) including and encouraging participation of low-income and other marginalized or excluded groups, 3) accountability by government, all leaders, and decision-making figures, and 4) local capacity for individuals and groups to coordinate and mobilize resources towards common goals.(Narayan, 2002) These elements must then be applied, and more work is

needed to create processes and forums which ensure that all perspectives are represented. So far, efforts have not been balanced across the four elements, but rather have focused largely on increasing participation with lagging progress on the other three.(Narayan, 2002)

### **Implementation Assumptions**

This section reviews the literature about how change occurs during the implementation of primary care projects and programs. The three assumptions of interest in this dissertation are 1) that motivated and trainable people are available to do the work of CHWs, 2) that accumulation and sharing of best practices and learning is taking place, and 3) that communities will accept new ways of obtaining primary care services. These assumptions, are tested in the historical and county case study analyses later in this dissertation to see if they hold true in WV.

### **Motivated and Trainable People to Do the Work of CHWs**

Primary care workers are essential to any health system because of their central role in making health systems function, their management of other resources needed to improve health, and the large proportion of health budgets—often up to 75%—that are allocated to human resources.(Harvard College, 2004) Despite their centrality and considerable expense, efforts focused on strategic planning, management, and appreciation of health workforce contributions are frequently lacking within primary care systems.(Harvard College, 2004) Physicians and nurses, while the most ubiquitous cadres of health workers, often comprise a small proportion of the primary care workforce. While these workers are critical, evidence is mounting about the importance of the

functions of many other supportive providers—especially collaborative teams connected to the communities they serve.(IOM, 1996) This kind of inclusive community planning and action has not been standard practice or focus within the US system.(IOM, 1996)

The US primary care system lacks an adequate number of physicians, nurses, and other workers.(Salsberg & Grover, 2006) These deficiencies are predicted to increase in coming decades due to an aging population and the resulting increase in demand for health services.(Salsberg & Grover, 2006) Even more concerning, perhaps, is the fact that, even if enough physicians existed to provide the health services needed by the US population in the year 2020, there are concerns about whether the cost of this model of care is sustainable, even in a high income country.(Salsberg & Grover, 2006) These near-future realities raise questions about what kind of appropriate providers can be identified to perform different kinds of health services in order to deliver high quality and affordable care in the coming years and decades.(Salsberg & Grover, 2006)

In addition to shortages of health workers, available health workers are often not distributed according to the health service provision needs of populations, particularly taking into consideration geographic, racial, and other social gradients.(Harvard College, 2004; IOM, 1996; Starfield et al., 2005; WVRHA, 2014) This phenomenon is driven by health worker migration, professional burnout, as well as the impact of poor living conditions and limited support systems on the well-being of health workers.(Harvard College, 2004) In search of better opportunities, health workers, particularly physicians, tend to migrate from rural areas and the public sector to urban areas and the private sector.(Harvard College, 2004) While the presence of primary care physicians can improve a number of primary care outcomes,(Macinko, Starfield, & Shi, 2007; Starfield

et al., 2005) the question remains whether this physician presence is a feasible, sustainable, and ultimately desirable approach.

In addition to physicians, nurse practitioners, physician assistants, alternative medicine practitioners, midwives, social workers, women's groups that include peer educators focused on health, sanitarians, public health promotion workers, CHWs, and others may be working in and with a community to address primary care service needs.(Proser, Bysshe, Weaver, & Yee, 2015) The US public health workforce is also expected to face dramatic changes in the coming decades. A traditional focus on environmental health and centralized regulatory authority is giving way to the need for more community-based, integrated, and holistic primary care services that link traditional public health functions with clinical care and community engagement.(Amodeo, 2003) As the existing public health workforce ages and recent assessments identify gaps in experience and training for essential public health competencies, changes in the kind of public health workers that are needed, as well as necessary skill sets for effective work, must be addressed rapidly.(WVBPH, 2012)

Alternatives for the composition of the primary care and public health workforce, which converged to a greater extent under the ACA, can continue to be explored regardless of the future of the ACA. This exploration must include strategies to address the need for greater emphasis on care coordination, mental health, and social support services. All of this must be done while recognizing that there will likely not be a one-size-fits-all solution for every local population.(Bates, 2010)

*Community Health Workers (CHWs):* Since at least the 1930s, the roles of CHWs around the world have varied widely from providing health education, to referring

patients to the formal health system to providing basic clinical services.(Crigler et al., 2014; Z. Hill et al., 2014) In the 1932 Ding Xian Experiment, “farmer scholars” were trained as front-line social welfare workers. Their success became the foundation of Mao Tse Tung’s Barefoot Doctors movement, directly influencing WHO/UNICEF (United Nations Children’s Fund)’s vision of “Health for All.” A pillar of the global “Health for All” strategy articulated by WHO and UNICEF in the Declaration of Alma Ata in the late 1970s, the term “community health worker” has subsequently been applied to diverse personnel around the world. CHWs tend to be community members from the front lines who are specifically selected and trained to address primary care system limitations.(WHO/UNICEF, 1978)

A recent global review of large-scale CHW programs charted the history—including the ups and downs—of the CHW legacy.(Henry B Perry & Crigler, 2014) Models put forward and tested in the 1980s and 90s did not all meet expectations, though this was due in part to lack of funding and political will during a time of economic difficulty and general disenchantment with holistic and community-based approaches to health service provision.(Henry B Perry & Crigler, 2014) More recently, CHW program models have often been sustained and supported in countries with a national commitment to providing universal health care or willingness to invest in community-based primary care; examples include Brazil, Pakistan, Nepal, and Ethiopia.(Henry B Perry & Crigler, 2014)

Since at least the 1960s and 70s in the US, CHW programs have been implemented—including efforts to reduce infant mortality.(RWJF, 2016) The shift in focus to chronic conditions for many US CHWs took place during the 1980s and 90s in



the course of the HIV/AIDS response and due to the rising burden of non-communicable diseases. The overarching focus of CHW efforts in the US has consistently been on improving equity in access to primary care services for underserved populations.(RWJF, 2016)

The term “community health worker” and the roles that these workers can encompass include a wide range of skills and responsibilities. Grouping all of these workers into one category that includes a large number of variations in position titles and meanings contributes to confusion. Depending on definition and data sources, there are 54,000-175,000 Community Health Workers in the US.(O\*Net Online, 2016; Henry B Perry & Crigler, 2014; RWJF, 2016) The wide range in the estimated numbers of these workers suggests a lack of consensus about who CHWs are and a lack of data on who is doing CHW work.(Rosenthal, Rush, & Allen, 2016) Part of the complexity is also the range of job titles given to these workers across the US—many are not specifically called CHWs—which include *promotores*, health extension workers, health advocates, community health volunteers, and many other titles.

Several definitions for CHWs were reviewed for this study, particularly those relevant to the US context. First, the WHO has produced a widely accepted definition of CHWs as follows (WHO, 2007):

*Community health workers should be members of the communities where they work, should be selected by the communities, should be answerable to the communities for their activities, should be supported by the health system but not necessarily a part of its organization, and have shorter training than professional workers.*

The Centers for Disease Control and Prevention (CDC) define CHWs as, “a member of the health care workforce that helps community members access health care,

overcome barriers to appropriate care, and improve self-management of chronic diseases”(CDC National Center for Chronic Disease Prevention and Health Promotion, 2011), while in contrast the American Public Health Association (APHA) focuses more on the CHW as “a community member who builds individual and community capacity by increasing health knowledge and self-sufficiency through a range of activities such as outreach, community education, informal counseling, social support, and advocacy.”(APHA Policy Statement Database, 2009) This dissertation utilizes the ACA definition of CHW as a person who “promotes health or nutrition within the community in which the individual resides by serving as a liaison between communities and healthcare agencies.”(*Patient Protection and Affordable Care Act*, 2010) The ACA’s detailed description of CHWs also includes roles as an advocate and guide for communities in order to enhance community capacity, and strengthen the community voice to communicate with the primary care system and help with coordination of care.(*Patient Protection and Affordable Care Act*, 2010) While the future of the ACA is uncertain, the thinking behind this definition can continue to be built upon going forward.

Understanding what CHWs do and where they fit within the primary care system is particularly challenging because they “generally fall somewhere between the formal health system and communities, and rely on the involvement of a wide range of stakeholders at local, national, and international levels.”(Crigler et al., 2014) Consequently, confusion, inefficiency, and sub-optimal integration with the of the primary care services exist because CHW voices and responsibilities are unclear and/or inconsistent. Particularly for large-scale CHW programs, maintaining a locally responsive, participatory structure can be challenging because of the need (or at least

preference) for centralized structures and standards.(Crigler et al., 2014) At present, few functional examples of effective local leadership exist in large scale CHW projects.(Crigler et al., 2014)

CHW roles vary widely—providing health education, referring patients to the health system, and providing basic clinical services.(Crigler et al., 2014) Numerous studies demonstrate the CHW’s ability to provide cost-effective services across various levels of training, especially in maternal and child health services, persons with HIV (Henry Perry et al., 2014), and in rural or underserved populations.(Viswanathan et al., 2010) Much of a CHW’s success stems from his or her roots in community culture, sensitivity to and awareness of social norms, and his or her ability to gain community acceptance and trust.(Z. Hill et al., 2014; Miller, 2015a; Henry Perry, Freeman, Gupta, & Rassekh, 2009; Henry Perry et al., 2014)

In the US context, CHWs often do tasks including outreach, representing their communities, supporting patients to navigate the health system, providing health education, being role models, as well as serving as peer supporters and counselors.(Crespo et al., 2015; Miller, 2015a; Henry Perry et al., 2014) Other common roles include promoting healthy behaviors, providing preventive health services, providing specific curative health services mostly for maternal and child health, and being a community organizer.(Crigler et al., 2014) Regardless of their specific roles, CHWs are often appreciated as a source of health information and leadership within communities as well as providing a link between health facilities and communities.(Crigler et al., 2014; Miller, 2015a) A CHW’s “common characteristic is their work outside of health facilities directly with people in their homes, neighborhoods,

communities, and other nonclinical spaces where health and disease are produced.”(Henry Perry et al., 2014, p. 400) Recent literature points toward the critical need for commitment to and understanding of the community: CHWs are assumed to be embedded in community, to be respected and trusted by those members, and to possess an adequate understanding of the priority health issues and culture so they can effectively reach the populations—particularly underserved populations—that they are meant to serve.(Nemcek & Sabatier, 2003)

The US Department of Labor’s O\*Net Online job taxonomy and the ACT (American College Testing) WorkKeys® include a detailed list of potential skills relevant to the CHW occupation in the US context.(ACT WorkKeys, 2015; O\*Net, 2016) These identified competencies include advocating for individual and community needs, performing basic diagnostic procedures, contacting patients to ensure that they complete required or recommended health actions, and teaching health and wellness principles and behaviors.(ACT WorkKeys, 2015; O\*Net Online, 2016) The Department of Labor’s description specifies the knowledge, skills, and abilities CHWs should have. Knowledge domains include understanding the medicine and dentistry system, organizational and management skills, and interpersonal and communication skills. Essential skills include listening, oral and written communication, and reading comprehension. Recommended CHW abilities from the O\*Net description include strong communication skills, problem solving experience, idea exchange, and accumulating issues and tailoring discussions about them to different audiences.(O\*Net, 2016) The ACT WorkKeys® also includes a very detailed list of potential skill sets for the CHW occupation that ranges from providing first aid to advocating for individual and community needs to performing basic

diagnostic procedures to contacting patients in-person or by phone for follow-up to ensure that they complete required or recommended health actions such as taking prescription medications.(ACT WorkKeys, 2015)

Research conducted in 2010 in WV analyzed and compared approaches to developing CHW cadres implemented in other states to determine what could be done in WV.(Crespo et al., 2015) This comparative analysis was followed by a series of multi-stakeholder fora that produced a list of competencies grouped into three categories: 1) interpersonal, cultural, and communication skills, 2) chronic disease self-management and care coordination skills, and 3) and knowledge of community resources and skills to connect patients with those resources.(Crespo et al., 2015)

The lack of US standardization for CHW roles and training—if any formal training is provided at all—provides room for experimentation and innovation, but also creates confusion and the possibility for limited acceptance and impact of CHWs within the complex primary care system.(Miller, 2015a; Strong & Patnosh, 2015) So far, only a few states have developed any standards or certification processes for CHWs, and these tend to either be limited to existing cadres of health professionals or managed by a state Board of Nursing.(Miller, 2015a) The few states within the US that have moved forward in developing certifications and standards for CHWs include Texas and Ohio.(Rush, 2009) In Texas, a state code has been adopted that governs the role, standards of education, and scope of practice for CHWs. The role of CHWs in Texas encompasses serving as a liaison between providers and patients, providing health education, making referrals, gathering data, making home visits, and serving as a health interpreter.(Rush, 2009) In Ohio, CHWs are certified via the Board of Nursing, which requires a standard,

medically-focused curriculum and allows CHWs to work on specific tasks delegated by a Registered Nurse.(Rush, 2009) Other states and institutions are in the process of developing their own CHW models, which remain varied in terms of roles and skill sets. As many states move toward formalizing systems for credentialing CHWs, considerations concerning the cost of credentialing and the enforcement of standards, whether certification has added value to CHWs, and whether credentialing excludes demographic sub-groups otherwise well-suited to be CHWs need to be explored further.(Rush, 2009)

### **Accumulating and Sharing Best Practices and Learning**

Some of the major challenges for shared learning among local stakeholders involve the perceived and practical power divides that often occur between primary care professionals, other local authority figures, and the general public.(Roussos & Fawcett, 2000; Wallerstein & Bernstein, 1994) These divides may occur along culture, race, class, gender, educational level, or other social status lines.(Wallerstein & Bernstein, 1994) One of the possible ways to mitigate this challenge and get more diverse actors to participate is to ensure that training and technical support to local communities and various community groups is available throughout the lifespan of a project or program, from problem identification through the project evaluation phase.(Butterfoss, Goodman, & Wandersman, 1996; Roussos & Fawcett, 2000) Another challenge is aligning the many different vocabularies, approaches, and interests of diverse local actors, who often lack experience with or understanding of perspectives other than their own.(Lasker & Weiss, 2003; Roussos & Fawcett, 2000) Without working to build social ties between the actors, identifying areas of potential synergy, and empowering each actor first, the potential for

coordination, collective problem solving, or shared learning is greatly limited.(Lasker & Weiss, 2003)

The concept of “learning health systems” is an approach to building a culture and processes for continuous improvement and sharing of information and experiences across multiple stakeholders. In 2012, the IOM released a report that highlights the potential for improving quality of care, reducing costs, and achieving more coordination and shared learning among health care providers, patients, and the communities to which they belong.(IOM, 2012) Key to creating an effective learning system is strengthening relationships between primary care providers, patients, and relevant communities, which includes engaging and empowering patients and their communities through those relationships.(IOM, 2012) In addition, greater transparency regarding cost and outcomes to inform decision-making at individual and population levels is needed. Advances in technology continue to make this information sharing easier.(IOM, 2012) Finally, a “culture of learning” must be developed and nurtured where leaders at all levels promote and model the value of collaboration and improving practices and behaviors based on previous experiences.(IOM, 2012, p. 5)

### **Community Acceptance of New Primary Care Provision Strategies**

Cultural beliefs, preferences, and traditions drive decision-making and what care is considered acceptable and of good quality in any given context. A great deal of scholarship and effort have been invested in understanding Appalachia’s cultural influences as well as the economic, social, and health challenges facing the region. Much of the literature focuses on how health professionals can understand and work to overcome barriers to community acceptance of care providers, the treatments that they

offer, and the behavior changes and practices that they prescribe for their patients. These changes and practices may include following medicine regimens or other health and hygiene practices that may be different from or even counter to Appalachian tradition and culture.(Keefe, 2005)

Barriers to acceptance of care in Appalachia involve the assumptions made by both primary care workers and rural communities about the values, homogeneity, needs, and priorities of each other—particularly since many care providers have been people from outside of the community or who are bringing new ideas into their community.(L. L. Morgan & Reel, 2003) Unless health workers are exposed to the underlying diversity within rural communities and communities can become familiar and comfortable with their care providers, these social and cultural assumptions can lead to missed opportunities for the creation of shared solutions, learning, and understanding from both providers and communities.(L. L. Morgan & Reel, 2003)

Sometimes, quality of medical care, trust in care providers, and institutional mandates or protocols may be perceived as “insensitive or controversial”(Cullinan, 2013; Keefe, 2005)—leading community members to seek information, support, and treatment recommendations from family members and friends rather than from health professionals. Religious beliefs have also often been suspected as a contributor to decreased agency and a sense of fatalism among Appalachian people. Further research has found, however, that if accessible and respectful health services are available, faith is not a barrier to seeking primary care and can strengthen and comfort people when they experience disease themselves or their families do.(Behringer & Friedell, 2006) Pride and the cultural ideal of self-sufficiency also often steers Appalachians to try to manage their



health conditions on their own rather than accepting government assistance or being exposed to medicines or procedures they are afraid they might become addicted to or not fully recover from.(Cullinan, 2013)

Respecting and—when appropriate—integrating and harnessing local knowledge and beliefs to improve health in collaboration with local communities can be the first step for health workers to gain acceptance and understanding within Appalachian communities.(Keefe, 2005) Setting up the communication pathways and a foundation of trust in order to share information with patients and whole communities can be a challenge, but once the networks and relationships are set up, they are usually not easily broken.(Behringer & Friedell, 2006) Often the onus is on the primary care workers to make sure that accurate, understandable, and up-to-date information is available and shared in the communities, and not solely within health facilities in order to activate and sustain these communication channels.(Cullinan, 2013)

### **Risks for Engaging and Empowering Communities**

This section reviews literature focused on a set of risks that could put pressure on or limit the outcomes of projects or programs that are designed to support and strengthen the interface between communities and the primary care system in WV. How these risks are handled can influence the ability of local and state level stakeholders to understand each other and work together. These risks can contribute to which primary care outcomes are achieved, and sometimes to which ones are considered achievable or worthy of achieving. The risks selected for this study based on their centrality to the interface between communities and the primary care system include: 1) funding consistency, source, quantity, and purpose for primary care, 2) coordination among stakeholders on

primary care projects and the work of CHWs, 3) community capacity to engage with the primary care system, and 4) timeframes for primary care project implementation and outcomes. These risks were tested in this dissertation to ascertain their influence on the historical and contemporary experience of engaging and empowering WV communities to interface with the primary care system.

### **Funding for Primary Care**

Despite spending a large amount of money on health, funding for primary care and particularly the work of CHWs in WV and the rest of the US has been a challenge for a number of decades. Funding consistency and quantity over time as well as the source of those funds and the purposes for which they can be used have been an ongoing negotiation in order to offer necessary services to those who need them.

Total annual expenditures for primary care in US are \$200-250 billion,(UnitedHealth Center for Health Reform and Modernization, 2014) which is only 6-8% of total national health care spending.(Kaiser Family Foundation, 2012) At the same time, primary care physician office visits account for over half of the one billion health care visits conducted each year.(UnitedHealth Center for Health Reform and Modernization, 2014) Averaged out, per capita health care expenditures in 2012 were \$8,402 and accounted for 18% of national Gross Domestic Product (GDP).(Kaiser Family Foundation, 2012) In comparison, the US total health expenditure in the mid-1970s was only \$356 per person per year (\$1,310 in constant 2010 dollars) and about 7.2% of GDP.(Kaiser Family Foundation, 2012)

US healthcare costs are largely concentrated within a small portion of the population. For example, five percent of the US population used nearly half of the health

care dollars, and 1% accounted for nearly a quarter of all health expenditures.(Kaiser Family Foundation, 2012) Hospitals, drugs, and specialist physicians are the largest budget line items, and often particularly expensive investments are involved in treating chronic conditions such as heart disease, cancer, and mental health conditions.(Kaiser Family Foundation, 2012) Spending on health is not uniform across regions of the US, and regions with higher spending do not necessarily have better health outcomes.(Sirovich, Gallagher, Wennberg, & Fisher, 2008)

If the ACA, or some version of it, continues into the future, it will likely increase the number of annual primary care visits by as many as 25 million across the US as more people access health insurance, plans cover additional procedures many of which are preventative, and copays on those services are reduced or removed completely.(UnitedHealth Center for Health Reform and Modernization, 2014) In order to manage this increased demand, additional strategies for leveraging a diversified primary care workforce that works collaboratively—using Information Technology (IT) to improve efficiency,(UnitedHealth Center for Health Reform and Modernization, 2014) and seeking options for reducing wasteful spending due to inverted or misaligned incentive structures or lack of coordination—are needed.(Shortell & Rittenhouse, 2016)

Despite increased demand, the pool of available resources to pay for health care is unlikely to grow significantly, so using existing resources more efficiently and with less waste and fragmentation must be the continued focus.(Nettleman & Yanni, 2003) A blanket increase in funding for primary care provision in WV and the US would also likely not solve core challenges to the primary care system—particularly issues related to fragmentation of funds. In fact, more money could lead to more inefficiencies. Instead,

strategically redirecting available resources towards building necessary capacity for the local management of primary care needs,(Institute for Alternative Futures, 2012; Sirovich et al., 2008) experimenting with local models for how to engage communities to share in the responsibility for their health, and ensuring that the primary care system is providing value that communities want will be important.(Institute for Alternative Futures, 2012; Nettleman & Yanni, 2003) Increasing social cohesion through additional outreach and awareness among diverse community groups (Institute for Alternative Futures, 2012) may be another important objective towards which resources should be applied.

Historically, support for the kinds of investments described in the previous paragraph has come mostly from grants, private donors, and other funding sources. Within the ACA, there has been some room for an innovative approach to achieving desired outcomes through collaborative, coordinated work involving CHWs, and renewed focus on preventive care.(Trust for America's Health, 2013) More experience with and commitment to these approaches is needed if they are to be mainstreamed into the US primary care system, which has thrived on fragmentation and inefficiencies for several decades.

Debates continue about whether CHWs should be paid for their services or not. Generally, the decision of whether payment is appropriate and possible revolves around the level of training, time commitment of the work, and the availability of funding.(Crigler et al., 2014; Henry Perry et al., 2014) Assuming that a number of CHWs in WV and the rest of the US are and will need to be paid in some form in the future, limitations on which services commonly provided by CHWs are billable to health insurance plans has been one of the limitations in having more CHWs involved in

primary care in the US.(Trust for America's Health, 2013) In recent years, the ACA has been a driving force in shifting greater attention to quality of care, health outcomes, and a shift away from “volume-based” to “value-based” care; this transition has brought with it new debates on what to pay for and how to provide needed services.(Trust for America's Health, 2013) At the same time, the evidence to support community-based, prevention-focused services is increasing for measures of quality and cost, with the potential for a return on investment in preventive services being as high as 5 to 1.(Trust for America's Health, 2013)

Medicaid regulations have been changed recently to allow states to reimburse services that are not only provided by a licensed health professional, but also for services that those professionals recommend, whether they directly provide these or not. This is a fundamental shift, since non-licensed care providers can be appropriate providers of services such as care coordination, home visitation, health education, and other services such as those provided by CHWs.(Trust for America's Health, 2013) Each state wishing to pursue this approach must file a State Plan Amendment with the federal Centers for Medicare and Medicaid (CMS) for changes that fall within existing rules and regulations, or a waiver that proposes to test new services or policy approaches.(National Center for Health Housing) Both amendments and waivers must outline the services that will be paid for and who will provide them including a description of all proposed education and credentialing that those providers are required to receive.(Trust for America's Health, 2013)

Several major challenges remain with implementing this approach. First is how to put in place appropriate checks and balances to prevent abuse of the system while

keeping it accessible and relatively easy to use.(Trust for America's Health, 2013)

Secondly, figuring out how to bill for and pay for these services is a challenge that still needs to be worked out. Further, clarifying the scope of work of each care provider and addressing any tension or confusion that surfaces between providers about the changing sphere of control and responsibility will be necessary.(Trust for America's Health, 2013)

### **Coordination in Primary Care**

The health care system in the US, including primary care, has been striving to work in a more coordinated and collaborative fashion for several decades.(Lasker & Weiss, 2003) Lack of coordination is assumed to lead to inefficiencies and missed opportunities for sharing information, resources, and ideas that can improve the health of populations. Coordination within the US primary care system and communities remains a challenge due to the multiple agencies and kinds of workers that are part of the system, and the ways in which the services provided are financed and evaluated.

Scholars looking at different kinds of community participation have described coordination functions as relationships between communities and local authorities or experts over a “medium” period of time.(Head, 2007) Coordination among individuals and groups requires building on established relationships as well as being willing and able to plan and implement projects collectively, while each actor in the coordinated effort remains largely autonomous.(Head, 2007) Coordination and the development of local coalitions and partnerships to increase shared understanding and community engagement require strong community leadership, relationships between diverse organizations, and a process for inclusive decision-making.(Butterfoss et al., 1996; Roussos & Fawcett, 2000)

Care coordination is a recent buzz word related to primary care—often identified as a solution for managing healthcare costs and as a potential role for CHWs.(Piekes, Chen, & Schore, 2009) Care coordination is a key function of primary care teams, which often involve multiple health professionals including a physician, a nurse, and other support staff.(Chiocchio, Rabat, & Lebel, 2015; Piekes et al., 2009) Within primary care, the notion of working in teams, particularly in clinical settings, has seen growing popularity and has been ever more commonly implemented in recent decades.(Grumbach & Bodenheimer, 2004; Mickan & Rodger, 2005; Poulton & West, 1999; Yaffe et al., 2001) Some scholars argue that, while groups of health professionals now commonly provide team-based patient care, they need to earn team status through the demonstration of teamwork. Identified characteristics of teamwork include: measurable outcomes, effective administration systems, appropriate division of labor, training of all members of the team, and a communication strategy.(Grumbach & Bodenheimer, 2004) Non-physician professionals on health care teams, though interactions among staff including power dynamics and the manifestation of personalities, may become more complex as the team structure and roles become more complex.(Grumbach & Bodenheimer, 2004)

In practice, care coordination has been a focus within the primary care system, dealing with how diverse care providers can coordinate better to improve patient outcomes.(Piekes et al., 2009) Despite the popularity of care coordination, there is limited research looking at the effectiveness of this approach.(MacColl Institute for Healthcare Innovation, 2010) A number of articles and reports note that current models for care coordination need far more patient, family, and community engagement, support, accountability, and relationship-building.(MacColl Institute for Healthcare Innovation,

2010) Better transitional care is also needed when patients are discharged from the hospital or undergo a referral process as those transition points are often when care coordination systems break down.(MacColl Institute for Healthcare Innovation, 2010; Macinko et al., 2003; Piekles et al., 2009)

### **Community Capacity to Engage**

Particularly for rural and low-income communities, building and maintaining local capacity to engage with the primary care system in order to plan, manage, and evaluate projects and programs can be complex and challenging.(Liberato, Brimblecombe, Ritchie, Ferguson, & Coveney, 2011) Increasing community capacity can be a positive factor in improving access to services as well as local ability to respond to health concerns as they arise. Community capacity describes a “process that increase[s] the assets and attributes which a community is able to draw upon in order to improve their lives—including but not restricted to health.”(Gibbon et al., 2002, p. 485) Community capacity has also been described as “characteristics that enable communities to protect or improve their well-being.”(Freudenberg, Pastor, & Israel, 2011)

Recent efforts have also analyzed the mechanisms by which community capacity works, as well as the linkages between community capacity and desired outcomes.(Liberato et al., 2011) A set of common “domains” has been developed in a number of models for community capacity, which include community learning opportunities and skill development, partnership creation, networking opportunities, local leadership engagement, resource mobilization, inclusive decision-making, communication, asset-based approaches, and a “sense of community” as key factors that can be used to assess the competence and capacity of communities.(Liberato et al., 2011,



p. 6) While specific contexts and diverse kinds of programs influence which domains are most important as well as how they are defined or prioritized within community sub-groups, there is consistency in the domains across time and place.(Liberato et al., 2011)

A number of specific activities can facilitate progress in the domains described above.(Freudenberg et al., 2011) The most common kind of activity in which communities participate is implementation of interventions to solve health problems. Fewer activities involved communities identifying and defining the problems to be addressed.(George et al., 2015)

A dearth of consistency and specificity in terms of measuring changes in these capacity domains remains a challenge for primary care and public health projects that aim to target building community capacity.(Liberato et al., 2011) Efforts to use simple ranking scales to assess progress across domains have been found to “unacceptably influence the behaviors and actions of the participants” during field testing; consequently, a more qualitative process—asking participants to choose from a series of unranked statements those that best represented their view on the status of progress in each domain—has been utilized instead.(Gibbon et al., 2002) Even after an unbiased methodology has been developed, substantial communication with participants to explain the statements and allow discussion among them was necessary.(Gibbon et al., 2002) Further, whether similar results can be identified over time or by different community stakeholders is also an important consideration for measuring capacity. Others have taken a more quantifiable approach to measures of community capacity such as enumerating community participation in meetings, resources, or individuals holding leadership roles.(Freudenberg et al., 2011) These can be very useful and informative, if they are

nested within an understanding of the community's historical narrative, sense of belonging, and "feelings of connection, support, and collective problem solving."(Freudenberg et al., 2011, p. S125)

### **Timeframes for Project Implementation and Expected Outcomes**

In primary care—as in many fields—funding cycles, stakeholder motivations, and other pressures to produce tangible results in short timeframes are a commonly faced reality.(Woolcock, 2013) At the same time, engaging or empowering communities often requires building capacity among a number of different individuals and groups. Essential to achieving successes are building the capacity for long term sustainment of efforts and investing in the necessary relationships near the beginning of a local collaboration.(Head, 2007) Relational factors such as developing trust and confidence among the various participants, however, often requires even more time.(Head, 2007)

Particularly for efforts that include substantial community engagement or control, coordination among multiple and diverse local actors, or building new relationships or roles for workers, progress towards objectives is not linear and often not rapid. The time at which the effectiveness of an intervention is evaluated matters,(Woolcock, 2013) regardless of whether the desired outcome is cost savings, health outcomes, improved quality of care, equity, or a combination of metrics. At certain times, the intervention may appear to be highly effective, not to have any impact, or even to be reversing outcome patterns.(Woolcock, 2013) The progress, or lack thereof, of an intervention towards producing desired outcomes can also vary considerably across different contexts.(Woolcock, 2013)

## **Achieving Primary Care Outcomes and Impact**

This section reviews evidence and experience about how to achieve desired primary care outcomes including the identification of appropriate metrics, unpacking power dynamics, and data disaggregation and analysis challenges that influence who has control of tracking the outcomes, and whose outcomes are tracked. Ultimately, the primary care outcomes of interest (access to services and level of community engagement) are the proposed intermediaries that lead to equitable impact on health status, though the final linkage is not a focus of this dissertation.

## **Improving Access to and Utilization of Primary Care Services**

Increased access to a designated primary care provider, appropriate referrals, and support to coordinating and managing care has been associated with active community and family participation in primary care provision. These access-related outcomes are particularly important to assess across socioeconomic and racial and ethnic population groups.(Peters et al., 2008; Strickland, Jones, Ghanour, Kogan, & Newacheck, 2011) This dissertation looks at the linkage between the assumptions and risks described in the conceptual framework in Chapter II and access to and utilization of primary care services by community members in WV, particularly for rural and low-income populations.

Access to care has been defined as simply as “the availability of financial and health system resources” in a given area.(Aday & Andersen, 1974) Yet, research over several decades has revealed many nuances to fully defining and measuring access to and utilization of health services.(Aday & Andersen, 1974; J. W. Thomas & Penchansky, 1984) Access and utilization can be examined by looking at characteristics of the health system (supply side) and of the population being served (demand side), both of which

influence the services being offered. Access has been further defined across several “dimensions” (Peters et al., 2008; J. W. Thomas & Penchansky, 1984) including:

- 1) Geographical accessibility: distance or time to the primary care service provision location from where community members live or work.
- 2) Availability: appropriateness of the volume and type of services offered.
- 3) Financial accessibility: balance between the price of services and patients’ options for paying for them.
- 4) Acceptability: alignment of patient and provider attitudes about acceptable or desirable characteristics of each other.

CHWs are often able to contribute to addressing these barriers to accessing services by providing services in the home or other convenient community locations, being available to discuss concerns as community members face them (including outside of normal business hours.(Henry Perry et al., 2014) CHWs also often help connect patients to available resources and navigate cultural and practical barriers to accepting and utilizing available services. (Bracho, Lee, Giraldo, De Prado, & Latino Health Access Collective, 2016; Rosenthal et al., 2016)

Health equity considerations for access and utilization of services are also important—carefully assessing the effects of socioeconomic status, gender, and age of the patient and provider, and geographic location where services are offered and looking at whether those who need services are equitably receiving what they need and value.(Aday & Andersen, 1974; J. W. Thomas & Penchansky, 1984)

Within the primary care system, a number of socio-cultural and logistical factors must be considered regarding access to and utilization of health services. Socio-cultural

factors include the sex of the provider as well as their experience, specialization, and the cost of services.(J. W. Thomas & Penschansky, 1984) Logistically, the deficiency in numbers of qualified primary care providers is a challenge for access to primary care services—particularly for rural and low-income populations.(Aday & Andersen, 1974; Bodenheimer & Pham, 2010) Recent geospatial analysis in four Appalachian states (not including WV) confirmed the geographical differential between urban and rural populations in terms of access to primary care services, with areas of higher population density having shorter commutes and greater choice among primary care providers.(Donohoe et al., 2016) Longer commutes and wait times as well as fewer providers to choose from are important considerations.(Aday & Andersen, 1974)

In order for community members to access and then continue using primary care services, both social acceptability as well as practical considerations must be considered. Important social factors include the level of knowledge about health, how disease and medical care is understood in the local culture, and the value placed on medical care—all of which contribute to a consumer’s perception about access to and “willingness” to utilize services.(Aday & Andersen, 1974) Practically, primary care services must be available at the times, places, and for a price that the community can afford.(Forrest & Starfield, 2005; Shi, 2012) Operational factors related to seeing a doctor such as ease of making an appointment, office wait times, office hours, degree of dignity and respect received from providers, and being able to see the same provider consistently also influence whether patients seek follow-up care after an initial visit.(Forrest & Starfield, 2005; Lambrew, DeFriese, Carey, Ricketts, & Biddle, 1996)

Looking towards the future, considering a number of factors that could be influencing access to and utilization of health services is necessary—particularly since the interaction and relationships between these factors are not uniform or predictable across different contexts, sub-populations, and timeframes. (Peters et al., 2008; J. W. Thomas & Penchansky, 1984) For WV, one of the major questions is the influence and future of the expansion of Medicaid that took place under the ACA on access to and utilization of health services. In a national analysis of Medicaid or private insurance expansion in 26 states and the District of Columbia, gains in access to services are clear, and most data suggests good or improved quality of available services as well. (Sommers, Blendon, Orav, & Epstein, 2016; Wherry & Miller, 2016) Yet, utilization and linkages to health status improvements are not so clear or simple. (Sommers et al., 2016) Continued monitoring and analysis—that considers locally relevant cultural and social values as well as a number of practical factors influencing primary care service access and utilization—is needed.

### **Extent to Which Communities Engage in Primary Care**

One of the primary care outcomes of interest in this dissertation was the extent to which communities engage in planning, implementing, and evaluating primary care projects and programs. Much work remains to be done to identify and validate appropriate participation measures for communities and the primary care system. (Wallerstein & Duran, 2006) While complex and analytically advanced measurement scales for community engagement in mental health programs, disaster response, other situations have been developed, these scales make it difficult for communities to be directly involved with managing and controlling the measurement of

their engagement, and these composite measures often either lack transferability across contexts or contain a large number of assumptions that limit the local applicability and usability of the findings.(Harpham, Grant, & Thomas, 2002; Israel, Checkoway, Schulz, & Zimmerman, 1994; Tait, Birchwood, & Trower, 2002) Instead, an accessible, inclusive, and sustainable approach to measuring and monitoring community engagement in primary care systems is needed. This section describes a number of important considerations, several limitations, and gaps in the literature related to achieving such an approach.

The first consideration for measuring community engagement is that interactions happen on several levels including between individuals, social groups or organizations, and communities.(Israel et al., 1994; Laverack, 2006) The kinds of interactions taking place at each level may serve the purpose of engaging others to share information and resources, collaborating to achieve the goals of one or more of the collaborators, or sharing leadership to achieve mutual goals among a number of partners.(Eder, Carter-Edwards, Hurd, Rumala, & Wallerstein, 2013; Laverack, 2006)

In addition to measuring which activities occur—such as simple counts of how many people attended a meeting, completed a training, or voted in a local election—the tenor of these interactions, including trust and synergy, may deserve greater attention.(Butterfoss, 2006; Costa & Kahn, 2003; Eder et al., 2013) Trust and synergy are social phenomena open to interpretation from multiple perspectives such as the power relations and diversity among the actors.(Butterfoss, 2006) If communities are actively involved and invested in project implementation and in the outcomes that are achieved, then levels of trust are also often higher among partners including health workers,

researchers, and policy makers.(Eder et al., 2013; Wallerstein & Duran, 2006) Continuing to seek appropriate metrics for these qualities can provide directly useful information that might otherwise be buried within composite measures.

The types and extent of standards, regulations, and accreditation procedures for health care agencies have been on the rise in recent years, and are intended to increase the quality and safety of the services that are provided.(Hinchcliff et al., 2016) Many of these standards and accreditations incentivize or require community engagement, while also providing the resources needed to do this engagement well. In the US primary care system, the PCMH model has been in use for nearly a decade, and provides a widely-used framework for provision of appropriate and good quality primary care services. PCMH strives to improve health outcomes by coordinating care and measuring outcomes, particularly at the community level.(Rittenhouse, Thom, & Schittdiel, 2010) This model focuses on providing health information and services using an approach that engages patients in managing their health, and measures how well relationships among patients, providers, and community partners are working. Often, a combination of “numbers and narratives” is used to track referrals, services, and costs as well as the quality of the care and patient satisfaction.(Stange et al., 2010)

Under the ACA and recent Internal Revenue Service regulation, non-profit hospitals have been required to demonstrate “community benefit,” which entails a jointly prepared plan to articulate how the hospital is improving the health of its catchment area in collaboration with local partners.(Rosenbaum, Byrnes, Rothenburg, & Gunsalus, 2016; Szilagyi et al., 2014) The emphasis on tracking the expenditure of community benefit dollars has largely been limited to whether funds were used for legally acceptable



purposes, but current and potential future initiatives could help broaden the scope of what kinds of health investments could qualify for community benefit funding, including initiatives to address many local social determinants of health.(Rosenbaum et al., 2016)

Measuring community engagement entails considering the availability of structures needed to support and sustain the engagement, the processes through which engagement occurs, and the outcomes that are jointly achieved.(Szilagyi et al., 2014)

Process evaluations often track metrics such as who is participating, and why, how, and when they are engaged or disengaged during the course of a project.(Butterfoss, 2006)

Often, the specific metrics used or emphasized need to adapt to and reflect the local context to the extent possible, but it is also advantageous to align with national standards and goals, such as the *Healthy People 2020* metrics.(Szilagyi et al., 2014) Such alignment can help show comparability of results across different contexts, and help others understand using a common language what work is being done.

Showing cause and effect between community engagement and health outcomes has been challenging, partly due to the many social, structural, and physical factors in the environments where people live.(Israel et al., 1994; Laverack, 2006) When communities and community members are able to access information and work together, however, they are more likely to be able to achieve health goals due to social support, access to shared resources, and the presence of role models similar to themselves.(Laverack, 2006) Regardless of the specific activities or the objectives to be met, who gets the credit for jointly identified, pursued, or achieved outcomes is essential.(Wallerstein & Duran, 2006)

## **Impact on Health Status**

Ultimately, the goal of many primary care efforts, including the use of CHWs, is to improve the health status of the populations they serve. To assess that impact, a number of factors including cost and quality of care are necessary to measure.(Kindig & Stoddart, 2003) The term “population health,” though used in a variety of contexts today, is most often associated with the Canadian health system, and while a concise definition remains evasive, the central theme relates to understanding and addressing determinants of the health of populations.(Kindig & Stoddart, 2003) The overall goal of a population health approach is to “maintain and improve health of the entire population and to reduce inequalities in health between population groups.”(Kindig & Stoddart, 2003) Major components of population health include understanding patterns of health determinants, health policies and interventions, and health outcomes and their distribution within populations. While these may not be a new ways of looking at public health or the field of health promotion (Kindig & Stoddart, 2003; Labonte, 1995), a clarification of the term and assurance that it embraces the concept of broad determinants and holistic thinking—arguably a foundation for many historical articulations of public health—may be warranted.(Kindig & Stoddart, 2003)

Population health, despite renewed interest and motivation for addressing equity and underlying determinants of health (Mechanic, 2003; WHO, 2008), faces several fundamental challenges in order to sustain itself through political and scientific cycles of change: 1) population health must be further legitimized as a field of study, 2) relevance to policy development and reform must be clear, 3) the definition of the field must be further clarified, and 4) career opportunities within the field must be evident, in order to

attract young professionals and to sustain and develop strong leaders for the field.(Mechanic, 2003) One proposed lens through which to advance the principles of population health is through a strategy known as the Triple Aim—namely, addressing determinants of health of populations, improving quality of care, and addressing the per capita cost of care.(Stiefel & Nolan, 2012)

Recently, health equity has been added as an essential component of population health, specifically in relation to CHW contributions.(RWJF, 2016) Health equity refers to “the highest attainable standard of health for all,” while inequity refers to systematic and avoidable, and therefore unjust, disparities between different sub-populations.(P. Braveman & Gruskin, 202) Disparities or inequalities (terms often used interchangeably) include any difference or inequality between persons.(P. Braveman & Gruskin, 202) Inequities are of particular interest in public health because of the potential to reduce or completely eliminate inequitable differences in health status across population groups specifically considering education level, income, race, gender, or geographical location. In addition, the definition of terms can influence the emphasis on and resource allocation for addressing these issues in both policy and practice.(Paula Braveman, 2006) Equity has also been defined specifically in reference to primary care services as the “distribution of benefits according to demonstrated need [health status] rather than on the basis of political or socioeconomic privilege.”(C. Taylor, 1992)

Inequities can be measured in terms of many variables including health outcomes, wealth, power, and others.(P. Braveman & Gruskin, 202) Analysis of inequities can be conducted at many levels, and certainly can and should inform national and global policies. (P. Braveman & Gruskin, 202) Many argue that in order to fully address

inequities, greater focus on analysis and action at the community level are necessary, where a holistic and in-depth understanding of the many underlying determinants can be developed to inform direct engagement strategies with those most affected.(Arole & Arole, 1994; Newell, 1975; D. Taylor-Ide & Taylor, 2002) The importance of considering equity in terms of providing primary care services, and also in building effective structures to engage and empower communities has been demonstrated in a number of articles.(George et al., 2015; Rifkin, 2003; C. Taylor, 1992)

## V. Historical Methods

### Sampling

*Document review:* An online review of WV literature was conducted in order to arrange major historical events as well as current state-level projects and policies related to primary care in chronological order. Google, Google Scholar, PubMed, and Web of Science were searched for the following terms: [[“West Virginia” OR “WV” OR “WVa”] AND [“primary care” OR “primary health care” OR “community health” OR “access to care” OR “community health worker” OR “health worker”]]. To this basic set of search terms, additional terms for major projects or time periods, such as the New Deal or the War on Poverty were also added to focus the search on a specific period or initiative. As new projects or programs were identified through the online searches or via archival research or oral histories, additional online searches were conducted for them as well.

The archival literature review initially included searching the “finding aids”—indexes with varying degrees of detail on the contents of collections of archival materials—of West Virginia University’s *West Virginia and Regional History Center*. The collections of interest included the congressional and political papers, manuscripts, oral histories, and the printed ephemera which were searched for simplified search terms based on those described above. Simplified search terms were used in order to gain an inclusive sense of available archival material as terminology has changed substantially over time and the finding aids often had a limited amount of detail. A series of conversations with archivists at the Center also helped identify specific collections belonging to key leaders and additional specialized finding aids which were not available electronically that led to the identification of additional relevant materials. The researcher

used this site to pilot test procedures for identifying source documents, taking notes, and prioritizing which documents to take photos of or request copies for later in-depth review.

The state documents collection at the West Virginia State Archives in Charleston, WV was the second major source of relevant material for this study. Online finding aids for the state documents collection were searched with search terms based on those described at the beginning of this chapter. Due to limited detail in the finding aids and the implied focus on WV, simplified search terms such as “health,” or “medicine,” or “primary care” were often used to scope the kind and quantity of results; then, based on the initial results, more specific search terms were developed to help sort potentially relevant collections and documents into manageable categories. In addition, the WV Bureau for Public Health’s Biannual Reports, also housed in the WV State Archives were valuable sources of information on how the public health system has worked since 1930—specifically valuable were the historical trends on the primary care workforce and the kind of community engagement.

The researcher also visited the special collections at the Marshall University Archives in Huntington, WV and met with the resident archivist. While very little new information was discovered, the visit was worthwhile as it confirmed the degree of completeness of the materials in the other state archives and was part of the due diligence of systematically covering possible data sources. The WV School of Osteopathic Medicine Archives were also visited, but the researcher determined that there was nothing relevant there that was not also accessible within the other much larger archival collections.

Based on data collection from all WV sources, the importance of the role of the United Mine Workers of America (UMWA) and the Black Lung program became clear early in the study. The UMWA collection is located at the Penn State University Archives in State College, PA and the researcher spent several days at these archives after a series of meetings and online searches to determine which materials would be the most relevant to review. Finally, National Archives' Works Projects Administration (WPA) collection was the last archive visited for this study to review materials from the New Deal and post-depression recovery era.

In addition to these archival collections, documents on specific projects and time periods were obtained from three private collections. One was a collection of historical files from the WV Higher Education Policy Commission focused on the state-wide efforts to place and retain more primary care professionals in rural areas. The second was the Kellogg Foundation Archives including proposals, reports, and evaluations of some key funding from the foundation that was provided to WV's medical schools in the 1980s and 1990s to support the development of the primary care workforce. Finally, the private collection of Dr. Henry Taylor, a long-time rural physician and former WV State Health Officer, was reviewed for documents related to the models for community-oriented medicine and population-based health interventions that were piloted in WV during the 1980s and 1990s.

*Oral histories:* Based on the first round of archival research at WVU, the WV State Archives, and Marshall University Archives, as well as talking with people around the state about this project, a list of the names of key leaders and experienced persons who could be valuable oral history respondents was developed. The list included people

who had created or managed major relevant projects and people in key positions—such as Health Commissioner for the state or in a leadership role for one of the social movements—during a critical period of time with significant activity in the interface between communities and the primary care system. They were also scholars and funders of primary care grants in addition to leaders of health insurance agencies.

The researcher kept an evolving list of potential oral history respondents and worked to get in touch with as many as possible. Often, respondents would recommend additional respondents, which were then added to the list and researched online to learn more details about their experiences before deciding whether to contact them. Many names came up repeatedly in different documents and conversations, which the researcher took as a sign that that person had an important role or perspective. It was not possible to connect with or even find all of the potential respondents on the list. This was often because the respondent moved away from the area or out of the field of work some time ago, retired and was no longer interested in the work, or was deceased. No one directly declined to be interviewed, though several were cautious about confidentiality of their views, and some of the non-responses may have been a way of declining to even engage with the researcher or the study.

Of all the potential respondents, 25-30 people were contacted by the researcher or by another WV contact who knew the respondent on behalf of the researcher. Of those, 18 introductory conversations took place by phone, email, or in person. Some of the people with whom a dialogue was started ended up not having relevant information or experiences to share, and were excluded from the study.



Twelve oral history respondents (Table 1) gave in-depth, relevant information. The oral history respondents were most often male health professionals with vast experience with primary care and community engagement and empowerment in WV.

**Table 1: Summary of Oral History Respondent Characteristics**

Type of interviewee	Gender	
	Male	Female
Health workers	8	2
Community representatives	1	1
<b>Total</b>	<b>9</b>	<b>3</b>

### **Data Collection**

*Historical document collection:* The timeframe covered in this study was 1930 until the present day. A few references to events that took place before 1930 are mentioned, if these related directly or were precursors to later events within the study period. The time period of the study was researched online and discussed in early conversations and oral histories to identify major events, key individuals, and important evolutions in terminology over time. This information served as an orientation and guide for searching archival materials, online databases, and for purposive sampling of additional oral history respondents who had first-hand or extensive second-hand knowledge of key time periods and events. Of course, each database and archive had a unique collection of materials, so relevant information for each time period was not identified in every archive or database. Each archive was returned to as many times as was necessary to review all relevant documents. The WVU collection and the WV State Archives were visited a number of times during the data collection period, and each visit included discussions with the archivists and additional searching of finding aids and collections prior to the visits.

During the archival data collection process, the researcher took extensive notes and photographs, and made copies as needed to ensure clear and complete documentation of data sources as well as to capture researcher reflections and notes based on the findings. These notes were digitized, if possible, and stored in a secured electronic database that was backed up regularly. A set of file folders for all paper copies of notes and documents was stored along with all other study documentation in a secure location.

*Oral history data collection:* Oral history respondent interviews served three purposes. First, they helped identify additional programs and interventions across time periods that the study had not yet identified. Secondly, they provided further detail and explanation to contextualize identified documents. Finally, they helped draw linkages and also confirm or identify gaps between interventions and time periods. The researcher had periodic contact with them between the time of initial contact until the conclusion of the data collection process. Many of the oral history respondents shared both their own experiences and views as well as additional documents or references for documents available in an archive or online. The oral history study instrument which was used to guide conversations with respondents can be found in Appendix 2.

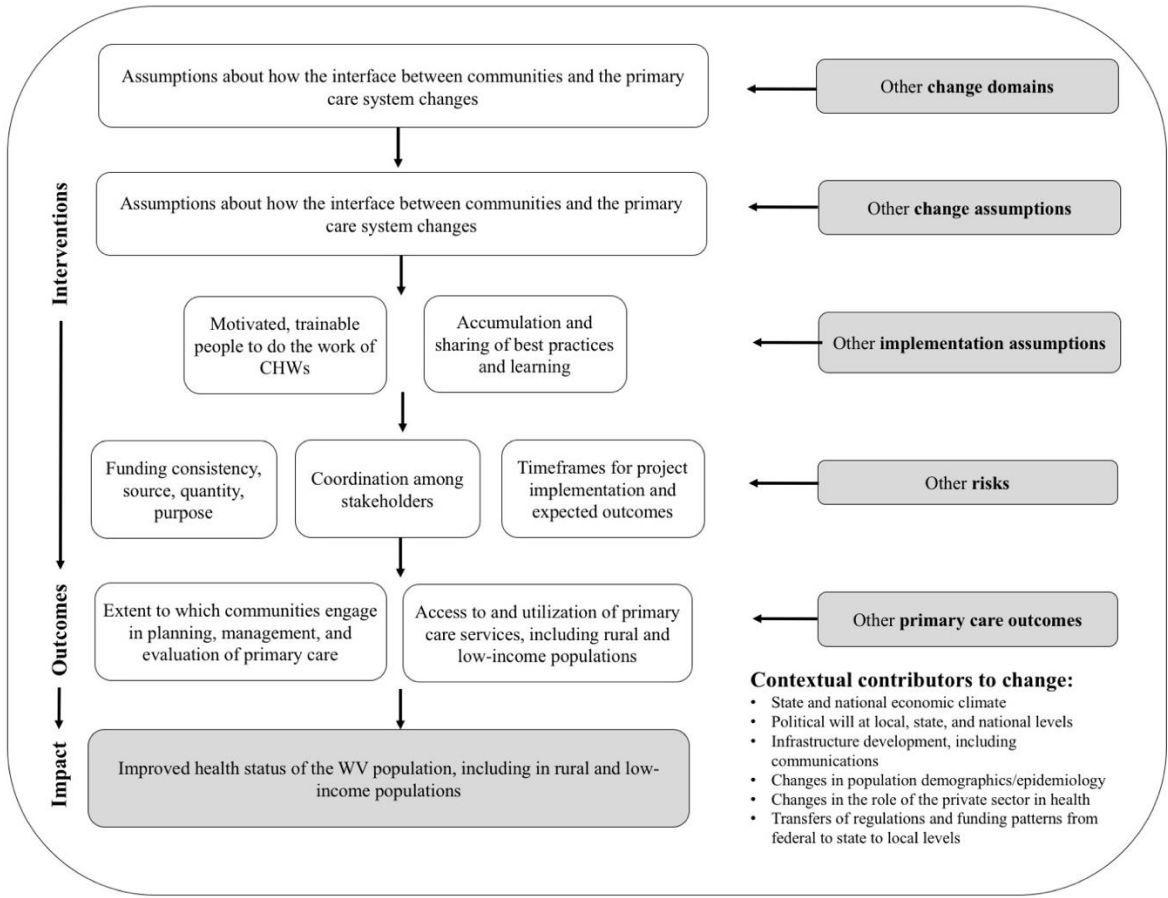
Oral history respondents were each formally interviewed at least one time. After that in-depth discussion, follow-up conversations often took place related to specific topic or ideas that were mentioned, but not fully discussed in the original interview session.

### **Data Analysis**

All historical data were organized chronologically. Archival notes were reviewed systematically and organized by intervention or project into a single MS (Microsoft) Word document. Scanned and copied documents were reviewed; then, descriptions and

quotes were added, along with footnotes or bibliographical citations, to the same word document. The oral histories were reviewed carefully in their entirety as is done in narrative analysis. (Riessman, 2008) Notes and memos were created based on the different topics covered with each respondent. Quotes and descriptions of the perspectives of different stakeholders were also added in chronological order to the master MS Word document. A number of follow-up discussions with oral history respondents, often by email or phone, took place during the analysis period in order to clarify key points, check facts, or ask for further details about a particular project or conclusion drawn by the respondent.

After preliminary organization and review of the results were conducted, patterns began to emerge, and an overarching argument was developed. Major time periods were identified, which spanned one to two decades and each involved a major national health-related policy change, and other major associated funding and political changes. The overarching argument, the time periods, and the lessons and experiences that this study identified were analyzed and organized based on the assumptions and risks leading to primary care outcomes of interest as outlined in Figure 4. Although using conceptual frameworks such as the one in Figure 3 is not common in historical research, aligning the historical analysis with the rest of the study using this figure was helpful in organizing the findings from the study and are aligned with the research questions. All grayed out sections of the figure indicate additional components of the full conceptual framework detailed in Appendix 1 which, while they are related to the interface between communities and the primary care system, are not analyzed in the historical results in Chapter VI.



**Figure 4. Historical Analysis Components of the Conceptual Framework**

## **VI. Historical Analysis: The Community and Primary Care System Interface in WV Since 1930**

### **Introduction and Purpose**

This chapter explores the major policies and programs at national, regional, and state level that have influenced the interface between communities and the primary care system in WV since the 1930s. The purpose of including a historical perspective in this dissertation is to synthesize WV's experience with the interface between communities and the primary care system across nearly a century. The resulting narrative and argument is meant to be accessible to current stakeholders and to draw out lessons learned that can inform WV's strategies for CHWs in the future.

The data used in this chapter were gathered through archival research and a series of oral histories, which were described in Chapter V. Since 1930, numerous policies and programs to promote, incentivize, catalyze, and require community engagement and empowerment to strengthen and improve the primary care system have been implemented. This chapter explores these earlier efforts.

The challenges and opportunities faced by communities and the primary care system in WV as they worked to implement these policies and programs, as well as the outcomes that were achieved, are assessed to the degree possible. Attention is paid to underlying implementation assumptions and risks from the components of the conceptual framework described in Chapter V. The progression of policies and programs over time, the processes driving them, and their implications for CHW opportunities in the future are analyzed in each section of this chapter, particularly in the discussion at the end which ties back to the major components of the conceptual framework.

The background problem in this chapter—a common one in medicine, public health, and beyond—is that policy makers and other leaders frequently make decisions concerning health systems and health service provision that are disconnected from historical experience. This problem may occur because historical evidence and experience are difficult to find or access, are not packaged in a form that is easy to digest or use, or are not considered valuable by those in key leadership roles. Recent attempts to promote community engagement and empowerment in the building of the primary care systems in WV have failed to examine earlier efforts to do the same and thus missed the opportunity to learn from these past efforts.

Communities have held key interfacing roles with the primary care system across the timespan of the study and in a wide range of projects and programs around the state. In particular, WV has extensive experience with projects and programs similar to the ideas about developing a CHW cadre that are currently being discussed. Many of these projects and programs were externally designed, funded, and often mandated at federal levels and lacked grassroots planning or ongoing support. Communities have often had to pick up the slack to fill voids when externally driven efforts changed or came to an end. This recurring dynamic has led to limited and inconsistent motivation for communities to participate in new projects and has also stymied the results of the participation that has occurred.

There have been exceptions to this pattern in WV. When community participation is handled well, at both the local and state level, it has affirmed the social value, program improvements, and potential for future change stemming from committed collaboration with the primary care system. In addition, many individuals have dedicated their careers

and lives to implementing community-engaged projects and have spoken out across decades about lessons that can be learned, what should be sustained, and what is working. These individuals have often faced inertia in the form of bureaucracy, lack of experience and capacity among their staff, and resistance or uncertainty to change from many stakeholders. Strategically building on WV's experience of what has and has not worked within the interface of communities and primary care has strong potential to contribute to the health of WV's citizens, particularly rural and low-income ones. Providing this evidence to current WV decision makers can help overcome concerns and hesitation regarding further investments in community engagement for primary care and inform the organization of future initiatives.

Within WV's primary care system, many cadres of workers and many visionaries and leaders have worked to address shortages of primary care professionals—particularly those who have or can do the work of CHWs—since 1930. Over the past few decades, WV has worked hard to increase the numbers of health professionals, particularly primary care physicians, that choose to practice in rural and underserved areas.(Heady, 2007) Figure 5 illustrates trends for the number of different cadres of primary care workers in WV. These historical data contain gaps (data points shown by large dots in each series), but still show historical trends. Importantly, the number of Registered Nurses (RNs) has risen dramatically while the numbers for many other cadres of health worker have remained fairly stable over the years. Some contributors across the US and in WV for the increase in RNs, however, include increased demand for nurses to support a complex primary care system—including administrative roles, rising nursing care needs for chronic diseases and a growing elderly population, expansion and dynamism of

training programs, and increased wages.(Auerbach, Staiger, Muench, & Buerhaus, 2013; Buerhaus, Auerbach, & Staiger, 2009)

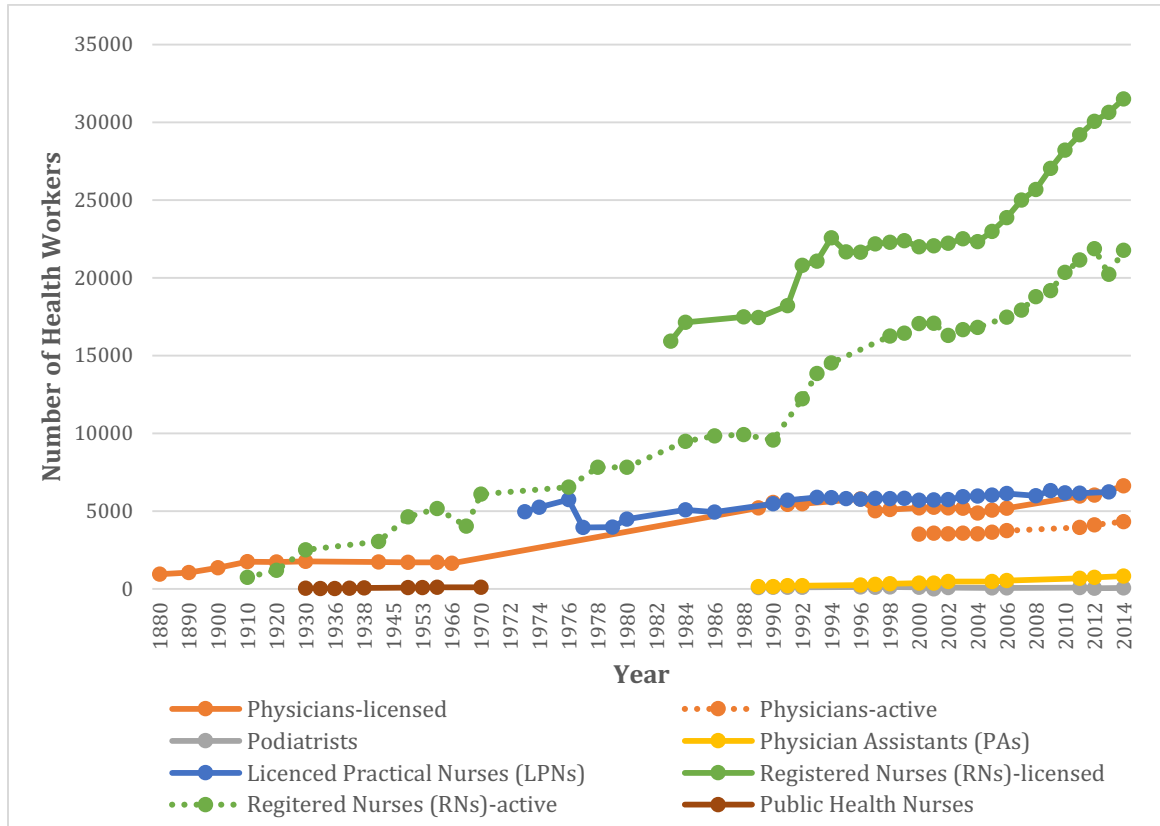


Figure 5: Trends in the Number of Common Primary Care Worker Cadres in WV Over Time<sup>4</sup>

Figure 5 does not include data for CHW-type workers. This omission is because there has been no state-wide consensus on the role of CHWs, no certification or registration process, and no systematic way to track these workers in terms of who they are, where they are, and what they have been doing. Although a variety of local projects have developed or adapted variations of health workers holding CHW-type roles over the

<sup>4</sup> These data have been compiled from occupational census data, biennial reports to the WV legislature by the WV Board of Examiners for Licensed Practical Nurses and for Registered Nurses, and from WV Board of Medicine Annual Report to the Legislature. Access to these data was made possible via the WV State Archives.



past decades, WV does not have any certification or licensing procedure for CHWs.(Miller, 2015b; Vanderbilt University, 2015; WV Legislature, 2014a, 2014c)

### **Tracing the Community and Primary Care System Interface Since 1930**

Since the 1930s, WV has undertaken a series of policies and programs related to community engagement and empowerment with the primary care system. In this chapter, analysis of these policies and programs will be conducted across five time periods generally reflecting cycles of federal policy and funding, regional and state-level action, and acceptance, pushback, or adaptation at the community level. The time periods include: The Great Depression and Recovery (1930-1949), The Coal Boom (1950-1959), the War on Poverty (1960-1979), Community Health Centers and Modern Primary Care (1980-1999), and the Great Recession and Affordable Care Act (2000-present). While some events in each period overlap, the periods are also distinct. Each period described in this chapter includes a federal initiative or major policy and funding shift—often in response to an identified crisis—which was then adapted and implemented at regional, state, and local levels. Out of the successes and failures of these national efforts, more localized initiatives often emerged. These community-based initiatives enhanced, adapted, or worked to counter the influence of the federal programs. Lessons and a recap from each time period are captured and then discussed collectively at the end of the chapter.

#### **The Great Depression and Recovery Era: The 1930s and 1940s**

This section describes the major shifts in the community and primary care interface that took place across WV during the years between 1930 and 1949. Major changes in the roles and perceptions of medical providers took place in the state at the

same time as a global professionalization of medicine was transpiring. Questions about appropriate training and scope of lay worker responsibilities arose as their historical place in WV communities was questioned by a changing population demographic faced with new options and pressures from primary care physicians and the physicians' advocates. A number of enduring entities, such as the state's public health system, and also influential regional institutions such as the Frontier Nursing Service, were established during this period. Over the course of a major fluctuation of external inputs of money and other resources, the balance between the public sector primary care system and private programs to provide primary care services shifted as well. The time period is characterized as a time of formalization of, experimentation with, and some of the first large-scale debates about how to support the interface between communities and the primary care system in order to effectively address the challenges of the times.

*Leading up to the Great Depression:* In the decades leading up to the Great Depression, primary care provision evolved substantially in the mountains of Appalachia. At the turn of the 20<sup>th</sup> century, the medical profession was just achieving a recognized stance as a scientific practice for which only those with official medical training were qualified. Physicians, particularly younger ones who were more likely to have formal training, envisioned careers in the medical field that their predecessors had not even imagined. To achieve their ambitions, they teamed up with the rest of a rising so-called "middleclass" of mine owners, lawyers, and politicians to gain control over more of the primary care system. This middleclass remained fairly small in size and elite in nature compared with the majority of the population in WV and the rest of Appalachia. Simultaneously, public health nurses, such as those trained at the Frontier Nursing

Service in Eastern Kentucky, were vying for professional recognition.(S. L. Barney, 2000, p. 100)

Lay midwives in particular were under increasing pressure to become certified during this time. Some refused or chose to discontinue their practices entirely. Physicians, nurses, settlement workers—middleclass volunteers choosing to share culture and knowledge with low-income populations—and other middleclass women all aligned in opposition to the way midwifery was being practiced in Appalachia’s rural communities. They set out to gather evidence on the problems and risks with lay midwifery and advertised an “objective” and “tangible” alternative—licensed physicians—for the obstetric and maternal and child care that midwives had been providing.(S. L. Barney, 2000, p. 102)

Until the turn of the 20<sup>th</sup> century, midwives provided more than assistance during a delivery. They would often stay at the home and help with housework, cook, and do laundry for new mothers in addition to acting in a nursing role during the delivery.(Bickley, 1990) Oftentimes, midwives did not charge for their services—not only because their patients often lacked money, but also because their motivation was in caring for their communities rather than for remuneration. In addition, a new WV state health law in 1925 forbade payment for health services provided by unlicensed personnel.(Bickley, 1990) Middleclass women, who were often the wives of the rising numbers of doctors, lawyers, businessmen, and politicians, and settlement workers advocated and negotiated to convince rural and low-income communities about the value of the professional medical providers. These advocates gained ground despite the continued availability of traditional care by midwives and neighbors, which were also

often less expensive, more accessible, and more culturally accepted options due to being primarily female and known and respected in communities.(S. L. Barney, 2000, p. 102; Bickley, 1990) These shifts influenced who was considered motivated and trainable to provide necessary primary care services in rural and underserved areas.

Until and then again following the Great Depression years, coal production was on the rise in WV. The industry and the associated labor unions provided substantial amounts of primary care to mining communities, while the government did not have a strong role in providing clinical care during this time.(S. Barney, 1994) As coal declined into the 1930s, many private sector physicians were no longer providing services, and some communities struggled to access any medical care at all.(S. Barney, 1994)

*The New Deal: FERA, FSA, and WPA Programs:* During the 1930s and early 40s, the whole country was reeling from the Great Depression and then trying to figure out how to rebound. West Virginia received substantial resource inputs via the Federal Emergency Relief Agency (FERA), the Farm Security Administration (FSA), the Works Progress Administration (WPA), and high-level political attention during these years—particularly by Eleanor Roosevelt.(*New Deal Photographs of West Virginia*, 2012)

The New Deal programs and the accompanying media coverage of the massive effort “made it impossible for American Society to ignore the destitution that had been hidden for so long in the hollows of Appalachia.”(Grey, 1999, p. 34) FERA, one of the first New Deal programs aimed at decreasing unemployment rates, was established in 1933 and replaced by the WPA in 1935.(Trowbridge, 2016) The FSA and WPA provided both economic development programs and health services during the Depression Recovery Era. The FSA, a federal program, took a multisectoral approach to addressing

the economic and health challenges of rural populations. WV proved to be a challenge for these efforts due to its heterogeneous and difficult to access populations of industrial and commercial workers as well as subsistence farmers.(Cahill, 1998) This local variability reduced the envisioned impact of FSA programs on the populations served and foreshadowed the kind of lack of uniformity in program organization and impact that would be repeated in the following time periods.

During the implementation of the New Deal projects, aspects of medical intervention acquired federal mandates due to the economic context and unsuccessful non-governmental relief agencies working in the field in ways that had never been seen before.(Grey, 1999, p. 35) The Appalachian region, including WV, did not receive the same emphasis on medical programs during this time as other states such as Louisiana, Nebraska, and Texas did with large scale experimental health cooperatives and insurance scheme.(Grey, 1999) Some key areas for health care that assumed federal oversight based on the experience from New Deal medical programs included reimbursement rates for primary care providers and eligibility criteria for which populations should be able to access services under different federal programs.

A National Health Survey was conducted in 1935-1936 and led to a National Health Conference in 1939, revealing a number of major needs among the estimated 5-6 million Americans living with poor or very poor health—largely communicable diseases and disabilities—across the country.(Interdepartmental Committee to Coordinate Health and Welfare Activities, 1939) The researchers who conducted the survey identified overall declines in health since 1880. Many of these declines were particularly pronounced among poor communities—those receiving relief through the Federal

Emergency Relief Agency (FERA) and the WPA program. The health concerns focused on maternal, infant, and child health. The survey also showed that, nationally, populations were not equitably accessing health services by physicians, and that underserved populations—particularly rural and low-income—were receiving care instead from midwives, neighbors, and other “unskilled” workers.(Interdepartmental Committee to Coordinate Health and Welfare Activities, 1939, p. 7) The National Health Survey collected adequate data to disaggregate findings across various equity categories, such as income and ethnicity, and also identify who was in need and who was receiving various services. Inequities in terms of access to services, availability of workers to provide services, and health outcomes were identified: “Never before had it been so convincingly shown that in many areas and localities, those economic groups that are most in need of such preventative services and medical care are receiving far less of both than families with larger means.”(Interdepartmental Committee to Coordinate Health and Welfare Activities, 1939, p. 11) The economic argument of lost productivity was more central than any social mission to alleviate suffering or support underserved communities.(Interdepartmental Committee to Coordinate Health and Welfare Activities, 1939, p. 7) Ms. Josephine Roche, the coordinator of the conference report, stated at the national conference that, “every dollar spent on a soundly-planned and well-executed program will yield a national saving many times over in future years—a saving in human values and a saving in actual cash.”(Interdepartmental Committee to Coordinate Health and Welfare Activities, 1939, p. 14)

*Debate over who should provide health education:* Several programs designed to improve rural health under the FSA included health education strategies. For example, in

the mid 1930s in Cabell County, WV, a project to use school teachers as health educators was proposed. Concerns over the level of preparation and skill of the teachers that were to be used were debated between federal and state agencies, with the feds deferring to the state of WV to make an appropriate recommendation. A research project on whether nurses or teachers would be better health educators was proposed, which was rejected at the federal level with the argument that both could be most effective in their own spheres of practice.(Works Projects Administration)

In December 22, 1934, a thoughtful letter was written by Dr. C.E. Waller, Medical Director of FERA, to Mr. L.T. Bengtson, the State Planning Coordinator for WV Relief Administration, about whether teachers or nurses should be the ones providing health education. Dr. Waller wrote that, without proper training in both content and presentation, neither would be successful. He stressed that each could contribute within their particular sphere:(Works Projects Administration)

*I do not believe that many sanitarians or educators today would question a preference for teachers trained in health teaching for presenting health education in schools. On the other hand...the nurse's opportunity to gain entrance to the home and establish an intimate acquaintance with members of the household often is afforded by the need for professional services which she is especially prepared to render—the care of the sick, or demonstrations in the management of communicable diseases—services that a teacher would not be able to give.*

*Housekeeping Aide Controversy:* One of the wide-reaching and perhaps most impactful provisions of New Deal programs in terms of improving primary care provision and outcomes in rural and low-income communities was the Housekeeping Aide (HA) project, which was the CHW-type program that was developed during this time period. The HAs were community women serving in a “visiting housekeeping” role to help families care for ill, aged, or homebound family members on a temporary basis.(Swain,

1995) In the late 1930s and through 1940, the housekeeping aide project generated extensive discussion and some controversy over its quality and effectiveness.<sup>5</sup> Debates over the tasks and an appropriate scope of responsibilities for these workers were central to the discussion.(Works Projects Administration, 1935-1944b) On January 25, 1940, Mr. Joseph Alderson, WV State WPA Administrator, wrote a pointed notification to Mrs. Florence H. Wilkinson, the WV Director of Women's and Professional Projects stating, "In order that the project may be kept within its proper scope, we wish to remind you of the limits to which such activities may be carried. The items included under home care of the sick and pre-natal and post-natal care should be cleared with the State Department of Health and the work performed under the direction of a doctor or graduate registered nurse." No further description of the planned services and activities within each of the areas of health service provision was provided.

The perspectives of community members on the HA project were positive, at least according to available evidence. A mother living in a rural situation who received services from an HA wrote a letter to the WV WPA administration on Sept 25, 1942 stating that the aides were providing an invaluable service to the country. The perception of a number of the program beneficiaries was that the workers were "certainly well qualified."(Works Projects Administration, 1935-1944b)

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<sup>5</sup> The variety of the WPA projects being undertaken (ranging from Christmas toy making and repair, barberry plant eradication, nursing, school lunch and other nutrition programs, sewing, canning, book repair, projects for the blind, teaching crippled children, libraries, and other services) is astounding! It appears that many were started, and then they were cut off again, much to the disappointment of beneficiaries and the people working on them. All were driven by funding, and the memos in the NARA files mostly have to do with asking for more funding, addressing administrative questions and issues related to cost and continuation of financing.



On May 23, 1938 from Wheeling, WV Ms. Jeannett Lees Wilde wrote to Mr. Harry Hopkins, federal FERA director, about the HA project, of which she was a beneficiary, “It has been my experience as an invalid, to have two members of it [the project], taking care of me and seeing to my wants, etc. Those girls come to me and get my breakfast for me and will get my other meals as necessary. I have felt keenly the need of my letting you know of this, because of the wonderful thing is it proving to be.”(Works Projects Administration, 1935-1944a)

The focus of the HA was not medical, but focused more on providing a caring, clean, warm, ventilated, and quiet environment for the sick or disabled person, particularly if that person was the mother in the household, in order to allow them to rest and recover. The HAs were also encouraged to clean and feed sick and disabled persons in dignified ways to help them regain strength.(WPA, 1941, pp. 45-48) A memo from April 25, 1938 on the Housekeeping Aide Project made an effort to unpack the definitions and scope of practice of the housekeeping aides. The report proposed that the housekeeping aides could be “unskilled,” and workers could become eligible to be “field workers” and assist project supervisors with oversight of other aides after a year or two of successful service.(Works Projects Administration, 1935-1944a)

The HA’s manual, which was developed rather late in the WPA program, likely in response to state-level confusion and concerns from other health providers, outlined the personal attitudes and demeanor expected of an HA, and then provided detailed instructions on cleaning, doing laundry, preparing and serving meals, and safe storage of food. A very brief section described management of handicapped and sick persons in the home. This section primarily focused on what these aides should not be doing, which

included prescribing cures and remedies, giving injections, applying medicines in any form, or providing first-aid.(WPA, 1941)

*Frontier Nursing Service:* Frontier Nursing Service (FNS), based in Hyden in Eastern Kentucky, was one of the pioneer training programs for professional nurses in the region and it relied on the model of sending nurses on horseback into the mountains to educate and care for communities. Mary Breckenridge, the founder, worked hard to instill in FNS's vision for providing quality care to rural communities and in the nurses who provided the care the importance of building trust and social capital within each community.(Crosby, Wendel, Vanderpool, & Casey, 2012) Institutions like FNS that have endured over many decades are one way that certain kinds of sharing of best practices has occurred among organizations and from one generation of workers to another.

The FNS model relied initially on sending Appalachian women to Britain for training and recruiting trained British nurses to come to Appalachia as instructors.(Breckenridge, 1952) In addition to the focus on reaching rural Kentucky families with health services, FNS trained several WV nurses with the intention that they would be able to go back to their home state and both provide care and also facilitate the training of additional workers; no information about the direct impact of this training for WV has been identified.(Breckenridge, 1952) Based on FNS, an experimental nursing service was established in Wetzel County, WV in 1939 that included assigning a nurse-midwife to each end of the county, and then training and supporting them to carry out deliveries and other specific public health services for their end of the county.(Bickley, 1990) This new model lasted only four years before being discontinued due to the

challenge of nurse recruitment to the area and physician preferences to send patients to the local hospital.(Bickley, 1990)

*The Last Years of FSA/WPA and Looking Forward:* By the second half of the 1930s, some programs were already being downsized or considered for termination. This rapid reduction and evolution of New Deal programs illustrates the kind of short-term investment of resources to address a crisis and the challenges of sustaining components that work well and could produce continued outcomes over longer timeframes. Some local New Deal program administrators, like Ms. Marie Pell, the administrative nurse for the Relief Nursing Service in Tucker County, WV, fought back against budget cuts and program closures. On November 5, 1935, Ms. Pell wrote to First Lady Roosevelt that the nursing program she was in charge of needed to continue. Her simple reasoning was that “the nurses working in this county have families depending on them.”(Works Projects Administration, 1935-1944b). According to Nurse Pell’s report, the nurses were providing field visits for a number of health issues including prenatal care, delivery, and post-partum care, child health, school-based care, tuberculosis (TB) care, eye care (including blindness assessments) and other services including a relatively small amount of non-communicable disease care.(Works Projects Administration, 1935-1944b)

By 1938, major cost controls were being placed on FERA/WPA projects, particularly costs of personnel to work on the projects. These cost controls were part of a complex negotiation between the rising labor unions wanting better pay and more manageable work hours, business men pushing back against these demands, and pressure on the federal government to manage spending and the looming budget deficits.(“The New Deal,” 2016) The Wheeling, WV office of the United Federal Workers of America

condemned the forced reduction in man-year costs among the WPA professional projects. These projects were supposed to be cut from prior salary levels to a maximum of \$1,000 per person per year including personnel costs, materials, supplies, and equipment, which forced a number of projects, such as the nursing projects, to terminate within the year. The authors local chapter 102 of the United Federal Workers of America wrote that this mandate of work cost reduction would result in the demoralization of thousands of workers and undermine progress in providing health services to rural West Virginians.(Works Projects Administration, 1935-1944b)

*The shameful and indefensible waste of hundreds and thousands of dollars already spent on unfinished professional projects, the shifting of professional workers to menial and elementary clerical jobs, the substitution of worthless and useless projects of the leaf-raking variety, the lowering of standards of living, the wholesome and pronounced wage cuts, the violent blow to Trade Unionism and everything it stands for, and an indefensible contradiction of the Administration's social and economic philosophy.*

In the early 1940s, the Medical Care Cooperative Program (MCCP) efforts to provide effective health services to rural populations in the Appalachian region and beyond were underway. The goal of these efforts was to establish a model for a national health service for the US.(Grey, 1999) The model focused on primary care provision and linkages to dental care, nursing, access to basic drugs, and referrals to hospital care, specialists, and necessary health technologies.(Grey, 1999, pp. 110-111) Simultaneously, the coal industry provided professionalized primary medical care to a large part of WV's population, particularly in the southern coals fields. Until as late as the 1950s, miners paid a monthly fee for basic medical care.(Frazier & Brown, 1992) There is little evidence in the records of these programs that local communities played any significant role in their development, implementation, or evaluation.

*The Public Health System and Public Health Nursing:* The role of government during this period was focused on developing the Public Health System, which is still in place today. In 1933, a Public Health Council was formed (WV Senate Bill No. 149) with the mandate to oversee the promotion and protection of child health and mental health as well as to improve sanitation. Public Health Nurses (PHNs) were already actively providing services throughout the state, including school health, home visits, tuberculosis treatment, and industrial and policy-oriented work.(WV State Health Department, 1928) A 1938 State Health Department report declared that Public Health Nursing's greatest challenge was filling the needed positions, a process which often required identifying hospital nurses and paying for the necessary additional training as public health nurses using public funds.(WV State Health Department, 1938)

World War II had a devastating effect on the public health nursing workforce in WV; of the 50 nurses who left the workforce during 1942-44, half were taken into the war effort. Some of these vacant positions were filled with other nurses, but these individuals often had limited experience and wanted additional education.(WV State Health Department, 1944) Communities adapted by picking up the slack left by the departure of these nurses, who had often been the most accessible primary care provider in rural and low-income communities, by relying on neighbors and anyone with knowledge of health issues who remained.

*Lessons and Summary of the Time Period:* In the years after the New Deal, a number of the WPA/FERA projects were discontinued as program funding ended. Other projects morphed into new structures and funding models. Many of the institutions that were formed at that time, including schools set up by the settlement workers as well the

Frontier Nursing Service, have been sustained until the present day. Progress in sanitation and public health has also been sustained and built upon in the following corporate-dominated era.

The programs created during the New Deal provide several lessons related to encouraging community participation with the primary care system. First, the increase in professional and trained workers, including primary care physicians and nurses, took place along with increased federal oversight and regulation. This may have improved quality, consistency, and effectiveness of primary care services, but it also devalued and overrode existing community health resources including the role of midwifery and also of neighbor women helping each other during childbirth and during other illnesses. These midwives and neighbor women, who often did much more than provide needed clinical care, were largely left out of the federally mandated programs or were actively marginalized.

Along with oversight and regulation came the need for additional evidence on the primary care service needs and who was benefitting from the available services. Findings from early surveys showed the differential between rural and urban populations as well as across income categories. Finally, segments of communities played an active role in advocating for and against these shifts, but they did not speak with a unified voice. Middleclass women spoke in favor of the professionalization of medicine while low-income families, in the limited documentation that is available, spoke in appreciation of the basic help they were able to receive from their peers.

## **The Coal Boom and Corporate Health Services: The 1950s**

Following World War II, the 1950s brought an era of reinvention of American life and rapid social change in Appalachia. Emerging victorious from the war and entering a time of economic productivity and technological advancement, US health care provision and financing underwent substantial evolutions.(LaBar, 2008; Stevens, 1996) Described by some as “American medicine’s golden age,” the 1950s were a compressed period of global “conquest” of infectious diseases, advances in hospital and medical technological advancement, and changes in health financing.(Stevens, 1996, p. 15) These changes were driven by the dramatic rise of the pharmaceutical and for-profit hospital industry, and corporate and governmental pressures to prioritize curative care over preventive services and push back against labor union demands for greater attention to long-term occupational hazards.(LaBar, 2008; Robinson, 1991; Stevens, 1996)

Primary care services lacked a strong “base” upon which a package of services—including chronic conditions, health education, and coordination and organization of care—could be built. An avoidance of the need for such a package was then institutionalized by the passage of Medicare and Medicaid in the 1960s which focused on providing curative services for a fee to defined populations.(Stevens, 1996) Finally, at a national level, these shifts did not benefit everyone equally—despite pressures to expand the economy for the benefit of all and put in place insurance schemes oriented towards certain vulnerable groups. There remained “another America” of 40-50 million people who were mostly poor, remained without adequate health services, and lived under the radar of the majority of health planners and the general public.(Stevens, 1996, p. 13)

The Appalachian region, which has long constituted a significant portion of the US's low income people, was under intense pressure to perform economically in the post-World War II years; its young people became aware of rising comfort levels and quality of life in American society and were looking for opportunities to participate in that lifestyle.(Photiadis, circa 1970) Family size in Appalachia decreased during this time, partly due to popular recognition that family resources could be concentrated in order to provide better opportunities for fewer children.(Photiadis, circa 1970, p. 10) During this time, family structures changed as well, due to migration of working age individuals and new systems of support for the ill and elderly. Further, the social stratification was changing, with families coming from “old money” having to reinvent their place in the world and share social spaces and roles they alone had occupied with an expanding middleclass.(Photiadis, circa 1970, p. 11) These demographic and social shifts had profound long-term impacts on local capacity for motivated health workers and volunteers and ability to engage with the primary care system—all of which are being felt at the local level today as will be described in the two county case studies.

The coal industry as well as steel, glass, textile, and electric power production were booming in WV the 1950s.(Rice & Brown, 2014) This would change quickly, though, as other countries were also developing their economies, and technologies were rapidly evolving to change the way coal was mined. These factors made the economic boom in WV short-lived and resulted in mass emigration of unemployed miners who were not trained for the few higher tech jobs that emerged to replace the manual labor that they had been doing.(Rice & Brown, 2014)



During this period, the private sector—and especially the coal industry—took on a larger role in the provision of primary health care in the region. Coal companies hired “coal camp doctors” who provided self-proclaimed “patient centered care” to miners which was often a series of basic health services focused on maternal and child health.(S. Barney, 1996) The existence of company-run primary care services also offered new avenues of practice for entrepreneurial physicians providing fee-for-service care.(S. Barney, 1996)

In 1959, Robert C. Byrd became a US Senator from WV and served as such until 2010 when he died at the age of 92. During those years, he dedicated himself to developing WV’s infrastructure, including championing a state highway system and negotiating for other major investments in health and education infrastructure.(Citizens Against Government Waste, 2006) As a member of the US Senate Appropriations Committee, Byrd was nicknamed “King of Pork,” a title making fun of the large amount of money that he was able to steer towards WV and the Appalachian region during his tenure in the US Congress.(Citizens Against Government Waste, 2006) A large number of projects, including highways, medical centers, industrial complexes, and schools have been named after Byrd. Some people argue that this legacy and his efforts to raise the profile of WV in the national agenda have had a larger impact on economic growth and improvements in education and health than the direct infrastructure improvements have had.(Hagen, 2007) These investments were an example of how funding—even when sustained over time—had limited impact due to what it could be used and how efficiently the funds were managed.

The WV experience “came alive” to the rest of the nation in 1960 when then Senator John F. Kennedy was campaigning for President.(Long time rural health scholar and educator, 2016) He won in WV after campaigning heavily in the region, including visits to many rural communities.(Fleming, 1992) The Appalachian region gained special recognition during this time, which resulted in efforts to promote healthcare infrastructure and economic development. These efforts, by painting the region in need of help, reinforced cultural stereotypes about West Virginians as “uneducated and unrefined” people.(M. Walker, 2013)

In the course of this research, no oral history respondents who remembered or had additional documentation from this era were identified, and the researcher could find very little archival material related to the community and primary care system interface during this time. In alignment with the dominant philosophy of the time, it is likely that industrial monies and communities’ internal economic means were expected to allow for the purchase of necessary primary care services. This system worked as long as individuals had jobs that included health care benefits or had their own resources to pay out of pocket for what they needed. No entity was systematically looking out for those individuals who did not.

The State Department of Health instituted a number of key interventions during this time, including water fluoridation in nearly 40 cities and towns around the state by 1954.(WV Public Health Association, 2015) Other advancements included instituting a series of awards and recognition for individuals and localities in public services, and also holding a number of conferences and producing publications commemorating the history

of public health and reflecting on the events of World War II.(WV Public Health Association, 2015)

In summary, the decade of the 1950s was a time of economic growth and federal investment in infrastructure. Some technological advancements for health, as well as symbolic commemoration of the past and establishment of formal (and political) pathways to recognize good work, were the major memorials to this time. Because of the economic boom—particularly in the coalfields—many people had more resources with which to purchase primary care services that they needed. Limited evidence of community health efforts from this time period was identified. This dearth of documentation is likely due to the corporate actors that were involved in an industry that was under decline by the end of the decade, and to the lack of major federal, state, or academic involvement in primary care at this time.

### **The Age of Medicare and Medicaid and the “War on Poverty:” The 1960s and 70s**

This section describes major efforts to develop the community and primary care interface between 1960 and 1979. During these years, major federal programs were created including the Appalachia Regional Commission, Medicare and Medicaid, and the National Health Service Corps. Other federal initiatives such as the Office for Economic Opportunity and the War on Poverty, brought extensive resources as well as large number of people from other places to the state and region to address primary care and related development issues. The health-related vision of the War on Poverty was for communities to take over from the services that the coal industry and other industrial actors had provided until the 1950s. During the War on Poverty, the experience with managing and supporting—or dismantling—social movements grew. Policy reforms as

well as new programs, such as the Black Lung Program, brought additional primary care services to populations in need. Initiatives for community engagement with and control of health centers, Local Health Departments, and other primary care programs matured and became institutionalized. A number of political efforts to invest in primary care and public engagement as well as plan for the future also took place.

*Medicare and Medicaid:* The passage of Public Law 89-97 in 1965 established Medicare and Medicaid.(US Congress, 1965) The Medicaid system was created as a national health insurance program offered to states as an optional insurance plan for low-income persons, while Medicare was a social insurance program focused on caring for the elderly population.(US Congress, 1965) Over the fifty plus years since Medicare and Medicaid were established, however, the region has witnessed a degradation in health status including life expectancy and rates of chronic disease.("Appalachia: The Fifty Years War," 2015; CREC & WVU, 2015)

*The Appalachian Regional Commission (ARC):* The Appalachian Regional Commission (ARC) was created in 1965 through the Appalachian Regional Development Act.(Speer, 2010) This federal policy and its associated funding initiatives led to substantial investment in infrastructure and social support services—including health—in the Appalachian region. The ARC added its primary care component in the early 1970s, but had developed demonstration sites that combined primary care with public health, sanitation, and environmental health leading up to that point. In the late 1960s, the OH-9 program in southern WV initiated by Governor Hulett Smith was a flagship demonstration site.(Former health project developer and former state health administrator, 2015) The OH-9 program included a mobile health unit, staffed by medical

teams of “doctors, nurses, technicians, and other clinic personnel,” to provide “modern examination facilities” at nearly 50 sites across all nine WV counties in the project in an unprecedented effort at coordination and sharing of best practices within teams of providers and across communities.(Flanigan, 1998) The project included substantial infrastructure development and focused on providing clinical services, staff members describing the effort focused on the importance of workers who “really care about what happens in the lives of the patients they encounter.”(Flanigan, 1998) The efforts of the primary care workers often went beyond providing the required medical services to include patient advocacy, connecting patients to other community resources, and sometimes stepping in to provide other services such as transportation, housing, or childcare if these were barriers to patients accessing needed healthcare.(Flanigan, 1998)

The ARC funded the start up and the first year of operational expenses for a number of community health centers. The funding allowed for some key aspects that were different from what the focus of primary care had been until that point. As a former health project developer reflected, “They had funding for a different staffing model. They had a much more multi-disciplinary approach, and funding really for outreach and social services. I think that was the really big difference that I saw.”(Former health project developer and former state health administrator, 2015) Today, the ARC and other programs that have invested in Appalachian infrastructure and welfare programs have helped narrow the income gap between Appalachia and the rest of the US.(“Appalachia: The Fifty Years War,” 2015; CREC & WVU, 2015)

*The War on Poverty:* The ARC took a fairly traditional approach to investing in Appalachia, mostly in the form of infrastructure such as highways and partnering with

state and local agencies. Alternatively, the “War on Poverty,” which was established in 1964 and coordinated through the Office of Economic Opportunity (OEO), and required the “maximum feasible participation” of community members. This participation included leadership by the poor, to the extent possible, to implement social programs ranging from reforms of the political system to improvements in local educational offerings.(Williams, 2001) The OEO, as part of it’s Comprehensive Neighborhood Health Services Program (Office of Economic Opportunity, Health Services Office, & Community Action Program, 1968), mandated that health outreach services be made available in low-income neighborhoods. These services were often provided by community “health aides” who received specific training to provide screening, health education, and referral services, including to the elderly.(M. N. Hill, Bone, & Butz, 1996)

The OEO also sought to bring young activists into the region through the Appalachian Volunteers (AV) Program, which later became the Volunteers in Service to America (VISTA) program. These activists were tasked with raising awareness, particularly among low income segments of communities, of individual’s rights, the region’s needs, and the avenues available to improving individual and community situations.(Williams, 2001, pp. 192-193) Hundreds of volunteers came to the region, largely from middleclass backgrounds in other parts of the country, to “save” Appalachia.(Glen, 1988) The volunteers repaired school buildings, improved roads, and established community centers by working to engage and empower community members to participate. While the idea of maximum feasible participation was noble, it soon left volunteers and communities frustrated and disillusioned about the national political motives behind the effort, as well as about local corruption’s strong negative influence on

the process.(Glen, 1989) This local corruption often took the form of wealthy and politically-connected minorities who had held control of land, funds, communication channels with state politicians, and other resources attempting to take control of EOE funding or of the agenda for projects for which it would be used. There is evidence from Mingo County in particular of the struggles, strife, and overt stand-offs between factions of the community who wanted to retain or gain control over both the local OEO program and, by extension, the leadership of the county as a whole.(Huey Perry, 2011)

After a period of time of exploration and unpacking of the complex issues and dynamics at play in the region, reports from just a few years into the program (1965-66) document progress as well as the consensus that “solutions seem much further away.”(Glen, 1989, p. 45) By 1967, many AVs were re-organizing to focus their efforts on rallying the public, particularly poor people, to stand against strip mining, and to demand representation in various agencies controlled by private sector and political leaders. The AV’s approach alienated many local people who viewed AVs as “long-haired outsiders who looked and talked different,” and often exhibited what was perceived as poor judgment or lack of communication with stakeholders other than “the poor” whom they had come to help.(Glen, 1989, pp. 50-51) Although, due to mounting political pressure, the objectives and profile of the AVs diminished over time, many of the original volunteers remained in the region and have continued to carry out life-long organizing, advocacy, and development efforts.(Glen, 1988)

In the wake of the early Medicare and Medicaid efforts and the War on Poverty, a report prepared by the WV Governor’s Office in 1973 advocated for synthesis and institutionalization of some of the progress and learnings of the many “demonstration”

efforts of the prior decade.(*Considerations for a Health Service Delivery System in Rural Areas of West Virginia*, 1973) The report specifically recommended the expansion of health education efforts on topics such as “prevention of common diseases, the cause, effect, and treatment of various types of diseases, the health values of personal hygiene, and the health value of good nutrition;” it also recommended types of training for citizens, paramedics, ambulance drivers, and “other nonprofessional and semiprofessional medical personnel.”(*Considerations for a Health Service Delivery System in Rural Areas of West Virginia*, 1973, p. 4) The report concluded with several additional recommendations about creating and supporting not only local teams of primary care workers, but also using regional collaborations to ensure effective referral processes and data-sharing for continuity of care.(*Considerations for a Health Service Delivery System in Rural Areas of West Virginia*, 1973, p. 7)

*The Black Lung Act:* Occupational health has long been a major primary care issue in WV, including injuries and work-induced diseases. Significant resources have been allocated to address symptoms of occupation-related diseases like Black Lung and also the policy and awareness issues that allowed the extent and etiology of the problem to be largely covered up for many years. These resources have also become an opportunity for the primary care system to set up packages of services—including black lung programs—using those funds as will be described further.

Black Lung is the name given to Silicosis disease, which is caused by the inhalation of coal dust over time coating the insides of the lungs and turning them black. Black Lung caused many deaths among miners until more recent reform efforts began to implement measures to better protect and treat workers.(Morman, 2000) Despite



knowledge of the harmful impacts of coal dust inhalation at least as far back as 1900, health care providers—largely operating under economic and political pressures—hid or waved aside these findings and focused on elevating other scientific expertise in order to reassure patients. The tide turned around this perspective only under social pressure in the 1960s when a push for compensation for victims of Black Lung included the efforts of many physicians working on behalf of the affected miners.(Morman, 2000) Black lung treatment fell to the primary care system, and motivated substantial community advocacy and engagement to champion the necessary policies and then help put them into practice.

A tipping point for the passage of the Federal Mine Safety Bill in 1969 was the Farmington #9 mine disaster near Mannington, WV on November 20, 1968 that killed 78 people. President Nixon had been stalling on signing the bill because of the perceived high costs of implementation—which were anticipated to be \$300 million per year from the Federal Government according to news reports aired by NBC-TV on December 26th and 30th, 1969.(NBC-TV, 1969) Included in the Federal Mine Safety Bill was The Black Lung Act, which provided for miners with symptoms of silicosis, or Black Lung Disease, with options to receive testing and appropriate treatment and financial compensation.

In the months prior to the passage of the Bill, a number of speeches and reports were delivered to the Subcommittee on Labor within the Senate Committee on Labor and Public Welfare. One delivered on March 14, 1969 by Dr. Lorin Kerr, the Director of the newly established UMWA Department of Occupational Health, decried the role of the medical establishment in dismissing, downplaying, and incompletely documenting the effects on coal mining workers' health; these speeches ultimately led the UMWA to advocate for further protections. Dr. Kerr quoted Mr. W.A. “Tony” Boyle, President of

the UMWA saying, “In the absence of the Fund and the Union none of these achievements would have been possible. Working together with all other interested groups, it is possible today to record an impressive development little known to those outside the coal industry. Despite this record, of which we are justly proud, much remains to be done.”(Kerr, 1969, p. 13)

In June 1970, a conference on the Black Lung Act was held in Washington, DC. The conference report argued that the “American industrial plants represent a ‘natural point of first contact’ with the health care system for the employed population” and that a “health [center] at the workplace would have a very high potential for being used as a multipurpose primary care center for emphasizing health promotion and preventive medicine. There would be opportunities for using new health technologies and for the creation of new health careers for paraprofessionals.”(United Mine Workers of America, 1970) Further, such centers could serve as stable referral and payment entities that could anchor the rest of the health system in communities.(United Mine Workers of America, 1970, p. 287) The report recommended the use of more “categories of allied health professional workers”(United Mine Workers of America, 1970, p. 89) though it also recognized immediately the challenges that this might result in “more malpractice problems, with the courts making the determination of what constitutes quality medical care.” Finally, the report philosophized about the need to consider not only a system that would work for coal miners, but one that would also work for all people. The report suggested “could we not, through Federal leadership and through the participation of responsible local officials qualified in the fields of health and medical care, devise a pluralistic approach to solve our medical problems wherever they appear by whatever

reasonable means it takes to solve them?”(United Mine Workers of America, 1970, p. 295)

The authors of the report summed up their view suggesting the lack of attention to preventive services could be attributed to:(United Mine Workers of America, 1970, p. 300)

*An amazing double standard of scientific proof in this nation...even when the efficacy of a suggested therapy is not yet well proved, we are quite willing to try it in the treatment of symptomatic disease, because it is all we have, and the patient demands care. In the case of preventive medicine, we follow the opposite policy. We do not employ a preventive technique until it has been completely proved, because we must not risk creating a demand for it if none yet exists, unless we are absolutely certain that it is entirely effective.*

In 1972, President Nixon added his concerns about the lack of accountability and responsibility by the owners and operators of coal mines for the burden of Black Lung.(Nixon, 1972) He wrote:

*There are too many victims of the dreaded disease for me not to have acted. Therefore, I have moved to pick up the responsibility that others [states and the coal industry] have neglected—so that disabled miners and their families will not be deserted by our society in their hour of critical and justified personal need.*

Progress continued to be made on certain fronts. On March 24, 1972, Dr. Lorin Kerr wrote a memorandum to Tony Boyle alerting him to recently added requirements to provide preventive health services to miners.(Kerr, 1972) This last memo in a series of correspondence discussed the requirements of a renewed wage agreement to provide health education and regularly administer a questionnaire to miners via local mine health and safety committees. The accountability of the new requirement, which had been put in place in 1971, was a clause specifying that, if health education requirements were not met, the wage agreement for the worker would be violated as well. Thus, miners gained

stronger and more consistent legal backing to ask for and receive promised services and information. Kerr wrote, “This is the first time to the best of my knowledge that any wage agreement has incorporated a Federal Health and Safety Act within the contract and thus made the act doubly binding on both the union and management.”(Kerr, 1972) The local mine Health and Safety Committees were to receive initial training and then remain in regular contact. Finally, Dr. Kerr noted, “It is impossible for the Department to implement any portion of this new program in the absence of additional personnel.”(Kerr, 1972) He suggested several additional high level positions to help manage the effort, with the understanding that additional local personnel would also be necessary. No discussion of specific competencies nor qualifications were described, nor was it outlined how these workers would interface with the miners that the effort was intended to serve.

According to a physician who worked with the Black Lung clinics as both a clinician and as one of the leaders and visionaries for how the program could be successful,(Clinician and leader in Black Lung program, 2016) the Black Lung program put forward fairly general requests for proposals to clinics interested in providing services to miners. Several of the early community clinics, including the Cabin Creek Clinic at Dawes, WV, were able to “shoehorn” their existing model of community-engaged care using local workers to provide outreach into the Black Lung funding requests. As the number of clinics providing Black Lung services grew, a biannual gathering called the Appalachian Health Providers was organized and held at the Highlander Center in Tennessee. It served as a platform for cross-pollination of ideas, as well as mentoring and encouragement for the many frontline workers who included many community members. The physician interviewed for this study noted that, “Cabin Creek wasn’t unique, at least

a few years later.” As the program evolved, a complex process of changes, learning, and mergers driven by external factors, including the national perceptions of the War on Poverty, the rise of community health centers, and community-based approaches took place. It now appears “impossible to tease apart the many factors and determine any kind of causality”(Clinician and leader in Black Lung program, 2016) between whether the Black Lung program mandated outreach to communities or whether health centers made it standard by consistently writing it into their funding proposals.

*Shifts in the composition and compensation of primary care workers:* Salaries for physicians at state health institutions, which ranged from \$7,500-\$10,000 per year plus benefits at that time, made it a lucrative market to foreign-born primary care workers, some of whom had not met the residency and professional requirements to become licensed for private practice elsewhere in the USA.(WV Dept. of Commerce & Office of Research and Development at WVU, 1966, p. 3) The main causes for the shortage of interest and commitment to the primary care profession across all cadres were low salaries, poor working conditions, and remote living situations that were often less desirable than the growing urban centers within a few hours’ drive away from home.(WV Dept. of Commerce & Office of Research and Development at WVU, 1966, p. 4)

In addition to physicians, other cadres of workers were also being attracted from abroad, and the report noted that their training was “not always adequate.” For RNs, the demand in WV was high while training programs at hospitals were being shut down due to lack of applicants. Hospitals were “being operated in some cases with only one RN on duty during each shift.”(WV Dept. of Commerce & Office of Research and Development at WVU, 1966, p. 4) Despite the challenge of recruiting nurses, the 124 public health

nurses in the state conducted 90,000 visits to families from 1961-1965.(State of WV, 1962-63) The work of public health nurses was on the rise as well during this time period, and the care that they were providing was already shifting substantially from infectious diseases care to chronic conditions. A mobile clinic providing “medical examinations, mass inoculations, health surveys, as well as general and child health clinics” was used extensively in rural and “depressed” communities in WV to help improve access to basic health knowledge and medical services.(Hardman, 1962, p. 12)

*Public Sector Policy and Planning Efforts:* Issues related to retention of primary care workers in rural communities and an aging workforce seemed to be a prominent concern 50 years ago and still are today. In a 1966 report, the WV Department of Commerce and the Office of Research and Development at WVU described the status of health service delivery in WV.(WV Dept. of Commerce & Office of Research and Development at WVU, 1966) The report noted that health personnel, perhaps more than other sectors, often required, “a high level of skill and in more cases serious dedication to purpose.”(WV Dept. of Commerce & Office of Research and Development at WVU, 1966, p. 2) Physicians were discussed first, and the report noted that not only was there a low physician-to-population ratio in WV, but also that the physicians were aging. The WVU medical center was new at the time, and was a source of hope for the development of the next generation of primary care workers. The authors of the report noted that many of the physicians practicing in the state came into WV or began their practice during the 1940s when the coal and other industries “encouraged the recruitment of physicians to the more remote sections of the State, as well as to the urban areas.”(WV Dept. of Commerce & Office of Research and Development at WVU, 1966, p. 3) Without

continued recruitment and incentives to stay in WV, the next generation of physicians would not automatically continue to be in place.

During the 1960s and 70s, many of WV's other health-related programs were centralized under the State Board of Health. These included preventive medical services, health mobilization, public health education, public health nursing, as well as several specific programs, such as nutrition programs, which also focused on offering outreach and educational services.(WV Dept. of Commerce & Office of Research and Development at WVU, 1966, p. 12) In addition, the Department of Mental Health offered community services, which were intended to deliver regional services in five or six "major metropolitan areas" of WV through the Federal Community Health Centers Act.(WV Dept. of Commerce & Office of Research and Development at WVU, 1966, p. 15) The 1966 report concluded by saying, "As can readily be seen, the programming efforts for health services in WV have largely been rather disjointed. There has been a lack of coordination and communication among responsible personnel and components in the health system. Planning, as in other areas, has been sporadic and lacking in comprehensiveness."(WV Dept. of Commerce & Office of Research and Development at WVU, 1966, p. 17)

Governor William Wallace Barron's administration from 1961-1965 began several major initiatives including the WV Clean Project, which focused on cleaning up roadways, dealing with water and sewer issues, and addressing other dirty or abandoned aspects of the environment.(Hardman, 1962) A "Flame of Pride" was erected in the capitol city of Charleston as a symbolic effort to mobilize communities to take pride in their state and communities and work towards building cleaner and healthier living places

which could be lucrative draws for tourism and other economic opportunities. The program created jobs for people to support local and state-level clean-up efforts. The Barron administration also had substantial vocational training programs, which made practical nursing a priority. The objectives of the vocational training programs were to decrease unemployment, improve the economy, and improve services in sectors such as the health and industrial capacity of communities around the state.(Hardman, 1962, p. 10)

*The National Health Service Corps:* Beginning in the late 1950s, new providers were brought into rural communities across the state through programs such as the National Health Service Corps (NHSC).(D E Pathman, 1992) The NHSC produced smaller than desired returns on investment in terms of physician retention after the completion of the service requirements, and was determined not to be a long-term solution to the physician shortage.(Former health project developer and former state health administrator, 2015) An interesting wrinkle in that story, however, is the list of distinguished NHSC physicians who, while they did not stay solely as primary care providers in rural communities, did serve in key health-related leadership positions at the state level. These positions included State Health Commissioner, President of the WV Board of Medicine, and important highly visible faculty posts and policy-making positions around the state.(Tyler, 1997)

Support for the NHSC has varied over the years, partly due to difference in opinion among leaders about how much was a reasonable amount to invest. On July 31, 1975, US Senator from WV, Jennings Randolph, gave a speech to a panel of WV leaders. In this presentation, he decried a presidential veto for a Health Service and Nurse Training Act and the lack of federal support for the NHSC—which was \$30 million for



1976—Randolph said the US President considered this “excessive” and which he termed “meager.”(Randolph, 1975)

In 1976, a report from the Governor’s Health Task Force reviewed progress on the development and statewide as well as community adoptions of national standards—particularly for licensed practical nurses, pharmacists, and dentists. Improvements and related considerations were raised concerning the provision of additional avenues for entry into a variety of health professions, such as options for veterans with relevant backgrounds to take licensure examinations without completing an entire course of study first. Due to the rapidly expanding and changing knowledge base and protocols, concerns about one-time certification or licensure without continuing education or periodic testing on core competencies—something newly incorporated into the physician professional requirements—were raised as an emerging consideration requiring further study and action.(*The Governor's Health Policy Task Force Report, 1976*)

Following the identification of these problems were the reports’ recommendations for sustained provision of “technical services” to communities to aid in health manpower recruitment.(*The Governor's Health Policy Task Force Report, 1976, p. 14*) The report also recommended that, in order to utilize different cadres of workers to their optimal capacity, payers of health services should consider accepting new or expanded “schedules of individual charges for services by a variety of health workers including physician assistants and nurse clinicians.”(*The Governor's Health Policy Task Force Report, 1976, p. 41*)

*The Creation of the Nurse Practitioner and Physician Assistant Professions: The* Nurse Practitioner (NP) profession was established in the US in the mid-sixties. The

curriculum and the motivation for developing this new cadre reflected population needs identified through a series of surveys.(WVU Medical Center Charleston Division, 1977) The NP concept took off rapidly, and many NP training programs targeted at different medical specializations developed even before the initial 5-year pilot program and evaluation could be completed. A key reflection on the introduction of nurse practitioners was that, “most people (physicians, nurses, consumers) need experience with nurse practitioners to gain confidence in and enthusiasm for the new role.”(WVU Medical Center Charleston Division, 1977) In addition, the role of NPs emphasizing health maintenance and behavior change could be practically and philosophically framed as a role complimentary to those of other health professionals. The appropriate use of NPs (and other allied and supporting roles in communities) was originally envisioned to increase the efficiency and impact of the services provided by physicians and other established health professions.

In 1980, the WV Board of Registered Professional Nursing’s Annual Report included a formal introduction of the role of the Advanced Nurse Practitioner (ANP).(State of WV, 1980) This role was designed to provide primary care to communities within a variety of settings including homes, schools, and private practices. In addition, the report described the results of an early longitudinal study of ANPs across the nation. ANPs were overwhelmingly providing services to the lowest income communities, and, though ANP programs had been underway for several years, most ANPs are still the first and only ANP in their practice setting. Employers of ANPs reported being “almost universally satisfied” with the quality of care as well as with access to care among disadvantaged persons. 93% of employers considered ANPs to be

cost beneficial. Patient acceptance of the ANP role was also reported to be high.

Employers and ANPs perceived barriers to the employment of ANPS differently, though both actor frequently cited legal restrictions, space limitations, and resistance from other health care providers. ANPs also reported dissatisfaction with pay levels and benefits as well as the proportion of time spent on nonprofessional tasks.(State of WV, 1980)

The Physician Assistant (PA) profession was also established in the 1960s, and gained recognition and “maturation” as a medical profession in the 1970s.(Henry B. Perry & Breitner, 1982) The PA profession was intended to extend the role of physicians in managing patient conditions in order to address physician shortages—particularly for rural, low-income, and minority populations.(Mittman, Cawley, & Fenn, 2002; Henry B. Perry & Breitner, 1982) PAs were defined as, “ a clinically trained professional capable of expanding the services offered to patients by physicians in both primary care and hospital settings.”(*Alternatives in Health Care Delivery: Emerging Roles for Physician Assistants*, 1984, p. 4)

From the beginning, PAs have been primarily facility-based, with workplaces ranging from hospitals to community-based clinics to industrial settings. Their training has evolved from an early set of unstandardized two-year curriculum focused on gaining basic clinical experience to a series of advanced degree programs—including many specializations—as well as certification and licensure procedures.(Henry B. Perry & Breitner, 1982) Some physicians who supervised early PAs and who were accountable for the services these new professionals provided opposed the efforts to bring oversight by state Boards of Medicine and consistent qualification requirements to the new profession. The advantages of being able to disperse the responsibility for training and

assurance of quality of the PAs as well as being able to innumerate and track PAs, however, led to increasing support for licensure and state-level oversight.(Henry B. Perry & Breitner, 1982) In 1991, Alderson-Broaddus College in Philippi, WV, launched the first Master's Degree program for PAs in the US.(Rural Health Partnership Task Force, 1991)

PAs were fairly easily integrated into the health workforce, and were accepted by physicians, other health professionals, and patients. They were less expensive than physicians, in terms of training costs as well as salaries.(Henry B. Perry & Breitner, 1982) Today, PAs function as semi-autonomous clinicians who can examine, diagnose, and treat patients including writing proscriptions. They work together in teams with physicians and other health professionals and often staff rural satellite clinics, provide on-call services, and see patients in academic teaching centers and other facilities.(Mittman et al., 2002)

Compared with NPs, PAs have had a high proportion of male workers, and they have tended work more hours per week and see more patients.(Henry B. Perry & Breitner, 1982) At the same time, PAs and NPs have served an overlapping but different patient population with diverse needs. NPs tend to see more complicated patients, be based in outpatient facilities or other primary care agencies providing a range of services—often including preventive care and health education—and to spend more time with each of their patients.(Henry B. Perry & Breitner, 1982)

*Evolutions in the public health system:* West Virginia's public health system has evolved since its establishment, with a major shift being from a state-level health department to county-level health departments in the 1970s.(Bundy, 2015; Former WV

Bureau for Public Health worker, 2016) Under the structure from the 70s, each county has a locally-elected Board of Health to oversee the functions and finances of the local health department.(WV Legislature, 2014a) County health departments are required to provide health promotion services. Specific required activities include assessing community needs and mobilizing the community to address these, protecting the quality of the water, air, food, and facilities, and responding to and working to prevent communicable disease outbreaks through surveillance, vaccinations, and investigations.(WV Legislature, 2014a) In addition to these mandates, local health departments also provide a range of other services, which have evolved substantially in recent decades; services commonly provided by health departments include family planning, breast and cervical cancer screening programs, sexually transmitted disease testing, diabetes testing and management, lead poisoning testing, and tobacco cessation programs.(State of WV, 2016)

*Lessons and summary of the time period:* The 1960s and 70s brought a massive influx of external resources, in the form of both primary care and other professionals as well as funding. Financial support was provided by Medicare, Medicaid, the ARC, and the NHSC, all of which continues in some form today. Human resources included the AVs, NHSC physicians, and other primary care providers, many of whom went on to hold leadership roles and commit their careers and lives to working in WV or the Appalachian region. Along with these human and financial resources came a number of new ideas as well as mandates for the process of allocating and expected outcomes of those resources. During this period, community involvement in primary care and in development efforts—across sectors from education to local economic stability—was at

an all time high. Many of the responsibilities taken on by communities in collaboration with health centers and health departments fell within a generalized CHW job description. Community involvement, however, was not consistently well supported and was often led by external experts including the AVs and physicians. In order to facilitate learning and coordination among the many projects being developed, several fora for periodic discussion and sharing of experiences among stakeholders were created. While some of these have evolved, others have ceased or have been replaced; this was the first time that such scale and depth of networking and discussion had taken place.

Several political efforts to increase public motivation and engagement were instigated, including Governor Barron's "Flame of Pride." Frequent examples of local corruption and defense of deeply engrained processes and ways of holding power in the public sector put a damper on some of the community engagement (the Mingo County case study in Chapter VIII describes a local in-depth example), particularly among low-income and rural populations. Finally, limited accountability of corporations, particularly the coal industry, about the wellbeing of workers and the communities in which they lived created gaps in care and emphasized the need for sustainable investments of resources from the federal level which came in the form of the Black Lung program and others.

### **Community Health Centers and Building Modern Primary Care: The 1980s and 90s**

In the wake of the War on Poverty Era, the Appalachian region came under increasing media scrutiny, and was poised to either continue to develop and improve using the experience of the preceding two decades, or to spiral into confusion and chaos.

As it turned out, some of both would happen in the years between 1980 and the end of the century.

The public sector in WV assumed a much stronger role in health care during this time. The philosophy of political leaders focused on spending all available monies as quickly as possible, and not focusing much on underlying issues or questions of sustainability. Major investments by the state as well as federal and private monies made this approach possible. At the state level, the government went through major structural reforms, resulting in demoting the focus of health in the larger political landscape. Despite this, a number of leaders were able to harness state funds to match several private grant-funded programs aimed at formalizing and strengthening the primary care system and workforce. All these grants included community engagement in planning for local health priorities as well as for educating student physicians, nurses and other primary care cadres during rural rotations.

During this period, the local infrastructure and processes for providing primary care were formalized through a growing network of community health centers. Although programs such as Maternal Infant Health Outreach Worker (MIHOW), Right From the Start, and others were re-vamped, home visitation was already an effective and long-standing practice the reach rural and low-income communities.

*Economic and political shifts:* The entire US was struggling economically in the late 1970s and into the 1980s. Having lost substantial economic activity and population due to the decrease in coal production and emigration of many working age persons in search of better jobs, West Virginia was no exception.(Rice & Brown, 2014) Decreases in coal production were due to a number of factors including increased environmental

regulations on the coal industry and decreases in easily accessible coal reserves.(Rice & Brown, 2014) While the oil crises in 1973 and 1979 countered the environmental protection movements to some extent due to the pressures to produce energy within the US, regulations increased during this period.(Rice & Brown, 2014) As the economy continued to falter, many young people left the region in search of better opportunities, which contributed to changes in the capacity and structure of communities to be self sufficient.(Photiadis, circa 1970, pp. 6-7)

By the early 1980s, WV had a sprawling government. Jay Rockefeller, who came to WV as a VISTA volunteer and who would later become a US senator from WV, took over as Governor with the vision to reform the government. Because no division or office ever goes away in the WV government, those in power just keep adding new ones. At this time, the WV State Department of Health moved from a high-level department with representation in the Governor's Cabinet to being a bureau within the Department of Health and Human Resources. This shift reduced attention to health at the state level, fewer opportunities to advocate for continued funding for primary care, and resentment on the part of a number of actors who had invested their careers in improving the health of WV communities.(Former state health officer, 2016) A former state health commissioner described the current dynamic of state-level health leadership as follows, noting that these dynamics were established during the transition in the 1980s or even earlier:

*That is why I think we are standing still to some degree in the organization. It is under-organized and too compartmentalized... They are very self-focused and untrusting. You can't run anything if you don't trust anybody.(Former state health officer, 2016)*



*The rise of Community-Oriented Primary Care:* During the same time period, a number of new models for primary care were emerging, building on global and national experiences. Community Oriented Primary Care (COPC) was one of them. (Nutting, 1987) For WV, the objective of COPC was to combine “epidemiological and behavioral science methods of public health with individual medical care to bring about systematic improvements in the health of identified communities. Through the COPC process, stronger links were to be created between clinics and communities.” (Rural Health Partnership Task Force, 1991, p. 27) As the Medical Director at one of WV’s first COPC sites described it, “Health care should concentrate first on procedures that are applied in the home, the community and the primary care clinic. Early care and changes in health habits...increase both individual self-reliance and community competence to solve its own health problems.” (Rural Health Partnership Task Force, 1991, p. 27) The State Health Department (SHD) provided a powerful backdrop for local implementation of COPC by supporting educational processes and mediation between local actors, and not through coercion. The SHD emphasized providing additional preventive services and on “helping communities and medical practice become more responsive to health needs.” (Hansbarger, 1983, p. 223) In addition to promotion of the COPC model around the state, \$1 million dollars of state matching funds for a Primary Care Block Grant were added in 1982 to support training, technical assistance, and a series of conferences. (Hansbarger, 1983)

*Community health centers:* Partly in the implementation of COPC and partly as an evolution of efforts during the War on Poverty, community health centers were on the rise across the nation, including in WV. Health centers were a layer added on top of the

existing United Mine Worker clinics. A retired physician and WVU faculty member, commented that, within the political climate of that period, and if someone had the right credentials and connections among communities, politicians and funders, it was possible to find the necessary resources:(Retired WVU faculty member, 2016)

*Every time a new clinic came up, he'd [the leader of the initiative] find out how much money they needed and he could get the Appalachian Regional Commission to give it to him... I think being an MD and being a university professor was helpful for getting started, and his personality was terrific, he did the trick, and once he got, once everybody got the idea of what we were doing. it was easy to get the money. We got about 50 million altogether for the clinics.*

The same respondent continued to describe the essentially “open playing field” in terms of WV community health centers in the 1980s, where using available evidence of the needs and political connections at the state level paved the way for action:(Retired WVU faculty member, 2016)

*It was most beautiful thing you can imagine, which I don't think happens very often... I had wanted to get family practice program going on in Connecticut, for instance, but...I didn't have the power to do anything and that's why I left, and why I came to West Virginia.*

*The MIHOW Program:* The MIHOW Program was founded at Vanderbilt University in 1982 and initially operated at five sites in Tennessee, Kentucky, and West Virginia. The model, which continues today, trains parents to be peer advisors to other parents with children under three years of age, often starting during pregnancy. The objective of the program was to provide quality outreach services to underserved populations, including ethnic minorities and rural populations.(Vanderbilt University, 2015) Currently, there are four MIHOW sites in WV, including the New River Health Center Network, which was one of the original five sites.(Vanderbilt University, 2015)

The MIHOW program received funding from the state of WV, but failed to qualify for federal monies because it lacked a rigorous evidence base compared with other home visiting programs such as Right From the Start have. Thus, the services provided by MIHOW cannot be reimbursed by Medicaid.<sup>6</sup>

What distinguished MIHOW was the “strength-based” approach that the program used.(MIHOW program worker, 2015) The focus of the home visits was to support and build upon the positives—what mothers are doing well, what they are proud of, what they are enjoying—rather than going into a home and making an assessment of all of the things that are wrong and should be changed.(MIHOW program worker, 2015)

*We would go into the homes, and make a checklist of all the things that were wrong. And then, are we surprised if moms don't want us back? We're going to have to be begging for them to let us back in the door after that.*

That underlying philosophy paired with the flexibility of the program to empower mothers in whatever their goals for themselves and their families were have had the power to support transformative experiences for participants.

Another change identified in the role of the MIHOW workers over time has been that, unlike nearly 35 years ago when the program was founded, more mothers now have access to vast amounts of information about nutrition, parenting, and maternal health. Rather than being the channels for health information, the home visitation program now serves more to help mothers navigate through the deluge of information coming at them each day.(MIHOW program worker, 2015)

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<sup>6</sup> According to the MIHOW program worker, while the lack of federal funding is limiting in terms of where MIHOW can seek support, not being limited to Medicaid beneficiaries as some of the other home visiting programs that do have the evidence base to qualify for federal funding can be seen as a positive thing. MIHOW is not incentivized or limited to a particular target population but can serve any pregnant woman who wanted to participate.

*What they do need us for is to take a look a look at their life and figure out if that's what they want... Sometimes it might be: I want to be a better mother. Sometimes that might be: I want to go to school. I want to create a different life for myself.*

Finally, while the MIHOW model has remained a maternal and child health-focused program, the program worker affirmed repeatedly that the same approach could be used for other groups including the elderly and people with chronic diseases. What is transferrable across different cadres of workers and specific role allocations is the team-oriented philosophy, which includes the women themselves and the communities of which they are a part.

Women often see multiple care providers during a pregnancy, but if the woman is informed and supported by these providers, including the MIHOW home visitor, then she can build relationships and get the most out of the care she accesses. The motivation has to come from each individual woman, not from outside. If the motivation is identified and nurtured, women can harness it to address many challenges. (MIHOW program worker, 2015)

*You can't comment and just tell them [women] everything. People have to learn to find it and decide what is important and what they're ready to address... The current system doesn't teach people, like doctors and nurses, to help people learn how to do things right... So much of the training that's needed is about communication, listening, and taking a strength-based approach. If those things are present, they can be used for everything.*

While the potential for positive outcomes is exciting, and the changes in women's lives is part of what motivates those who have managed and worked in the program over many years, the program worker also raised concerns over whether these dynamics and changes can effectively be documented within the kind of randomized trial and standard

metrics that are being used to measure results. Focusing measurement on quantitative outcomes such as numbers of antenatal care visits, breastfeeding rates, and use of birth control may not fully capture the value of MIHOW. In part, it is a challenge of metrics, and in part an issue of the assessment timeframe.

*Though there may not always be a difference in some of these immediate indicators between MIHOW program participants and others, over the long term there could be a huge shift in the course of life that these women choose.*

While evidence is one aspect of why MIHOW services cannot to paid for through health insurance plans in WV, a former Health Commissioner also noted that when MIHOW was advocating for reimbursement a number of years ago, there was push-back from Medicaid and other payers to show how reimbursement for such services would not “break the bank” if everyone suddenly wanted these services.(Former state health officer and primary care physician, 2016) In addition to wanting further evidence regarding the return on investment and expected results of providing services, how, within a limited pool of funds, to manage and ensure that paying for additional services would not cause severe over-spending was at the forefront of deliberations.

*Precursors to the WV Rural Health Initiative (RHI):* In the early 1980s, teen and expectant mothers were trained on how to interact with their communities and how to approach other teen mothers to provide health education and peer support. Project participants were recruited because they were well-known and actively participating in their communities. Leaders in technical schools and other community organizations were asked to identify the strong local activists.(Former WVU professor, 2015) Efforts were made to communicate clearly to the health professionals and communities that these workers were not practicing medicine. Instead, these workers focused on social

challenges and also participated in gathering data on community needs and barriers and mapped health service needs across rural populations.(Former WVU professor, 2015)

This project was guided and supported by local steering committees, formed by a majority of community leaders.(Carlton & Weston, 1997) The results of this project provided a structure and some experience that informed the design for the RHI and RHEP projects.(Former WVU professor, 2015)

*The RHI and the Rural Health Education Partnership (RHEP) Project:* In the late 1980s, the chaos and crisis of the health system in WV could no longer be ignored. Under Governor Gaston Caperton, the government was restructured and resources were reallocated, leading to higher Medicaid reimbursement rates and a continued focus on primary care. Due to deep federal budget cuts, some of the resources, such as those paying for NHSC physicians, of which there had been over 100 in the state in the mid-1980s, could no longer be relied upon. By the late 1980s, as the amount of resources available for NHSC positions dwindled, a J-1 visa program (Thompson, Hagopian, Foryce, & Hart, 2009; WVU Medical Center Charleston Division, 1977) was created by the federal government. The objective of this program was to bring foreign-trained physicians to fill slots in rural areas and underserved communities that NHSC providers no longer filled.(Tyler, 1997)

Funding also pressured the reorganization of education for WV health professionals. In a memo to the Governor's Taskforce on Medical Education in 1991, John Hoblitzell, a business man and a briefly-serving Republican US senator from WV, outlined the budget crisis that the WV State legislature was facing and the need for the medical schools to consider additional sources of funding, improve supportive

infrastructure to students, or face the possibly necessary decision of cutting funding to one or more of the programs.(Hoblitzell, 1991) The medical schools were a funding priority, and the amount of pressure placed on these institutions is indicative of the kinds of funding cuts seen across less-prioritized initiatives, including health education and outreach to communities.

The Carnegie Foundation for the Advancement of Teaching’s 1989 report on “Building for a New Century,” outlined a number of recommendations all having to do with coordination among educational institutions and community-based training centers in the state. The report also recommended regionalizing training opportunities in order to create scalable networks of opportunities within an accessible geographic area.(The Carnegie Foundation for the Advancement of Teaching, 1989) The report advocated for the creation of a pipeline for health professions from grade school through post-graduate education, and also for reforms to the governance of higher education for WV. Further, it argued that consolidation and centralization of education could help improve the health of rural and underserved communities.(The Carnegie Foundation for the Advancement of Teaching, 1989)

The Carnegie report, along with several others written at the same time, laid the foundation for the project that became the Rural Health Education Partnership (RHEP). To inform these efforts, a review of medical education and the health service delivery system in WV was conducted. The review emphasized the need to include “the personal qualities essential for successful medical practice” in training programs as well as the need to reach and engage communities throughout the state as part of primary care professional education and recruitment. The review stated, “WV cannot afford a medical

education system which is isolated from rural communities and their needs. Medical education should reach out meaningfully to all WV.”(R. Walker, 1989, pp. 9-10) In order to achieve these goals, the report urged stronger focus on teamwork and having primary care physicians “sharing” the healthcare arena with other providers such as NPs, Nurse Midwives, and PAs.(R. Walker, 1989)

Just two years later in 1991, a second report by the Rural Health Partnership Task Force, which had been appointed by the Secretary for the WV Department of Health and Human Resources, Taunja Willis Miller, was published. It focused on the lack of health workers across cadres and the need to seek alternatives to the NHSC and foreign-trained physicians both of which were proving unsustainable due to funding cuts, visa complexities, and challenges related to retention of both groups in rural communities.(Rural Health Partnership Task Force, 1991) To incentivize health professionals to work in rural areas, the report also focused on the need for substantially increased resources through tax benefits and by increasing state and federal insurance reimbursement rates for primary care.(Rural Health Partnership Task Force, 1991, pp. 11-13)

Original funding for the RHEP initiative came from the W.K. Kellogg Foundation in 1991 as part of a series of \$6 million grants to each of seven academic medical centers in the US, including the three medical schools in WV plus the schools of nursing and dentistry, pharmacy, and allied health professionals associated with them.(*Appropriation Recommendation*, 1991) Project sites were carefully selected, choosing those with the least amount of bureaucracy and those lacking substantial resources. The thrust of the RHEP model was to shift a substantial portion of medical education to community health



centers and provide approximately one-third of WV's health professional students with opportunities to learn the medical profession within the context of rural communities. (*Appropriation Recommendation*, 1991, p. 14) The program was envisioned to “increase the collaboration between health professional education and rural communities” and also incorporated a number of community representatives on its governing committee with the goal that communities would be empowered to assume greater responsibility for their health. (*Appropriation Recommendation*, 1991, p. 14)

Many promising functions were included in the design, specifically: networking and collaboration across the seven national RHEP sites, leadership development of key members, and informing and directly linking to public policymakers. An extensive evaluation plan that analyzed the context in which the programs were working, the process of implementing the program, and the program outcomes was also provided. The final reporting form outcomes encompassed curricular changes and relationships with community partners and changes to state policy including a state budget allocation to continue the program. (*W.K. Kellogg Community Partnership in Health Annual Report Form*, 1997) In terms of the impacts at each rural health center, the report lists the benefits each community derived from participating in the program. The combination of experienced benefits was different in each community, as was evidence of community buy in, which ranged from the creation of walking trails, upgrading and increasing the profile and utilization of school-based health centers, and a number of health education programs including tobacco cessation, diabetes management, and exercise. (*W.K. Kellogg Community Partnership in Health Annual Report Form*, 1997, pp. 17-22) WV leaders argued that they should receive the Kellogg grant because they already had structures in

place in the form of “Regional Health Advisory Committees and other community advisory groups,” to carry forward the involvement of communities in the project.(Trustees, 1989)

*Governor Caperton’s Administration:* Also in 1991, under Governor Caperton’s leadership, the Board of Trustees of the new University of WV System, including the three medical schools, endorsed an ambitious plan to retain more health professionals in rural and underserved communities in WV. This plan involved developing “primary health care education sites” as well as a centralized coordinating agency comprised of local community partners who were using state funding totaling six million dollars or more per year.(Board of Trustees, 1991; Pearson & Taylor, 2002) Later in that same year, legislation followed; it described the establishment of the educational sites and scholarships and loans for health professional students, all to be overseen by the Board of Trustees of the University of WV System.(WV House of Representatives, 1991) Within that legislation, which was a proposed substitute for House Bill 213, it stated that the efforts of the University of WV System were not intended to, “relocate the fundamental responsibility for healthcare from the community to the board of trustees.”(WV House of Representatives, 1991) Rather, the community-based health education sites around the state, most of which were located in underserved areas, were to work closely to help set priorities, and then to identify and build the necessary capacity to improve health education and primary care outcomes.(Pearson & Taylor, 2002)

In 1992, the Caperton Administration released a report entitled *Health Care Reform in West Virginia: Our Options*.(State of WV, 1992) The report’s recommendations included providing health screenings and care at the local level,

improving effectiveness of processes to get input from communities about their priorities and perspectives, and increasing collaboration among physicians, nurses, and PAs. Lastly, the report recommended increasing the rigor of the Certificate of Need (CON) process for proposing new clinics in rural communities. All of these efforts were aimed at avoiding fragmentation or duplication of primary care services that could be provided with limited resources.(State of WV, 1992) On page 13, the report mentioned the potential of CHW's roles as a way to increase access to primary care through outreach services and home visits.(State of WV, 1992, p. 13) An additional priority the report underscored was the need to provide continued social and technical support to health workers in rural communities to reduce feelings of isolation, overwork, and lack of professional growth opportunities.(State of WV, 1992)

Early during the rollout of RHEP and the Caperton Plan, observations from the field sites indicated mixed results. In 1992, Dr. Don Weston, Vice Chancellor for Health Affairs for the University of WV System, described the different results across sites of getting local partners to work together to move these initiatives forward, "I assumed when I went to a community of 3,000 or 4,000 people in a little hollow that the resources have meshed—and there are some beautiful examples where the resources have meshed. And I can take you some other places where they might as well be in three different counties and instead they're all in the same small community."(Weston, 1992) He went on to advocate for increased community involvement and shared decision-making between communities and primary care providers in order to not "homogenize the system" or to force one solution to address all local contexts.(Weston, 1992) In 1993, Dr. Bill Carlton wrote to Don Weston stating that progress was being made in the

introduction of lay community participation in the educational process in the rural academic centers. He reported that “community members are involved in most aspects of the project. There is an organizational plan in place that enables community members to be involved in the decision-making process relating to the education of students in rural communities.” Communities got to vote about what they needed, and they were encouraged to utilize the various services offered by field site students and staff.

One of the sustainability strategies that RHEP experimented with, particularly to help with recruiting students and other health professionals to stay in rural communities, was for communities to manage this process themselves through a local committee. This committee was chartered with the responsible of reviewing local health needs and the primary care worker recruitment environment to determine what types of candidates might be available, screen and interview candidates, facilitate community visits, and negotiate contracts. Retention grants to help with local repayment and other incentives were also made available. A reference manual was prepared and utilized in some communities; it was still in print until at least 2001.(Shannon, 2001) The effort did not get fully implemented and was abandoned. Recent inquiries into the process led to a lot of smiling and waving of hands by those involved in the current iteration of the RHI project, which was recently re-designed to articulate a more specific set of goals and technical support services for all of the primary care worker training programs in the state.(Clinician and leader in Black Lung program, 2016)

The WV Health Care Planning Commission, led by George Farley, also created a WV healthcare reform report that emphasized the need to focus on multidisciplinary teams, building on the effort currently being developed through the Rural Health

Initiative with Kellogg Foundation support. (*Health Care Reform in West Virginia: A Shared Responsibility*, 1992) The teams were envisioned to view patients “holistically as individuals and as members of families and communities.” (*Health Care Reform in West Virginia: A Shared Responsibility*, 1992) The report noted that teamwork and community engagement were not new; it reiterated that there were models already in place, including the standard staffing of primary care clinics, examples of health centers and county health departments combining efforts to provide preventive and curative services in tandem, and the use of primary care centers as health education sites. (*Health Care Reform in West Virginia: A Shared Responsibility*, 1992, p. 13) The report also noted that, despite the value and growing experience with non-physician professionals—namely nurse practitioners and PAs—the non-physicians’ ability to be effective within his/her scope or practice and legal authority required continued clarification as well as uplifting through awareness and continuing education about the roles, responsibilities, and scope of work for each cadre of primary care worker. (*Health Care Reform in West Virginia: A Shared Responsibility*, 1992)

*Regulatory issues at the turn of the century:* In the 1980s, efforts to manage costs and primary care outcomes led to new payment structures. Some of these changes resulted in Medicaid providers receiving a fixed payment for patient care (US Congress, 1973) and the creation of several variations on managed-care organizations or Health Maintenance Organization (HMO) structures coordinating and managing patient care. The dramatic and rapid increase in malpractice cases and the cost of malpractice insurance, the 1980s into the 1990s, contributed to what is now a major recent regulatory issue. For nurse-midwives, for example, malpractice insurance costs rose from \$79 to

\$9,450 per year between 1987 and 1992.(State of WV, 1992, p. 16) In response to this escalating cost, many primary care providers moved across state lines where costs were lower, and WV providers and patients experienced increases in costs.

*Dead ends for community participation:* In 1994, as part of the Clinton Administration's national Empowerment Zones/Enterprise Communities (EZ/EC) Program, 15 WV communities submitted applications to participate in a year-long planning and mentoring relationships. In this program, participants would collaborate with each other and with community liaisons focusing on helping to connect communities with state, federal, and private sector resources to address locally identified priority issues, including social determinants of health such as economic development opportunities, cultural tourism, housing, job training, and educational dropout prevention.(West Virginia Partnerships, 1994) No information about what happened to this program was identified.

In 1995, in an editorial of the *Rural Health Partnerships* newsletter series, Dr. Renate Pore, long-time health care policy analyst and advisor in WV, commented on the need for rural primary care providers and communities to share their challenges and solutions; she wrote, "unless rural voices come together to speak as one for their community, they will not be heard in the clamor for restructuring and reform that is now occurring."(Pore, 1995) Subsequent issues of the newsletter do not include community voices in particular, and none stood out clearly from the historical findings in the following few years.

*Lessons and summary of the time period:* During the 1980s and 90s, the primary care system, including infrastructure and processes for managing community

participation, staffing, and financing, were formalized in WV. Federal monies, through Medicare and Medicaid as well as special innovation, capacity building, and infrastructure development, made it possible for more people to access the community health centers which became the focal point of local primary care systems in most WV counties.

Governor Caperton used his influence to invest heavily in hands-on experience for the primary care workforce through the RHI/RHEP programs, countering the formal reduction in public sector focus on health during this period by concentrating on building workforce capacity. A number of reports, prepared by experts from WV and beyond, examined the state's primary care needs and analyzed historical experiences in order to avoid repeating mistakes. The need for responsiveness and adaptation as well as integration with communities was a central finding, but it was challenging to integrate strategies to achieve this uniformly across the RHEP sites.

Despite the desire of many leaders at federal and state level to have more community voices, an audible and organized community voice did not materialize during this period. A number of local examples, such as in Pendleton county (described in Chapter IX), provide evidence for the potential for improving primary care system when communities are engaged.

Home visiting programs received renewed attention during this period. Some programs, such as MIHOW, focused on building on successes and empowering the women served by the program to direct and control their own futures. Others turned the spotlight on assessing all of the primary care need needs and dictating to recipients of the services what those recipients needed to change about their lives.

Toward the end of this period, rising costs for malpractice insurance, coupled with changes to reimbursement structures based more on outcome-based payments, put pressure on providers. These demands forced many providers to focus more on compliance with regulations and on improving the efficiency and administration of their work. These requirements left many primary care providers with even less time to interface with communities they were serving.

### **A New Century and the Affordable Care Act: 2000 and Beyond**

By 2000, WV was grappling with rising Medicaid costs, increasingly loud calls to support non-clinical interventions in communities, and changes in primary care financing structures. In 2009, WV was in the 4<sup>th</sup> lowest quintile for health insurance coverage nationally. Along with its high rates of many diseases and disease risk factors, and lower-than-national-average household income levels, these indicators pointed toward the likelihood for inequities in health, lower and inappropriate utilization of health services, and poor health outcomes for West Virginians.(WVU, 2014)

When the financial crisis hit in 2008, the situation only became more urgent. Since then, recent efforts, including the expansion of Medicare and Medicaid under the ACA, only addressed part of what is needed in order to address the range of contemporary health issues. A number of efforts, including the RHEP program and the NHSC, have continued and have benefitted from revamping and renewed investment in recent years. At the same time, national movements toward “value-based” rather than “volume-based” care continue to push the entire primary care system to improve access and utilization, cost effectiveness, quality of care, and ultimately leading to improved health status.



Critical reflections of oral history respondents on the level of meaningful community involvement with the primary care system planning, action, and evaluation exposed stark contrasts between the vision of major initiatives—including RHEP—to engage communities and the reality of how communities received and perceived those efforts. In addition, renewed interest in involving lay persons in their own health, the health of their neighbors, and communities inspired the Community Health Education Resource Person (CHERP) training program, which faced its own tensions between both the career pathways for the trainees as well as how it was received by primary care professionals. Finally, the last several years and the present day have included another round of comprehensive review and analysis of the primary care workforce, including the involvement of communities, by a number of agencies including the WV Rural Health Association and the Bureau for Public Health.(State of WV, 2016; WVRHA, 2014)

A former State Health Officer spoke about the turn of the 21<sup>st</sup> century as a time of testing the longevity and impact of primary care programs in WV. He described the common tendency towards wanting to create a social revolution that then often did not end up achieving the desired outcomes of improving the primary care system.(Former state health officer, 2016)

*Everybody wants to build a grassroots political organization that will go storm the gates if the funding is cut. It sounds nice in theory that we'll create this ground swell of advocacy for all the things we need. But when you do that you just, I just think you really undercut support, you undercut longevity.*

Instead, he suggested separating or putting more effective checks and balances between political aspirations, opportunities for social advancement, and ensuring access

to affordable and good quality primary care could help prevent mission creep or muddled and contradictory motivations among communities and the primary care system.

*RHEP and RHI Continued:* By the turn of the century, the RHEP effort had matured into a well-known and highly experienced state-wide initiative. Operating in 47 out of 55 counties with over 250 training sites and nearly 500 rural health professionals serving as field faculty, over 1,600 rotations were completed by students across nine health disciplines, and the program benefitted an estimated 156,000 West Virginians.(WVRHEP, 1999) RHEP was in full swing, and its vision was for WV to be “on the cutting edge of community-based health professions training.”(WVRHEP, 1999, p. 6) In parallel to the efforts to build health professional capacity, a mentoring project in six communities around the state was introduced to “enhance the community’s role in recruitment and strengthen ties with residency programs” to develop best practices that could inform both recruitment and retention challenges across the state.(WVRHEP, 1999, p. 7) RHEP students, in collaboration with their field faculty mentors, engaged in community outreach activities such as screening programs, health fairs, nutrition education, alcohol abuse, domestic violence, and community-specific health programming based on local interests and needs.(WVRHEP, 1999, p. 9)

Together between 2000 and 2007, RHEP and the Area Health Education Centers (AHEC) increased the number of physicians who participated in the RHEP or AHEC training and who were practicing in rural areas in WV from 88 to 213 in 2007 (a 143% increase).(Heady, 2007) Between 1992 and 2006, the partnership recruited 820 health professionals ranging from physicians to pharmacists, nurses, nurse educators, and physical therapists to work in underserved areas of the state.(Heady, 2007) In addition to

recruiting and training health professionals, the RHEP and AHEC partnership oversaw provision of a wide range of health services, including prevention and health education, to WV residents. This partnership also coordinated rural rotations in sites across the state for students at the three participating institutions of higher education offering relevant health sciences programs.(Heady, 2007)

One of the aspects of RHEP during its heyday of the 1990s and early 2000s was strong political will to support it. Governor Caperton, who wanted to leave a legacy as the “Education Governor,” not only strongly supported and helped build the donor relationship with the Kellogg Foundation, but also pledged and delivered substantial additional funding using his own position and his clout with the legislature. With this political backing and external funding, the RHEP initiative was viewed by the medical schools, providers, and health professionals students like “God, motherhood, and apple pie,” meaning that everyone wanted to be part of it.(Former WVU professor, 2015) Governor Caperton ensured essential political buy-in for these kinds of projects and invested in making them at least somewhat sustainable. State funding for the RHEP project remained active until a new chancellor for the University of WV System changed the funding so it went directly to each university. After that, due to fragmentation and a loss of the state-wide vision for rural health professionals across all three medical schools, the state budget line item for RHEP was also discontinued.(Physician and state health policy expert, 2016)

Reflecting back on this time period, in terms of providing meaningful experiences and high quality projects for the health professional students who were doing projects in communities on rural rotations, it was clear that the expectations, levels of support, and

quality of the projects conducted with student involvement in communities were, on average, low. Both community and student evaluations indicated a lack of support services necessary to do meaningful work, as well as low levels of perceived value attached to this component of primary care worker training.

*Too often I saw canned projects, projects that you just hand [them] ... “Here is your cookbook, this is how you are going to do anti smoking...” We really need much more vigorous kinds of community projects because I don’t think you should look down on students who think that they’re just going to put in a little time here. Get your best students and get them actually working together on our community health project! Students routinely gave low marks to the community service aspect of their rotation. That’s embarrassing. It wasn’t important to them. —  
Health project developer*

*The Affordable Care Act (ACA):* Collectively, the Patient Protection and Affordable Care Act (PL 111-148) and the Health Care and Education Reconciliation Act of 2010 (P.L. 111-152), commonly known as the ACA or “Obamacare,” was a massive health care reform effort.(USDHHS, 2014) The ACA was said to be the greatest reform since the passage of Act that created Medicaid and Medicare in 1965. In WV, the ACA resulted in the state electing to expand Medicaid, a move estimated to have expanded coverage for the approximately 267,000 individuals not covered by insurance in 2010. Of the uninsured, 76% of the nonelderly (who qualify for Medicare) were eligible for some financial assistance for health care, and over half were eligible for Medicaid or Child Health Insurance Program (CHIP).(Kaiser Family Foundation, 2014) Among these beneficiaries, as well as those covered by other insurance, the ACA also expanded the definition of preventive services that can be reimbursed to include preventing disease, prolonging life, and promoting physical and mental health.(Centers for Medicare and Medicaid Services, 2013)

*The CHERP training program:* The CHERP program was started by the WV School of Osteopathic Medicine in Lewisburg, WV in 2010. It currently has two levels of training and the third level was planned but has not been developed yet. This training targets individuals without clinical, allied, or public health training who are interested in being volunteers to improve health in their neighborhoods and communities. With just under 200 people trained at Level 1 and fewer at Level 2 across WV, this is a small-scale effort. It shared many facets of a traditional volunteer CHW program in a Low- and Middle-income Country (LMIC) that includes training in wellness and health promotion for community members as well as basic skills for chronic disease management at the Level 3 training, which is under development. Training is on-going, and a study of a set of health centers using CHERPS is currently underway to evaluate CHERP effectiveness in case management and care coordination, and to see if the project managers can establish evidence of significant differences in patient satisfaction and short-term health outcomes as compared to control sites without CHERPS within WV.(Hassen, 2015) A recent evaluation of the Level 1 curriculum showed positive results—all CHERPs reported a positive experience with the training and most felt that the learning objectives were met and the training was done adequately; activities after training have been tracked with each CHERP completing several visits to community members, follow-up visits, and being able to answer most of the questions they are asked in community settings.(Miller, 2015b) Challenges and questions remain, however, about scopes of work, appropriate career pathways, effective supervision models, and the viability of the remaining planned levels of the CHERP training program.

Other current projects have also used peer counselors and community-based trainers to provide chronic disease care and peer support structures.(Henry G. Taylor, 1995, 2013; J. Taylor-Ide, 2015) Challenges related to adequate follow-up with these workers, and limited recognition of the training programs as qualification for employment of graduates within the primary care system remain. In addition, controversy among physicians about the possibility of CHERPs assisting patients or performing services such as taking blood pressures has dampened spirits for the future of CHERP.(Project manager and faculty member, 2015)

*Recent Efforts to Strengthen Community Engagement:* Between 2009 and 2011, in the years immediately following the 2008 crash of the stock market and the subsequent Great Recession, the number of NHSC-funded positions dramatically increased across the US, including in WV.(Donald E Pathman & Konrad, 2012) While the spike in funding for workers no doubt was a boon to economically struggling communities, the study authors note that the shotgun approach to cover all communities with all kinds of providers is unlikely to be sustained and the future of the NHSC may be brightest if it is able to better target its efforts, geographically as well as in terms of which kind of providers are prioritized to fill available openings.(Donald E Pathman & Konrad, 2012)

Recent competency-based analyses of the public health workforce (in 2004 and 2012) have identified gaps in skill sets and training priorities by occupation and tier in the workforce—entry level/non-managerial (Tier 1), managerial level (Tier 2), and the leadership level (Tier 3)). These assessments respond to and coincide with on-going efforts to build capacity for the healthcare workforce in rural communities of the state and region. This process has rigorous scholarly and methodological underpinnings,

including extensive task analyses, economic evaluations, and short- and long-term goals, focused primarily on creating jobs and showing that more health workers are placed within communities with the highest needs.(Henry Gordon Taylor, 2015) Some of the persisting gaps in skills include managing budgets and organizational data, evaluating organizational performance, and communicating and sharing outcomes. Interestingly, the highest level of trained personnel identified the largest needs for additional training, while entry-level workers had much lower perceived trainings needs for their work.(WVBPH, 2012)

Among the most recent initiatives working to address the future of CHW work is the West Virginia State Innovation Model (WVSIM) design grant, which explored opportunities to change financing structures for the provision and reimbursement of primary care services, and who can most effectively and efficiently provide the necessary community services.(WVHIC, 2015) The WVSIM planning process was part of a larger health systems restructuring effort with support received from the Centers for Medicare and Medicaid Services (CMS).(WVHIC, 2015) To maximize WV's opportunities to analyze and learn from CHW models used in the US and internationally, a series of state-level fora with academia, large non-profits, hospital representatives, and other stakeholders were conducted.(Crespo, 2015) The conclusions of the forum discussions were that many stakeholders are in support of doing more CHW work in WV and moving towards a certification process, though a larger number of practical considerations including payment, supervision, scope of work, and others will require solutions.

*Perpetuation of Primary Care System Limitations:* Among the greatest challenges continuing to face rural Appalachia today is lack of access to primary care providers and

services. The reasons for the continuation of this reality, despite decades of effort and investment to change it, are complex. A major factor is that while WV's governmental programs and receipt of external funding to support health, education, and other social services have expanded in recent decades, they have not been able to counter declines in economic opportunities in the state.(Rice & Brown, 2014) Without jobs for the working age population, keeping communities intact and with adequate capacity to take care of the health and wellbeing of their members has been a great challenge. Currently, according to the US Health Resources and Services Administration (HRSA), the 50 of the 55 counties in WV are designated in full or in part as Health Professional Shortage Areas (HPSAs) or Medically Underserved Areas (MUAs) by.(HRSA, 2016) Overall, WV still has lower patient-provider ratios than the national average.(WVRHA, 2012)

In order to more clearly understand the nature of the primary care workforce and also more accurately plan for the future, several recent analyses have been undertaken in WV. Between 2012 and 2014, the WV Rural Health Association (WVRHA) conducted an in-depth analysis of healthcare professionals including physicians, Nurse Practitioners, Physician Assistants, other nursing cadres, dental professionals, and pharmacists.(WVRHA, 2012, 2014) Key findings from this extensive analysis include an overabundance of specialized physicians clustered in urban centers, inadequate numbers of many other cadres of workers including primary care physicians, nurses, dentists, and pharmacists, as well as an inequitable distribution of the health workforce as a whole.(WVRHA, 2012, 2014) More recently, the state has undertaken efforts to assess the governmental public health workforce's outreach capacity in order to target capacity development efforts to skills and experience that are needed most.(Public Health



Foundation, 2014; Rockett, McCunn, & Taylor, 2006; WVBPH, 2012) Looking towards the future, an even greater need for primary care care is expected to arise. Among factors driving this increase in demand are policy changes—including the ACA and the Medicaid expansion in WV—rising chronic disease burden, and an aging population.(WVRHA, 2012, p. 4)

A common rationale for the lower rates of health care access and utilization in rural areas in Appalachia is a lack of “appreciation factor.” These populations often place less value on education and health care, particularly if they are planning to remain in the agricultural or mining industries and not seek other employment opportunities.(Nesius, 1966, p. 42)

*Lessons and summary of the time period:* Since the year 2000, a number of efforts have collectively improved access to primary care services for rural and low-income populations in WV. The maturation of RHEP in the first decade of the century, and the more recent expansion of Medicaid eligibility via the ACA are major examples of these efforts, and represent significant investment of federal, state, and private dollars.

Underlying these successes, however, are several risks and challenges to sustained and expanded success. The first such challenge is power and political dynamics among the three medical schools in the state, which led to fragmentation of the RHEP initiative and loss of state support as well as competition for resources to invest in primary care. Even more fundamental to this dissertation is the lack of meaningful engagement with communities reported by both students and community representatives; this lack of engagements and accountability has been pervasive despite efforts to build relationships and trust. Invested in rural placement and training of students as well as in developing

models for community feedback and involvement have consumed large amounts of money over time. Although resources, energy, and time have been expended, the trust, values, and commitments to excellence that are necessary for engagement have often remained superficial and a great challenge to instill in every student and community. Finally, the CHERP initiative and other recent pilot efforts to use lay individuals for outreach, advocacy, and education roles have revealed limitations to current capacity and experience with supervising and mentoring such workers. In addition, dead ends for career pathways, and resistance from the rest of the primary care workforce to involve these lay workers in anything remotely clinical in nature have dampened interest of prospective candidates in this work, and have limited the resources available to invest in creating more opportunities because of uncertain and returns on investment.

### **Analysis of Themes Across Time Periods**

#### **Summary of CHW Roles: Who Performed Them Across Time**

*Communities doing CHW work:* Community members have served in many roles to support, interface with, advocate for, extend the reach of, and provide feedback to the primary care system. Often, holding these roles has been personally transformative and has positively impacted the worker's personal health, the health of their families, and the health of others in their communities.

In terms of advocacy, a number of efforts have spanned all five time periods described in the study. In the 1930s, rising middleclass women, who were mostly the wives of doctors, lawyers, and businessmen in WV, championed the professionalization of medical practice, and began raising their voices in concern over the practices of lay midwives. At the same time, women who received help in their households from the New

Deal “housekeeping aides” program advocated heavily for the kind of care that peers and those familiar with the culture and needs, not limited to clinical care, could provide. A number of home visiting programs ranging from the MIHOWs, Right from the Start, Parents as Teachers and other “evidence-based” home visiting programs have also enabled mothers to advocate for and support each other.(MIHOW program worker, 2015)

In the 1980s and 90s, the OH-9 project in southern WV included community advocates and resource persons as part of their mobiles health units, and as a core tactic within their overall strategy. Leading up to the RHI and RHEP initiatives, which focused on placing trained primary care providers in rural communities, teen mothers were trained to be advocates and health educators in their communities. Recently, CHERP training has been employed—and is being revised as a more extensive training program—to prepare community members to be peer advocates for healthier lifestyles.(Physician and state health policy expert, 2016)

Community partners and learning sites have been a component of many of the major initiatives across the decades. In the 1960s, the ARC approach to setting up primary care clinics included using community partners. The War on Poverty worked through existing and new community organizations. The UMWA Health and Welfare Fund included communities as partners in their local health centers. During the period in which RHI and RHEP were developed and matured, communities were used extensively as learning sites for primary care worker rotations, and communities also received technical support to help them recruit and retain primary care workers locally. All of these efforts sought to extend the primary care system’s reach into communities by using existing local institutions and networks.

Communities have also been direct providers of many basic health-related services, particularly in terms of health education, social support and patient advocacy, and maternal health care over the decades. Early on, “granny women” and neighbors provided outreach and home visits to rural communities. The Black Lung Program utilized outreach workers from the community as part of the care team for sufferers of Silicosis. In several instances, such as during World War II and during the 1990s when the funding for NHSC primary care providers decreased, communities have had to pick up the slack left by the departure or non-replacement of health workers. Many activities associated with home visiting programs including the early Housekeeping Aides, the OEO health aides, MIHOW, and other efforts could fall within the scope of CHWs.

*Primary care workers doing CHW roles:* The primary care system has become exponentially more complex and regulated since 1930. A number of cadres of health workers have gained greater recognition, clarity of roles, and levels of professionalism—and new cadres that were non-existent at the time of the New Deal have come into being (NPs, PAs). Ways of providing primary care have also shifted from a larger proportion of home visits early in the 20<sup>th</sup> century to a largely facility-based primary care system today. Recently, a number of initiatives trend back to a more direct home-based strategy, or family- and community-oriented approaches to reach people where they are, though these remain a minority.

Early on, primary care physicians often conducted home visits and were responsible for providing basic care using limited knowledge, technology, and other resources. Nurses as well as lay and trained midwives provided extensive home visitation services, often for maternal and child health. They also conducted a number of public

health functions in communities including helping to treat and manage communicable disease outbreaks and providing childhood immunizations. More recently, many nurses—particularly LPNs—spend part or all of their time doing care coordination, patient education, and sometimes even home visits to the elderly and patients with chronic diseases.

As new cadres of workers, such as NPs and PAs, were added to the workforce, their roles were defined and then often revised over time. For example, the original conceptualization of NPs was as a community-based provider who could focus on getting health information and services into homes, workplaces, and local social institutions. While the philosophy behind these workers may not have changed, in practice their roles have become much more facility-based and clinically focused. Some reasons for this shift include the kinds of services that could be easily paid for, looking for ways to improve efficiency of care provision, and general trends towards facility-based health care in recent decades.

Finally, a number of primary care providers at all levels have become community advocates, particularly for underservices or adversely affected groups. The most significant example of this is the Black Lung Program where teams of doctors and other health care professionals gathered evidence, treated patients, and lobbied for policy change that would work to ensure safer working conditions and access to necessary care for workers. Collectively, the professional primary care workforce has done a number of common CHW roles over the years and continues to do so today.

## **Drivers of CHW Roles: Enabling and Undermining Dynamics**

A number of the historical initiatives have worked hard to strengthen the community interface with the primary care system. Some of them have given merely lip service to this vision, while others have created expansive and thoughtful efforts to engage communities, to create stronger and more unified voices, and increase decision-making ability and participation in the planning of primary care system functions through implementation and evaluation of the outcomes and impact of projects and services. A number of key political leaders—including governors and US Senators from WV as well as physicians and activists—have also dedicated their careers and life’s work to raising awareness and finding resources and support to implement policies and programs and help these initiatives sustain over time.

*Implementation assumptions for CHWs:* Having motivated and trainable people who are available to do the work of CHWs is essential. Recruiting and retaining trained professionals in WV’s rural and low-income areas has been an ongoing challenge. In a number of projects, recruiting people from within their communities has been a common and viable strategy; the roles they play have, however, often been limited to supporting higher trained professionals, getting their communities to use services determined by outside planning groups, and sometimes being able to provide specific feedback, a community perspective, and a clearly articulated set of local priorities.

Being able to share best practices and learning across sites can reduce repetition of the same mistakes as well as feelings of isolation and burnout among workers. A number of projects have explicitly integrated networking, sharing experiences, and learning from the work of others into their plans. Many also utilized community partners

as ways to promote and support local learning. A number of state and regional discussion, planning, and study groups—often coordinated around a specific program such as the Black Lung program or the early efforts to establish community health centers—offered ways for a variety of stakeholders involved with primary care to connect with each other and share experiences. These opportunities for change ebbed and flowed and often included an overlapping and evolving nucleus of the same personalities.

*Risks for the Roles of CHWs:* Resources for primary care have waxed and waned. They have mostly been recognized as external funding, although local investments in health have contributed to spreading, sustaining, and strengthening primary care systems. Local investments have been valuable despite the challenges in measuring their impact and limited documentation and reporting of the quantity, purpose, and source of these local investments. In times of significant external funding, communities were often initially engaged and consulted, only to be forgotten or no longer included when funding shifted or dried up. This has contributed to lower levels of engagement, trust, and willingness to invest in and feel empowered to contribute to changing the primary care outcomes which many have been working on for so long. Many projects, like the Black Lung Program, created an opportunity for the development of additional primary care services around them; while many dedicated health professionals and communities recognized this as an opportunity and made the most of it but “shoehorning” their more comprehensive and prevention-oriented services into these programs, they were not a substitute for well-thought-out and sustained general primary care support.

Many projects and policies have incentivized, idealized, or mandated coordination across implementation sites, among donors, or of evaluation approaches. As a result, WV

has experience coordinating and aligning different providers and community partners. Effective and sustained coordination is also an aspect for which repeated and more extensive evaluations and analyses have been demanded. Challenges for coordination have included staff turnover among both primary care professionals and community representatives, geographical isolation and limited communication options (at least until recently, although internet speed remains a challenge in many rural areas). Enablers for coordination have been the development of strong local and high-level relationships built on trust and investment in mutually agreed-upon outcomes.

Often, primary care projects programs have been implemented, expanded, or modified because outside funding was available to support them and were based on timeframes dictated by donors and policies. Communities often had little say in the choices about what to support, what to measure, and when to measure outcomes. They were often not the lead grant writers or the direct recipients of the funds; they did not have the local financial resources to pay for the necessary professional salaries and infrastructure to support primary care services themselves. Communities, along with donors, have also often wanted to see short-term results. Fundamental changes to community engagement, access to services, and ultimately health status often take more time and must be part of a larger vision and strategic plan reflecting perspectives and priorities of multiple stakeholders. In order to work within relevant stakeholder timeframes and attention spans, change must often be made incrementally, tangibly, and in ways that communities can perceive and value in order for them to continue to invest themselves.



## **Achieving Desired Primary Care Outcomes**

West Virginia's historical efforts to engage communities in achieving primary care outcomes has influenced community engagement levels and also access to and utilization of health services. Numerous efforts have contributed to progress and experience, but have not been adequate to substantially improve population health over time at the state level and elevate it from among the poorest in the US. This is partly due to unintended consequences within the complex context and to emerging issues. A number of contextual factors such as the national economic fluctuations, booms and busts in WV's historical leading economic driver (extractive industries), WV's unstable population, and other issues such as how to translate and implement frequently changing policies to diverse local contexts have contributed to WV's primary care outcomes. Finally, the shift from communicable to non-communicable diseases over the study period, as well as the recent increases in opioid addiction and Post Traumatic Stress Disorder (PTSD) have been affecting the health status of WV's rural and low-income communities.

Communities have played powerful roles in either embracing and utilizing available services or in rejecting or de-valuing services and approaches that they did not want. The War on Poverty is the most obvious example of state-wide action in this vein as communities found a voice and began demanding new services and stopped supporting and even publically opposing other structures and services that they did not value (particularly exploitative local political powers). Not all of the War on Poverty efforts were health-focused, but the process utilized was the same regardless of the field of the work. Often, the form of embracing or rejecting services and approaches was through

community member recognition of the value (or lack thereof) of services being offered, and then sharing their experiences with family and neighbors.

As WV and the entire US looks forward to a future of uncertain and limited resources, continued increases in chronic disease burden, an aging population, and increasing pressure to deliver value-based care, a number of historical lessons can inform the needed strategies. First of all, WV's primary care infrastructure has been a major area of state progress and pride and has consumed vast resources. The infrastructure is valuable, but in and of itself, it is not sufficient to ensure access to services for rural and low-income populations. Integration of those facilities into community life and action beyond the clinic walls is needed to ensure that communities use services wisely, and that those who cannot or will not come to the facility are receiving the care that they want and need. West Virginia's long history of recruiting and retaining health professionals in rural areas also indicates that workers are more likely to stay in the communities in which they are placed for rotations or residencies if they are professionally and socially integrated and feel effective and appreciated. Loan forgiveness programs or other financial incentives in isolation have had limited effectiveness for retaining workers. Those workers who invested major portions of their careers to provide services and advocate for primary care in WV have helped sustain and evolve efforts across the decades despite the challenges of working within what have often been politically-polarized and resource-limited contexts.

Finally, when there is political and community support behind an effort, resources can be "found" or identified from either local or outside sources. Spending on health in WV is high; re-directing resources away from wasteful or "downstream" purposes and

allowing for reasonable local flexibility and ownership can lead to improved health within financial limitations. Clarity on what each stakeholder values and expects, and clarity in what stakeholders need from each other is critical in order to contribute to primary care outcomes.

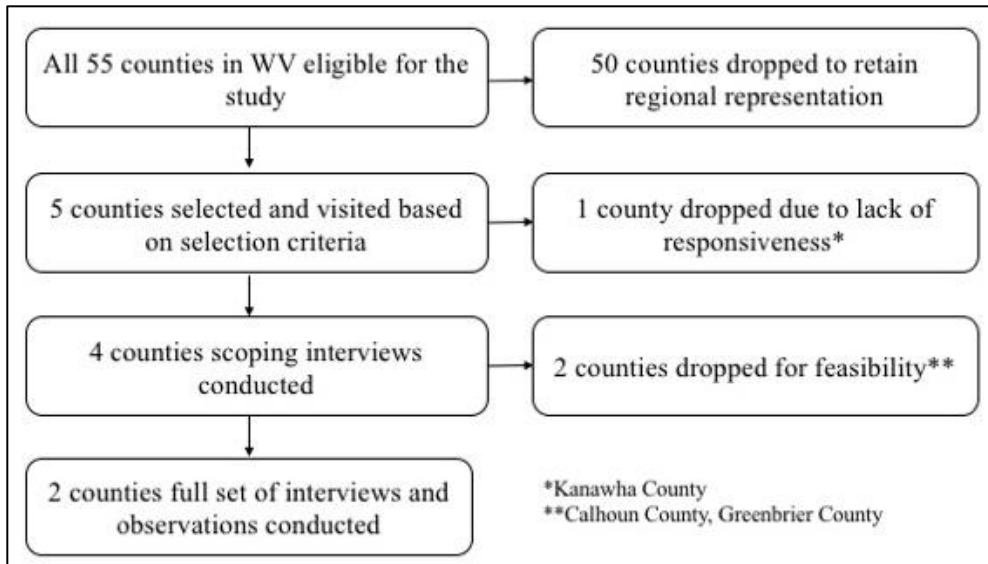
## VII. County Case Study Methods

The county-level cases in this study were designed to look in-depth at how historical experiences and influences shaped the current views of local stakeholders regarding the interface between communities and the primary care system. These cases also analyze contemporary dynamics and priorities influencing the level of community engagement and access to and utilization of primary care services. Finally, these county-level findings identify opportunities for CHWs to contribute to managing assumptions and risks by facilitating dialogs and relationships between communities and the primary care system in order to help achieve primary care outcomes.

### **Sampling**

*County site sampling:* Counties were determined to be an appropriate unit of analysis in WV because they are the smallest administrative unit that consistently has a public health office or department, at least one primary care center, representatives of various non-profits and businesses, and community groups and leaders engaged in addressing health issues, often focused on or mandated to serve the county population. In addition, many rural residents, while they may belong to a number of social networks and closely-knit sub-groups within the county, feel loyalty and responsibility for other people in their county.

The process of selecting counties for in-depth local exploration of the interface between communities and the primary care system is illustrated in Figure 6.



**Figure 6: Overview of county case sampling process**

Beginning with all 55 of West Virginia’s counties, a sub-set of five counties was selected to retain representation of major regions around the state while limiting the study to a more feasible size. All 55 counties were eligible for this study because, even within counties classified as “urban,” most of the towns and cities are small, and individuals living even a few miles outside of the urban center often reside in isolated, difficult-to-reach areas. Of the 55 counties, only 21 (or 38%) of WV counties are designated as “urban” according to HRSA guidelines.(HRSA, 2013)

Regional representation was a viable way to narrow down the number of counties since West Virginia has substantial internal variability related to geography, economic base, and demographic characteristics. Some examples of this internal variability across regions include coal-producing and other regions. Counties with relatively poor or relatively better health outcomes also tend to cluster together within regions. The state has also been divided into regions for the purpose of providing technical assistance, managing infectious disease surveillance, and conducting other planning processes in a

number of ways over the decades.<sup>7</sup> Therefore, a number of state-wide examples of regionalization were reviewed. In this study, the WV Area Health Education Center (AHEC) regions were utilized as the basis for defining the regions from which to select county sites.(AHEC, 2014)

Within each region, a representative county was selected based on criteria listed in Table 2. The factors used to select representative counties, and compare criteria across regions included: geography, economic drivers and prospects, relative health status, and the county’s historical experience with community engagement and empowerment in relation to the primary care system. While many combinations of counties were possible at this stage of the sampling process, the counties selected represent a careful consideration across all counties of the factors in Table 2. In addition to the comparative criteria, the dissertation researcher also considered the likelihood of being able to access and engage with diverse primary care workers and community representatives in each county-level community and primary care system.

**Table 2: Comparative criteria for counties considered for inclusion as case study sites**

<b>Criteria</b>	<b>Calhoun</b>	<b>Greenbrier</b>	<b>Kanawha</b>	<b>Mingo*</b>	<b>Pendleton*</b>
<b>Geography</b>	Mountains	Mixed/valley	Mountains	Mountains	Mixed
<b>Urban/Rural</b>	Rural	Rural	Urban	Rural	Rural
<b>History of community engagement</b>	Weak	Weak	Strong, but isolated	Weak until recently	Strong over several decades
<b>Health outcomes (relative to rest of WV counties in 2015)</b>	Medium (37/55)	Medium (31/55)	Medium (38/55)	Poor (53/55)	Best (1/55)
<b>Primary economic drivers</b>	Services/retail	Retail/hospitality	Coal/ other retail	Coal	Agriculture/tourism/management

\* Shaded columns indicate that an in-depth case study was conducted for this county.

<sup>7</sup> Planned Approach To Community Health (PATCH), Assessment Protocol Excellence Public Health (APEXph), WV Bureau for Public Health (WVBPH), Area Health Education Centers (AHEC)

Of the five counties selected to represent regions of the state, four are classified as rural, with the exception of Kanawha County which includes WV's largest and capitol city of Charleston. Three were in coal-producing areas and two were not. The counties represented a range of relative health outcomes. Mingo and Pendleton counties were on extreme ends of the spectrum of health outcomes, with Pendleton having good outcomes relative to other counties, Mingo having poor outcomes and the other counties falling in the middle.

After selecting five counties to represent major regions of the state, initial contacts were made at the counties' community health centers, many of which also designated as Federally Qualified Health Centers (FQHCs) (CHNWV, 2014), and the local public health departments. Introductory site visits were conducted in all five counties between July and August 2015. Meetings with representatives from the community health centers were arranged in all five sites, and with local health departments in four of the five (minus Kanawha county due to challenges described). The purpose of the study and the planned fieldwork was explained to leaders of the community health centers and health departments. The objectives of the introductory visits were to scope out the local capacity, programs, and existing and potential local partners in each county, as well as to gain buy-in for and feedback on the proposed follow-up visits to conduct interviews. Following these introductory site visits, an initial set of scoping interviews (3-5 in each county) were conducted in four of the counties.

No formal interviews were conducted at the Kanawha County site due to lack of responsiveness to the researcher and the community health center system's limited

capacity to contribute feedback, time for interviews, or connections to a range of local contacts. Despite having an urban center, many parts of Kanawha county are very rural and experience the same challenges of access to primary care services and community engagement as rural counties do. This coupled with the challenge that many county-level offices, such as the local health department, are located within the Charleston city limits, leaves many rural areas of Kanawha County with even less attention and resources than many other completely rural counties. The community health center system that serves rural areas of Kanawha County operates in greater isolation than those in many other counties. The community health center also carries a larger responsibility to provide a comprehensive set of services to rural residents who cannot reach urban-based resources in the county, and this workload resulted in contacts there not having enough time to contribute to this study.

In order to represent different regions and economic bases within the state, different configurations of local capacity over time, and different models for managing the community and primary care system interface as well as the work performed by CHWs,<sup>8</sup> the dissertation team selected Mingo and Pendleton Counties as the two case studies to analyze in depth. Mingo County is an historically coal-producing county with some of the poorest health outcomes in the state. Pendleton County is not a coal-producing county, and demonstrates very good health outcomes for WV. The two counties provide not only a different historical and contemporary experiences but also lessons learned that can inform the future of CHWs in WV.

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<sup>8</sup> Due to the extensive travel and fieldwork time required as well as the number of interviews needed to reach theoretical saturation in each county, only two counties could be analyzed in depth.



The map in Figure 7 illustrates how the two counties are located on opposite sides of the state. Pendleton (the black star at the upper right) is on the border to Virginia, has no coal reserves and no history of mining, and is more connected to the metropolitan East Coast. Mingo (the black star at the lower left) is solidly in the central Appalachian coalfields, and has connections to the rest of southern West Virginia, eastern Kentucky, and southwestern Virginia.

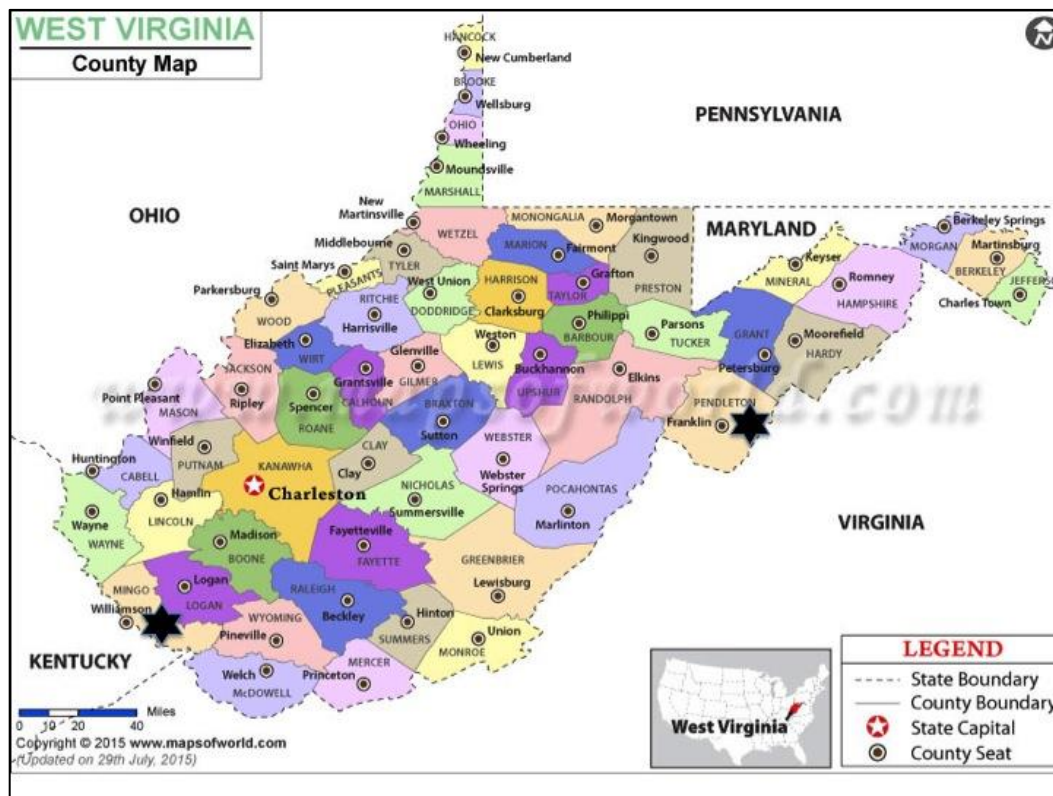


Figure 7: Map of West Virginia Denoting the Locations of the Two In-depth County Cases<sup>9</sup>

*Historical and online literature sampling:* Online and archival literature reviews were conducted for Mingo and Pendleton Counties in order to create a chronological narrative of the unfolding of major historical events, current activities, and local partners involved in primary care. For the online review, Google, Google scholar, PubMed, and

<sup>9</sup> Map source: <http://www.mapsofworld.com/usa/states/west-virginia/west-virginia-county-map.html>.

Web of Science were searched using the following search terms: [[“[insert county name] county” OR “[insert county name]”] AND [“West Virginia” OR “WV” OR “WVa”] AND [“primary care” OR “primary health care” OR “community health” OR “access to care” OR “chronic disease manage\*” OR “community health worker” OR “health worker”]].

The county-level archival literature review included searching the finding aids of the West Virginia University’s *West Virginia and Regional History Center*’s congressional and political papers collection, manuscripts collection, oral history collection, and the printed ephemera collection for simplified search terms based on those described earlier. The researcher also reviewed the *Pendleton Times* and the *Williamson Daily News*’ (Mingo County’s major newspaper) microfilm collection using key dates and time periods identified in the other findings. A series of conversations with archivists at the center also helped identify specific collections of key persons and additional finding aids not available electronically, which led to additional relevant materials.

At the West Virginia State Archives in Charleston, WV, the state documents collection was the major source of relevant content, though the book collections for each county were also valuable sources of historical information, particularly for Pendleton County. Online finding aids for the state documents collection were searched with terms based on those described earlier. Due to a limited amount of detail in the finding aids and the implied focus on WV for the majority of the material, simplified search terms such as “Mingo,” “Pendleton,” “health,” or “primary care” were often used to assess the kind and quantity of results; then, based on the initial search results, more specific search terms

were developed in order to isolate the most relevant material without inadvertently excluding any.

### **Data Collection**

*Ethical approval:* This study was determined not to be human subjects research by the office of the Johns Hopkins Bloomberg School of Public Health's Institutional Review Board (IRB). All respondents received a copy of the informed consent document to keep, which included contact information for the study Principle Investigator (PI), the researcher who conducted the fieldwork, and the Johns Hopkins Bloomberg School of Public Health IRB. Respondents were given time to review the consent document and address any questions or concerns that they had. If consent was given by the respondent, interviews were audio recorded.

*Historical and online literature:* The majority of the relevant identified material was in the form of strategic plans, project reports, and other media such as newspaper articles, organizational newsletters, and blog posts by local organizations. The researcher also identified documents about historical and contemporary efforts to improve health status and engage the communities. Many of these documents drew heavily on federal, state, and local data sources, and referenced other literature and models in addition to describing local efforts and experiences.

Archival findings for Mingo County included a number of political memos, several pamphlets, and newspaper clippings mostly from the 1960s during the War on Poverty in the region. Relevant archival materials for Pendleton County included a series of newspaper clippings from the 1980s which were the early years of the community health center system and the initial development of the primary care system that is in

place today. In addition, the researcher accessed a private collection of historical documents of one of the key leaders of Pendleton County's primary care system development. This collection included additional documents about the founding, growth, programs, and collaborations of the local primary care system over the years as well as some county-specific information about the New Deal Era programs. A list of documents reviewed for each county case study can be found in Appendix 3.

*In-depth Interviews:* Selection of Mingo and Pendleton County interview respondents was conducted by a member of the study team, with input from contacts at the community health centers and health departments in each county. Respondents were eligible to be interviewed if they met the following inclusion criteria: 1) were a health worker or community member with an interest in health in the county, 2) spoke at least conversational English, and 3) were at least 18 years of age. A copy of the data collection instrument utilized for these interviews can be found in Appendix 2.

An initial list of possible interviewees was created by brainstorming with local contacts in both counties. Then, the researcher prioritized respondents based on the potential interviewee's level of experience and their ability to represent a different and relevant perspective of the county level primary care needs and activities through the lens of their work. Careful consideration to developing a balanced perspective of each county case study was given. This included seeking out dissenting perspectives, if present, and to reflect different social networks and collaborations within the community and primary care system. Respondents were purposively selected to include a representative mix of primary care professionals and community representatives, a gender balance, and a

diversity of perspectives that could represent population sub-groups within each county context.

A semi-structured interview guide was developed to facilitate the discussion with respondents. This interview guide included topics related to the nature of local primary care-related collaborations, both within and among local agencies as well as with state and national agencies. It also asked about major successes and challenges faced in the county, particularly related to the interface between communities and the primary care systems, and local needs and opportunities for strengthening that interface through the use of CHWs. All respondents provided oral consent prior to participation in an interview.

A total of 35 interviews were conducted between August 2015 and May 2016: 18 in Mingo County and 17 in Pendleton County. Individual interviews ranged from 20 minutes to nearly two hours. Four interviews were conducted with two people simultaneously, and one interview with three people at the same time, for a total of 41 respondents. All group interviews were comprised of participants working within the same organization, often with teams who worked very closely with each other and wanted to give their shared perspective on the study questions. The majority of the interviews across the two counties (n=22) were conducted in person with the remaining ones conducted by phone following a site visit. Of the respondents interviewed by phone, all but three of them had already been visited in-person by a member of the study team, making the phone interview a formal follow-up, and not the sole contact with the respondent.

In Mingo County, an initial set of respondents was selected based on the list of key leaders and local partners generated in a brainstorming session with representatives from the primary care center, Sustainable Williamson, and the Mingo County Health Department. Then, during the first round of interviews, a number of new names were added to the list of potential respondents. These additions were then prioritized using the same methodology applied to the initial respondents. Health worker respondents included Primary Care Physicians, a Nurse Practitioner, CHWs, and a trained administrator from the clinic. Respondents representing the community were involved or had been involved in public housing, recreation, agricultural and nutrition, and local politics. Patients who both had and who had not received care through the CHW program also participated in interviews. In Mingo County, one of the respondents had been a participant in the community health worker pilot project operating in Mingo County from 2012 to 2014 was also part of the current CHW project. Two CHWs active in the ongoing project that began in March 2016 participated as well. Table 3 provides a summary of the interviewee characteristics that were included in the study.

**Table 3: Summary of Mingo County Interviewee Characteristics**

Type of interviewee	Gender	
	Male	Female
Health professional	2	7
Community representative	7	4
<b>Total</b>	9	11

In Pendleton County, an initial set of respondents was selected based on a list developed during conversations with Pendleton Community Care, the county’s FQHC, and the Pendleton County Health Department. Health worker respondents included primary care physicians, social workers, an epidemiologist, nurses, a member of the local

rescue squad, and home health service providers. Community respondents included teachers, local politicians, users of health services within the county and beyond, and leaders of local nonprofit organizations focusing on health and educational programs. In Pendleton County, in-depth interviews were conducted with local health professionals and with community representatives who were knowledgeable about and somehow engaged in health-related issues and efforts but did not have professional training in a health-related field. Table 4 summarizes the distribution of community representatives and primary care workers by gender in Pendleton County.

**Table 4: Summary of Pendleton County Respondent Characteristics**

<b>Type of interviewee</b>	<b>Gender</b>	
	Male	Female
Health professional	2	9
Community representative	6	2
<b>Total</b>	<b>8</b>	<b>11</b>

In both counties, more health worker respondents were female and more community representatives were male. While a balanced perspective of community and health worker perspectives was sought in each county, the priority for selecting respondents was knowledge and experience about the study topic. Interviews were conducted until theoretical saturation was reached in each county. This meant that no significant new relevant ideas, experiences, or perspectives were identified by conducting additional interviews.(Charmaz, 2006, p. 113)

No potential respondent who was approached for an interview directly declined to participate in the study. Five potential respondents (three in Mingo County and two in Pendleton County) who were contacted could not be reached. One of the potential reasons they did not answer calls or return messages may have been because they did no

want to participate. Most of the people we were not able to reach were community members, some of whom were elderly or lived in remote areas with limited communication possibilities.

*Participation in local meetings and events:* During the data collection process, the researcher spent extended time in each county conducting a series of multi-day field visits. During those visits, a number of local meetings and events took place within and among local organizations. The researcher joined these meetings, when possible and appropriate, in order to compare local partner dynamics that had been described in individual interviews, and also experience more of the local culture. Sometimes, the researcher would be invited to join routine staff or partner meetings, and sometimes the researcher would hear about a larger event that and ask to be included in it. The researcher obtained permission or invitation by appropriate gatekeepers to join each of these events.

In Mingo County, the researcher participated in two community health center team meetings including a weekly staff meeting involving several local partners and a weekly team meeting of the CHW program. She also attended a women's wellness event hosted by West Virginia University to observe the dynamics when an external partner convened a meeting of local stakeholders. In Pendleton County, the researcher attended a county-level community needs assessment meeting hosted by the public health department, and also a community planning session for a local non-profit organization involved in wellness activities for youth, locally and around WV. During the data collection period, the researcher lived primarily in the county for six months.



Notes from the meetings were typed up as soon after the completion of the meeting as possible—providing a detailed description of the meeting location and participants, the nature of the discussion and focus of the meeting. Memos about the researcher’s comments and reflections from the meeting, connections or contradictions with other data, or other important or unexpected points were added to the end of the notes about each meeting. Findings from these observations helped to compare and validate information collected during the interviews in the selected counties.

*Data storage and protection:* Each respondent’s personal identifiers were limited to their name and contact information. These data were stored in a separate file not included in the case study database. All data, including transcripts and other related documents, were anonymized before storing them in NVivo and in the case study database. All electronic data were stored on a private password-protected computer. Back ups of the full dataset were kept by the study PI on a secured hard drive. All paper files, including consent forms and background materials collected on site visits, were stored by the field researcher in a designated set of folders in a secured file cabinet.

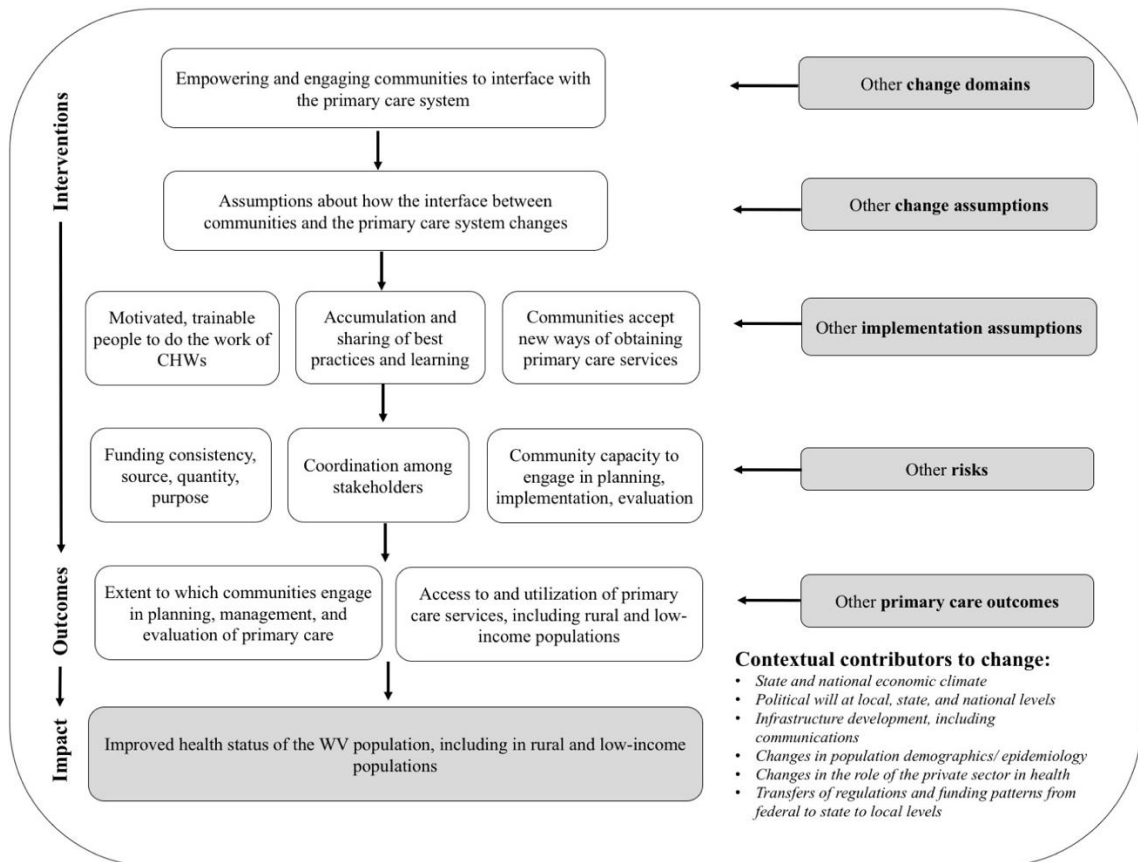
## **Data Analysis**

*Historical and online literature review:* All historical and contemporary documents were stored in electronic and papers files by county with events in chronological order by the date on which the event occurred. Then, taking one county at a time, the researcher reviewed the documents and took notes on important events, findings, and illustrative quotes. Using Microsoft Word, these notes were organized into a narrative describing the development and changes to the primary care system, and the interface with the local community at the county level. Major contextual shifts in

economic, political, and social forces, and the influences of external events were also mentioned as appropriate.

*In-depth interviews:* All interviews were transcribed verbatim, read, and checked for completeness as well as any easily corrected formatting or typographical errors. All transcripts were reviewed to remove personal identifiers and they were then imported for coding into NVivo for Mac. An initial codebook was developed based on the research questions and the researcher's prior knowledge of major themes contained in the data. Inductive coding of the early transcripts resulted in themes being added directly from the data. New codes were added as the original research questions were refined and made more specific. The resulting set of codes was applied to relevant sections of all transcripts, often with multiple codes being applied to a specific section of text. The data were also coded by county site and year, or decade if more appropriate.

Following completion of a full round of inductive coding, all transcripts were read again to code the entire data set using the fully developed codebook. Then, the codebook was re-organized to cluster related codes within the sub-set of assumptions and risks in the conceptual framework (Figure 8) through a process of axial coding.(Charmaz, 2006) A framework analysis approach was utilized to review data from one county at a time, and also to clearly and systematically compare data related to key themes across the counties.(Gale, Heath, Cameron, Rashid, & Redwood, 2013) The conceptual framework components were utilized to organize the findings from each case study. All shaded portions indicate additional components to the full conceptual framework in Appendix 1. While these additional components are related to the interface between communities and the primary care system, they were not analyzed in the county case studies.



**Figure 8: County case study analysis components of the conceptual framework**

During the writing process, coded text was often reexamined within its original context to help ensure that appropriate conclusions were being drawn, and that quotes and interpretations were not being misrepresented without their context. Results were developed for each county by organizing illustrative quotes and text based on the assumptions and risks from the conceptual framework. Assumptions were factors related the pathway for community engagement that this dissertation anticipated would hold true, and risks were factors that this dissertation anticipated would be a limitation or challenge for the interface between the community and the primary care system. Direct quotes from respondents are included in the text of the county case study chapters either in quotation marks or as indented and italicized paragraphs for longer quotes and identify the

respondents as either a health worker or a community representative; in Mingo County where a designated CHW cadre exists, CHW quotes are identified separately.

*Bringing the data sources together:* Findings from the historical and online literature review, interviews, and participant observation are organized into two sections for each county—an historical narrative of the county context and experience, and a contemporary analysis of the interface between the community and the primary care system with a focus on the current use and future potential for CHWs to facilitate that interface. Both community and primary care worker perspectives were represented.

In Chapter X, this dissertation compares and contrasts the findings of the county cases with the state-wide historical analysis. The objectives of this cross-case and cross-experience analysis are to illuminate areas of similarities, differences, and most importantly learning related to the interface between communities and the primary care system in order to inform the future role and potential of CHWs in WV.

## **VIII. Mingo County: Context, The Historical and Contemporary Interface Between the Community and the Primary Care System, and the Work of CHWs**

This chapter presents data from Mingo County, WV, to answer the three county case study research questions outlined in Chapter III and uses the change pathway outlined in Figure 8 in Chapter VII to guide the analysis. The first research question asks how the history of the county's relationships between the primary care system and the community have influenced the priorities and aspirations of current local stakeholders. This historical examination is followed by a analysis of the nature of the interface between the community and primary care system in the county today, specifically focusing on how the interactions between these local stakeholders affect levels of community engagement and access to primary care services. The final research question specifically explores the current models and future aspirations for CHWs working with communities and the primary care system to instigate or support dialogues and relationships that help these stakeholders trust, understand, and respond to each others' needs. The change pathway described in the conceptual framework outlines a series of critical assumptions and risks related to community engagement and empowerment with the primary care system. The linkages between these assumptions and risks and the primary care outcomes of interest—the extent to which communities engage and access to primary care services—are analyzed in order to understand the influence these assumptions and risks have had in Mingo County. A summary at the end of the chapter synthesizes the findings and experience in the county.

## **The Interface Between the Community and the Primary Care System in Mingo County: Context and Historical Experiences**

Since the early 1900s, Mingo County has transformed from a booming town reliant on the coal industry to a ghost town with a declining population and limited economic opportunities. Today, the county seems to be on a slow rise again, though still hampered by the last several decades of declining wealth, health, and opportunities that have plagued the county. ("County Health Rankings 2015: West Virginia," 2015; "West Virginia County Health Rankings," 2016; WV Division of Culture and History, 2016)

A promotional pamphlet from the Williamson Chamber of Commerce in 1931 stated, "Williamson [population 9,410] is the county seat of Mingo County, the chief city and trade center not only for the county but for a population of more than 100,000 people who live within 35 miles of the city. There is no other city closer than Huntington so large or so important." (Arnett, 2015) The Chamber was promoting tourism and commerce in the town, which was nicknamed "The Heart of the Billion Dollar Coal Field." This area had only become its own county 35 years earlier, developing initial industry and infrastructure in 1895. (Arnett, 2015)

At the beginning of the 1930s, an estimated 465 towns in southern WV, including in Mingo county, were owned by coal companies; a number which has dwindled to zero at present day. Some smaller neighborhoods are still privately-owned today. The culture, structure, and functionality of these towns are reminiscent of that corporate-dominated time when there were railroads running through the centers, wealthy neighborhoods for the owners and local politicians, and "coal camps" in rows of look-alike houses lining the hollows where the workers lived. ("The West Virginia Encyclopedia," 2006) These

company-owned towns had coal company-employed doctors, and often company-sponsored clinics or health insurance plans.

In April 1932, as the Great Depression set in, a national conference of the President of the US's Office for Unemployment Relief and the American Friends Service Committee (AFSC) was held in Williamson, WV to discuss solutions to the increasing unemployment of miners in southern WV counties. Although the simplest strategy was to re-settle miners on small farms and have the coal camp houses demolished, the practical challenges of implementing this plan—including the steep terrain, and occupation of many small valleys and flat areas by railroads, coal camps, tipples, and other coal industry infrastructure and remains—limited the options. The lack of preparation (in terms of knowledge or experience) and interest of many of the miners to be successful farmers also made this a difficult option.(J. B. Thomas, 2010) Farming was not necessarily a lucrative profession either, as over 80% of farmers in Mingo and surrounding counties at that time fell into the lowest income category.(J. B. Thomas, 2010)

Relief programs through the New Deal helped ease some deep needs of the southern coal field communities, since substantial portions of the financial aid were directed there. The whole state continued to struggle as the region grasped at different ways to proceed in the post-industrial era.(J. B. Thomas, 2010) During this time, according to interviews conducted in Mingo County for this study, public housing was also established in Mingo County and still operates to this day. According to community representatives, it has expanded from two sites in the 1940s—one for whites and one for

African Americans—to four desegregated sites in different neighborhoods of the city that house 248 families today.

Many photographs and narratives from the New Deal Era capture the role of the community in the Southern coalfields at that time. One photographer, H.W. Francis, who visited Mingo county in 1934 wrote (*New Deal Photographs of West Virginia*, 2012, pp. 131-132):

*I leave Mingo amazed at the docility and capacity for suffering of most of these people who, I had always understood, were hot-headed and temperamentally given to unreasoning revolt. I have found more common sense in the mining camps and in the dark hovels of mountain ravines than I have in the homes and offices of the controlling class.*

She then went on to describe conversations with members of that “ruling class” including doctors, lawyers, and merchants who had gone as far as to open fire upon crowds of striking miners and their community supporters, and who showed no qualms about doing so again should further demonstrations for labor rights take place. The tension between the laborers and the industrial leaders was palpable, with both parties feeling taken advantage of or used to the benefit of the other. Part of the divergence of opinion between these groups lay in their beliefs about whether there was an abundance of coal for centuries to come or whether people realized that alternative industries would be needed to replace finite coal reserves, even though no viable alternatives were on the horizon. (*New Deal Photographs of West Virginia*, 2012)

Since 1930, the population of Mingo County fluctuated significantly. It ranged from 38,000 people at the time of the 1930 census to hit a record high of 47,000 in the 1950 census to a steady decline to just over 25,000 in 2010 (Figure 9). Interestingly, before 1930, the population grew from just 27 people to nearly 10,000 between 1893 and



the year 1920.(Sustainable Williamson, 2013) due to job opportunities in the mines, rapid growth continued from the time the area became a county until the population peaked in the 1950s.

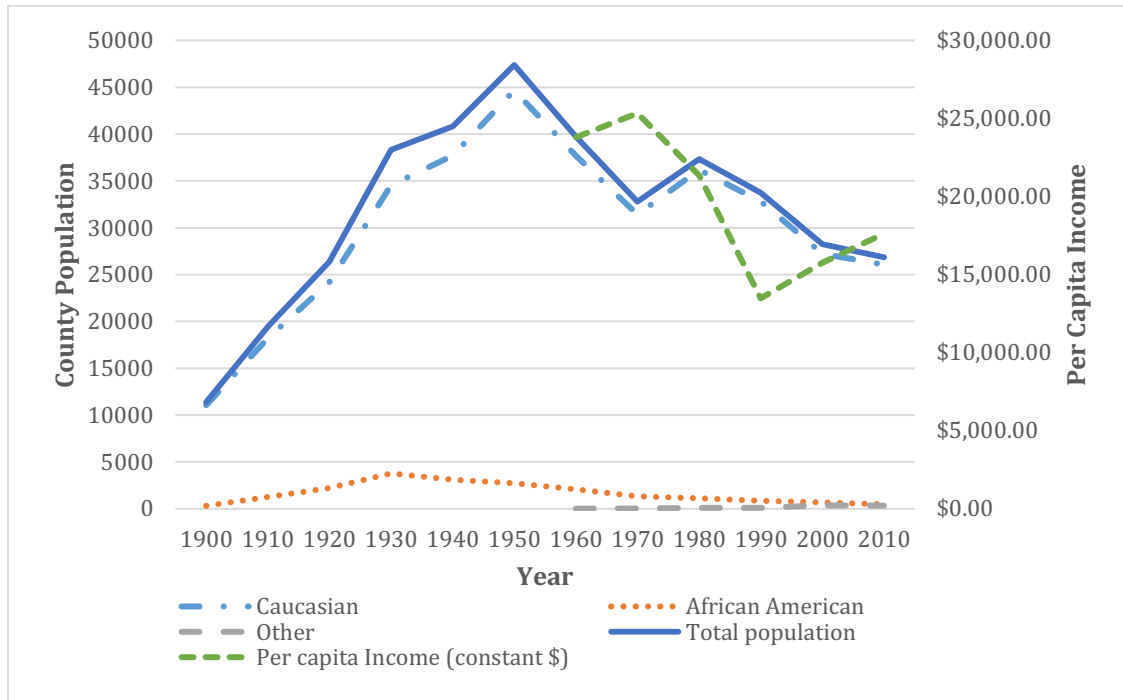


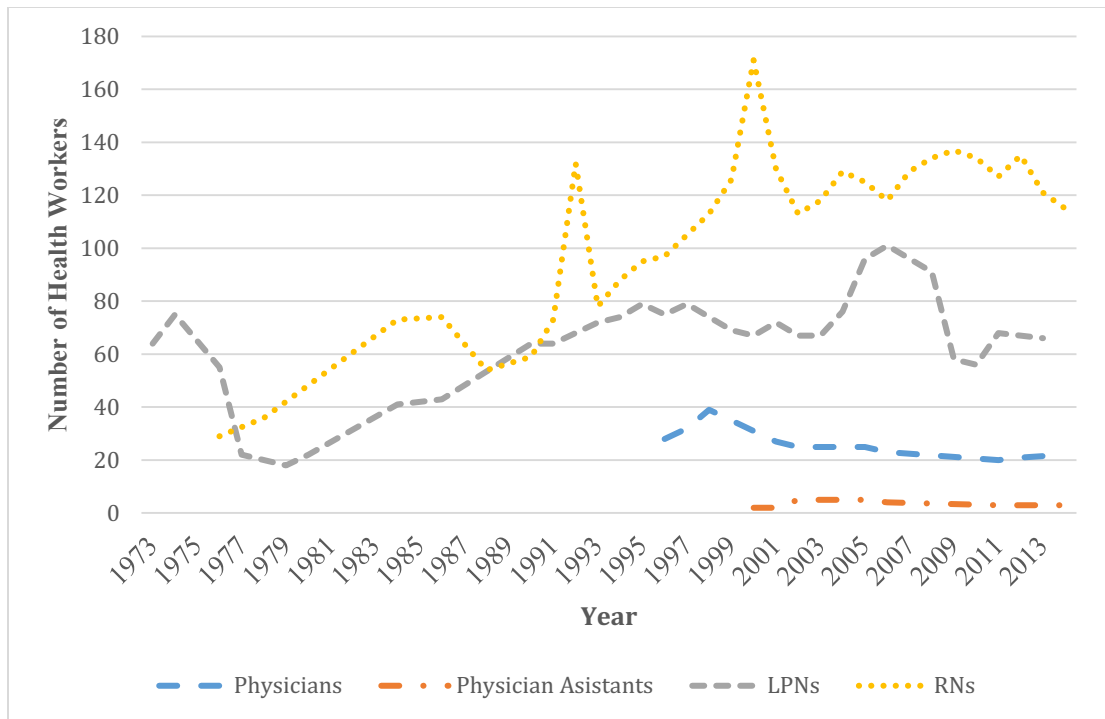
Figure 9: Historical Population and Per Capita Income Trends in Mingo County, WV<sup>10</sup>

Per capita personal income (in constant 2010 \$) in Mingo County declined sharply between 1970 and 1990, and has seen a slight rebound in recent years. The main employment sectors in the area have consistently been mining, other extractive industries, and public sector employment.(WVU, 2015) Recent efforts have been made to grow the local tourism and service sectors through developing an extensive Hatfield and McCoy Trail Network for ATVs (All-Terrain Vehicles), other hiking and biking trails, and

<sup>10</sup> Data from U.S. Decennial Census, US Census Bureau, 2016. Retrieved from <http://www.census.gov/prod/www/decennial.html> and from the US Census Historical County Income data <https://www.census.gov/hhes/www/income/data/historical/county/county3.html>. Per capita incomes were calculated in constant 2010 dollars using the US Census Bureau’s Consumer Price Index (CPI) available at <http://www.census.gov/topics/income-poverty/income/guidance/current-vs-constant-dollars.html>.

various infrastructure including lodging and restaurants to welcome and serve tourists in the region.(Carlton & Weston, 1997)

At the turn of the 20<sup>th</sup> century, just after Mingo County was formed, there were very few physicians or other professionally trained health workers to provide primary care services. By 1910, with the rise of the coal industry, the number of physicians grew rapidly, because many were hired by the industry and entrepreneurial private practitioners saw an opportunity with the strong economy to serve these rural populations (S. Barney, 1996). In Figure 10, available data going back as far as the 1970s illustrates a rise in the number of nurses (LPNs and RNs) until recently, when those numbers have largely leveled out. For physicians and PAs, the numbers are fairly steady, though there are currently fewer physicians than there were back in the late '90s when these data first became available. The current primary care physician to population ratio is 2,350:1 ("West Virginia County Health Rankings," 2016), which, although higher than in other parts of WV and within the range for a medically underserved area, is below the HRSA's HPSA threshold of 3,500 population per primary care physician.(HRSA, 2016) Shortages of health workers has been a chronic state of affairs in Mingo County and across rural and low-income WV, and this problem continues today.(WVRHA, 2012, 2014)



**Figure 10: Historical Primary Care Workforce Data for Mingo County, WV<sup>11</sup>**

In 1964, when the Congress of the United States passed the Economic Opportunity Act, it was envisioned to, “eliminate the paradox of poverty in the midst of plenty.” (“Public Law 88-452, Economic Opportunity Act,” 1964) News spread rapidly to Mingo County about the new program and associated resources, and President Lyndon Johnson made a highly publicized visit to Inez, Kentucky, just a few miles from the Mingo County border, to meet with low-income communities and demonstrate his commitment to eliminating poverty. (Huey Perry, 2011) A Mingo County Community Action Organization was formed which, over the following three years, was successful in addressing several major concerns of the low-income public by providing improved roads

<sup>11</sup> These data have been compiled from occupational census data, biennial reports to the WV legislature by the WV Board of Examiners for Licensed Practical Nurses and for Registered Nurses, and from the WV Board of Medicine Annual Report to the Legislature. Access to these data was made possible via the WV State Archives.

in remote portions of the county, educational programs for children, a community-owned grocery store, and other support. The efforts of “the poor” in Mingo’s communities to organize, however, did not take place without substantial and sometimes drastic push-back from political forces in the county. Entrenched power dynamics were being tested, and everyone from US Senators to locally elected officials was feeling threatened and bothered by the changing rhetoric, the poor’s demonstrated abilities to accomplish projects collectively, and some overt challenges to corrupt and unjust practices that had been taking place for decades.(Huey Perry, 2011; "The West Virginia Encyclopedia," 2006) Memories of the War on Poverty period and the original community-driven activities, which have evolved but still exist, remain vivid among community members and health workers who witnessed those times. These experiences and recollections have contributed a somewhat conservative filter to recent discussions about community engagement goals and activities.

From the 1930s through the 1950s coal boom, the main county health concerns were occupational hazards from working in the mines and communicable diseases such as tuberculosis. Over the past few decades, rising rates of obesity and diabetes far above national averages have compounded economic concerns and revealed a number of underlying determinants including lack of access to nutritious food and primary care (Arnett, 2015; Sustainable Williamson, 2013).

As the coal industry collapsed, the county and region’s economic opportunity has declined because no other substantive and sustainable industry has moved in to take its place. The city of Williamson has not only been dwindling in terms of population, but also in levels of engagement and interaction between the remaining community members.

*Our town, as you can see... it seems to be wasting away. I've been away from here for twenty some years. And when I came back like...there was no Williamson.* –Community representative

Recent years of effort to build a new vision and add services for the town and surrounding area have begun to bring new talent and people back into the area, but such changes are still at a very early stage. Getting the town back to the way it used to be—with a strong working-age population and a vibrant downtown community life that many long-time residents of the area remember—will take more time.

*I mean you, you see people out going to the Farmer's market, and before they put that there I think they had a mosh pit, a mud pit, there for four wheelers I'm thinking "Man, who's gonna go in that thing?" ...But, now they're there...I don't think people were involved in the community before.* –Community representative

In 2007, Williamson became part of the WV Community Development Hub's "Blueprint Community" project and then, in 2010, participated in the Hub's 23-month Community Development Achievement (HubCAP) strategic training program. These two planning and capacity-building efforts have helped to clarify work processes and increase the leadership skills and confidence of community members who are involved.

In 2009, a set of community organizations and local government officials, led by a team of concerned citizens, formed Sustainable Williamson as a joint initiative bringing together the City of Williamson, the Williamson Redevelopment Authority, and other local partners.

*Sustainable Williamson took the form of a broad initiative or a plan where all the moving pieces were in one place and you were able to see involvement from several different types of organizations towards a common goal. What we realized quickly in developing that plan was that, in this particular community, health was a driver that got people interested and motivated to make change happen.* –Health worker

A thorough and inclusive community dialogue and planning process identified a number of community priorities within the new multi-partner structure.

*We started...opening our strategic planning efforts up to the community by having these ongoing meetings. They've taken on a bunch of different names, but basically it's getting people together in one place to make plans happen. Sometimes they're like broad parts of a plan or sometimes they're small sections of a plan, but it was just this regular pattern that we've still continued and gotten a lot better at this point, of bringing in the right partners and the outside expertise to challenge those partners. –Health worker*

The mission of strengthening the local economy by “connecting health, wealth, and innovation to attract past, present, and future generations to Williamson” helped steer the direction of the work. Ultimately, the vision and activities grew to include health, food systems, education, sustainable construction, energy optimization, and tourism. So far, not all of these initiatives have been developed to the same extent.(Sustainable Williamson, 2016) According to some of the founders, efforts started small, but grew, driven by local resources as well as by the clear, consistent investment of vision and effort of local partners.

*We didn't have a lot of money...I believe that's when we were most innovative. We would just bring in small \$10,000 or \$15,000 grants and leverage the shit out of it...basically, it pressed us into an arena of having to come up with a variety of innovative strategies and getting stakeholders to build these projects... enabling them to see the already available assets that they have right now and then building from that. – Community representative*

In 2012, with technical assistance from the ARC and the US Environmental Protection Agency (EPA), several community partners put together a strategic plan for Sustainable Williamson. One of several participatory planning processes implemented by Sustainable Williamson included a series of working groups and public discussion sessions in the community. Stakeholders identified the poor health of many community

members as a critical factor in being able to move Williamson and all of Mingo County towards greater sustainability. In particular, high rates of substance abuse and its underlying determinants including cycles of poverty, low educational attainment, low levels of morale, motivation, and hope, as well as the difficult-to-access services due to disabilities or lack of transportation options experienced by many community members.(Sustainable Williamson, 2013)

As leaders looked ahead at how to scale up and replicate the model being used in Mingo County in other counties, many respondents agreed that one key theme contributed to the success of the work: community engagement and empowerment depends on clear communication pathways, facilitated by a focal organization.

*Well, honestly, I think having...an anchor institution really allows us to have such success because we have a staff that is dedicated to getting people involved. And like, I talked with this woman from Pikeville... and she said that we have such cohesiveness over here and we have this platform where we are really trying to replicate, and I thought they were doing well over there. I think we've had success, but there is a ways to go. –Community representative*

Some of the project leaders also identified challenges and opportunities of keeping the community and the primary care system engaged, working, and helping all partners envision a better future; although noticeable and valued changes have occurred, leaders wanted to ensure that local stakeholders do not consider the engagement and progress they have achieved as a finished product.

*The most important kind of theoretical distinction is between symbolic community action and connective community action... So now you're seeing a lot of these projects that are emerging with a community garden that are functioning outside of the perimeters of that very rich participatory consensus process that birthed these projects. So now... it's recognition that what I'm perceiving to be more of a burden to Sustainable Williamson... It's making a lot of stakeholders believe that, you know, the job's already done. –Community representative*

In order to maintain momentum, making the work timely and relevant to individuals from across the community has been essential to Sustainable Williamson. Partners involved in recent efforts worked hard to make different groups active as well as to ensure that the community knows what is happening, feels encouraged to voice different perspectives, and helps work on shared priorities and needs. Many respondents felt that having these structures in place was essential to the collective progress achieved so far.

*[Sustainable Williamson] is transcending those perceived barriers between hollers, between towns, between families, between states. So, trying to leverage different assets from different partners and showing how they synergistically help each other as opposed to kind of a tension or conflict between both visions was a fundamental part of the original vision that led up to a lot of the wide variety of partners which you see in all [of the] work. –Community representative*

*We intentionally went about educating our community on better options, and then to made things real for them. We just brought it down... We trying to improve. Obviously, you're looking at population health, but you have to make it personal for each person. –Community representative*

In both 2015 and 2016, Mingo County ranked 53rd out of 55 counties in West Virginia in terms of health, meaning that it had among the poorest health outcomes. ("County Health Rankings 2015: West Virginia," 2015; "West Virginia County Health Rankings," 2016) The metrics considered in this composite ranking included premature death rates, quality of life, health behaviors, clinical care, as well as social, economic, and environmental factors. Although Mingo county ranked much better than 53rd for some individual metrics, like low levels of air pollution and no safe drinking water violations in 2016, its overall health status measures leave it at the bottom of the charts. ("West Virginia County Health Rankings," 2016)



The most recent documentation from the West Virginia Bureau for Behavioral Health and Health Facilities showed substantially higher rates of overall poor health (38.9%) in Mingo County as compared with the WV state average (23.6%).(WVDHHR, 2014) In the years between 2008-2010, smoking prevalence among those aged 12 years and older was 31.7%, about the same as the state average, but mortality rates (per 100,000 population) were substantially higher for key tobacco-associated diseases including lung/bronchus/trachea cancers, Chronic Obstructive Pulmonary Disease (COPD), and cardiovascular disease.(WVDHHR, 2014) Finally, drug use was identified as a serious concern in the county, with illicit drug use rising from 8% to almost 9% of the population between 2006 and 2010, of which an estimated 50% was marijuana use.(WVDHHR, 2014) In addition, the non-medical use of pain relievers rose from 5.7% of the population in 2006 to 6.3% by 2010, on par with state averages. Drug overdose rates, however, were at 58.6 per 100,000 population, significantly higher than the state average of 26.8 per 100,000.(WVDHHR, 2014)

### **The Contemporary Community-Primary Care System Interface: Assumptions and Risks**

This section analyzes the nature of the interface between the community and the primary care system in Mingo County using a set of assumptions and risks from the study's conceptual framework. The assumptions are a set of important factors influencing primary care outcomes that were thought to be true at the outset of the analysis. Risks were factors thought likely to limit or undermine the ability to achieve primary care outcomes of interest. The conceptual framework's change pathway including these assumptions and risks is detailed in the data analysis section of Chapter VII, and each assumption and risk is discussed below for Mingo County.

*Motivated, trainable people to do the work of CHWs:* In Mingo County, new strategies to address the workforce crisis through training and new job opportunities are currently being developed. According to one of the project leaders, these efforts can help the workforce in general, not just those working in or with the local primary care system.

*We are trying to...help clean up the workforce, build jobs, help ecotourism in the area. It has been a journey these last decades of just struggle, so...this is pretty amazing just getting all these different organizations together and the hope to push this for the next five years or so. We can bring back jobs and recognize the things that are already going on in this area, create small businesses, stuff like that. –Community representative*

Hiring the right people to be CHWs is also essential. The requirements to be a successful CHW go beyond professional qualifications, as discussed by a respondent below. The focus CHW qualifications in Mingo County is mostly on personal characteristics, motivation, and commitment to the work—particularly efforts to engage with the community as they are and where they are, and help to empower those who need the primary care system the most.

*You have to have people that are comfortable in any home setting... [one of the CHWs] probably told you she got bit by a dog a couple of times. Some of the homes are so poor and dirty. Roaches running over your shoes and things like that. The people that you hire have to be non-judgmental. They have to be open with the patient. And they have to have a passion. I think everybody on our team had a passion that we wanted to see these patients do better and they became so proud of themselves. –Health worker*

Thus, strengthening the primary care workforce is part of a broader effort, which has also been supported by bringing back and engaging talented local professionals in the many recent projects.

Investments in training were needed, and many respondents mentioned training as a contributor the progress achieved so far as well as an ongoing need for the future.

While the Mingo County CHW program has workers with prior training, as will be detailed later in this chapter, it is clear that this training is not absolutely necessary depending on the roles these workers will play. Specific training for how to navigate situations that might arise during home visits and specific information about the chronic diseases that the CHWs help to manage was integrated into the previous training that the CHWs already had when they were hired. As a primary care worker described:

*We were fortunate enough that when we posted or advertised for the positions, we actually had some people that were trained in healthcare... So, we were able to hire community health workers that have a little bit of expertise in the medical field, had some experience. That really helped us a lot because these were pretty sick patients and we are in a very rural area... It probably saved us time and training people of what to do. Our community health workers already knew how to take blood pressure, they were familiar with some medications, some of the signs and symptoms of high or low blood sugars, some of the things that would be crucial to identify. – Health worker*

Most importantly, Mingo County has motivated, qualified people who are able to do the work of primary care and CHWs in the community. In fact, questions about whether someone could be over-qualified to be a CHW were also raised. Often, utilizing someone with the minimal necessary qualifications is considered most efficient, but primary care workers and community representatives pinpointed the value of utilizing whoever is available and motivated, even if that individual may have more training than necessary.

*I prefer to look at it as...what's your unemployed population and how can you put people to work in this functional role of community health workers? Are you going to eliminate a retired doctor or nurse? If they're a retired physician and they're looking to help someone in the community, are they overqualified? – Health worker*

*I just think that whole argument is...they're choosing to stay within, and, and taking a job where they can get a job where they want to be. Are you going to*

*force them to move? You're telling them they need to move? You're going to tell them where they need to live because of their education? Once again, you can't legislate common sense. – Community representative*

According to some of the founding leaders of the Sustainable Williamson effort, ensuring that a clear, inclusive, and up-to-date understanding of community needs and existing resources is important for any community that wants to systematically and efficiently work on improving primary care and its interface with the community. Without evidence upon which to make appropriate decisions, workers may lose focus and motivation, or not know which additional capacity is needed to address the primary care issues.

*I think one thing is to do a survey of community resources. Because you need a lot of resources for these patients. Identify food pantries, transportation services, pharmacies that will deliver, somebody – a social worker – to help with patient assistance. –Health worker*

Continuing to build the capacity of leaders and the next generation of the community was essential and was an area of early investment for Sustainable Williamson.

*Education is where it started, for us as leaders, or people desiring to make a difference and make it...we had to reach out for leadership training, you know, and then as we developed and had our ideas and projects, you know, we looked at our weaknesses, and those weaknesses are our opportunities.*  
–Community representative

As they critically reviewed how current efforts are working, how to move forward, and how to build and support a culture of change and new possibilities for the young people who will be inheriting the community, respondents continually returned to this point.

*It has to start with, you know, younger people... a grassroots effort is no different than how we train our small children in school. You know, if mom and dad's throwing garbage in the river, then the kids are gonna throw garbage in the river. Maybe we failed with mom and dad, so let's start with the child, and say "Hey, that's not good!"*

-Community representative

Living in Mingo County, respondents including some CHWs, described a context in which there are few opportunities, costs of living are relatively high, and life can be stressful. Having an enjoyable job, even if it does not pay much, can make the difference between a fulfilling life and discouragement.

*A lot of people wanted to leave for the money. Maybe it's not the money that's keeping them [people involved with the CHW program and related services] here or something. I mean... maybe it's the people that's trying to do right, that they're getting to help... I think they get inside the faction of helping.*

-Community representative

Respondents said that, if people are struggling with multiple life stressors and also dread their job—because these people know that there is too much work to do and they are going to be exhausted, not be able to do their best, or not be acknowledged for the effort—then they can become depressed. Community members and primary care workers, including CHWs, see it happen to many people and the workers know how it feels. Therefore, they are very grateful for opportunities where the fulfillment and enjoyment that they get from this work balances out the rest of the challenges. One CHW explained, “In community health, like I said, it just brought back why I came to be a nurse in the first place. So, it has helped me a lot, too. Not only the patients, it helped me.”

The personal gratification and value to the health workers, other employees, partners, and visiting volunteers is central to the mission and values of Sustainable

Williamson. From the core staff—all of whom started off as volunteers—to each new partner or contributor, the experience of working collectively towards a common goal shifted the perspective of many from a “me-centered” one towards a feeling of fulfillment when they realized that they are able to help others. One community representative who is closely involved in the effort described it as, “You see the light come on in peoples’ face, and it is the coolest thing...It’s contagious, I never knew I cared so much about my community!” This kind of personal transformation, and the deliberate investment in relationships among the many partners and leaders is at the core of how the Mingo County respondents characterize their successes, and their ability to strengthen the capacity and motivation for the interface between the community and the primary care system.

*Accumulation and sharing of best practices and learning:* Since the early planning stages in 2007 and 2008, efforts to learn from others and to make the learning that took place in Mingo County available and relevant for others have been common goals for Sustainable Williamson. Respondents from the community who were key to merging external experiences with local knowledge described the process, saying:

*We were keeping the pulse of what’s going on in the United States and...how communities are making it work... We were just looking for leaders in several different areas, but we had our little layout of, I think, six different areas that we thought might have activity... I want to call it a literature review, but it’s really just like listening to the news and what other communities are doing.*

–Community representative

*In southern West Virginia, we’ve become a resource center for... [other communities] to come learn the things that we’re doing... There’s a lot of groundwork that’s gotta be done there, and a lot of buy in from the community level. If the community’s not going to buy in, it’s really not going to go anywhere. So, being able to identify what can harness...the interest of the community is very, very key.*

–Community representative

One of the strategies that recent efforts in Mingo County have utilized was to ensure that successes got publicized, locally and beyond. After winning the 2014 Robert Wood Johnson Foundation Culture of Health prize (RWJF, 2014) in the wake of a number of other forward steps, Sustainable Williamson gained a steadily increasing level of visibility and profile in the region and even nationally.

*[There were] a lot of opportunities to...have synergy with other communities at the same time. So, I think when, as a team, we all started taking on this idea of, "Hey, let's make this replicable, and let's, let's see how, you know, rural communities in this region can be leaders in areas that they're good at and that we can learn from each other on that."* –Community representative

Sustainable Williamson, the central organization for Mingo County's recently developed model, integrated the Federally Qualified Health Center (FQHC), the CHW program, and a set of community projects related to agriculture, physical activity, and entrepreneurship and volunteerism. Sustainable Williamson is currently expanding to include healthcare providers in several surrounding counties in order to refer patients with chronic diseases to the CHW program; the model is being replicated with adaptations in Kentucky and North Carolina as other communities express interest in learning from Mingo's efforts.

According to several community partners, using social media and other media to publicize community events and successes, to the local population and beyond, has been a rapid and inclusive way to share experiences and learn. There are a number of Facebook pages and groups as well as is a vibrant multi-media website for Sustainable Williamson. Additional features for engaging and online tracking of community participation through "Passports to Health" are being developed.

Personal endorsement and sharing among local social networks is still essential and heavily emphasized, as this health worker's experience illustrates: "People talk and are like, ooh, I'd like to be part of that program! Word of mouth goes a long way." At the same time, using the internet to help share ideas more widely has the potential to continuously reach community members and the primary care system with timely and relevant information:

*Like you could have things in the newspaper or on Facebook, or some catchy thing, that... everybody has some computers and everybody has Facebook for sure, and I think a lot of education could be done that way... I think that would make for a healthier community.* –Community representative

*Communities accept new ways of obtaining primary care services:* A central cultural dynamic in Mingo County is the lack of trust and acceptance of outsiders, particularly of anyone bringing new solutions or directives to the area. According to respondents, some of this reticence is rooted in the underlying values or "strings attached" that sometimes accompany external ideas or support, such as projects being funded with tobacco industry profits or those with other ulterior motives. Other resistance stems from the cultural value of maintaining self-sufficiency and from suspicions about the motives and trustworthiness of "come-heres" to the area. Community representatives and primary care workers described these perspectives, outlining beliefs as well as resource and knowledge limitations as factors that influence whether patients and community members are receptive to new plans and ideas:

*Behavior change is against everything that people in this town stand for. We want things to be the way they've always been, and we don't want someone telling us how we should be.* –Community representative

*We are also realistic about what the patient will accept, or what they can do. Because sometimes things are beyond their reach as far as changing eating habits*



*or whatever. So we have to keep in mind their culture and their resources of what they have available so that we're not making things seem impossible for them.*

–CHW

A central strategy of the CHW model in Mingo County is conducting home visits, a common historical strategy of providing primary care, that has not been frequently used in recent decades. The CHWs and other primary care providers who created and run the program describe these visits as valuable as an extension of the health facility and also as a feedback loop to bring more of the patient's reality and the community context to the attention of the rest of the health workforce.

One CHW described patients' perceptions of doctors as "lawyers and policemen" with whom community members did not feel comfortable sharing problems. Another felt that patients wanted to please the clinicians and did not want them to know about their challenges.

*They [patients] want the doctor to think they're awesome! You know, it's like "Everything's good, I ain't got no problems." And then... But they'll tell your middle person [who is often the CHW].*

–CHW

Building relationships between communities and the primary care system, showing commitment, and caring about the work of improving access to primary care services has been a cornerstone of Mingo County's approach. Often, respondents pointed to the dedication of local leaders and the resulting increase in trust as the foundational elements that have mobilized the community to participate in and accept changes that can improve individual and collective primary care outcomes, even if the changes include strategies that go beyond or even against the culture. One community representative said, "I think the ingredients for success are honesty and dedication of health workers. If they

go the extra mile, it makes the patients want to go the extra mile as well.” Primary care workers had similar experiences, such as this one:

*[The founders of Sustainable Williamson] have the trust of the community, and they moved a lot of people to support effective efforts I think. Because of that community trust, and their healthcare expertise, their care for community health and individual health, and that trust that really moves people to...see the value behind it all.*  
–CHW

Patients notice if the primary care workers pay attention to and care about them. Particularly during home visits, patients have the opportunity to feel heard and understood as well as experience how the CHW is making an effort to come to them and meet them on their own terms. While the home visiting approach has turned power dynamics and the usual process of primary care on its head, patients largely accept and greatly value it. Several community members described their experience:

*Honestly...if I hadn't have got in the program, I wouldn't have ever gotten it [blood sugar] straightened up now, you know. It made me more, just a better patient....*  
–Community representative

*[The CHW] is not standing in a nine story building, waiting for people to sift through... People are obviously more relaxed at home... So, the healthcare provider is coming...if they come to [the patients'] home, they feel like they're taking an extra step right now, 'cause they're used to the other way it was. And then maybe they say, "Well, you're willing to go that far to help me... Then, then maybe I need to do more to help myself." So, I think those subliminal messages can be delivered, too.*  
–Community representative

*Funding consistency, source, quantity, purpose:* One of the key aspects limiting funding CHW services in communities is that many of these services are not directly reimbursable through insurance plans. A reimbursement structure could be established for key services such as more follow-up visits and health educational programs. Increased flexibility for local primary care providers to take the time needed to engage, as well as

educate, patients and communities so that they use services appropriately and are able to maintain their health themselves could also support the kind of CHW model that Mingo County has developed. Additional funding could also enable further development of complementary community development programs to address social determinants of health and local priorities such as job creation. As one Sustainable Williamson founder explained:

*If we do get some reimbursement, that allows us to have money to sustain a program and branch out into other types of active living... We've been creative...we're creating our recreation plan, and in doing so, we want to create a way of generating revenue through different...assets that the community has... We'll be able to enhance and help them so the money that they generate goes back into... creating more programs and also the people to help staff and work with the active living.*  
–Health worker

A number of primary care workers proposed that the insurance reimbursement for services should be given to a local institution that is providing a package of services and is accountable for achieving certain outcomes.

*The insurance company is going to be more likely inclined to reimburse for a service like that [home visits and patient advocacy] ...if they're being reimbursed through an entity such as a health center or something, some organized structure that would be responsible and accountable for their training, for their reporting, for their billing and all those types of things... If an insurance company is going to reimburse, we hope that it would be...more likely if we had that kind of model in place.*  
–Health worker

The institutions receiving the reimbursement could be FQHCs, county health departments, or other agencies that adhere to established standards, have the capacity to manage resources, and track impact within the US healthcare financing systems. Money could be given, with some flexibility, allowing agencies to allocate it for appropriate staffing and services to meet local needs.

*An FQHC or a private clinic or whatever, they already have to adhere to the regulations that insurance companies have set forth, whether that be what services they have to provide or what they expect. That would be a better model...to pass through an agency as opposed to freelance community health workers. Going through that entity would have accountability to the carrier already. I think it makes the most sense, because they're already going to have the know-how and be familiar with what's required to get reimbursed and to stay in good standing with that insurance company.* –Health worker

Not only do different kinds of services need to be paid for, people providing all kinds of primary care services need to be better supported. Several health workers described the need to provide competitive salaries to people who are willing to commit to working in rural areas:

*[The] CNAs do a lot of work, and they go in the homes and have to help the patients with taking care of things, their medication. They go get prescriptions filled, whatever they need like that. I think they're not paid enough and I think that a lot of services that are really needed...[are provided by] people on the lower scale of paying... I think that if they were paid better, then maybe they would stay...* –Health worker

*Coordination among stakeholders:* Meaningful relationships between people and organizations are needed to provide seamless primary care, bridge gaps between local programs, make linkages to other resources in the community, and build trust with the population being served. The relationships cannot be merely symbolic appearances or gestures, but must include sustained and mutually supportive interactions. One community representative described an instance where not enough was done by the primary care system to be available at a community event.

*If you want to do this, [key leaders] need to be down, and need to be introducing [themselves] and saying, "Come see me, dah, dah, dah..." [The clinic] did make a quick appearance and were gone again. They set up a table, that's been it...* –Community representative

According to several of the long-time leaders of the effort, the Diabetes Coalition grant within Sustainable Williamson's plan helped to develop and formalize some of the structures that are working well now. Having people working on multiple project sharing an office and collaborating to achieve mutual goals for the grant was a helpful kickoff.

*We formed an office of the community outreach people and...we have the activities, and then it's a matter of them being there in the office and us all trying to connect together for the benefit of the patient. We wanted to have resources for the patients to reach out to, and things to participate in to make those people be able to stand alone someday when we...kinda let go of their hands or, pushed them out of the nest a little bit at a time.*

-CHW

Outside of the FQHC and the CHW teams, partnerships and collaborations with others remain equally important, though not as uniformly well-functioning. Although the vast majority of respondents for this study spoke positively and hopefully about recent developments, a few remained skeptical about whether the new energy and vision would bring about the desired changes and reach the most vulnerable populations around the county. Others felt that they had not been offered as central or important of a role as they would have liked in the Sustainable Williamson strategy.

In the last few years, a few instances occurred in jointly offering health services and community events among multiple partners where trial efforts to collaborate led to unanticipated challenges such as limitations on which community sub-groups (the elderly, single mothers, unemployed, etc.) were eligible to participate in certain activities or access benefits associated with participating in the events. These challenges led to critical reflections from some local partners, and to some reminders about the local culture that need to continue to be considered in the future.

*I'm not saying we just need to do more health fairs, but I think there has to be a face attached to that. This is rural Appalachia and I think people trade on*

*personal relationships rather than, you know, resumes or letters after your name. That's always been my experience, and it's harder to say no when there's a familiar face.*  
–Community representative

*Community capacity to engage in planning, implementation, evaluation:* Within a rural county experiencing high rates of unemployment, an aging population, limited transportation options as well as a high disease and disability burden, there is no shortage of potential explanations for low community capacity for engagement in planning for, giving feedback to, and working to reinforce the primary care system. Yet, a number of unlikely candidates have been the driving forces behind mobilizing, aligning, and using available resources to make a difference. These local forces have included youth and young professionals motivated by family ties to the county and the desire for a brighter future for themselves and their children, chronically ill patients who feel heard and cared about—sometimes for the first time in their lives—and factions among the community did not used to work together. Several respondents noted how essential the diverse inputs have been and also the collaborative and creative process has made the recent efforts work.

*So... when you're doing a grassroots effort and you don't have money and you don't have institutions... you have to go find those partners or resources that you do have that aren't being leveraged appropriately.* –Community representative

*The people made it [the CHW program and related efforts] successful. I have to say that, yeah. We all was just easy going with it. We didn't really have a rule book.*  
–CHW

Often, patients and communities have immediate concerns and barriers to well-being, such as individuals with trouble seeing or breathing, and the whole community with a rundown downtown where no one wants to be. If these surface issues can be

examined and resolved, then patients and communities can identify and address the underlying causes of these issues. In a doctor's office or stand-alone community meeting, it is not always possible to know about or address underlying issues. Often, there is not enough time or there is not good follow-up. If the primary care system and community partners cannot address immediate barriers, some respondents suggested it may be difficult or impossible to go deeper and get the community and its members to start thinking about the root causes of their diseases and challenges and find ways to address those.

*One patient's exacerbation of breathing was because of anxiety due to his daughter. It wasn't actually his COPD, but he was going to the emergency room and getting treated over and over for flares of his COPD, and no one realized that it was actually due to anxiety. Now, we are able to treat the anxiety and he is much better. It can be lots of things, like an allergy, and then we say to get rid of the cat! You wouldn't know that in the doctor's office. It's just the overall person.*

–CHW

*The rapport that community health workers had was like a good neighbor coming over. There are people that come to your house and you wouldn't have to clean the house before you'd let [them] in. We also have other people, we know they're coming and we will clean for a week before they come. Community health workers were like those good friends that could anytime. The patient is receptive to them, and they don't think they are being judged.*

–Health worker

## **Achieving Primary Care Outcomes and Impact**

*Extent to which communities engage in planning, management, and evaluation:*

The success in Mingo County is attributed to several factors including: that all parties involved must be making efforts, remain engaged, and be generally optimistic of future possibilities in order for inevitable operational challenges to be overcome. One community organizer described how future engagement with a CHW would need to work in order to address the needs of their community organization:

*The people I trust, I trust implicitly, and that person [the CHW] would need to be part of that [team] so that we could call and say, “I’ve just brought in Mrs. Johnson and she’s expecting her first child. I am thinking it would be nice if you reached out to her...” Not somebody who’s just going to fly in or out. We want to build a long-term relationship. That would help us because, when you have this transient population, it’s because there are no anchors. Being able to bring families in and provide those kinds of services would anchor them so that you could see long-term results and change in their behavior.*

–Community representative

The local political context in Mingo County is sometimes not conducive to collaboration and coordination and community engagement. Some of the local structures, whether they are political, economic, or social, have been in place for a long time, and are unlikely to change easily or rapidly. Respondents described some of their experiences working in local organizations within the old dynamics while working to create new ones:

*It’s very political to work in this city [Williamson] ... When I was approached about applying for this position, I thought, Wow!” ...Little did I know that [this organization] has been used as one of those things where it was padding the pockets. [It had been] mismanaged for so many years that it was just... they couldn’t do anything more.*

–Community representative

*There’s a lot of fighting going on and politics and stuff, so we want to take the focus off all that, and just try to have something positive for people to do with no charge you know. Plus, our facilities are getting utilized. So, it’s kind of a win-win.*

–Community representative

Despite the challenges and limitations, developing goals, seeing the successes, and cultivating local pride for being part of work that can improve primary care outcomes keeps many of the respondents focused and motivated. One leader of Sustainable Williamson described the kind of shared goal that is helping to mobilize many people:

*One of the important things is that all of the pieces are working together. For 2016, there is an ambitious goal of 9,000 healthier lives in Mingo County. This pulls together the community health worker program, visitors to the farmer’s*



*market, participants in the walking groups, participants in the farmers market and the community garden, and other things. It is a true team effort to engage as many people as possible in different parts of the program. –Health worker*

*Access to and Utilization of Primary Care Services, including rural and low-income populations:* Barriers to accessing health services and information were several in number, with transportation being the most consistently raised concern by health professionals and community representatives. The transportation issues included being able to attend medical appointments at clinics and hospitals, picking up prescription medications, and accessing other resources for health such as the farmer's market and preventative services like immunizations at the county health department. With only one bus line that runs infrequently, public transportation is limited in the area and has recently decreased services to the options are even fewer than before. There is a taxi service with limited coverage area, but it becomes costly if relied on regularly. A few mostly faith-based transportation services are also available, but they require rides to be arranged ahead of time. Taking advantage of available transportation has required educating patients about the options, and helping them learn to plan ahead.

*We found a lot of times patients didn't have transportation and that wasn't a role as community health workers, to transport them, but we could help them identify services that were available in the community that patient had never used before. –CHW*

*Early signs of improved health status:* This study does not focus on the direct link between primary care outcomes and impact on health status. In Mingo County, the duration of the current efforts is still too short to determine the full impact of some of the efforts that have been implemented in the previous decade.

With the available evidence, however, changes in health status are measurable and promising—particularly for high-risk chronic disease patients, the African American community, and many elderly and disabled persons. Blood pressure and hemoglobin A1C levels have decreased and remained lower among many chronic disease patients, particularly those who were difficult to reach due to belonging to one or more of the vulnerable groups mentioned before.

Continued collaboration, learning, commitment, and enduring effort will be needed, and both the community and primary care system clearly see the work that lies ahead. One primary care provider shared his/her perspective, based on efforts so far, for what is needed to continue to move forward:

*If you really wanna make that effort [Sustainable Williamson's mission and vision] successful, then it's gonna require that the providers and the people with the knowledge to help people actually get to where they can help people and go into those [places] ...providing care and education and assistance in a way where it's most effective, which is in their everyday life, not once a month or not as an emergency arises.*  
—Health worker

### **CHWs in Mingo County: Current Practice and Future Aspirations**

*Current CHW uses and experience:* A cadre of CNAs, LPNs, and a pharmacy technician are doing home visits with high-risk chronic disease patients to help patients manage diabetes, Chronic Obstructive Pulmonary Disease (COPD), and Chronic Heart Failure (CHF). This is the only group of workers in the county whose official title is CHW though there are others doing work that could fall within a CHW job description.

One of the managers of the CHW program described the origins of the CHW program:

*[The CHW project] first came about when we started the...Southeastern Diabetes Initiative, which was a research grant-funded program with Duke University and the Centers for Medicare and Medicaid Services. The purpose of that program was to see if the use of community health workers with patients with uncontrolled*

*diabetes could decrease cost, keep them out of the hospital, keep them out of the ER, as well as improve their outcomes.* –Health worker

The responsibility for improving the health of the community doesn't lie only with CHWs or with the primary care system; it also rests with the patient and with the whole community to support, integrate, and mutually reinforce changes and services being offered to the community.

*We're trying to develop support groups and stuff here so they [community members and patients] can be accountable for themselves, you know. We just have to teach them to the best of our ability and, you know meet them where they are as far as knowledge of what they already know and then go from there.* –Health worker

Several CHWs described their roles as supporting their patients and connecting dots among people and services to improve access and utilization of the primary care system and other local resources that can help manage and improve health:

*We can teach them [patients and community members] clinical things, but if they don't have a place that they can go to practice, you know, what we teach them, then it's gonna...they're gonna fall short. They're gonna be cheated, you see what I'm saying? So we have to have that other person to connect them with... You know, like the Farmer's Market, we have to have a place for them to be at. We have to show them, and by them getting out and doing, then they're accountable to their self. Like "Hey I can do this! Hey, I can eat better! Hey, I do have options," you know?* –CHW

Ensuring that the work of the CHWs does not make patients and their families and communities more dependent, but rather empowers them and gives them knowledge, confidence, and encouragement to become more independent and in charge of their own health and care is the ultimate goal of the CHW project. One of the primary care providers supporting the CHWs described the ultimate vision:

*The goal of the program is not to make that patient dependent to where they can't do anything on their own. But actually to help them assume more responsibility and knowing when to call the doctor and what the problem is. –Health worker*

A vast amount of learning and collaborative effort among different primary care providers and community partners have helped inform policies and processes being put into practice during the second round of CHW funding that began in the spring of 2016. Key to this learning is CHWs working hard to empower their patients through small things like the following:

*We try to... not make them totally dependent, but teach them how to make that call to get that transportation. Some of the patients, it was getting their refills. Forgetting to call for the refills or... calling when their prescription ran out, that was it. Some of them have difficulty getting to the pharmacy to get their refill. So, there were two pharmacies in town that actually deliver to people. So putting them in contact with the resource to do that.*  
–CHW

An essential part of effectiveness of the Mingo County CHW program is the strong support and supervision from other health professionals. This can be a challenge since highly trained mid-level providers and physicians are sometimes too busy to give CHWs necessary support. In Mingo County, there is a designated mentor who is a central point of contact for the group of CHWs. She is also the case manager that works with the CHWs and their patients. They have a weekly meeting that includes at least one (and often multiple) primary care providers. In these meetings, each case is reviewed and discussed as a group to ensure that nothing is being missed. The team (peer CHWs and the providers) often troubleshoot and brainstorm solutions. CHWs and the non-clinical support staff working with them emphasized the value of these meetings:

*After a while if somebody's noncompliant for so long, you're kind of wracking your brain, "What do I do with them now?" You've got somebody to come back to. You say, "I've tried this, I've tried this, I've tried this, what do you think?"*

*And then your other community health workers is at the meeting as well, plus [the care manager] is there and the social worker, and your nurse practitioner. There's plenty of advice, and it's really good.* –CHW

In addition to the official CHW program, a number of home health agencies provide basic care to elderly and homebound patients. The quality of these programs is perceived to be variable by primary care worker respondents who cite insufficient drug and felony screenings of the workers as a major contributor to prescription medication theft and overall low quality care. Current levels of collaboration, synergy, and integration between these home health workers and the CHWs is limited.

Finally, Sustainable Williamson's outreach efforts in local agriculture and nutrition, physical activity, entrepreneurship, and leadership across the county fall within a common CHW job description. Community partners who are working on addressing health issues through recreation, rehabilitation, and school-based health and nutrition initiatives also contribute to outreach, advocacy, and education responsibilities that are part of the CHW roles.

*Future aspirations for the role CHWs:* The focus of the current CHW program is on high-risk chronic disease patients. Many of the respondents for this study were very clear, however, that confining CHWs to this narrow focus in the future would limit their potential for impact.

*We see patients smoking cigarettes every day. Smoking cessation is going to be a big thing. I have a lot of patients with COPD that continue to smoke... I still can't understand how you could struggle to breathe and continue to smoke. Yeah, I think that will be interesting. The community health workers are already receiving more training on congestive heart failure and COPD so they're targeting areas when they go out to their [community members'] house. So they'll be involved in that.* – Health worker

Another area where community health workers could be extremely valuable, according to CHWs and other primary care providers, which is not the focus of the current model, is related to hospital readmissions. Everything is very fast-paced in the emergency room and in doctors' offices; patients often get post-surgery instructions or large amounts of information when they are being discharged from the hospital. When these patients get home, they either do not understand or do not follow those instructions. Having someone who can do timely follow-up, reinforce the information, and help overcome any barriers to following instructions between discharge and when the patient goes for their official follow-up visit with their doctor could greatly improve patient outcomes. Other transitions between rehabilitation or nursing services, or when starting or stopping the use of medical equipment in the home could also benefit from such support visits.

### **Summary of the Mingo County Experience and Findings**

Mingo County has undergone a recent transformation of its community engagement strategies and primary care system functioning. A decade ago, local stakeholders identified that Mingo County's community and primary care system were facing a dire situation: the exodus of many talented and working-age people, high unemployment rates, rising incidence of chronic diseases, and a growing burden of mental health issues including high rates of drug and alcohol abuse. Several decades of economic downturn on top of a complex history of politically divisive and socially demotivating county leadership precipitated this situation.

What is now a vibrant and nationally-recognized model of forward-thinking progress and planning for primary care and local community development began with a

group of concerned primary care workers and community leaders in the county. This group felt that they had an opportunity to create an alternative approach to providing primary care services to the county's population. They saw an opportunity to make the choice to either watch their home continue to experience diminishing resources, declining capacity for engagement, and a lack of coordination and collaboration among local stakeholders—or they could help transform it into a place in which a desirable future was attainable for even the most difficult-to-reach and underserved groups in the county. Stakeholders in Mingo County have studied and built upon many other models and examples of community development efforts implemented during the past decade (particularly other CHW models and other multisectorial development efforts around the Appalachian region). Many respondents reported that learning from others' experiences has helped prioritize their tasks so that the available capacity in the primary care system and community does not get diluted or wasted, but is directed instead toward the tasks where it can make the most difference. High priority tasks have included building and maintaining relationships among partners and with patients as well as ensuring that diverse perspectives are consistently heard and acted upon.

In order for the community and primary care system in Mingo County to participate in the original planning phases and be willing to try new strategies, respondents described that the quality and value of the proposed plans and services had to be demonstrated to both community partners and individual patients. Value was demonstrated by addressing local priorities, respecting individual patients, and creating a shared culture of commitment and collaboration. The presence or absence of quality and

value was also also seen as an important influence on whether the new strategies would be accepted and sustained.

For the community respondents, the desired qualities and values that the new projects needed to incorporate were to retain community dignity, to respect and integrate local culture, knowledge, and capabilities, and to receive compassionate and committed care from providers. Community members experience life as an integrated whole and through their cultural and experiential lens, not through an externally-derived technical or theoretical lens. In this way, health is not isolated from employment options, transportation services, access to healthy food, recreation possibilities, or an overall sense of belonging to and being cared about by the community.

For primary care workers, the desired values and qualities for primary care and the community that respondents focused on were to have adequate resources to pay for the planned work, and for assurance that the additional of different requirements or work would improve their patients' care and their experience as health workers. The tasks that the CHWs started to perform had value recognized by some providers, but were challenging to pay for using health insurance reimbursement processes. Explaining how other similar models worked and providing direct experiences with CHWs were necessary steps in order to help primary care workers see the value of the effort. Primary care workers also needed assurance that new models would not undercut the current system or "steal" patients from them for the new project.

Given the history of mistrust and exploitation in Mingo County, the onus to demonstrate new values and commitment was on the primary care system and a core set of community leaders. Getting outside of the of the clinic walls and politically exclusive



local circles to meet people on their own terms and turf—often in their homes—has been essential in the views of many respondents to lessen the divide between providers and patients. Both the community and the primary care system are proud of the progress achieved thus far. Maintaining a balance between acknowledging and celebrating the progress and also recognizing the work that remains to be done is important for the future of Mingo County.

The vision for a healthier future, which the local stakeholders in Mingo County developed, is larger than any particular actor's success or any single step in the process. Being able to use this vision to maintain or regain momentum and guide decisions has helped these stakeholders overcome frustrations and challenges that inevitably arise while implementing community projects. While efforts to engage and coordinate multiple diverse local partners has not been without challenges and frustrations, the shared vision and recognition of the consequences if action is not taken have helped maintain forward progress.

The structured, inclusive, and consistent process for interaction established between the community and the primary care system was seen by respondents as central to Mingo County's success. From the beginning, everyone was welcome and encouraged to share their perspectives and needs. The regular process for interfacing between the community and the primary care system in order to discuss ideas has helped ensure that local priorities and solutions were not undermined or ignored in favor of external ones. The consistency of these meetings also supported accountability among the diverse partners, and created a space within which to build relationships. The number and diversity of current community partners within the Mingo County effort is exceptional.

Multiple generations of people with different backgrounds—ranging from medicine to sports to marketing to engineering to politics—have all found or created a niche for themselves in order to help move the shared vision forward. In contrast to earlier efforts during the 1960's War on Poverty, where the poor were pitted against the local ruling class, some of those barriers have recently been taken down.

Since the beginning, improving primary care outcomes has been the ultimate goal of Mingo County's multisectoral approach. Measuring community engagement and access to services proved to be a challenge. This challenge has become a motivator for investing in local partnerships and relationships as well as a way to attract continued resources and talented people to grow and sustain the project.

Community engagement has helped leaders of the Sustainable Williamson vision align their efforts with community priorities and has greatly increased local capacity to do the necessary work. For the primary care system in particular, building relationships with the community has helped these stakeholders understand each others' needs and limitations better, and has led to innovative solutions at individual and organizational levels. This increased motivation is seen as being due to primary care workers and community partners feeling included and heard during planning and decision-making processes, gaining confidence, and seeing the outcomes of their work.

Access to primary care services is a complex challenge for many people in Mingo County. The CHW effort and the multi-faceted approach to strengthening the county's economic and social capacity have begun to address this issue. Access to health information, primary care, and other opportunities is particularly limited for low-income, homebound, and remotely-located community members. Some of the strategies

addressing these barriers to accessing care—including the CHW program—currently rely on grants, volunteers, and other resources that may be challenging to sustain in the future. Evidence of their value for the county is increasing and additional sources of funding are being sought. These efforts could free up additional time and resources for local partners to work on identifying and addressing other underlying social determinants of health, Sustainable Williamson’s ultimate goal.

Having a designated CHW cadre is a new approach for Mingo County’s current primary care workers and community. Even though these workers have only been utilized for a couple of years, respondents described how they have been accepted and are valued by the patients they serve and the primary care providers with whom they work. Although coal company doctors and midwives used to make home visits many years ago, conducting home visits was a practice that needed to be re-introduced in the county, and respondents involved with the program described the efforts undertaken to raise awareness and make sure each patient was comfortable with the program. The analysis conducted about Mingo County’s experience suggests that supporting CHWs—all of whom are from the area and are committed to the work—to reinvent and actively hold that role can strengthen communication between community members and other primary care providers. Respondents felt that CHW efforts have contributed to improved access to health information, support, and basic care to many community members who would not have been able to access those services before. Training was needed for the CHWs, and training continues to be a priority for many young people who would like to stay in the county and get involved with one or more of the projects that are underway.

## **IX. Pendleton County: Context, The Historical and Current Interface Between the Community and the Primary Care System, and the Work of CHWs**

This chapter describes Pendleton County, WV's experiences across the research questions and uses the conceptual framework change pathway articulated at the beginning of Chapter VIII for Mingo County. This section traces the historical trajectory of and current interactions between Pendleton County's community and primary care system. In particular, it analyzes community and primary care system efforts to reach out to each other, work together, and communicate needs, priorities, and ideas to overcome challenges. Pendleton County's experience with the work of CHWs is also explored, including stakeholder perspectives on which services CHWs could provide and which roles CHWs could fill in the future to make the most impact.

### **The Interface Between the Community and the Primary Care System in Pendleton County: Context and Historical Experiences**

Pendleton County's economy is based primarily on agricultural production, and the county has attracted small businesses and industry. A Navy Base—Sugar Grove Station—was located in the county until 2015. Over the years, there has been an increasing focus on economic growth from tourism particularly from outdoor sports and recreation. The county also several non-profit organizations working locally and globally on education and environmental issues. ("The West Virginia Encyclopedia," 2006) Agricultural activities, as well as production of livestock and poultry, have historically been and remain the county's largest economic drivers. Some of the county's largest employers include logging, sawmills, and a lime manufacturing company. The Pendleton Manor and Pendleton Community Care (PCC) are two major providers of primary care

services that also employ a number of local people. The Hanover Shoe Factory, which employed as many as 700 people during peak production, closed its doors completely in the year 2000 after a slow decline in production. ("The West Virginia Encyclopedia," 2006)

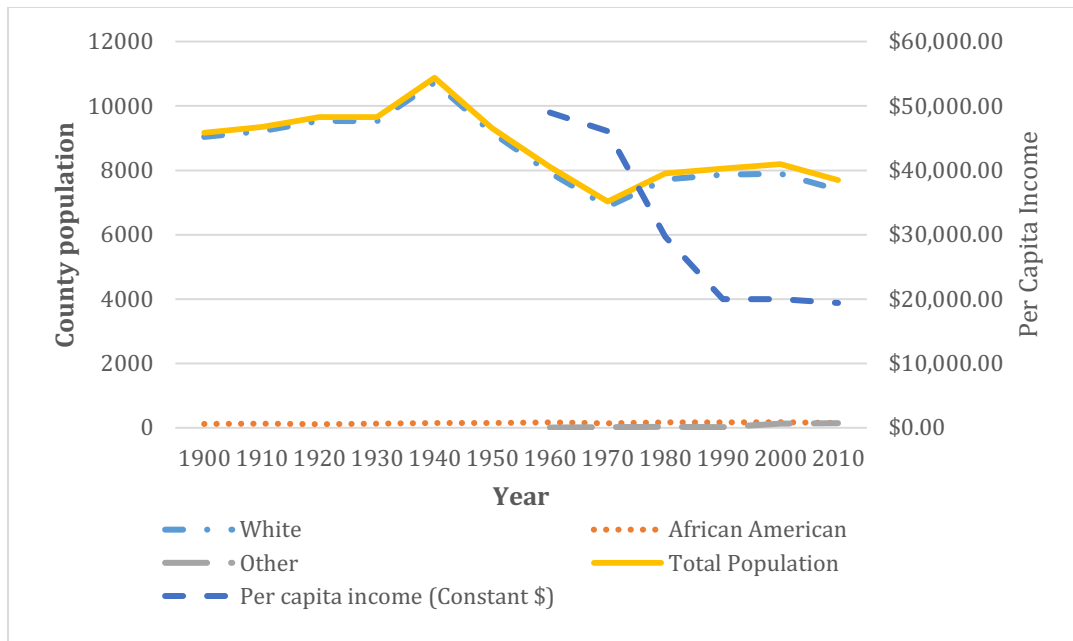
At the time of the Great Depression, the economic downturn that spread to Pendleton County did not hit a thriving population, but rather one that was already supplementing farming incomes and seeking alternative livelihoods by having family members work for the Department of Highways, logging companies, or county schools. (J. B. Thomas, 2010) Farmers focused primarily on producing crops for local consumption, with the exception of livestock and wheat which were sold as cash crops. (J. C. Taylor, 1980) Particularly in the North Fork—the county’s northern and most rural valley—those without debt managed to continue living fairly normally during the Depression years with the only direct burden being payment of real-estate taxes. Many of them were described as living “less from income than from lack of expense.” (J. C. Taylor, 1980)

The Depression did not dramatically depress conditions further in the county, but rather it brought them into the public awareness. In those years, as before, “the poor survived because they knew how to be poor” meaning that they knew how to be self-sufficient and leverage the value of common homegrown or homemade items that they could produce and use or trade. (J. C. Taylor, 1980, p. 821) Further, the 1931 failure of all three county banks and lack of any local bank until 1937 led much of the population to resort to a barter system. ("The West Virginia Encyclopedia," 2006) The county benefitted from New Deal’s construction of over 300 miles of new or improved roads and state-

level investment in the school system ("The West Virginia Encyclopedia," 2006), but not specifically from health programs as in other parts of the country.

During the 1930s, the 4-H program—a youth health and leadership program—and several farm women’s clubs were developed and contributed to “educational enlightenment and also Pendleton’s social and organizational life.”(J. C. Taylor, 1980) Such changes toward modernization of society took place to a greater extent in Pendleton County’s close-knit community than in other parts of Appalachia, and created a strong social fabric and shared local identity within which there was a sense of belonging.(J. C. Taylor, 1980, pp. 830-832)

The population of Pendleton County peaked in the 1940s, declined until 1970, and then leveled off (see Figure 11). The Post-World War II years spurred the beginning of this out-migration as people left to serve in the war and then to seek better opportunities in the national post-war economic boom.("The West Virginia Encyclopedia," 2006) The population of Pendleton County has been overwhelmingly white since 1930, with a small number of African Americans and a few persons of other ethnicities who arrived beginning in the 1960s. The per capita income in the county (in constant 2010 \$), decreased dramatically between 1970 and 1990 and then leveled off. A qualification to recent income figures is necessary: an increasing number of the people living in the county are commuting outside of the county, and even across state lines, for their work.



**Figure 11: Historical Population by Ethnicity and Income Trends in Pendleton County, WV<sup>12</sup>**

In addition to the declining population size in Pendleton County, the residents also have a higher average age than that of WV or the US.(Grant Memorial Hospital, 2013) This elderly population brings with it additional primary care system capacity concerns and specific challenges to ensure access to primary care for the elderly population.(Grant Memorial Hospital, 2013)

Figure 12 includes available data going back as far as the 1970s and illustrates an upward trend for the nursing profession and a fairly stable but fluctuating workforce of physicians and PAs in Pendleton County. The current primary care physician to population ratio is 1 to 1870.("West Virginia County Health Rankings," 2016)

<sup>12</sup> Data from the US Decennial Census, US Census Bureau, 2016. Retrieved from <http://www.census.gov/prod/www/decennial.html> and from the the American Community Survey 2006-2010 (<http://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=bkmk>). Per capita incomes were calculated in constant 2010 dollars using the US Census Bureau’s Consumer Price Index (CPI) available at <http://www.census.gov/topics/income-poverty/income/guidance/current-vs-constant-dollars.html>.

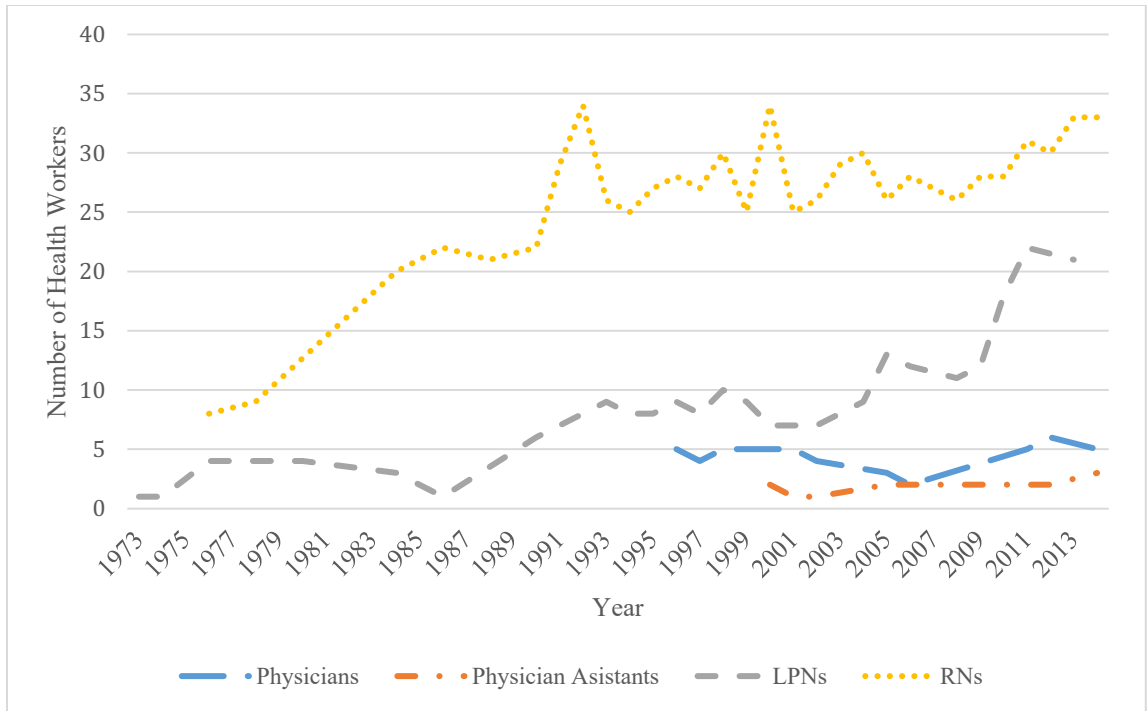


Figure 12: Historical Primary Care Workforce Data for Pendleton County, WV<sup>13</sup>

In 1965, Congress created the Spruce Knob-Seneca Rocks National Recreation Area, a 100,000-acre holding including the peak of Spruce Knob which is the highest point in WV; this area now serves as a tourist and environmental education destination for the US's East Coast. ("The West Virginia Encyclopedia," 2006) Looking back at the time when War on Poverty programs were being implemented, reflections of how those programs functioned still color the perspectives of long-time health workers today:

*We've certainly had experiences with agencies that were federal in nature that have come in from outside over the last 50 years. I guess in the 1960s we had... I can't even remember the name of the groups that came in to help refurbish homes and work...there were some programs associated with War on Poverty, and people came in, "I'm going to help you guys do this." And that's fine, but people here need to help themselves do this and that's really what we need plus it would add jobs here which is...we need people that live here. —Health worker*

<sup>13</sup> These data have been compiled from occupational census data, biennial reports to the WV legislature by the WV Board of Examiners for Licensed Practical Nurses and for Registered Nurses, and from the WV Board of Medicine Annual Report to the Legislature. Access to these data was made possible via the WV State Archives.



No additional documentation of activities related to the primary care system or community engagement in health was identified for the period between the 1950s to the late 1970s. While national programs—including the War on Poverty—and economic shifts in WV such as the decline in coal production after the 1950s likely indirectly affected the county, no major changes in the practice of primary care or community engagement due to these programs were identified in this study. Pendleton County’s primary care services were limited to a couple of elderly family physicians with private practices.

In 1978, the Memorial General Hospital in Elkins, WV in neighboring Randolph County established the North Fork Clinic in Riverton. In 1982, the new clinic was closed due to lack of a physician to staff it. The Riverton facility was re-opened shortly thereafter in collaboration with the Spruce Mountain Ruritan Club and Grant Memorial Hospital in Petersburg, WV, until the flood in 1985 washed it away completely. Within a week or two of the flood, the clinic was re-established in a nearby trailer. In the autumn of 1989, the clinic re-located to the Riverton Community Center building, where it remained for a number of years until moving to a newer building where it remains today. The clinic has been staffed primarily by a PA since at least 1986. The clinic also shares staff with PCC, which assumed management of the clinic in the 1990s.(Pendleton County Commission, 1991)

Until the 1980s, the Pendleton County population relied on country doctors to provide basic health services—often including home visits. Even today, many of the primary care workers in Pendleton County have spent their entire careers working in the

county. The resulting continuity of care providers layered on top of a fairly stable, though declining, population created benefits and challenges which will be described in the following sections.

Beginning in the 1980s, local non-profit leaders realized that the need for health services was not being met by the two private physicians working in the county.(H. Taylor, 1984) Increasing community engagement was central to early discussions about addressing this concern.(D. Taylor-Ide & Taylor, 1983). Engaging the community in this fashion was a different approach than the way primary care services had been provided in the county up to that point, and it was initially done in two ways. First, meetings with the local Lion’s Club, the Rescue Squad, and other community groups were held. Secondly, a county-wide survey was sent to all postal addresses which resulted in response rate of just under 20% and overwhelmingly pointed to the perceived need for an additional local physician.

A community group with outside advisors was formed, and a thorough literature review and site visits to other examples of best practice for primary care provision around the state and region were conducted. Conversations with donors and global leaders in field of community health were arranged to inform the design of a new health center. The envisioned center would be equipped to help respond to the needs of the county, including high rates of infant mortality and lack of trained primary care workers. One of the founders remembers:

*[Having a health center] was a major need because the county was very proud of its county health department and the two practicing county physicians were beloved of the county, but... a department of public health which theoretically should be providing a systemic framework and with clinical providers of good kind benign country docs were not creating the culture of health and so, I said “This is a great opportunity.”*

–Community representative

When PCC, the new community health center, was formed in the early 1980s, the team that organized and was hired to staff it included health professionals and community representatives such as members of the local Lion's Club. The Lion's Club was a key player and viewed the new clinic first and foremost as an economic development opportunity—because a good health care option would be an attractive draw to businesses starting in or moving to the area. Even with substantial support from local leaders and decision-makers, the team knew that, in order for the new primary care clinic to have credibility and the capacity to do what was needed, a doctor on the team was essential:

*We were starting to have the community conversations...but it's not going to work to have a community conversation unless there is a doc there.*

–Community representative

*The thing they [the community] wanted was a doc, and I say it makes sense. That's, you know, that's like healthcare 101. Yeah, I want a doc, and, as you take a broader look at things, you see that there are other issues...I mean a doc, having a doc in the county doesn't fix everything. So, I think it was the beginning of educating the community to think about their own healthcare, and I think the thing that really sold the clinic was the personal encounters.* –Health worker

The early years of running the clinic coincided with a national and global movement to increase the practice, profile, and effectiveness of COPC. In an effort to adapt to the needs of each community within the US health care system, demonstration sites around the country were established, of which Pendleton County was one.(Henry G. Taylor & Taylor, 1989) These sites focused on increasing the amount of preventative health education and services, putting additional attention on the home and community to improve health status rather than relying solely on health facilities. PCC was an early

implementer of COPC, which took a population-based perspective to improving health status by building a local care system—focusing on community needs, implementing interventions as an iterative process, and periodically evaluating desired outcomes.(Nutting, 1987) The founders of the clinic brought in outside expertise and ideas from around WV, the US, and the world. Community health centers (or “family health centers”) had recently emerged as a concept in the US; one of the first WV models to be promoted for PCC to learn from was the New River Health Center in Fayette County (Madison, 1980), according to a member of the founding team.

Some of the elderly country doctors raised early opposition to the idea of setting up a new community-oriented health center in Franklin, the Pendleton County seat. Some community members also remained suspicious and complained about how they were being asked to be involved and how the clinic was managed, even after it began offering services. As one health worker who worked at the clinic near the beginning of the project reflects, significant shifts, such as establishing PCC, take time.

*I think it's just the nature of the process, that... some people in the community don't like change so they're going to come up with reasons why they don't like it and... it's not worth putting a lot of energy into worrying about the people who were complaining about stuff. We need to just do what we do and do it well and they will work out.”*  
–Health worker

Plans for PCC moved forward, and the process of gathering data and experience led to the formation of key concepts for how the clinic would function. PCC was envisioned to be a major provider of primary care in collaboration with the community and other agencies that were also working to improve the health status of the county. According to one of the founders:

*I talked to a bunch of people and...they came up with the conclusion that you had to do two things. Number one, you had to build the confidence in the community, and that meant you had to take care of them when people were sick, and you had to provide quality service... If you're providing something that isn't wanted in the community, [they] will resist it. Secondly, I needed some leadership that was in the community. So, I went and talked with the "Franklin Fathers."*

–Community representative

The “Franklin Fathers” was a local term for an informal group of preeminent community figures who ran the banks, nursing home, and churches, and owned large tracts of land in the county. Some of them very quickly understood the concept of creating a primary care center that engaged the community and worked to improve health for the population by focusing on systemic change. Buy-in for the idea of a community health center was strong because of the current state of the health in the county and the growing realization that it would be difficult to find a young primary care doctor to continue the work that local physicians nearing retirement age were doing.

The founders of PCC faced a dilemma: how to find the balance between being a community clinic focused on servicing the community and being answerable for the county’s health, and with striving to be a model that pushed the boundaries on what primary care practices could accomplish in and with communities. The COPC principles and the thinking of the day advocated for primary care to include work outside of health facilities in order to address the health of the community through a more dialogical and intentional way. PCC’s founding team was eager to experiment; they analyzed the trade offs and made decisions about the future:

*[We had] motivations to do something that was outside the clinic walls. [Other leaders than the ones we chose] would have supported it, but it would have been different. It would have been managed. It would have been really... the community would have loved the clinic. They would have owned the clinic more... If they would love it the way they loved [the preceding country doctors,] it would*

*have been their personal clinic, but it wouldn't have been a model. It wouldn't have been [able to compete] for grants. It wouldn't have become an FQHC.*  
–Health worker

PCC officially opened on October 4, 1982 focused on a strategy of listening to and giving the community as much space and agency for input into evolutions of the design and structure of the clinic as possible. The original staff included a NHSC physician, an NP, and one administrator. The clinic began with a small ARC grant to address the high infant mortality rate and a modest line of credit at the local bank. (Henry G. Taylor, 1995)

A key component of the original model of PCC was health education to reach every home in the community. A health membership service with several tiers was constructed—ranging from a basic option of receiving health newsletters up to participating in health education and exercise programs; it included the opportunity for members to vote on certain decisions about the future of the clinic. (Henry G. Taylor, 1995) The thrust behind the educational approach was to inform and mobilize the community to better understand the root causes of their illnesses so that they could to prevent and manage these, as well as access services and information as needed.

The membership service ran for the first several years of PCC's operation, but was discontinued due to low enrollment. A few respondents suggested that community members may not have seen adequate benefits to warrant the required investment.

*So, the design that came in the model was, we absolutely have to do education and it has to be a three-pronged educational approach. Number one, we need to have a newsletter that goes out into as many homes as possible. Number two, we need to be running classes that are open to the public, but if you were a member of a program you got in free... and thirdly, you had to be prioritizing education [in the clinical setting].*  
–Community representative

An alternate perspective on why the membership did not succeed was that, without strong administrative support and promotion of as well as investment in the educational effort, the membership program got neglected.

*Some patients in the community were frustrated because of the heavy emphasis on education, and they just wanted to go in and get the pill and come out. So, that was a cultural shift that I could see and hear about in the county which is interesting to me. What I thought was the most important service; many people were thinking it was a waste of their time. –Community representative*

Even among one stakeholder group, these quotes illustrate the importance of seeking and considering a number of perspectives about why an idea or venture did not function as planned.

According to a 1984 description of PCC's formation, the Board of Directors of PCC was composed of a majority of elected community members with additional board members appointed to contribute technical expertise.(H. G. Taylor, 1984) These early notes about the clinic also observed that a fee-for-service program for “preventative care or health education are not very viable.” The concept of “community care” which guided the organization, was defined as: “the collaboration between a community and its health providers in solving their health problems.” These notes described the importance of an equal partnership between community and primary care system that included defining health needs, clarifying problems, developing and implementing solutions, and evaluating the ultimate success or failure of these strategies.(H. G. Taylor, 1984)

While the early efforts to engage and work closely with the community to improve health were not without tensions and trials and errors, reflections of community members and health workers on that time indicate that that vision and implementation of early ideas helped to frame the foundation for an enduring community institution. A

community representative described his early efforts to integrate the community with the clinic as on the things that was done right:

*I spent a lot of time on the streets and met with a lot of people. I was a local person, and there was some skepticism in the community towards the beginning of the project because outsiders aren't as easily trusted. This is something that the local people needed, to be talked to.* —Community representative

Primary care workers credit the community—as much as anyone else—for raising awareness about and PCC's reputation as a good place to go for primary care. This community advocacy built on long-time community support for the local health department and the independent primary care physicians.

*I think, the residents themselves are the ones that have really pushed it [PCC] into the neighborhood, I mean we can do all the outreach stuff that we want to do. But until you can say, I had a good experience there and you can tell your babysitter that you had a good experience there, they are not going to come to anywhere without that word of mouth saying, "Hey! it was good, go there."* —Health worker

PCC's early interventions included providing basic health services, identifying priorities through a series of community meetings, and facilitating the community response to the 1985 flood.(Henry G. Taylor & Taylor, 1989) The flood of 1985 caused significant damage throughout the eastern part of WV, but it hit Pendleton County particularly hard—causing massive property damage, contributing greatly to the erosion of some of the best farmland in the county, and killing 16 people in the county.(Counts, 1989) It also may have reinforced some of the division between the northern and southern valleys of the county, a local rift dating back at least to the Civil War and further entrenched by the presence of North Mountain that geographically separates the two.(Counts, 1989) This resentment between people in the county's two valleys was



underscored by differing degrees of access to flood relief services and varying perspectives on how to rebuild afterwards.

Equally traumatic to the community, however, was the chaotic, political, power-fraught response of external agencies interfacing with local leaders all of whom sought—and at least many claimed to find—ways to further their aspirations, agendas, and viewpoints for the community’s future in the aftermath of the disaster.(O'Brien, 2001) Vying for various proposals and control over the vision for the future of health and education in the county, a collection of strong characters caused an uproar that nearly ran several local leaders out of town and showed clearly that the community—even in a crisis—did not appreciate having others’ ideas imposed on them.(O'Brien, 2001) The 1985 flood was a turning point for the role and reputation of PCC in the community since the clinic provided a significant amount of flood relief, and a number of post-flood ideas related to health emerged from clinic affiliates.("The West Virginia Encyclopedia," 2006)

As PCC continued to work, it faced several transitions and traumas including—the flood, the move from the clinic’s first location in a large house on Main Street in Franklin to a larger building just off the main street, and major staffing changes as founders changed roles or moved away and new team members were added as the institution expanded. One health worker remembers this early transition of leadership:

*For the clinic as an organization to be stronger, the founder had to leave. It had to go into its adolescence, I call it. Adolescents need to rebel! –Health worker*

Even during these changes, engaging, listening to, and appreciating the community remained a continuous theme, as noted by a long-time community representative:

*It was all about making the local government aware that you support and value them. It is also an opportunity to put yourself in front of a group of citizens, and that helps you gain trust and respect. [Health organizations] can support and promote all sorts of ways to engage in the community.*

–Community representative

In 1989, an in-depth General Ethnographic Nursing Evaluation Studies In the State (GENESIS) assessment was conducted in Pendleton County to identify the main factors contributing to the county's mortality rates, which were considerably higher than those at the state or national level. The assessment process included interviews with health professionals, homemaker aides, and the clergy and incorporated a quantitative analysis of county health data. The survey found that PCC was regarded as a provider of good quality services and that the local health department services were greatly valued. Key health issues from the community perspective included alcohol abuse, heart disease, cancer, arthritis, and lack of access to services while understanding that issues such as obesity, smoking, and other lifestyle factors contributed to these health problems.(Counts, 1989) On the other hand, the priorities of health professionals were quite different and focused on access to care at the top, the need for job and economic development, expanding the scope of public health, and services to the elderly.(Henry G. Taylor, 1995, p. 140) Further, state and federal risk factor data suggested a third priority list that included cardiac risk factors, obesity, sedentary lifestyles, and injuries as leading health concerns.(Henry G. Taylor, 1995, p. 141)

These three divergent yet overlapping lists left local stakeholders “very confused” about how to move forward. To make sense of the seemingly incompatible findings, additional community focus groups with teenagers, working adults, and the elderly were conducted to prioritize next steps.(Henry G. Taylor, 1995, p. 142) The findings from this

assessment were examples of true community engagement because many stakeholders provided input and analysis, and everyone was included in receiving the final results and recommendations so they could be informed and guided in as they contributed to determining the best way forward. The findings of the GENESIS survey also helped to direct activities of local health agencies for the following years; these also contributed to stronger relationships between PCC, the local health department, the nursing home, and local employers.(Henry G. Taylor, 1995, p. 144)

The results of the GENESIS survey and subsequent community meetings provided the basis for a series of projects which would contribute significant learning about which community engagement strategies gained traction in the community, and which did not. For example, the “Falls Project,” which tracked deaths due to falls among the elderly, led to the development of checklists to prevent falls. The checklists were created for “Assessors” going out to people’s homes and evaluating the fall risks in an elderly person’s home. This project was not very popular in the community due to people not seeing its value and not feeling comfortable with the risk assessments that were conducted in homes as part of the project; so it was discontinued.

The Teens Project within the school system, which was also the beginning of the school-based health centers, provided education on Sexually Transmitted Diseases (STDs), reproductive health, anti-violence, and also substance abuse including tobacco and alcohol. Basing the program within the schools helped to avoid singling out teens who could not attend sessions elsewhere, and raised students’ general awareness about these issues.(Seegar & Seegar, 1990) Risk assessment and reporting tools were developed and utilized, and the school-based health centers continue to this day. One health worker

who participated in the early development of this program described how the school-based health centers helped overcome geographical, weather-related, and parental work schedule barriers to care for children:

*I'm terribly proud of school-based health centers. We started the first two [in WV]. There are 191 in the state now, and it works! ...when we've done school-based health we can take our healthcare and the doctors and nurse and mid-levels to the clinic at the schools, and the school bus brings the child and we see the child. We do a tremendous amount of preventive care also. So we don't just do acute care at the schools, we do preventive.* —Health worker

In addition to school-based health, the Worksite Wellness Project was also an early success that became a model for the state of WV. Worksite Wellness was developed to address low levels of health services utilization as well as high rates of stress, alcohol abuse, cardiac risks, and accident rates among the working population.(H. Taylor, 1992) This wellness program identified “natural helpers” from the participating community worksites who could provide information and support. These volunteers conducted a baseline health risk assessment, which included questions about family history of disease, physical activity, and diet. The survey was re-administered periodically to track changes over time. The Worksite Wellness program ran for several years, and follow-up data were collected showing variable successes. The program is no longer active in its original form, but lingering pride remains among those who worked in the program more than 25 years ago, and saw it morph from a county initiative to a large-scale model:

*Word got out that it was effective. It was helping people in workplaces get their blood tested and keep their blood pressure under control, etc. and the idea spread. Charleston heard about it, and all of a sudden that whole idea was adopted and became a state-wide program... It's evolved certainly over time, and it's still there... It's worked well for our county, and the kind of gratification that people get here feeling, “Wow! Our little county! Look what happened.”* —Health worker

Over recent decades, health has improved in Pendleton County. From a baseline of poor health statistics on infant mortality and a very limited primary care workforce in the late 1970s, the community and a number of local agencies have been working to improve access to services, quality of care, and the health status of the county population.

In recent years, educational and outreach work by PCC and other local agencies has shifted toward grant-supported efforts. Some of the grant-funded work has been well-received, including the receipt of several honors and awards. The projects began to focus on specific populations, such as the continued worksite wellness programs. PCC's current functions have become focused on what several of the respondents call, "sickness services" rather than on a broader development of a culture of health. The perception of several of the respondents who have been involved with the clinic since early on is that the clinic has seen a substantial downturn in levels of community engagement.

*If you don't have somebody who believes in the bigger vision, you're not going to have [community engagement] ...because there's no money there. The effort that we tried to create money... [the membership approach] failed, and the alternative is to get grants. But anyhow, the point simply is that there's not a culture of health anymore and soon...you might have a well-run clinical services, but it might as well change to be called Pendleton Clinical Care rather than Community Care.*

–Community representative

Though utilization of local clinical services is high across many different demographic sub-groups and the general perception of the clinical services provided remains good, some of the health workers identified the need for continued innovation and change.

*What is happening here in Pendleton... you know it's a little bit of a mature phase where the clinic was started partly by outside people, but it has been accepted. It seems like generally people think good quality healthcare is provided there. They have tried some things, you know, maybe they have realized it didn't work or whatever. And now it's sort of like how do you go even beyond the stabilization*

*phase to a really long term effort where new people have to come in?*  
–Health worker

Building trust and engaging the community have been central foci and goals for a number of local health agencies in Pendleton County in the past few decades. The need to carry that vision forward as an ongoing process came up again and again in interviews. Clearly, it is not enough to engage the community once. The effort must be ongoing and the relationships have to be built on trust. Trust is also needed among local agencies, who have to establish relationships and then work together.

*Without trust, people can't start working together towards a common goal. And if the common goal is something as complex as health, you need a lot of trust. And you need a lot of people. And they need to be people with radically different backgrounds and experiences and perspectives in order to deal with this really complex situation...If you get widely disparate people, maybe they even speak different languages, you need to have dictionaries, you need to have grammar, you need to have things... if you have two armies who are going to be fighting in a battle side by side, not against each other but you're trying to do... it's called joint command.*  
–Health worker

In rural communities such as Pendleton County, developing agency-level trust and coordination is also essential to build the commitment and trustworthiness within each worker so that patients can build relationships over time. When primary care workers leave and fail to maintain trust with their patients, long-term health workers have witnessed the challenges and the ripple effect on access to and utilization of services.

*They're here for a couple of years, and then they're going. People in these small areas, especially the older people, develop a rapport and a relationship and a [level of] trust, and then they lose that and you're starting over again them....so, that is hard, you know, having that kind of continuity...because, that's a big thing in a small area like this, especially with our population who are aging to have that trust. I mean, if they don't trust or like their provider, they're not going to go have health care.*  
–Health worker

One of the community representatives notes that Pendleton County used to be a place “where neighbors looked after each other.” In the last 20 years or so, however, some of that behavior has changed due to economic declines, an aging population, people moving in from the outside, and other factors such as rising levels of opioid and alcohol abuse.

*We're kind of like a lot of the other mountainous countries even in the third world where neighbors looked after neighbors and family helped family. Until the last 20 years I guess, it's always been family looking after family, neighbor looking after neighbor. That's probably one of the strongest things not only in the healthcare but the makeup of Pendleton County.* –Community representative

Among some population sub-groups, that sense of collective support and belonging is still very strong, as a long-time primary care worker observed:

*But, you can see that happening in different direct, different paths depending on the different neighborhood. So, our African American communities, we have two here in the county, are very tight knit. They take very good care of their elderly. You know, they are the elders of the tribes, if you wanna call them that, but I mean, they will take care of them without hesitation with you know, they recognize them as their elders and they will see that they are taken care of. You know, if they need wood, they will also pitch in to do that. Don't necessarily have that with any other communities in the county.* –Health worker

Although it dropped to 6<sup>th</sup> place in 2016, Pendleton County ranked first in WV's 2015 County Health Rankings, ("County Health Rankings 2015: West Virginia," 2015; "West Virginia County Health Rankings," 2016); it has been consistently among the healthiest WV counties in recent years. Despite an overall positive ranking, improvement is needed in quality of life measures, which include physical and mental health status. In 2015, the Centers for Disease Control and Prevention used a series of morbidity and mortality indicators as well as health behaviors and determinants to score peer counties across the nation. Pendleton County ranked better than or on par with peer counties for

mortality and morbidity measures. It ranked lower in several key health determinants including on-time high school graduation rates, access to healthy food, and routine screenings such as pap smears.(CHSI, 2015) Recent data showed that Pendleton County's adult smoking rate was 22%, just below the state average of 24%; its adult obesity rate of 35% was in line with WV's obesity statistics and was among the highest in the US.("West Virginia County Health Rankings," 2016)

### **The Contemporary Community-Primary Care System Interface: Assumptions and Risks**

This section analyzes the nature of the interface between the community and the primary care system in Pendleton County by looking at a set of assumptions and risks, as well as at the ability of the current interface to contribute to desired primary care outcomes and impacts. The assumptions and risks are described in the data analysis section of Chapter VII.

*Motivated, trainable people to do the work of CHWs:* Hiring motivated, qualified primary care providers and support staff to work in Pendleton County is getting more difficult. The skill sets necessary for primary care provision and administration are changing, and many jobs are becoming more complex and demanding. As one Pendleton County respondent described:

*We are now hiring college graduates into some of those jobs that, fifteen years ago, we would have said it was a clerical job... We might have hired that person, and they may not have gone to college, but they had the tools in the toolbox and could do the work... But we clearly are asking more out of everyone that works in the building, whether they are in finance, whether they are check-in people at the front... Obviously a doc is a doc, but you know, the people that are below the professional levels providing health care, all of this has turned the wick up on we are expecting of these people.*

–Community representative



The local profile of people available to fill these jobs are also changing, and these two dynamics are not in alignment. According to several respondents with first-hand experience, skill requirements are increasing yet the skill level of the majority of the locally available workers is decreasing, which makes filling positions difficult.

*I think there are less people who probably had all the tools in their toolbox who chose, for whatever reason, not to go to another level of education. In other words, you know, people that could have but they didn't, and because they had a good set of tools in their toolbox, there was a lot they could do... Those that had the tools have gone on and attempted to do something with that, and therefore we have a diminishing population.*

–Community representative

Hiring the right people is essential for primary care. These workers must be committed to and at least familiar with the community in which they are working. Several of the health worker respondents shared their perspectives on the importance of understanding and being connected to the place they are working, but the different ways that be effectively accomplished.

*We've all grown up here. Our families are from here so that just makes it that much easier. I don't want to say better... It really does make a difference because when you go in their home, they say, "I remember your dad" or "My dad had a service station or general store." Or "I used to stop at your dad's every Sunday." You know, just things like that, they kind of remember who we were, where we came from. I think that makes a big difference and I think that is one positive thing about doing healthcare in rural settings.*

–Health worker

*As long as they understand the community, not being from the community it is fine. Being from the community can be a hindrance because you have been known since you were in diapers. If there is familiarity, and you can appreciate the demographic and the context, then it is fine. Being from a rural area, or at least being familiar with how people are responding to you is important.*

–Health worker

Sometimes when an outreach worker does not end up being a good fit, it is not because they are unqualified, but because they lack other characteristics such as motivation and willingness to listen and learn.

*You work with people and build rapport and see what their knowledge and skills are. We are always asking ourselves whether the worker will be comfortable in someone's home. It is totally different than an exam room because you are seeing their kitchen and living space, how they keep their home clean, all their personal space. We have learned to keep an eye out for warning signs like attitudes and behaviors. We basically want to make sure that they can do triage of the people they are visiting, and be knowledgeable and aware to notice what is going on.*

–Health worker

Just because someone has the credentials does not mean they are going to be a good fit—or even that they are a “good” health worker—as several primary care workers have discovered:

*I think it's going to be difficult in the future to have good health care providers. Just because they have a piece of paper that says they are an RN or a doctor... What do they call the person who graduated last in their medical school class? Doctor. It doesn't matter if you were first or last. So, it doesn't matter if you're considered a good doctor or an awful doctor or provider or nurse. You know, they may have the credentials, but they might not be the best providers.*

–Health worker

The value of being primary care providers was raised in a number of interviews, and was identified as a key to addressing some of the needs for a committed and trainable workforce. In short, health workers who feel satisfied with their work and who feel valued and acknowledged by their community are more likely to be committed to the work and to strive for excellence in the long term:

*I enjoy my patients. I'm seeing two or three generations at a shot which is amazing. People know you. You trust them. They trust you. It's enjoyable going into the clinic and seeing people that you just know for that long a time and that's*

*an intangible, that's not...you can't talk about that's worth that much, but it's invaluable.*

–Health worker

In a local environment, getting to know the patients and being familiar with—or even going and seeing—the places where your patients are living makes the work enjoyable and sometimes even an adventure.

*Home health nursing...gives you such a wonderful sense of purpose with what you're doing. I mean that you're doing something so important for helping people to stay in their homes to get better there. We're trying to be very respectful of their wishes... Now, don't get me wrong, it does have its challenges, and I come across many snakes. I was scared to death of snakes...and I've been taken in on tractors and just things like that you wouldn't believe!*

–Health worker

To retain dedicated good quality staff and volunteers, respondents said that it helped when there were motivating factors like community members saying thank you, incentives and opportunities to strengthen their knowledge base, or when additional equipment was purchased.

*You know, maybe more training or something to make them feel challenged. There has to be some reward some place at the end of the rainbow so to speak for anybody in this business, and we're really fortunate in this county. Our average EMT in this county is probably, I don't know, 10 years [of experience] or more versus the national average which is about two to five or something like that, and then we have some people here that have around, you know, 25, 30 years so.*

–Community representative

Similarly, for the work to be sustained, spouses and families of health workers and everyone who contributed to the community needed to feel appreciated and supported. According to a respondent who manages many volunteers, acknowledgement of the provider's family can help the health worker do a better job and increase the tenure of that worker in a rural area like Pendleton County, where they are very much needed.

*We tend to forget about spouses. So if your spouse is happy with what you're doing and happy that you're out in the middle of the night...knowing we supported them that makes it worthwhile... And in healthcare in general we have to be looking at the providers' other half so to speak in order to make them comfortable with what's going on around them. –Community representative*

*Accumulation and sharing of best practices and learning:* Building trust among team members and partners takes time, and is necessary to foster a willingness to learn from one another. In Pendleton County, a monthly meeting called the Family Resource Council (FRC) not only provides a forum for partners to hear others' concerns, but also explores additional ways that different groups could work more closely together. A larger meeting of regional partners in the county offers an additional idea-sharing opportunity three times per year. While this larger forum currently focuses on health and does not necessarily spotlight the many contextual factors and determinants of health, it is fairly well attended, and several respondents identified it as an existing gathering space where meaningful dialogue and planning could take place.

Some respondents were optimistic that recent changes in local organizational leadership, and increased pressure to show improvements in health status as a result of primary care provision are nudging local organizations and agencies to work more closely together. In the past year, a number of local agencies have been working on tracking users of welfare services. One of the interviewees for this study has been a key person in getting various groups together to compare lists of who has been coming to which agency for help. This comparison has helped to ensure that people who are really struggling and using a number of services are somehow being followed-up with and taken care of so that they can get back on their feet and become a contributing community member. This cross-referencing can also reduce burden on the system,

“double dipping,” or misuse of other services that they do not need. Attending the monthly coordination meetings has helped:

*We didn't have a staff person that was going to like our local family resource council meetings and things like that, and being a part of that and knowing what was going around in our community has really helped a lot.*

–Community representative

Whether respondents were talking about partnerships between organizations, or the internal dynamics between primary care workers based within a clinical practice, having strong relationships has made learning and sharing of experiences possible.

*It's just hard when you get to a private practice versus a clinic such as ours. So, you know, you kind of filter your way through it. You learn that there is a person in this office you can talk to...and they learn you, and then you get to the one-on-one, aspect of it versus an office calling the other office, which helps, but if you don't have that personal connection, that's really hard to speak with the private office.*

–Health worker

The relationships must be appropriate to the culture and working environment, according to health workers describing recent efforts to integrate a behavioral health services into the primary care offerings at PCC:

*Every community health center has its own culture and consequently...integration has to fit the culture they're in... We're really integrated, I mean I will collaborate with our behavioral health colleague and we'll go talk together and we'll put notes together and we'll work with a person over a short period of time for certain kinds of problems.*

–Health worker

Due to the stable population and many long-time primary care providers, the Health Department, PCC, and other local agencies have been able to accrue data over a long period of time. The challenge now is how to continue to expand the accessibility of those data to appropriate parties (new providers and community partners). As one primary care worker notes,

*We do have accumulated information sometimes over 30 years. That's invaluable to understand economics, transportation, the kind of job (or not-jobs) people have had, their education level, and the families. We've got people that I can go to within the clinic and say, "Gee wiz, I remember this child. Who's his grandfather because I think he had leukemia?" That may not be in our record but somebody will remember that." That's the kind of... reservoir we have and if it's not within my memory it will be in the memory of the clinic somewhere... I've talked to friends who practice in Boston, Washington, Pittsburgh, and there's nothing like that.*

–Health worker

Some of the data-sharing challenges and opportunities facilitate referrals and reduce issues such as abuse of prescription medications. Other opportunities and challenges revolve around privacy and being able to provide optimal care for the patient without violating trust as well as privacy regulations such as the Health Insurance Portability and Accountability Act (HIPAA).

*We struggle a lot with how to integrate our records, because the law requires behavioral health, psycho therapeutic...and medical notes. All three are protected legally in a different way. And so, we like to think of ourselves as on the cutting edge there and sometimes we say, well we want the doctors to have this information that we get when we speak to our patients and we don't want to bury it deep in the records where nobody has access to it, because that's not integrated behavioral health care. So, that's one thing that we wrestle with is the record keeping and note taking in, sharing information electronically and in the records.*

–Health worker

According to several respondents, working only at the local level may no longer bring the necessary mix of skills or the economies of scale for certain services. Relying only on the local capacity of health workers and communities may not result in appropriate and timely access to information and care while also managing administrative functions, such as data tracking and analysis. Considering alternative ways to organize the primary care system in order to retain local relationships and also harness some larger

scale efficiencies pose important questions for the present and future. One respondent with extensive administrative experience suggested a regional approach:

*There is a lot of talk about being responsible for groups of people. Well, that's not going to be state-wide. I mean that's just not doable, and so the practical side, I think, is more you know, regional. And, I think, it will come somewhere almost out of necessity as opposed to people deciding to do the right thing because we had lots of years for we could have decided to do the right thing, and that never won out. You know, we are an awfully independent lot. –Community representative*

*Communities accept new ways of obtaining primary care services:* A long history of self-reliance, a stable population in Pendleton County, and complicated outside interventions in the state and region as a whole have created some distrust of and resistance to outsiders as well as outside ideas. Like families who may argue among themselves and create local conflict, they will all align against an outsider who is coming in to tell them what to do or against anyone that they don't like. Many respondents noted that this can make it difficult for outreach workers to be effective, particularly if they are not from the area or if they are diverging from the way things have always been done. Particularly in the North Fork, the most rural and isolated part of the county, suspicion or resistance to the primary care workforce can be a challenge.

*People in the [North Fork] area don't want “outsiders” in their business, or telling them what to do. This makes it difficult for health workers from the outside, even if they really want to help. And families and communities walk and band together against outsiders, even if, under normal circumstances, they have tension and fighting among themselves. –Health worker*

Pendleton County, with its proximity to Virginia and lack of coal, has often been considered a “lucky” county because it avoided the environmental impacts and economic turmoil of the southern coalfields, and enjoyed more direct access to east coast opportunities than other parts of the state. The county's more independent agricultural

history has also fostered a population of self-sufficient people. One health worker contrasted the dominant mindset in Pendleton with coalfield communities:

*A coal community is so very different... They're used to being taken care and they expected to be taken care of because of the way the coal companies took care of them... Whereas in Franklin it's subsistence farming and people didn't expect to be taken care of...They didn't get taken care of [before] and so, they would not come to the clinic unless they can pay. We had to do some educating to let people know that they could come even though they couldn't pay. So it's a very different, very different community.*  
–Health worker

A community member described personal pride and the closely-held value of self-sufficiency common to Pendleton County resident as major the challenges of getting people to use services provided by their agency:

*We have services available, but we are not really reaching the core of it to change their way of life. It's a kind of...some people have pride. They don't want to use other people for their help.*  
–Community representative

A dichotomy has emerged between those who are there to help, who often come from other places or have outside experiences, and the general population for whom services are being provided. This sense of disparity troubled several respondents, one of whom described it this way:

*I think we're looking at different cultures within our county, and I feel that the culture that I am in that is providing these services haven't really been able to penetrate the other culture that we're providing the service to... They don't want anybody to know what's going on behind those doors unless they absolutely need help, and they know where to go to get help.*  
–Community representative

Ways of life in Pendleton County have, to a large extent, been the same way for generations, and those deeply engrained, comfortable, and sometimes dearly-held traditions and norms do not change quickly or without some struggles. Transitions between generations, integration of new workers, and other factors such as the aging



population have escalated as issues and provided opportunities for change over time.

Observing change takes time, while at the same time, the complexity of the changes with time can mask the specific impacts that the primary care system would like to achieve.

One observant primary care worker described how it took an entire generation for a positive change to become the new norm:

*I have got kids coming now with their babies, and they were babies when I came and it's like, no, they can't be that old! ...but it's nice to see that evolve because well child [visits] were not important. You only went to the doctor when you are desperately ill. And from the kids that were brought in to the doctor for well child, and learned how important well child are, it's nice to see that they are bringing their children on time for their well child. It's taken 25 years to beat the cycle, but they understand now how important the well child is. They understand how important the immunizations are. So, it's nice to see that some of that preaching 25 years ago is starting to pay off!* —Health worker

*Funding consistency, source, quantity, purpose:* Health worker salaries and medicines are two areas of substantial yet variable cost to the primary care system. As noted by a primary care worker, particularly as payment for services moves towards payment for patient outcomes, these costs need to be carefully managed. During the transition period, clinicians are under exceptional pressure related to how to spend their most precious resource—their time.

*We're at a pivotal time in the evolution of our healthcare system where we're still being paid for volume but we're being asked to produce outcomes. The problem with that is it takes time to produce outcomes, but because we're still being reimbursed on the volume of patients we see and the administration is stuck in this catch-22 also. In order to stay solvent, you got to see patients, but they want us to do better with outcomes.* —Health worker

Managing medicines for chronic disease patients, who often need or end up taking medicines over a long period of time, can be a challenge. Sometimes, simple education

and careful attention by a professional can reduce or entirely remove the need for expensive medicines:

*The ultimate thing is less drugs...somebody shouldn't need a nerve pill forever, same with antidepressants. And then I had a nurse who called me today and offer thanks because I pointed her in the direction of a very, very good omega fatty acids supplement to use because her cholesterol was creeping up. So, she started that and we talked about walking, we talked about diet and she started making some changes and in ten days her points were down dramatically. She called me all excited, but I spent extra time out there.*  
–Health worker

While education and outreach may produce population-level cost savings in the long term, simply shifting towards nurses, social workers, other health professionals, or other lay people doing more outreach work with the appropriate supervision also requires investment above and beyond the salary time needed from everyone involved. In addition to the time commitment, other costs are described by a concerned yet optimistic primary care worker:

*The outreach work has other costs as well. We have to have a car, pay car insurance, and pay for the care coordination. It is hard to answer whether it is worthwhile yet. But, specifically in the wintertime, it is invaluable. People cannot always get out in really cold weather, and this way, we can send someone to them.*  
–Health worker

Often, these expenses are not readily reimbursable through insurance plans, making consistent and sufficient funds to cover them a challenge. Grants, private donations, and general funds in a clinic can cover some of these expenses for periods of time, but are not a complete solution.

In several of the interviews, the issue of billing for services was raised, particularly for chronic conditions which now account for the majority of the burden of disease in the county. A number of the care coordination, follow-up, preventive care,

and health education services that are currently being provided are not billable services and are, therefore, very challenging to pay for.

*One of the major changes, that the current structure of the health system does not address well, is that for chronic conditions, you often need multiple visits. This is quite different than acute care, and the stipulations in insurance plans, and the way that we bill for services, does not often lend itself to providing patients with good quality care for chronic conditions.* —Health worker

As one health worker noted, the services that are needed to create and maintain health:

*[Are] not necessarily all reimbursable, but valuable... the country and the healthcare policy folks have to figure out how to value those things, and they got to understand that they are valuable.* —Health worker

For each community, what is valuable also often varies, which adds further complexity to policy development and implementation.

The key to building a more cost-effective system seems to lie with financing an honest and rational system, at the population and institutional level, as well as at the individual patient level. Just offering “sick care” services and preventive education is not enough according to some of the respondents who have been working to create sustainable approaches to strengthen the local “culture of health” over time.

*The question is how do you do something about it [building a local culture of health] in a way that doesn't require an external subsidy of money because otherwise you are just doing a one off and creating a light house or a pilot project or something like that and you're not really providing a systemic example, nor are you providing a likelihood of sustainable change.* —Community representative

If patients see value in the care they receive and also understand their role in improving their own health, community representatives believe these patients are more

likely to do their part to contribute what they can and to use services in an appropriate and timely manner.

*What we found was that, when people care, then people will find a way to pay. Even if they are very poor.* –Community representative

While more people qualify for Medicaid since the implementation of the ACA, there is still a gap related to the “working poor” who, while they are working and making some money, are not making enough to afford basic insurance coverage, let alone pay for better health insurance coverage with a lower deductible. Many of the deductibles for less expensive plans are high; unless people have very large health expenditures, sometimes it almost seems as if they didn't have any health insurance because they end up paying so much out-of-pocket before they meet their deductible. Some of the locally available jobs, such as those at the sawmills and stone quarry, do not pay very much. This means that many people are working minimum-wage jobs, sometimes without benefits, and struggling to cover their expenses even before the cost of health insurance. One respondent who works with low-income families described such as example:

*With Obamacare, they just can't afford it. I mean I had a family that come in here and she told me it was like \$300 a month and her husband might have made like \$800 a month. There's no way that they can afford that, so it's really discouraging... I don't think Obamacare is reaching everyone. Everyone needs healthcare, yeah we do, but we need affordable care and it's just not there... Unless, you work like in the public school system, or at one of our clinics or the nursing home or with an agency where we have PEIA insurance [for WV state employees], it's not covering it for folks.* –Community representative

Despite the challenges, many respondents remain committed to moving forward and figuring out better ways to support more of the education, coordination, and outreach

that they are already doing and be a meaningful part of where they believe the future of primary care is heading. Regardless of whether all of it falls within the realm of what can currently be paid for through insurance or other funding sources, these respondents are working to find resources and they remain optimistic that the value of this will gain additional attention in the coming years.

*We have attempted to be positioned for where we needed to be, but there is almost no payment for...you know some pilot programs, and there is a handful of organizations like ours. They are earning some minimal incentives, and some things that they are trying to do if they're big enough to get someone's attention.*  
–Community representative

*Community capacity to engage in planning, implementation, evaluation:* At the core of the question of community engagement and empowerment is whether or not the community wants to bring about change. Perspectives in Pendleton County differ on this point. Fundamentally, the choices about whether to change and what kind of change is good may be part of the source of inter-valley and inter-organizational tensions that flare up occasionally. Following are two such perspectives from primary care workers about whether change is welcome and about the barriers to collective agreement about the future directions.

*Well I'm really not sure there is consensus [among the county's population] about what constitutes moving forward, and actually believing if they want to do that.*  
–Health worker

*I think that if people in their little pockets of community feel like they are part of a community that could make a difference. And then healthcare providers that service regularly those people, those same people and really get to know them that's the thing. That's what needs to happen.*  
–Health worker

Transportation and employment limitations are huge barriers to accessing health services and information. Internet access is increasing, but connection speeds still tend to

be slow and cell phone service remains very limited. Because of these access limitations, being able to get to a clinic, a workplace, or any other social gathering place is still essential to receiving care and knowing about the available opportunities.

*Transportation is and always has been an immense barrier... It's a barrier to get to a gym, it's a barrier to get to some place they can walk, it's a barrier to get to the clinic, it's a barrier to go to counselling, it's a barrier to go socialize. It's a barrier to get to a specialist, it's a barrier to get to the pharmacy... So, there are a lot of things that we need, a lot of things we want in the community and in the region, but if we don't have transportation, I don't mean to sound pessimistic, but what's the point? Because people won't be able to avail themselves.*

-Health worker

While families and neighbors do help with transportation when they can, the responsibility, particularly for a patient who needs many services over time, can be significant.

*People do help each other, by providing and sharing rides as they can. However, if someone has to go regularly for appointments, this can become a substantial burden on a family or neighborhood.*

-Health worker

The population of Pendleton County is aging and declining for several interconnected reasons: younger people leaving to find work, people coming from cities on the East Coast to retire, and families who live elsewhere but maintain the WV family house or farm and only come back for holidays. All of these factors influence the kind of primary care that is needed for the population, as well as the economic and social bases available to support these services. Two community perspectives outlining these dynamics follow:

*I was up at our business just now... And there's a little church right across the street. And the people that were coming out are one young man, teenager, and I think he was the... child of the clergy that's there. And they're all old and very ill. Many of them limping, on canes, and obese and that's what you see. That's*

*what gets left behind in a community that can't employ and support its own. All of that...trickles down to...the quality of all their lives.*

-Community representative

*The one thing that I know about the senior population, they always struggle with: "Am I gonna buy my medicine, or am gonna pay my bills?" And that's heart breaking you know... If something happens, and they need specific medicines, then maybe their insurance doesn't cover it at all, and they struggle with that, trying to decide...*

-Community representative

People who are of working age often travel long distances to work—impacting not only the availability of family members to take care of each other, but also the ability to allocate time to volunteer and support community needs more broadly.

*You see it in every area of the community: church events, civic organizations. I mean, people just don't have time... We are spread thin because we are a tiny community, and so many of our groups like our church groups and our rescue squad and others, it's all that's here. And, we're running out of the really good volunteers. They're aging out, and the younger people are moving away from the area, or have to work outside of the county because there's no industry here to keep them.*

-Health worker

Pendleton County also has high rates of mental health issues including anxiety, stress, depression, and PTSD. Other behavioral health issues such as drugs and alcohol abuse are also prevalent. The lack of local mental health care capacity has been identified as a serious limiting factor to the community and primary care system's ability to put energy and attention toward the future.

*There are a few resources for mental health, particularly in the North Fork. Oftentimes, sending people to the emergency room is the only option. This is because, either there are no referral options available, or that the system and the structure for referring people is so complicated and unwieldy that it's not worth while to put the practitioner or the potential patient through it.* -Health worker

Pendleton County is not unique in this situation, however, and respondents noted that, even for those who could travel outside of the county to seek care, the options around the state are limited.

*I mean I know we have our clinics in Martinsburg and Clarksburg, but...I mean, it's a distance. So, there's not something to travel to... I mean, that's a need through all of West Virginia, is more services for mental health because we have a lot of folks that have mental health issues, and there's just nowhere to get the services.*  
–Community representative

Regardless of the limitations and barriers to community capacity, a vision of how the community can be, inspired by the outcomes achieved so far, continues to motivate various local partners to keep moving forward. Community representatives and primary care providers focus on helping individuals within the larger goal of improving the collective health and wellbeing of the county population.

*I don't want this community and this county to be always supported on welfare....I'd like to see people get out there and work for what they have and take pride in that. I was a stay at home mom until my daughter was 4, and I got a job, and that's what I tell people: it makes you feel better about yourself, it helps your community, and all of these things just to get out there and work and not depend from month to month.*  
–Community representative

*For every person that leaves my office and say "Thank you, I feel better!" that's better for the community... So, from my perspective, helping people as individuals and families to live their healthiest, most productive lives they can has a positive impact on the community.*  
–Health worker

*Coordination among stakeholders:* Despite several decades of experience and repeated efforts to collaborate and align efforts, the general perception of local health organizations—including PCC, the health department, Pendleton Manor, and other agencies that provide services in the county—is that they are very siloed in their work.



*We've got a lot happening in Pendleton County, lots of funding sources for the many silos. Standards are different for the different siloes, and we don't talk to each other.*  
–Health worker

True collaboration is rare, whether with other local agencies or with regional partners.

*You know, we are not working together on any kind of a project other than taking care of an individual patient one at a time. I mean, you go west and you run into the hospital in Elkins, and it's big enough place to attract specialists and so forth. Same kind of thing, ok? The CEO...invited us to come for presentation and to begin to build relationships. But there are lots of islands [and] minimal true collaboration, unless somebody wants to say they are collaborating in order to get a grant.*  
–Community representative

Breaking down these local siloes is not a new idea and previous attempts have been made. Unfortunately, only a small core group of local partners has ever been committed to the idea, and even they have not managed to form a cohesive collaboration over a number of years.

*There was a group of us that formed what we called a network, and the whole intent was to centralize issues and develop some economies of scale... We started out strong... It was back at the time, where we had to develop HIPAA policies and compliance programs, and people were kind of on board when there was things being handed out. And then they began to fall away, and before it completely shut down two-three years ago, there was a small group of five or six of us left that really believed in the concept. But the point was even that five or six never really got to a point of collaborating on a service.*  
–Community representative

Several local organizations and agencies view themselves as a hub or convening body for a set of partners that are already working together. Long-standing conveners include the health department and PCC. The diverse local partners of these organizations range from the State Department of Health and Human Resources (DHHR), the Salvation Army, the Veteran's Administration, the Potomac Highlands Guild that provides mental

health care, Women Infants and Children (WIC), Right from the Start, to several other child health and family services organizations.

Not all of these collaborations have been static—based on personalities and capacities within each partner organization, the relationships have waxed and waned over the years. For example, collaborations with the Potomac Highlands Guild have declined in recent years due to its lack of capacity and responsiveness to partners. More recently, the new integrated behavioral health grant within PCC has shifted the way community members can access behavioral health services as well. Likewise, the collaboration between the county health department and other local clinicians, particularly PCC, has also evolved over time. Recently, new dialogues between local partners have been taking place; these have been spearheaded by new leaders in several local organizations and reinvigoration by long-term community and health professional advocates. Because these leaders are sensing new ideas and possibilities emerging, there is a new wave of energy in the community that could help community engagement and access to the primary care system.

### **Achieving Primary Care Outcomes and Impact**

*Extent to which communities engage in planning, management, and evaluation of primary care:* The health workforce and the community have important roles to play in achieving desired primary care outcomes and impact. For community engagement to be effective, it is critical to understand the many contextual issues that contribute to health. This awareness greatly influences not only the ability to deliver relevant and effective care, but also to meet the community where it is on the issues that matter most to the

population. Recently, local economic development has been the issue that galvanizes the most community participation and ideas.

*Economics are terribly important to the health of our population. If families and parents don't have job availability, then they don't have enough capital or resources to help ensure, you know, children can get to the clinic or they can take care of themselves if there's not transportation adequate to get to a job, so there are a number of variables that are extraordinarily important...as healthcare personnel to be involved with.*  
–Health worker

*Individually, a number of members [of the primary care system] are constantly looking at the economic development possibilities and come up with ideas here, there, and everywhere and not particularly as [health workers] but as active members of the community, and trying to figure out some way to up employment here.*  
–Community representative

For the community, it is clear that addressing pressing determinants of health, such as local transportation and employment, may be a prerequisite for being able to focus directly on accessing health services and improving health outcomes, though these determinants influence what kind of health services are available and there is often not agreement among the community about how to address them either. Despite these issues, there are many ways that the community can be involved; several respondents gave the following examples:

*It is about working with community partners. For example, transportation is something PCC could initiate, but not sure how to pay for it. It would be better for someone else who would have a different perspective on it. We need to be more collaborative and have dialogues to problem solve things like transportation.*  
–Health worker

*Having good health services makes it easier to attract industry. Since God was a little boy, it has always been this way. This is a quiet retirement community, and it could also be known as a clean industry community. There has been lots of pushback from different factions of the community on different ideas for industry.*  
–Community representative

*Access to and utilization of primary care services, including rural and low-income populations:* Several local agency representatives noted that they serve a wide range of people in Pendleton County and these representatives feel that they are generally reaching at least those in the community who want and need the services available. Such a focus on ensuring equitable access as well as health status is essential for moving the whole community and not just a minority—or even majority—toward better health.

*I think we have a good representation of everybody comes here. One of the ladies...with the black community, you know, she worked with the rescue squad when it was all volunteer. She came to work here at the clinic like 18 years ago... She, just them [the African American community] knowing that she worked here seemed to bring in a whole different population than what we normally would have seen. But, you know... they know it's the place to be, so they stay even when she's gotten more education and moved on.*

—Health worker

*I mean I'm sure that there are some clients out there that maybe we haven't touched yet, but maybe they don't need us or maybe they don't want us. You know...I mean we had a guy that had some kind of a heart issue lived up on a mountain and we were going to be taken in... and he did not want us to come. I mean, he did not have a phone so it was relayed through a friend that lived that had to travel up to his house and he did not want us to come so you know...that's their choice and whether it's right or not it's, you know, their choice.*

—Health worker

*Improvements in the county's health status:* In Pendleton County's context, looking over the past few decades during which extensive effort from many partners have sought to improve health status, it is possible to see changes in some key health status indicators, though these changes cannot be directly attributed to the interface between the community and the primary care system. Health outcomes were the focus early-on for PCC and have been central to the interest of many local agencies. These ranged from lowering the infant mortality rate to improving the living conditions and decreasing risks

of falling for the elderly. One health worker highlighted the progress made on child health outcomes over the last three decades:

*Before we started doing pediatric care here, I don't know if they were doing evaluations on various counties and healthy places to raise children, etc., etc., but since we started pediatrics here, we have improved a lot, and this year, for example, we're number one in the state for healthy children. –Health worker*

The challenge with tracking changes to health status—which is why it is not a main objective of this study—arises around how to measure progress across the desired dimension of impact. Often, these dimensions are measured in the short term for grant cycles and building a continual evidence base as well as in the longer term for population-level changes that require time and, hopefully, can be maintained appropriately and sustainably. The resources needed for such tracking and also the issues with attributing changes to any particular program add to the complexity. Managing expectations to create immediate or dramatic impact at the population level is also important in order not to give up on a promising strategy just because it did not have enough time to deliver the expected results.(Merzel & D'Afflitti, 2003; Wherry & Miller, 2016) Many complexities including not involving communities in key stages of projects such as identification of priority issues, insufficient sample sizes, secular trends, and short intervention periods all reduce desired impact.(Merzel & D'Afflitti, 2003) Finally, leaders must simultaneously keep a larger vision in mind in order to prevent stagnation and avoid missing new opportunities and issues as these arise.

### **CHWs in Pendleton County: Current Practices and Future Aspirations**

*Current CHW Role Distribution and Experiences:* Pendleton County has not had many recent discussions or engagement with the larger national dialogue and

experimentation with CHWs. There is also no specific CHW project, nor any program that is explicitly calling its workers CHWs. There are, however, a number of primary care workers within several local organizations that do community outreach, health education, peer support, and other common CHW roles. One of the main kinds of outreach work is home visits conducted by nurses at PCC and the Home Health agency that is based out of the nursing home, Pendleton Manor. The nurses at PCC are focused on home visits to the elderly, and the other home health nurses are providing skilled nursing care that also incorporates physical therapy and other services to help patients get better after discharge from the hospital or after an outpatient procedure when a physician refers them for follow-up care.

Beginning at PCC, and recently continued by the Commission on Aging, a program developed in the 1980s provided lay “homemakers” to help with daily tasks such as bathing, cooking, grocery shopping, and getting to doctor’s appointments. Sometimes, these homemakers also helped patients weigh themselves on a daily basis or perform other basic monitoring tasks that patients were doing anyway; these homemakers, however, did not provide any clinical services. According to one of the former homemaker project managers, the project has made a difference not only to patients and other family members who received help, but it also provided part-time employment opportunities to a number of local women. Many of them would like to be part of the local workforce, but cannot or do not want to work full time due to family responsibilities. Often, before they became lay “homemakers,” they already knew a patient or someone in that person’s circle because they lived near one another:

*A lot of times they [homemaker and patient] came as a package. A person would call and need services, and then say that Betty Sue lives down the road and could*

*you maybe train her to do that for me? ...when we transitioned the project to the Commission on Aging, they also went as a package; we would transition one patient over, and the homemaker would go with them in order to have as little upset for the patient as possible.*  
–Health worker

There are also other homemaker services available in the county, such as the ones described by the two following respondents, that use workers with very little or no clinical training. These programs focus on doing basic care for the elderly and sick, such as cooking, cleaning, and bathing, that do not require clinical skills. Some also provide services, including basic levels of services for special needs children and others needing mental health support.

*Family Preservation will come in, and they will provide a service...and sometimes it's good and sometimes it's not.. They come in from Petersburg or maybe Moorefield, which is where they're all stationed and they got an eight-county area that they're responsible for. These are not highly trained folks. They're not clinicians. I think they're college graduates and, but at any rate that kind of a thing better integrated could be helpful.*  
–Health worker

*And there are a lot of, I know that there're – and maybe they aren't enough but there're quite a few in home service providers particularly in like you know, in mental health capacities and I think that they're under-skilled and under-trained so we need a higher level of skillset.*  
–Health worker

The recently-added geriatric home visitation program in 2015 at PCC uses Nurse Practitioners (NPs). This skilled care outreach program has expanded upon the original Homemaker's Program with a strategy that is easier to pay for within the current reimbursement systems. As with any new program, some challenges and logistical details that been identified are currently being worked out. Although there are challenges from the provider and management perspectives, there is also substantial appreciation and value for the program. As one provider explained:

*We have struggled with the geriatric home visitation program due to the effort required to get into peoples' homes. The transportation limitations and low population density makes access to services and to where people live an important issue. But, we see that home visits are another way to reach the patient. It is almost like having another visit with them.* –Health worker

Patients also require some time to adjust to the new care delivery mode. Providers suspect that more experience and visits will be needed to build the kind of relationships with the NPs that patients already have with their regular providers.

*Well, the patients feel like they are switching doctors and they are reluctant to trust the NPs that are visiting them. Some refuse to do anything that the NP suggests until their primary provider signs off on it. I think time will help to build trust for this dynamic. It is really a natural extension, and it takes away the challenges of people having to come to the clinic.* –Health worker

Beyond care for the elderly, the Home Health Agency offers short-term skilled nursing home visitation for all ages groups. The focus on short-term care is to help patients transition back into the home and to normal (and ideally) independent life after surgery or injury. These visits ensure that proper follow-up and patient education is provided. The Home Health Program works closely with the Pendleton Manor which provides physical therapy and other rehabilitation services.

*Probably three fourths of the time maybe even more that happens, you know, that they got a knee replaced or congestive heart failure whatever and we'd monitor to make sure they're taking their medications, you know...got them going again. Wounds are healed, they're stable and they're able to return back to, you know, their previous level of functioning.* –Health worker

These skilled nursing services also provide substantial help to patients in identifying and getting access to other resources, such as food or nutritional supplements and other support for the patient and family. This way, the nurses are not only looking at



the patients' medical needs, but also monitoring and responding to their other basic needs as well as the needs of those around them

*The nurses especially do a lot of like social networking for the clients, and for the whole home environment. Sometimes it is not just the client that needs the help, it's the whole family.*  
–Health worker

The Pendleton County Rescue Squad covers the entire county and is highly regarded locally as a model for achieving equitable emergency response coverage of the entire population. It has also bridged social chasms and geographical barriers between different parts of the county.

*The Rescue Squad was the only organization that really tied the whole county together. There were organizations that were at Franklin and South Fork and there were North Fork organizations, but the rescue squad was the only one that's standing.*  
–Health Worker

The county is proud of and relies heavily on the rescue squad, which has a number of trained people working on emergency response who are very familiar with the community. The responders all have training—the requirements for which have increased over the years—and they attend regular meetings. Consequently, the time requirement for training and meetings plus responding to emergency calls represents a significant commitment.

*The EMTs [Emergency Medical Technicians] came along...and in basic EMT now you get a lot more training and can do things you couldn't do before. Along with that, more and more training. Again, that presents a challenge for the volunteer to keep up with the trainings and, while I understand it's important, it's also very time consuming.*  
–Community representative

Over the past few decades, services provided by outreach workers have been valued and appreciated, even more so as people become accustomed to these services and

the programs adjust to align with community needs and expectations. The home health nurses also never force a patient to allow a health worker into the home.

*We do not go in any home unless we have a doctor's order and also we always okay it with the client and the family before we go because, just because that they have an order for home health, does not mean that that person is in agreement to having someone come in their home and we have had some referrals from doctors that when we call they said that they would rather not have us to come in the home and you know that's their right.*  
–Health worker

Several respondents specifically commented on the importance of making sure that all patients know that it is their right to decide what kind of care they do and do not want. Several primary care workers who do home visits described the experience as follows:

*If they [the patient] decide not to have it then we, of course, do not go, but we then notify the social worker discharge planner from the hospital if that's where they're coming from and also the doctor so they're aware... The same thing is when you're in the home there are only so many things that you can do. This is their environment so you can't go in and dictate for them to do all these things. You just try to instruct the best you can.*  
–Health worker

Other times, what is needed is not skills, complex, or expensive care, but someone who listens or offers encouragement and support at a critical moment. This kind of behavioral health care is being integrated into PCC now. The program, however, may still not have the necessary capacity to be available to all patients who could benefit from it.

A primary care worker shared his experience:

*I've got a lot of new mothers, young mothers, and often and this will be their first baby and there's anxiety associated with that, particularly if they're short on cash. When I have a new baby and a mom, I will always have my behavioral health colleague come in and talk with the mother and there is a lot of resources they can bring to bear because they're social workers as well as behavioral health, and there are resources that they bring...but they can also talk and just sit and talk to a young mom is terribly, terribly helpful.*  
–Health worker

During a county-wide meeting held in October 2016 in Franklin, WV, the researcher shared an overview of major findings across history and across both counties in the state; this speaker also identified a number of other local programs that could fit within the ACA definition of CHW. Potential CHW tasks included some functions performed by local pharmacists, behavioral health services through DHHR, and the athletic coaches within the public school system. The work by these providers was not explored in detail, but was mentioned in other interviews, and the pharmacy profession was represented among the primary care worker respondents.

*Future aspirations for the roles of CHWs:* Several respondents expressed concern that veterans were either choosing not to or were not able to access appropriate health services guaranteed to them. Reasons for this include long waiting lists to receive care, bureaucracy in the Veterans Affairs (VA) system, as well as a sense of independence and pride among many veterans that often causes them not to seek care unless their conditions were very bad. One respondent described a frustrating situation she recently encountered that illustrates some of the challenges of getting care to veterans who need it:

*It's all this hype on TV about helping the veterans, you know, let's make bigger medical centers for them to go in to and we're some way overlooking all these veterans in these little areas that they're being bypassed... He needs to have a homemaker, which he would qualify for a homemaker through the VA, but because he's on a private doctor now, the VA won't even consider him for the Homemaker Program.*  
—Health worker

The other priority area for expansion of CHW roles is to use the Rescue Squad in additional ways that take advantage of their training, presence around the county, and motivation. Such role expansion can potentially increase local capacity to manage trauma.

*In the future...[a major need] could be trauma response, and our paramedics in the ambulance service are really important. For paramedics, it's important to remember that, even with all of the right training, you won't be able to save them all. Still, the squads are our biggest asset for trauma.*

--Community representative

PCC is also exploring ways that they could help staff the Rescue Squad during business hours when many volunteers are not able to be on call. PCC is also considering whether the EMTs could also be used to help monitor home-bound patients who have chronic diseases.

The importance of being able to network and help people navigate the health system is well understood, particularly in recent years with changes brought on by the ACA. In determining who should be responsible for these two tasks, a number of health workers commented that adding these tasks on top of a full clinical practice is not practical. Consequently, other people—who have the skills, knowledge, and time and can be paid—need to do this work. A critical aspect of effective system navigation is educating the population so that they know how to prevent disease, as well as what they need to do to engage with the health system.

*If someone could get out into the community at 4-H meetings, churches, and other clubs and start doing some education, this could really help. For the existing workforce, this education and outreach is too much if they have already been working all day in the clinical setting... The role is really something related to having someone whose job it is to be a liaison and have outreach.*

--Health worker

Finally, the Ministerial Association, which is a network of the leaders of the numerous churches that dot the county, has been involved in primary care over the years. Its members have played key roles in looking out for underserved populations and

contributing to earlier needs assessment and planning efforts regarding the county's health.

*The faith community is an opportunity for [health] education. The Ministerial Association is a good way to work with churches. Although some of the leaders in the faith community have different opinions, on basic things they will generally agree. There could be a role for a church liaison, who could explain about health services, raise awareness about them, provide other learning opportunities in conjunction with church functions.*  
–Health worker

### **Summary of the Pendleton County Experience and Findings**

Pendleton County has several decades of experience with engaging its community and working to improve primary care outcomes. Since the late 1970s, when the need for additional and different primary care services was identified, an evolving vision and numerous strategies have been implemented to identify and address the needs of the community and primary care system. Much of the vision and required changes have been driven by external experts who came to the county and worked to share ideas with the community, get feedback, and increase participation in a range of new programs. Some community members and the primary care physicians resisted and complained about the new model developed in the early 1980s. They reflected that they did not trust some of the providers who were very different from them, or the new processes that deviated from their prior experience of dealing directly with a private doctor.

Multiple respondents described how the community has enthusiastically adopted some of the new projects over the past decades. At the same time, other programs, including several focused on prevention and education efforts, were not equally valued or widely adopted. The local clinical services are generally perceived to be of good quality, and patients are the strongest advocates and advertisers, encouraging neighbors and newcomers in the community to utilize those services. As the quality and value of the

services became recognized, the community—including low-income and more rural families—became supporters of the clinic in a number of ways. The responses in this study made it clear that the community was prepared, if necessary, to work and fight to maintain the clinical services that are available.

Early efforts to provide primary care outreach services led to important lessons about what kinds of services the community would accept in their homes, as well as which ones they would pay for. For example, the project assessing hazards for falls in the homes of elderly residents was not popular. Similarly, the majority of community members chose not to pay for the health membership services offered in the early 1980s. Other initiatives, such as the school-based health centers and worksite wellness programs, were so successful that they became a model for other WV communities.

Today in Pendleton County, the way and extent to which community engagement is happening are quite different from the efforts in the 1980s and 90s. Currently, community members participate as board members with PCC and the County Health Department, and a number of local staff bring invaluable community knowledge to the primary care system and back into the neighborhoods where they live. Collaboration among local partners tends to happen informally because the population is small and most people know each other. The town of Franklin has only one major street and the odds of seeing other community partners and collaborators around town are fairly good. Opportunities for larger, more inclusive dialogues are limited, but those that do exist—such as the monthly Family Resource Council—are not considered by many respondents to be used to their full potential. Although discussions happen and the community has an ongoing voice within the primary care system, the county does not appear to have a larger

vision addressing the future of community engagement, CHWs, and how to achieve primary care outcomes collectively.

The requirements of the primary care system have also changed over the past several decades. Jobs are becoming more complicated, and the system is shifting from a fee-for-service to a fee-for-outcome system. These transitions require more skilled, experienced, and attentive workers. At the same time, the pool of available workers has been shrinking because of dwindling lucrative local opportunities and the increasing promises of better, higher-paying careers elsewhere. Consequently, finding qualified and motivated workers has become a great challenge. Under the ACA, many local stakeholders became aware of a need for greater collaboration—looking for ways to achieve economies of scale by looking to neighboring counties for services, and continuing to shift their thinking toward improving access to care and other desired outcomes. Despite perceptions of the current decline in local collaboration among county agencies, some new energy and enthusiasm is brewing. This enthusiasm is driven partly by economic pressures within the primary care system and the community as a whole to find additional funding mechanisms and employ more people in order to improve the health of the county.

Community engagement levels and perceptions about access to primary care services—and several key measures of health status such as infant mortality—have improved since the late 1970s. Among the persisting barriers to improving these outcomes that were identified in this analysis are limited economic opportunities and lack of transportation. New barriers or threats to the community's capacity and motivation to engage include rising rates of drug and alcohol abuse as well as mental health issues, and

specifically PTSD. In the last couple of decades, fundamental changes to family structures and the formerly built-in support systems to help care for the ill and elderly by family members has also been weakened as family members get older, leave the area, lack resources, or suffer from addictions or other illnesses. All of these interrelated factors influence how the community experiences life and health. A number of community representatives as well as primary care workers who interact with patients in care coordination and social support roles stated repeatedly that economic and transportation barriers must be addressed for the segments of the county population who are struggling most. Unless these barriers can be ameliorated, limited progress on health issues—particularly health education and preventive care—could be made.

Although Pendleton County agencies have provided extensive outreach, health education, advocacy, and other activities that are common CHW tasks, no dedicated CHW cadre has been established. One of the identified reasons that no clear and shared vision for CHWs has coalesced in Pendleton County is the culture of numerous local partners working independently in the county, many of whom have participated in dialogues, given feedback, and sometimes participated in projects and programs developed by other partners. Despite recurring interactions, the number of ongoing and committed collaborations is very small. Another detractor is that the ways in which local organizations and the community have interacted has not been consistent over time. Relationships among individuals have driven many of the collaborations, and as people have come and gone, so have the collaborations. In addition, a number of strong local personalities—particularly during collective crisis period after the 1985 flood and the following recovery period—have dominated, introduced conflict into, and sometimes



dampened the kind of inclusive and sustained dialogue that was originally envisioned. When a several different local stakeholders shared their priorities and needs, these priorities were often not aligned and required more discussion and facilitation in order to develop an actionable strategy to move forward.

## **X. WV's Community and Primary Care Interface Across Time and Place: Comparisons of Experience and Recommendations for the Future of CHWs**

This chapter compares and contrasts WV's experience of the interface between communities and the primary care system across time and place. This experience is then used as the basis for a set of specific recommendations for the future of CHWs in WV and beyond. This chapter is divided into three parts. The first section compares the two county cases with each other and with the state-wide historical experience, using the conceptual framework from Chapter II as a guide. The second section critically reviews several limitations of this dissertation and how these have been addressed. Finally, the third section provides a set of specific recommendations for how WV can organize and support the work of CHWs. The focus is on what is needed for CHWs to help build understanding of relationships and processes for interaction and mutual support between communities and the primary care system in order to contribute to improved primary care outcomes.

### **Comparison of the County Case Study and State-wide Historical Experiences**

As described in detail in Chapters VIII and IX, Mingo and Pendleton Counties have dramatically different contexts and histories. These contexts and histories have created different current priorities and consequently to different strategies and structures to engage and empower communities. Table 5 summarizes information about each county that were considered during the site selection process (described in the methods in Chapter VII), and other critical characteristics of the counties described in the respective case study chapters.

**Table 5: Critical Characteristics of Mingo and Pendleton Counties<sup>14</sup>**

<b>Criteria</b>	<b>Mingo County</b>	<b>Pendleton County</b>
<b>Geography</b>	Mountains	Mountains/valley
<b>Urban/Rural</b>	Rural	Rural
<b>Health outcomes (relative to rest of WV counties in 2015)</b>	Poor (53/55)	Best (1/55)
<b>Primary economic drivers</b>	Coal, more recently tourism	Agriculture/ tourism/ social services
<b>History of community engagement</b>	Politically fraught, divisive until recently	Strong though managed by outside leadership over several decades, declining recently
<b>CHWs qualification and experience</b>	LPNs and RNs, pharmacy tech	No designated cadre, though numerous workers doing tasks
<b>CHW target population(s)</b>	High-risk chronic disease patients	Elder care, school health, worksite wellness, rehab and post-discharge/procedure care

The current level of community engagement in Pendleton County as well as the motivation, shared learning, and acceptance of new strategies for care has developed and matured over several decades. Pendleton is less driven towards innovation, and has become comfortable with a set of services and practices that have been tested and evolved over time. No concerted effort is currently being made to look toward the future and to determine how to overcome old and emerging barriers in Pendleton County. Mingo County’s more recent efforts still have many of the original founders at the helm. These founders have a broad, ambitious perspective on what needs to be done. Additionally, they have a vision as well as high levels of optimism and motivation for improving primary care outcomes.

Mingo County’s current strategy includes a specific CHW cadre that is working to expand, support, and enhance the ability of the primary care system to understand, reach, engage, and care for the community. The model is built on extensive learning from others

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<sup>14</sup> Data in this table were sourced from the WV DHHR 2014 County Profiles for Mingo and Pendleton Counties, from the Robert Wood Johnson Foundation County Health Rankings for 2015, and from primary data collected from this study about CHWs.

and has now become a model other counties look to for guidance. Pendleton County has many examples of workers doing common CHW tasks, and has a great deal of experience with efforts to engage the community over several decades. Pendleton has not developed and sustained a cadre of workers or a shared vision for how to serve the community in this way.

Mingo and Pendleton Counties have several important differences in how they have implemented initiatives to engage and empower community members (Table 6). The implementation assumptions analyzed here are core components of the conceptual framework which this study expected would hold true and which the researcher assessed across the two counties. In terms of the availability of motivated, trainable people to do the work of CHWs, Mingo County has focused first on what kind of people are available in the community and then built and adapted programs around those people. Today, Pendleton County focuses on hiring qualified people to fill pre-defined and increasingly complex and demanding jobs while recognizing that the population is declining and many qualified workers are moving away. At the state level, numerous community members and health professionals have shown motivation to do the work of CHWs—often with additional training required. The many community members who have done CHW work as part of projects and programs—or to fill in gaps left by projects and programs—have often been supervised and controlled by health professionals. These health professionals—particularly physicians, NPs, and other nursing cadres have a great challenge to recruit to rural areas.

Mingo and Pendleton Counties have both worked in their own ways to gather and share information. Mingo County, conducts regular and inclusive multi-partner meetings

to build a shared vision as well as create and implement action plans to achieve it. Local stakeholders use these opportunities to share their experiences and learning from one another. Pendleton County has relied on a circle of long-time health workers and community representatives who have amassed large amounts of information and experience, but there is not an active and inclusive venue for sharing that knowledge or using it to inform a collective plan for the future or to engage younger people who can grow into future leaders. Historically at the state level, many projects and programs have aimed to document and share best practices, but the execution of these plans has been repeatedly proven difficult.

Pendleton County has had substantial success with getting clinical services out into the community in homes and schools where people know about and feel comfortable accessing them, but has struggled with gaining comparable buy-in for health education and preventive services. Mingo County has bundled services together under the home visits by CHWs and has had success with their adoption so far. Both counties have conducted large amounts of community dialogue, feedback, and advising—Pendleton over many years, and Mingo largely in the last few years. Overall, the WV experience points towards community willingness to accept changes to primary care provision. New cadres of workers—including NPs and PAs—and also dramatic shifts from a community- and home-based approach to health services leading to the New Deal to a highly professional and largely facility-based system today. Where communities across the state have drawn the line is when the services offered have intentionally or inadvertently undermined dignity, or have not produced value to the beneficiaries.

**Table 6: Comparison of Conceptual Framework Implementation Assumptions Across Counties**

<b>Assumption</b>	<b>Mingo County</b>	<b>Pendleton County</b>
<b>Motivated, trainable people to do the work of CHWs</b>	<p><b>Finding:</b> Motivated, trainable people exist locally, or can be attracted to the area from outside.</p> <p><b>Explanation:</b> Utilizing and attracting local talent has required being flexible about worker qualifications, and in which order projects move forward.</p>	<p><b>Finding:</b> More difficult to find local people who will stay long-term. More skills required, and fewer workers to select from.</p> <p><b>Explanation:</b> Looking for local capacity to fill pre-determined, often highly-skilled jobs in a shrinking population and economy.</p>
<b>Accumulation and sharing of best practices/learning</b>	<p><b>Finding:</b> In recent years, many local partners have been sharing information and learning. Some implementation challenges emerged, but were largely overcome by shared vision.</p> <p><b>Explanation:</b> A convening organization and ongoing dialogue among local partners has supported sharing of priorities, progress, and challenges.</p>	<p><b>Finding:</b> Accumulation of data over time among individuals. Limited fora and collective attention on preserving and using evidence for shared planning and action.</p> <p><b>Explanation:</b> Having a core group of individuals working together over a long time with knowledge of the community has led to less formal (and possibly less inclusive) sharing of information.</p>
<b>Accepting new ways of obtaining primary care</b>	<p><b>Finding:</b> New services, including CHWs providing home visits, have been accepted. Community also participates in nutrition and physical activity programs.</p> <p><b>Explanation:</b> Projects are integrated with each other, often presented as packages of services. Patients and the community are approached with respect and commitment by health workers.</p>	<p><b>Finding:</b> New clinical services that include outreach have been accepted, but several health education and prevention programs have not.</p> <p><b>Explanation:</b> Clinical services have been good quality. Other preventive and educational services sometimes operated in isolation, less attention was given to them, and developed and championed by people from outside of the community.</p>

In Table 7, the Counties’ approaches to avoiding and addressing risks—components of the conceptual framework that this study expected would limit or undermine community engagement pathways and the achievement of primary care outcomes—are summarized. Perspectives from the state level are included in the following narrative.

Funding has been a challenge for both counties, and neither one has found a sufficient long-term approach to funding the work of CHWs. Each county has taken its

own approach to either seeking funding for components of its larger vision (Mingo) or creating or evolving programs based on the availability of funding (Pendleton). While these approaches may not be mutually exclusive and are often both necessary, the counties have had different perspectives and priorities driving their search for financial support. State-wide fluctuations in funding have been substantial over the decades. In addition to booms and busts in overall funds, many monies have been earmarked for specific projects or services and have often had limited flexibility to adapt and respond to community priorities and needs.

The kinds of coordination and collaboration have been inconsistent over time in either county, but the variation in levels of local coordination over several decades in Pendleton County is much greater than in Mingo County's recent efforts. At times, Pendleton County has had extensive community engagement, and Mingo County's recent coordination experiences have yet to show how they will evolve over the long-term. Many projects and programs across the state have recognized the importance of having communities directly involved. Forms for this engagement have often included being learning sites for students, having community representatives on steering committees, and including communities as implementing partners. Having community engagement—or effective collaboration between a number of agencies for agenda setting, project planning, or evaluation and discussion of the results of an initiative have been much more rare.

Mingo County has been able to mobilize an exceptional amount of local energy, experience, and other resources to advance the Sustainable Williamson vision. How this capacity can be maintained—since it relies on volunteers, grants, and contribution of

various assets by individuals and organizations—in the long run remains to be seen.

Pendleton County has benefited from generation after generation of dedicated community leaders and volunteers who have organized their neighborhoods and advocated for vulnerable groups. In recent years, however, this group of people who has helped keep the community together seems to be shrinking as people age out and the younger generation is not engaged in the same time.

At the state level, the timeframes allowed for projects to show impact has also resulted in many short-lived ideas and challenges to build on successes or learn from what did not work. Often, focusing on keeping some kind of resources flowing and responding to take advantage of new initiatives has made it very challenging to retain any significant continuation in measuring and achieving complex primary care outcomes over longer time periods.



**Table 7: Comparison of Conceptual Framework Risks Across Counties**

<b>Risk</b>	<b>Mingo County</b>	<b>Pendleton County</b>
<b>Funding consistency, source, quantity, purpose</b>	<p><b>Finding:</b> Substantial input of resources recently in response to locally-developed plans.</p> <p><b>Explanation:</b> A number of grants are supporting the CHW and other health-related efforts; continued funding for the future is uncertain but being discussed.</p>	<p><b>Finding:</b> Resources invested across several decades. Also reliant on grants to support outreach, education.</p> <p><b>Explanation:</b> Seeking grants has partly dictated what kind of projects were done, and may have contributed to sense of locally siloed and fragmented efforts.</p>
<b>Coordination among stakeholders</b>	<p><b>Finding:</b> Structured interactions among stakeholders are taking place around a shared vision.</p> <p><b>Explanation:</b> Bringing local stakeholders together regularly has helped build relationships, improve accountability among local partners, and identify opportunities to help and support each other.</p>	<p><b>Finding:</b> Few examples of committed and lasting collaboration. New formal interactions among stakeholders.</p> <p><b>Explanation:</b> Local agencies are used to working independently and have struggled historically with many strong personalities and lack of a shared vision .</p>
<b>Community capacity to engage with the primary care system</b>	<p><b>Finding:</b> Capacity has increased in recent years, including among diverse partners, youth, and patients.</p> <p><b>Explanation:</b> The multisectoral approach with health at its core has helped community address barriers, find or creates roles for many different people, and make the interconnections between local efforts more explicit.</p>	<p><b>Finding:</b> Capacity has been strong in the past, though often driven by external ideas and expertise. Declines in capacity have been experienced in recent years.</p> <p><b>Explanation:</b> Perpetuation of the same barriers (lack of economic opportunities, transportation) plus a rising chronic disease and mental health burden combined with an aging and shrinking population.</p>

Currently, Mingo County has poorer health outcomes than Pendleton County. Pendleton County has spent several decades working to improve its outcomes, partly through community engagement efforts. In contrast, Mingo County has spent the last several years reversing the trend from being among the unhealthiest counties in the state and the likelihood of continued decline to a county with a vision and strategies in place to create a healthier future. Both counties are striving in their own ways to sustain achievements and continue to improve. WV as a whole lags behind the rest of the US in terms of many outcomes despite many decades of work to improve them.

Two particular primary care outcomes of interest for this study—which are intermediate outcomes that this dissertation assumes will contribute to impact on

population health status—are 1) increased community engagement and 2) access to primary care services (Table 8). Measuring levels of community engagement remains a great challenge. Mingo County has been working to identify what local stakeholders value and want, then assessing whether providing those services and opportunities increases community participation and also utilization of services. Mingo County has also worked to set up dialogues and relationships in order to get feedback from diverse local perspectives about why participation and utilization of services are working, and what barriers or concerns remain. Pendleton County has tracked participation in a number of different projects, but has not kept an active log or shared repository of what kinds of participation have been strong and which ones have lagged behind. At the state level, the amount of “meaningful” community engagement has been a small fraction of the many efforts to incorporate a participation component.

Findings related to changes in access to health services were limited at the county level to the perceptions of respondents about vulnerable groups feeling more comfortable seeking care, and being able to overcome barriers that have prevented utilization of primary care services in the past. Respondents in both counties described successes in reaching, connecting with, and supporting vulnerable or isolated populations to access primary care services, though not all kinds of services have been accepted and valued equally. Overall in WV, communities have driven access to services to an extent: they are often willing to fight for the services that they value, and will make significant sacrifices to pay for the things that they see value in. The barriers to access—including economic, geographical, and many other social factors—inequitably impact low-income and rural populations.

**Table 8: Comparison of Conceptual Framework Primary Care Outcomes Across Counties**

Primary Care Outcome	Mingo	Pendleton
<b>Level of community engagement</b>	<p><b>Finding:</b> Community engagement in programs has been high in recent years with many diverse local partners involved in dialogues and taking action.</p> <p><b>Explanation:</b> Perceived value of recent efforts to local stakeholders is high. Examples of community ownership of programs are increasing.</p>	<p><b>Finding:</b> Community engagement was high in the 1980s and 90s, but empowerment was limited. Recently, inclusive and deliberate engagement has declined and/or become less formal and deliberate.</p> <p><b>Explanation:</b> Engagement in 80s and 90s was largely driven by external ideas and expertise. Some of the community boards and relationships have sustained involvement over time.</p>
<b>Access to and utilization of primary care services</b>	<p><b>Finding:</b> Access to health information and services is perceived to be improving for vulnerable populations (homebound, low-income, chronically ill).</p> <p><b>Explanation:</b> Changes to service delivery modes (e.g. CHW home visits, regular programs for nutrition and physical activity that take place around the county) are making it easier to access, and are also raising the profile and value of the efforts.</p>	<p><b>Finding:</b> Access to clinical services for vulnerable populations (living in remote areas, African American population) is perceived to have improved.</p> <p><b>Explanation:</b> People feel comfortable coming to get services because they know staff and providers and their friends and neighbors have had good experiences. Health education and prevention services are not as widely accepted and utilized.</p>

At the state level, WV has faced a number of contextual shifts in terms of economic prosperity, kind and scale of external investments, and related shifts in population demographics and political priorities. Maintaining the continuity of efforts to strengthen community engagement and empowerment strategies as well as achieve outcomes in the primary care system have been great challenges. The resources—human, financial, and other—to support the primary care system and communities have fluctuated dramatically over time and were often inadequate or untimely to counter economic changes, particularly in times of economic downturn. Limited human resource capacity, restrictions on funding, and political pressures often influenced which solutions were even considered at a given time point. WV has relied heavily on external resources and has not invested in itself thoughtfully, particularly in terms of its people and in

relevant, strategic infrastructure for health service delivery. There is no significant Center of Excellence (COE) for research or practice in the state, although there could have been one related to extractive industries or chemical companies that rivaled Silicon Valley's COE, which could have attracted more motivated, capable people to come to or stay in the region.

Historically, WV has had more powerful governors and less powerful legislatures. Therefore, whoever sits in the governor's seat can make a big difference in what is included on state policy agendas and which initiatives receive support. Several governors have prioritized primary care and community engagement, but they often started a lengthy process of data collection and reports on the problems which then informed the development of strategic plans. After that important groundwork, there was often not enough time or capacity for an administration to implement these plans before the next cycle of analysis and reporting was being conducted by a successor. Politics has also been strongly influenced by the industry and by unions, both of which could and did buy the support of politicians periodically.

Overall, community empowerment has been fairly low in WV and Appalachia due to a long history of corporate dominance, poverty, geographical isolation, and deeply entrenched political corruption. Yet, each major time period reviewed in this dissertation—whether changes were driven by federal or state actors—has produced some vision or requirement to involve the community and its leadership as part of the planning, implementation, or evaluation of primary care programs. The most noteworthy is the 1069s War on Poverty, which endured many challenges and left behind a legacy for how not to engage communities as well as other unintended consequences. Some of these

consequences were positive—such as the influx of a new population of highly educated, liberal, idealistic people who went on to participate in and advance many other causes in the state and region.

Equally important and instructive are the often isolated local examples of community mobilization and innovation that have sprung up over the years—including recently. While these local efforts are often strong examples of empowerment and community engagement, they also tend to remain isolated successes that do not last beyond their founders in their original form—either the momentum wanes or there is substantial mission creep back towards facility-based, externally funded primary care services that can easily get disconnected from community realities and priorities.

The long timespan that was covered in this study—with its many contextual changes—has added even more complexity to determining the direct impact of different interventions. As the disease profile, the demographic profile, economic drivers, and population size as well as national and global influences including advances in technology, changes in policy and regulations, and other factors have all changed, these factors have influenced WV's primary care outcomes and will continue to do so. Despite the complexity of considering these influences, tracking the nature of community engagement and empowerment with the primary care system and the parallel changes in primary care outcomes is still informative. In fact, in times of economic downturn, population decline, rising disease burden, and other challenges, the role of an engaged and motivated community can be more reliable than external funding or highly trained primary care providers.

Activities in WV have not taken place in a vacuum sequestered away from national or global events and trends, and many of the experiences of community engagement with the primary care system are not unique to the state. Opportunities for WV to learn from the experiences with CHWs as facilitators and catalysts of engagement and increased understanding between communities and the primary care system from around the country and world are many, some of which have been outlined in the Chapter IV literature review. Reciprocally, a number of opportunities for other CHW programs and primary care system around the world can learn from WVs historical and current situation and experience. One opportunity for learning is to utilize a similar process to develop a theory of change for the interface between communities and the primary care system in a new context. The content of at least some of the boxes will be different to reflect local realities, but the purpose of teasing out major contributing factors and analyzing how they contribute to the ability to achieve primary care outcomes of interest could be the same. Secondly, this study includes significant description and consideration of the study context. Another CHW program implementer can consider the recommendations for WV at the end of this dissertation and how much of the principles and opportunities identified could be translated into their own context by considering similarities and differences in the study context.

### **Limitations of this Study**

This study had several limitations. First, time and resources constraints of the researcher limited the study to two county case studies, which, though carefully selected to represent diversity across a number of critical characteristics, cannot describe all of the experiences and local models that exist around the state. Diverse perspectives for both the

historical analysis and for each county case study were sought out, and information from a number of sources including documents and different local stakeholders. The researcher's first-hand experience living and working in the counties and around the state helped to validate and cross-check the data that were collected.

The historical data were often incomplete and oral histories were subject to the recall bias of participants. Historical researchers often face a lack of continuity and completeness of archival materials and information in oral history responses. Historians are reviewing time periods and events that may have taken place long ago, and are often relying on documents, memories, or other artifacts that were not initially created, collected, or preserved for the sake of subsequent research initiatives.(Storey, 2009) Consequently, some time periods and projects had much more preserved information about them than others did. When information was available, it was often isolated components of complex dialogues and negotiations that lacked consistent follow-up information to trace the direct outcomes and influence on subsequent efforts. For several practical and necessary reasons, many of the agencies and people who were involved in managing projects related to the interface between communities and the primary care system were not focusing on documentation, or they did not share their reports and communications in ways in which others could easily find and access them.

The limited time and resources narrowed the focus of the study that may have taken longer to reach—or may not ever have been reached—had there been even more data and more researcher perspectives to consider. At the same time, having a larger number of county cases and multiple researcher perspectives involved, particularly including more perspectives from others not already familiar with the WV context, may

have enriched the analysis process. Additional data—such as data on changes in access to services in each county over time—could not be collected.

A few respondents whom the researcher wanted to interview could not be reached. Access to respondents in rural areas, particularly community representatives, was a challenge. In each county, the researcher relied on the local FQHCs and health departments for an initial list of potential respondents and then utilized snowball sampling to seek out diverse perspectives. Despite efforts to reach several elderly and difficult-to-access respondents, not all of them were available. In addition, identifying oral history respondents within the community who had state-level historical experiences related to the interface between communities and the primary care system was difficult. The majority of oral histories were conducted with health professionals. Archival data and oral histories were utilized in tandem for the historical analysis. The county case studies relied on document review, in-depth interviews, and participant observation.

This study aimed to assess the change pathway for community engagement and empowerment with the primary care system that was outlined in the conceptual framework in Chapter II. Two limitations to doing this were the apparent interconnectedness of the components in the framework and the challenge of determining temporality of the different assumptions and risks due to the study design and type of data utilized in the analysis. A related challenge was how to determine clear linkages between components, including direct linkages to the achievement of primary care outcomes—particularly changes in access to primary care services. From the beginning, the study team was aware that showing a direct link to changes in health status was not feasible or appropriate. Although some data were identified showing changes in health



status at the county and state level during the timeframe being studied, no attempts were made to attribute these changes to a specific project or program.

Finally, because this study was conducted before the conclusion of the 2016 US elections it examined data and experience in a context while the future of the ACA and continued support for community health programs and innovations to improve primary care in the US seemed fairly certain. Since the results of the election, questions have emerged about whether the ACA will be repealed or changed, and what kinds of alternatives, if any, might be proposed or implemented. While it is never possible to know the future, some of the events that will likely take place in the coming years were not anticipated a few months ago, and could add further uncertainties as well as unexpected opportunities for the interface between communities and the primary care system, including the work of CHWs.

### **Recommendations for the Future of CHWs in WV and Beyond**

This section includes a set of specific recommendations for the future of CHWs in WV and beyond, based on the analysis and findings of this dissertation.

*Recommendation 1. Support the Development of Strategies and Visions for CHWs at the County- or Regional-level; Share These Visions with Stakeholders in Other Counties and at the State-level in WV:* A shared vision for CHWs is needed at the county level in WV. Some counties have already done this, and some neighboring counties (for example, the several adjoining Mingo County) are working together on regional efforts. Diverse stakeholders—including health insurance agencies, legislators, clinic administrators, primary care providers, and community leaders—need to be supported to think openly and critically about what CHWs can do and what kinds of outcomes and

impact can be expected. Then, engaging these stakeholders in solution-oriented discussions about how to adapt the range of possible CHW functions to each local context is an ongoing process. Above all, consistently and deliberately involving and empowering individuals who do the work of CHWs to inform policy and practice, and allowing self-determination in the future of this rising professional is important. Such CHW engagement could involve participation on local steering committees, regular feedback sessions with groups of CHWs to explore challenges, solutions, progress, new opportunities, and contribute CHW perspectives to policy-making discussions related to certification and support. If done well, this consensus-building approach can capture what is working in diverse contexts around WV and inform state-level policies, funding, and regulation. Having concrete examples of CHWs in action can inform other counties that have not yet thought in-depth about what they are already doing, what they need, and how they could use CHWs in a more coherent and strategic way to identify opportunities and avoid pitfalls and issues that other counties around the state have faced.

*Recommendation 2. Develop mechanisms to ensure that CHWs are sought out and valued by their community and the primary care system:* WV already has a complex and expensive primary care system. Several areas of inefficiency and falling short on reaching desired outcomes are well-known realities that WV has been working to address for many years. Adding a CHW cadre because it is “the right thing to do” is not enough. CHWs must have an essential advocacy and gate-keeping role which incentivizes the primary care system to listen to and rely on them to provide background and understanding as well as for patients to seek them out as a first point of contact and advice on health matters. Without building CHWs into the system in a way that shows

their value to communities and the primary care system and ensures that their knowledge and skills are utilized, these critical workers will not reach their full potential and may instead add to the complexity and inefficiency of the current primary care system.

Building on WV's experience, some examples of how to effectively integrate CHWs into the primary care system include ways CHWs could expedite how quickly a patient can access a physician, pharmacist, or other professional, or if certain services such as farmer's markets, counseling, or physical therapy were cheaper when a patient was referred by a CHW.

Paying for the services that CHWs commonly provide has been a challenge for a long time. Paying for coordinated care that includes CHWs as part of a team of primary care providers linked with a larger set of community services is one approach to addressing this challenge. The CHW is not getting paid separately by insurance, but rather a team of workers and a package of services are being supported. The primary care system and local partners are collectively responsible for achieving specific primary care outcomes. This approach fits within Managed Care Organizations and global payment models,(Burton, Chang, & Gratale, 2013) but puts more focus on the kind of interaction between the licensed primary care providers, the CHWs, and the communities that they serve.

*Recommendation 3. Do Not Overbuild the Credentialing of CHWs at the State Level in WV:* Given WV's diverse historical experience doing the work of CHWs and the varying needs and capacity of local communities around the state, a one-size-fits-all approach to CHWs may not be the most efficient or effective approach for the state to take. Broad, minimum qualifications—including basic skills such as active listening or

motivational interviewing, reading comprehension, and public speaking—could be the basis for meeting requirements for insurance reimbursement for commonly provided services. Many CHWs may require additional training tailored to the specific populations they will serve and the services they will provide; some of this required training may be satisfied by prior qualifications as was done with the nurses who were hired in Mingo County. In other situations, training on a particular disease or kind of patient may be appropriate and can be provided either as part of their job training or may be a prerequisite to apply for the job. Retaining flexibility for CHW roles and qualifications to be adapted to local contexts may create ambiguity and less uniformity for measuring state-level outcomes and impact over time. As a potential trade-off, allowing the CHW to fit into an existing primary care system and care for the community in the ways that are needed the most increases the likelihood that CHWs can be valued and effective in their efforts to facilitate understanding, dialogue, and trust between the primary care system and communities.

*Recommendation 4. Invest Time and Resources in Strengthening Relationships at Local and Regional Levels:* Achieving desired outcomes in the US’s complex primary care system requires coordination and collaboration. Coordination and collaboration must be built on relationships. Relationships require time to develop the trust and experience critical to functioning effectively. With strong local relationships, appropriate packages of services can be developed and provided to the population while avoiding gaps in care, inefficiencies in staffing, and other fragmentation in the service planning, delivery, and evaluation. Local relationships between partners and the community can help identify

where the community will find value within the available services and how best to incorporate the local culture and knowledge into messaging and delivery.

Some counties do not have the population size or resources to justify support of all of the services needed by its population. In Pendleton County, for example, some of the local care providers contract with regional partners for certain procedures that are essential but too rarely needed to maintain the required equipment and staff.

Consequently, outreach beyond the county boundaries to both provide better quality services as well as to obtain new ideas and information can be essential.

Having primary care system agencies reach out to the communities they serve and ask for input, participation, and ultimately facilitate community empowerment is part of this relationship-building. WV is now ready to tackle the additional challenge of “in-reach” where CHWs can become a channel to include the perspectives of community members back to the primary care system. Being able to capture perspectives that were not previously heard can help the system better understand, respect, and respond to the reality and needs of the community.

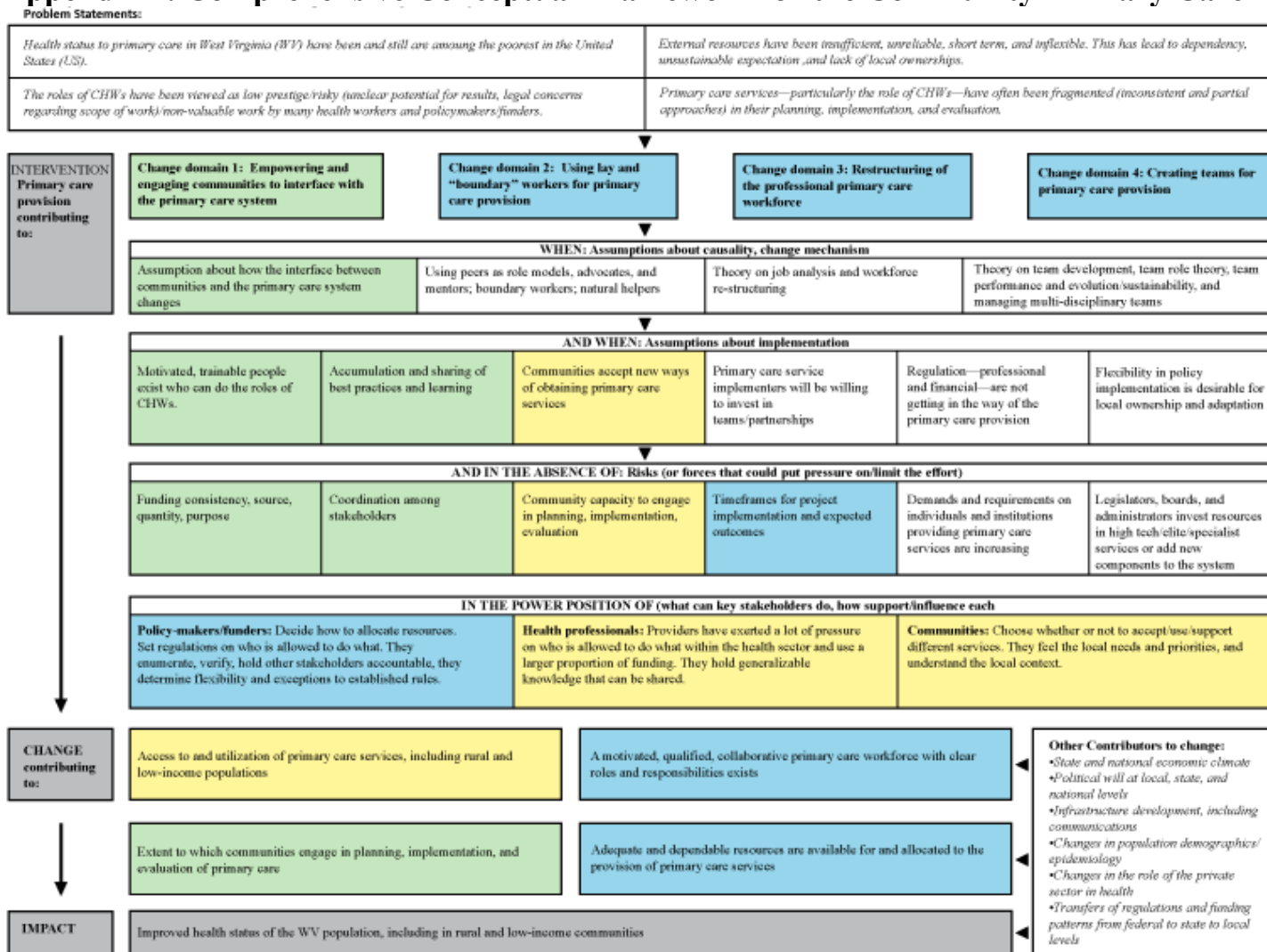
*Recommendation 5. Draw on Community and Primary Care Worker Experiences to Identify Relevant and Inclusive Metrics to Measure and Track Community Engagement and Empowerment with the Primary Care System.* Measuring community engagement and empowerment in a meaningful way is a great challenge. Dialogue among diverse stakeholders about CHWs in WV presents an opportunity to collaboratively develop, refine, and standardize methods and measures to assess community-level changes in engagement and empowerment. Mingo County is actively developing and using metrics such as participation in events and also CHW perspectives to understand barriers to

participation. Pendleton County's long-term leaders have their own measures, such as community representation on local boards, that have become meaningful over the last decades in which those leadership roles have become institutionalized and have gained a level of prestige in the community. State- and county-level averages or generalizations can also mask local positive deviants and ideas that could be encouraged, acknowledged, then strategically and sensitively scaled up. A mixture of quantitative and qualitative measures that assess what kind of engagement and empowerment is occurring as well as why it is or is not taking place is important. Identifying a core set of metrics that can be compared across local populations and can also allow space for measures that have specific meaning to a community would help balance the need for comparability and local flexibility.

*Recommendation 6. Maintain a focus on community engagement and the work of CHWs in times of diminished resources and political support:* The federal policy and funding changes that are likely outcomes of the 2016 US Elections will impact WV. These changes, while it is impossible to know what they might entail, may change the kind of external inputs and collaborations that are possible and may also alter the outcomes that are mandated or incentivized. What will not change, however, is the kind of care that communities in rural WV need. These changes do not diminish the powerful potential to engage communities and support connections between them and the primary care systems that exist to care for these populations. Although, the upswing in recent years in terms of interest, funding, and progress achieved from community engagement and CHWs in the US and beyond may struggle to sustain its visibility and political support, the work of community engagement and CHWs can continue. Just as community

health centers “shoehorned” their outreach strategies into Black Lung funding proposals and counties around the state sought out grant funds to continue work that they deemed valuable, it is possible to keep moving forward by identifying and maximizing viable sources of support. Through continued evidence of value and demonstration of impact, opportunities for CHWs and finding ways to keep engaging communities can and must be done by promotion of meaningful dialogue, listening to local priorities and concerns, building these services into existing delivery systems, and sharing learning and results among stakeholders.

# Appendix 1: Comprehensive Conceptual Framework for the Community-Primary Care Interface in WV





## Appendix 2: Study Instruments

### GUIDE FOR ORAL HISTORIES: ADULTS

**Study Title:** A Team-based Assessment of the Appropriateness and Role for Community Health Workers in Rural West Virginia: Historical Context and Local-level Experience and Perspectives

**PI:** Dr. David Peters

**IRB No.:** 6472

**PI Version No./Date:** V1, July 25, 2015

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Up to 15 oral histories will be conducted between July 2015 and March 2016. Some of these oral histories will be very in-depth and will constitute at least one and possibly up to three follow-up meetings with a respondents over time to delve in-depth into their experience. Each meeting will take place at a location that is easily accessible by the respondent, usually their office, a public space in their community, or possibly their home—particularly if they are retired. Each meeting may take up to 90 minutes, depending on the available time of the respondent and how the discussion is going.

Not all of these oral histories will go into the same level depth, though respondents will be welcome and encouraged to share and discuss in as much detail as they would like to. The aim of these oral histories is to tie together and more deeply interpret a rich history of efforts to build health workforce capacity in rural areas of WV—through policy development and implementation and state-level programs (largely focusing on medical schools and physicians and allied health professionals).

Oral consent will be obtained before initiating each meeting (see corresponding consent form). An interview guide (see below) will be used to guide in narrative around several general topic areas relating to the respondents' work. Oral histories will be audio-recorded and transcribed with permission from the participants.

#### Topics to be covered during the oral histories:

1. How did you first become involved with developing community-based health team capacity in WV?

*Notes: this question is aimed at gaining some foundational perspectives into the respondents' background and experience. It is also to get the respondent thinking about the various initiatives and projects they have been involved with, beginning with their first one.*

2. What type of involvement with capacity development for the health workforce have you had over time?

*Notes: probe about early projects, policies, evolution of projects and policies, and also ask about impacts achieved and challenges that arose. This question and the probes that follow should be informed by and focused on major projects that the informant has been part of. For example, for someone who has been involved with the Rural Health Education Partnership (RHEP), questions about its impact, sustainability, strengths, weaknesses, etc. could be discussed.*

3. As you reflect on the projects you have been involved with, and others that you heard about and saw evolved in parallel, what do you believe has been most effective for improving health in rural WV?

*Notes: this is asking about what has worked best from WV's experience working to improve health so far. Probes will include the role of various kinds of health workers and also about the role of the community.*

4. What are some of the greatest opportunities to strengthening the health workforce and improving health in rural WV?

*Notes: this and the following question about challenges might be discussed in tandem. Probes will include the role of CHWs, both from a historical and contemporary perspective.*

5. What are some of the greatest challenges for strengthening the health workforce and improving health in rural WV?

*Notes: this question is a follow-up to the previous one and may be discussed in tandem.*

## IN-DEPTH INTERVIEW GUIDE: ADULT IDIs

**Study Title:** A Team-based Assessment of the Appropriateness and Role for Community Health Workers in Rural West Virginia: Historical Context and Local-level Experience and Perspectives

**PI:** Dr. David Peters

**IRB No.:** 6472

**PI Version No./Date:** V2, September 13, 2015

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Identified clinicians, clinic administrators, health department staff, and community members will be asked to participate in in-depth interviews (IDIs). These IDI's will take no more than 60 minutes and will take place in-person or by phone at a time and location that is convenient for the respondent. Respondents may be asked to participate in a follow-up interview to facilitate member checking related to themes and specific facts or quotes during the analysis process; these follow-up interviews may be conducted in-person or by phone if this is more convenient for the respondent and may last up to 60 minutes. The total number of interviews conducted will be up to 70, which will be conducted between July 2015 and March 2016.

Oral consent will be obtained before initiating each interview using the corresponding consent form included with this IRB application. The interviewer will follow an interview guide that lists the topics that will be covered. Topics for this guide are listed below.

All interviewees will be asked between two and six questions on each bulleted topic, depending on the need to clarify or follow up on their responses. The researcher will not ask any questions addressing topics other than those identified in the interview guides. Interviews will be audio-recorded, but participants who do not wish to be recorded will be given the option to do a non-recorded interview. The interviewer will take notes of relevant themes and ideas during the interview.

### Topics to be covered during the interview:

1. What kinds of involvement have you had health care in rural West Virginia?

*Note: prompt respondent to include different roles held, different contexts worked in, etc. This is also an icebreaker.*

2. Who are the actors in providing health care in this county, and how are they working together?

*Note: prompt respondent to explain more about the actors (institutions, key individuals, key collaborations). This includes how these actors work together, or don't. Probe into how some of the collaborations developed or have changed over time and how some of them are more effective than others. The respondent is outlining the "health teams" in their county.*

3. What are the major health priorities in your county?

*Note: the focus here is not as much on what the data says the largest contributors to burden of disease are (that can be looked up), but more about what the community thinks are the pressing problems. Probe into which populations are most affected and what kinds of health workers are working to address these problems now.*

4. What are the major opportunities and successes of community-based health teams so far in this county?

*Note: This question is about whether CHWs could help facilitate existing teamwork, how they or others could fill current gaps, etc. If the respondent seems very knowledgeable and interested, ask about what they think about this at the state level as well.*

5. What are some of the greatest challenges for community-based health teams in rural WV?

*Note: the interviewer should introduce the concept of teams of health care providers—based on the overview that the respondent just provided earlier and how CHWs might fit into these existing teams.*

6. How are rural counties going to meet future health needs? What do they need in order to do so?

*Note: this question is still focusing on the health workforce, but also we want to ensure that other key considerations that must be addressed in parallel (or even as prerequisites) to strengthening the health workforce are included. If these arise in these from the interviews as well, they can shape the recommendations and theoretical findings of the study.*

## Appendix 3: List of Documents Reviewed for County Case Studies

### Mingo County, WV<sup>15</sup>

- Arnett, A. (2015). A New Kind of Energy. *West Virginia Executive*, 9.
- Barney, S. (1996). Bringing Modern Medicine to the Mountains: Scientific Medicine and the Transformation of Health Care in Southern West Virginia, 1880-1910. *West Virginia History*, 55, 110-126.
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- RWJF. (2014). Williamson, WV: 2014 Culture of Health Prize Winner. Retrieved from <http://www.rwjf.org/en/library/articles-and-news/2014/06/coh-williamson-wv.html>
- Sustainable Williamson. (2013). Sustainable Communities in Appalachia Technical Assistance Program: Action Plan for Sustainable Williamson Initiative. Retrieved from Washington, DC: <http://www.arc.gov/noindex/newsroom/newsbriefs/LivableCommunities2013ActionPlans/WilliamsonLivableCommActionPlan2013.pdf>
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- Thomas, J. B. (2010). *An Appalachian New Deal: West Virginia in the Great Depression*. Morgantown, WV: West Virginia University Press.
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- WVRHA. (2012). *Health Care in West Virginia: A Workforce Analysis*. Retrieved from
- WVRHA. (2014). *Health Care in West Virginia: A Workforce Supply and Demand Analysis Report*. Retrieved from

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<sup>15</sup> In addition to these publications and reports, a number of internal documents for Sustainable Williamson and specific programs being implemented since 2007 were made available to the researcher to review or copy. These included project evaluation forms, grant proposals, and various maps and photographs.

WVU. (2015). 2015 West Virginia County Data Profile: Mingo County. Retrieved from Morgantown, WV: <http://www.be.wvu.edu/bber>

### **Pendleton County, WV<sup>16</sup>**

- CHSI. (2015). Pendleton County, WV. In C. f. D. C. a. Prevention (Ed.).
- Counts, M. (1989). GENESIS III: Pendleton County, West Virginia. Retrieved from the private collection of Dr. H.G. Taylor.
- County Health Rankings 2015: West Virginia. (2015). Retrieved from [http://www.countyhealthrankings.org/sites/default/files/state/downloads/CHR2015\\_WV\\_0.pdf](http://www.countyhealthrankings.org/sites/default/files/state/downloads/CHR2015_WV_0.pdf)
- Grant Memorial Hospital. (2013). Grant, Hardy, and Northern Pendleton Counties, West Virginia Community Health Needs Assessment: Igniting a Sense of Health in our Communities. Retrieved from Petersburg, WV: [https://www.grantmemorial.com/images/documents/Grant\\_County\\_Community\\_Report.pdf](https://www.grantmemorial.com/images/documents/Grant_County_Community_Report.pdf)
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- Taylor, H. G., & Taylor, C. E. (1989). American Practitioners and Global Primary Care Movement. *MMJ*, 849-852.

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<sup>16</sup> The long history of local efforts to strengthen the primary care system and the careful storage by some long-term local leaders resulted in the accumulation of a large amount of documentation in Pendleton County. This documentation included descriptions projects, proposals, drafts of publications, and copies of the results and reports from a number of projects in addition to the publications and reports listed here.

- Taylor, J. C. (1980). *Depression and New Deal in Pendleton: A History of a West Virginia County from the Great Crash to Pearl Harbor, 1929-1941.* : University Microfilms International.
- The Pendleton Times*. Newspaper microfilm archives accessed via the *WVU State and Regional History Center*.
- The West Virginia Encyclopedia. (2006). In K. Sullivan (Ed.). Charleston, WV: West Virginia Humanities Council.
- Thomas, J. B. (2010). *An Appalachian New Deal: West Virginia in the Great Depression.* Morgantown, WV: West Virginia University Press.
- Wherry, L., & Miller, S. (2016). Early Coverage, Access, Utilization, and Health Effects Associated with the Affordable Care Act Medicaid Expansions. *Annals of Internal Medicine*(164), 795-803.

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## Curriculum Vitae

### Meike J. Schleiff

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<b>Education:</b>	Doctor of Public Health, International Health Dept. Johns Hopkins Bloomberg School of Public Health	May 2017
	Masters of Science in Public Health, International Health Systems Johns Hopkins Bloomberg School of Public Health	May 2013
	Bachelor of Science, Agriculture and Natural Resources Berea College, Berea, KY	May 2008 <i>Magna Cum-laude</i>
	Homeschooled, Renick, WV	1994-2004

### Research Experience:

Aug. 2013-present	<b>Doctor of Public Health (DrPH) candidate.</b> Johns Hopkins Bloomberg School of Public Health. Baltimore, MD, and a series of field sites in rural West Virginia, USA. The research topic was around the future opportunities for Community Health Workers (CHWs) to facilitate and be the link between communities and the primary care system in order to improve health outcomes. Responsibilities included IRB submission, research tool development and testing, conducting all fieldwork, transcribing and organizing all data, coding and analyzing all data, and preparing a manuscript for my final dissertation.
January 2015-present	<b>Assistant Professor and Director of Research,</b> Future Generations University, Franklin, WV ( <a href="http://www.future.edu">www.future.edu</a> ). This position includes teaching health-focused courses within the current Applied Community Change Masters program. It also includes managing a school-wide faculty development process, and developing additional courses and a health certificate program for the school. Finally, it includes coordination and growth of an applied research agenda for the institution covering five fields of study including community health, conservation, peace studies, pedagogy, and development frameworks as well as serving on the institutional IRB.
May 2014 - present	<b>Research Assistant and Database Developer,</b> Thematic Working Group (TWG) on Teaching and Learning Health Policy and Systems Research, Health Systems Global. ( <a href="http://healthsystemsglobal.org/twg-group/4/Teaching-and-Learning-Health-Policy-and-Systems-Research/">http://healthsystemsglobal.org/twg-group/4/Teaching-and-Learning-Health-Policy-and-Systems-Research/</a> ). This TWG has worked to identify and catalog existing training opportunities globally in the field of Health Systems/Health Policy and Systems Research and is now working to strategically address identified gaps. The findings of an initial mapping study were presented at the Health Systems Research Symposium in Cape Town, South Africa in October, 2014 and in San Francisco, USA and Vancouver, BC in 2016. We have also developed a



database of training materials, which can be found at:  
(<http://courses.healthsystemsglobal.org/>).

- Dec. 2013-June 2014     **Research Assistant**, “Consultation and Literature Review for Capacity Development for Health Policy and Systems Research (HPSR) in LMICs.” Alliance for Health Policy and Systems Research, World Health Organization. (<http://www.who.int/alliance-hpsr/en/>) We conducted a systematic literature review on the state of as well as methods and metrics for HPSR in LMICs. We coordinated a global consultation on HPSR in March, 2014 in Baltimore, MD. Finally, we prepared a post-consultation report for dissemination, and a peer-reviewed publication is also in progress.
- Jul. 2013-Jan. 2014     **Research Assistant**, “Systematic Review on the Effectiveness of Community-Based Primary Health Care Projects for Child Survival and Health” with Dr. Henry Perry at Johns Hopkins School of Public Health, Baltimore, MD
- Conduct literature searches
  - Identify literature that qualifies for the review
  - Manage a team of over 20 student reviewers
  - Data entry and analysis oversight
  - Lead author/co-author on forthcoming reports and a journal supplement in the Journal for Global Health

### **Teaching and Management Experience:**

- Summer 2008-present     **Founder and Co-Executive Director**, The G.R.O.W. Project, Inc. ([www.thegrowproject.org](http://www.thegrowproject.org)).
- Mentoring and collaborating with over 80 young Haitian professionals
  - Curriculum development for courses varying from advanced English, leadership development, and academic paper-writing for young Haitian professionals
  - Managed numerous earthquake relief efforts involving transportation, logistics of supplies and people, blood drives, food distribution in Cap Haitien as part of a team of young professionals
  - Response to cholera in un-served regions in rural northern of Haiti with Doctors without Borders/MSF-Suisse; in charge of population of 12,000 for logistics, managed personnel, sustainability strategy by local ownership since Feb. 2010
  - Conducted a series of mixed-methods community-level meetings, trainings, and surveys to help assess The GROW Project’s collective work and impact, get feedback from the community members, and share new ideas and possibilities with the local teams between 2011 and 2014
- Oct. 2014-Dec. 2015     **Gordis Teaching Fellow**, Johns Hopkins University Public Health Studies Program, Baltimore, MD (<http://krieger.jhu.edu/publichealth/>). This position includes developing a semester-long seminar style course on Equity and Disparities in Global Health for the undergraduate public health degree program at Johns Hopkins during the fall 2015 semester. It was organized around a series of case studies including Haiti, Guyana, India, and the United States where Meike has first-hand experience

- Jan. - May 2014      **Co-developer and Facilitator**, Doctoral Seminar on Teaching in International Public Health, Johns Hopkins Bloomberg School of Public Health
- In collaboration with Dr. Henry Taylor, we developed a vision for a seminar for International Health doctoral students in 2014 and which was offered for three years in a row. The seminar resulted in a network of doctoral students with an interest in teaching excellent who remain in touch today.
  - The focus is on practice, philosophy, and opportunities for teaching in cross-cultural settings and looking at innovations, ethics, and challenges of being an effective teacher in the field of public health abroad
- Sept. 2012-Jul. 2015      **Intern and Quality Improvement/Evaluation Consultant**, Konbit Sante, Cap Haitien, Haiti
- Quality improvement (QI) and monitoring of clinical services and record-keeping systems within the public system at Hopital Universitaire Justinien, Cap Haitien, Haiti
  - Mentoring staff to further develop and implement culturally-appropriate evaluation methods in a tuberculosis clinic in the suburbs of Cap Haitien, Haiti
  - Liaison for volunteer professionals during their visits to Cap Haitien
  - Lecturer and research advisor for hospital medical residents as they worked to prepare for their own independent thesis research requirement, often involving evaluation or monitoring of hospital processes
- Summer 2014      **Intern**, Future Health Systems/Africa Hub, Kampala, Uganda. (<http://www.futurehealthsystems.org/>). Revisions and further development of Health Systems Research curriculum for use in seven schools of public health in East Africa. Responsibilities included: review of past drafts, review of similar existing courses in the region, in-depth interviews with experts from the Africa Hub to ensure that the core mission and vision of the curriculum were adhered to, and presentation of revisions and final draft to Africa Hub team.
- May-September 2012      **Program Manager**, One Foundation, Lewisburg, WV 24901
- Work with Executive Director and founders to clarify the vision, values, and process of the Foundation as it shifted directions
  - Build and maintain relationships with partner/grantees in Appalachian region of the US
  - Co-managing a budget of over \$400,000 per year
  - Build constructive relationships based on trust, honesty, and shared values
  - Prepare and present a quarterly portfolio of potential grantees to the board
- Aug. 2009-Aug. 2010      **AmeriCorps VISTA Volunteer**, High Rocks Educational Corporation, Hillsboro, WV
- Branch office establishment: spearheaded the project including finding the real estate, assessing site, lease agreements, renovations, fundraising.
  - Wellness coordinator: gardener/nutrition program director and educator, head cook for over 60 people at summer camps, taught summer courses on food system and nutrition
  - Grant writing: wrote or co-wrote twelve grants for over \$3,000.00 each. Ten were received including AmeriCorps team project for over \$185,000.00.
  - Curriculum development and lead instructor for a wellness and nutrition program at a summer camp for teen girls

June-August 2008      **English Teacher**, Le Flambeau Foundation, Miami, Florida and Cap Haitien, Haiti. Traveled to Haiti to teach advanced English and Test of English as a Foreign Language (TOEFL) preparation courses for the summer. Meike was the only teacher that went to Haiti that summer, and she ended up teaching beginner and intermediate English in addition to the courses that she was originally recruited to teach.

### **Volunteer Experience:**

- February 2016-present      **Coordinator**, Thematic Working Group on Teaching and Learning Health Policy and Systems Research. Health Systems Global.  
[www.healthsystemsglobal.org](http://www.healthsystemsglobal.org).  
Responsibilities include facilitating linkages between group members, helping members upload courses and materials to the group's database, coordinating a series of webinars on teaching and learning topics, seeking funding opportunities, and preparing for a bi-annual conference.
- January 2012-present      **Delegate and Delegation Coordinator**. Global Health Watch/People's Health Movement (PHM). Geneva, Switzerland and Washington, DC.  
<http://www.phmovement.org/>.
- Global-level policy analysis, preparation of commentary, and public relations to disseminate information to country-level delegate
  - PHM Delegate to World Health Assembly in Geneva, Switzerland, May 2012
  - Coordinator, PHM from the region of the Americas to the Pan American Health Organization Regional Meeting in Washington, DC, September 2012, September 2013, and September 2014
  - Delegate to the Swedish Society of Medicine "Global Health Beyond 2015" conference in Stockholm, Sweden, April 2013.
  - Regional organizer for People's Health Assembly in August 2016 in Montreal, Canada in parallel with the 2016 World Social Forum
- August 2015-present      **Board Member**. Mountain Springs Farm and Heritage Center. Morley, WV.
- Oct. 2009-Aug. 2011      **Secretary, Board of Directors**. Child and Youth Advocacy Center. Lewisburg, WV.
- June 2009-Aug. 2014      **Local Food Steering Committee Member**, Greenbrier Valley, WV. Working on agriculture project, development, education, support local economy through strengthening the local agriculture systems.

### **Taskforces, Special Nominations, and Invitations:**

- \*Starting January 2017      **Member**, West Virginia (WV), USA Community Health Worker (CHW) Consensus Taskforce. Working to develop a model for Community Health Workers (CHWs) for WV building on the vast experience in the state and Meike's doctoral dissertation research.
- June 8, 2015-present      **Advisory Group Member**, Creating a Culture of Health in Appalachia: Disparities and Bright Spots Project. Kentucky Environmental Foundation and Virginia Tech. (<http://www.kyenvironmentalfoundation.org/>).
- May 29, 2015-present      **Facilitator and Process Observer**, Public Health Impact Taskforce (PHIT). WV Bureau for Public Health. Charleston, West Virginia.

(<http://www.dhhr.wv.gov/localhealth/Public%20Health%20Impact%20Task%20Force/Pages/default.aspx>). This is a state-wide public health sector reform process that is looking at the possibility of regionalizing the county public health departments for West Virginia. Provide an external process observation to task force meetings and facilitate regular rounds of reflection through a series of online surveys and feedback of results. Also manage the online collaboration platform for all taskforce members. The purpose of the taskforce is to consider and make recommendations for restructuring of the governmental public health system in West Virginia.

- Feb. 1, 2015-present      **Workforce Working Group Member**, West Virginia State Innovation Model (SIM) design grant. Centers for Medicare and Medicaid and the WV Health Innovation Collaborative. Charleston, West Virginia.  
(<http://www.wvhicollaborative.wv.gov/>).
- Jul. 2012-Jul. 2014      **Visiting Guest and Consultant to the Minister of Health of Guyana**. Georgetown, Guyana.
- Visited all levels of the health system from tertiary hospitals to mobile clinics
  - Made recommendations and discussed areas of where challenges and needs exist particularly related to equity and Primary Health Care; look forward to incorporating further work with indigenous peoples and/or health infrastructure in Guyana

### **Academic Reports and Publications:**

Schleiff, M., Kumapley, R., Freeman, P., Gupta, S., Rassekh, B., Perry, H. \*Currently undergoing peer review. A Comprehensive Review of the Evidence Regarding the Effectiveness of Community-based Primary Health Care in Improving Maternal, Neonatal, and Child Health: Equity Effects. *Journal of Global Health*, special issue forthcoming in 2017.

George, A., Schleiff, M., Mancuso, A., Lefevre, A., Sarriot, E. 2016. Rethinking Evidence for Community Health Systems to Support Ending Preventable Maternal and Child Deaths (EPMCD): Preliminary Report. Report for the *United States Agency for International Development (USAID)*.

Tancred T., Schleiff, M., Peters, D., Bigdeli, M, Balabanova, D. 2015. Teaching and Training in Health Policy and Systems Research: Global Status and Priorities. *Bulletin of the World Health Organization*.

Pappas, E., Schleiff, M., Pappas, J., Puentes, R., Taylor-Ide, L., Taylor, D. 2015. Curriculum Plans for Community Health and Prevention, Entrepreneurship, and Family Agriculture. *The Pew Charitable Trusts and University of the World*.

Tancred, T., Schleiff, M., Peters, D., Balabanova, D. 2015. Global Mapping of Health Policy and Systems Research (HPSR) Teaching. *Alliance for Health Policy and Systems Research, W.H.O.* Report and background document for an expert consultation on teaching HPSR. Available at: <http://healthsystemsglobal.org/twg-group/4/Teaching-and-Learning-Health-Policy-and-Systems-Research/>.

Rodrigues, D., Schleiff, M. 2014. Department of International Health Research Mapping: Final Report. A review and past and present foci in research within the IH Dept. at Johns Hopkins and recommendations towards a strategic plan.

Gupta, S., Hyder, A., Schleiff, M., Tran, N., Ghaffar, A. 2014. Global Consultation on Capacity Development for Health Policy and Systems Research in Low- and Middle-Income Countries. *Alliance for Health Policy and Systems Research, WHO*.

Schleiff, M. 2013. Analysis of the World Health Organization (WHO)'s Initiatives for Global Action Towards Greater Equity in Health: Primary Health Care and Social Determinants of Health. Masters Thesis, Johns Hopkins Bloomberg School of Public Health.

Report by WHO Watch and the People's Health Movement on the 65th World Health Assembly. Global Health Watch. May 2012. Geneva, Switzerland.  
[http://www.ghwatch.org/sites/www.ghwatch.org/files/WHOWatchReport\\_May2012.pdf](http://www.ghwatch.org/sites/www.ghwatch.org/files/WHOWatchReport_May2012.pdf).

### **Other Publications:**

Schleiff, M. 2013. Community-based Versus Community-directed Approaches. Tropical Health Matters guest blog post, December 17, 2013. Available at: <http://malariamatters.org/community-based-versus-community-directed-approaches/>.

Schleiff, M. 2011. Return to Haiti—And Haiti to Haitians. Huffington Post blog post on May Goldwasser's RED page, May 25, 2011. Available at: [http://www.huffingtonpost.com/amy-goldwasser/red-the-book-return-to-haiti\\_b\\_551215.html](http://www.huffingtonpost.com/amy-goldwasser/red-the-book-return-to-haiti_b_551215.html).

Schleiff, M. 2007. A 'Beautiful' Cause of Death that had me Dying for a While in: RED: The Next Generation of American Writers-Teenaged Girls-On What Fires up their Lives Today. Ed. Amy Goldwasser. Hudson Street Press, New York: 2007.

### **Presentations:**

**Training for Health Policy and Systems Research: A Global Online Resource Repository Poster Presentation for Health Systems Global.** Consortium of Universities for Global Health Conference. April 9-11, 2016 in San Francisco, CA and the Health Systems Research Symposium, November 17, 2016 in Vancouver, BC.

**Berea College's School-wide Haiti Speaker Series,** Alumni Lecture on Education as a Force for Upward or Outward Mobility in Haiti. March 24, 2015.

**Rights and Responsibilities in the Context of the Stories We Tell Ourselves.** Independent TED event, TEDxLewisburg presentation, June 22, 2013.  
<http://www.youtube.com/watch?v=LCSJURR3SS0>.

**Wisdom for Health Equity: Primary Health Care and the Social Determinants of Health.** Co-presentation at the American Public Health Association (APHA), 2013 Annual meeting, Boston, MA on a panel discussion with Dr. Henry Taylor.

**Prescription Drug Assessment and Administration Follow-up Study.** Operational research/quality improvement. Pediatrics Service, Hopital Universitaire Justinien, Cap Haitien, Haiti. November 2012.

**Comprehensive Rural Health Project (CRHP), Jamkhed.** Guest speaker in “Case Studies in Primary Health Care” Course, Johns Hopkins Bloomberg School of Public Health. March, 2012.

### **Awards:**

**West Virginia Rural Health Conference Scholarship.** A competitive state-wide award to enable students engaged in research and/or practice related to rural health in West Virginia to attend the annual conference and participate in sessions, networking, and sharing their work and ideas with colleagues and mentors. Fall 2016.

**Johns Hopkins Center for Qualitative Studies in Health and Medicine Dissertation Enhancement Award.** A complete school-wide award to support a doctoral candidate in a qualitative dissertation that has promise to further the future of qualitative research in public health. Winter 2016.

**Governor of West Virginia’s Commendation for Volunteer Service, 2010.** Given by Governor Joe Manchin, III for outstanding commitments to volunteerism and exceptional contributions making West Virginia a better place. Awarded for contributions as an AmeriCorps VISTA. Spring 2010.

**David F. Kinder Memorial Award.** For academic excellence, leadership, and involvement in agricultural extracurricular activities. Spring 2008.

**Burt-Steele Pathfinder’s Scholarship.** For leadership, dedication, academic excellence, and support of the High Rocks Educational Corp. 2007-2008.

**Joseph van Pelt Agricultural Award.** Leadership, social concern and outstanding effort. Spring 2007.

### **Certificates:**

**Preparing Future Faculty Teaching Academy (PFFTA),** Johns Hopkins Medical Institutions. Baltimore, MD, USA. The PFFTA Program offers advanced doctoral students from multiple schools within the university the opportunity for pedagogical, mentoring, curriculum development, and classroom training experience to help prepare them for future teaching roles in their careers. August 2014 to December 2015.

**CORE Group Practitioner Academy.** Jamkhed, India. Facilitated by CORE Group. (<http://www.coregroup.org/>). This was a 10-day intensive immersion training for public health practitioners on community-based health systems and health access to the poorest sectors of society. January/February 2012.

### **Spoken languages:**

- English, native speaker

- German, native speaker
- Haitian Creole, strong conversational
- French, conversational
- Farsi, beginner