

“Death is Due to Lack of Knowledge”:

Community Practices of a Successful Multi-Partnered Health Disparities Intervention for  
Low-Income African Americans in South Carolina

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**Dedication**

To people who volunteer and work for health equity in their community.

**Abstract**

The purpose of this study was to describe the methods—including practices, policies, and roles—used by public and academic library staff in a Centers for Disease Control and Prevention (CDC) Racial and Ethnic Approach to Community Health (REACH) intervention that proved successful in reducing or eliminating several diabetes-related health disparities in a vulnerable population. An intrinsic case study methodology was used to identify effective services, resources, and practices for library staff. A semi-structured telephone interview was completed by 11 community partners from a successful multi-partnered, community-based, diabetes-related health disparities intervention that included librarians as community partners. Questions included (a) What were some traditional or innovative library roles, services, or resources used in this successful intervention? (b) How was helicopter research avoided? (c) How was trust with the vulnerable community members established and maintained? (d) How were community members with low literacy included? Data were audio-recorded and transcribed. Eight major themes consistent with transformative adult learning theories were identified from the coded transcripts, including (a) autonomy, (b) community-based and community-led, (c) incentives, (d) a new role for professionals, (e) participants realizing success, (f) church participation, (g) transformation, and (h) perspective of the librarians. The insights and guidelines suggested by this research may be helpful when deciding how or when to participate in community-based health disparities interventions for vulnerable populations.

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**Abbreviations**

**A1c** – Refers to the name of a blood test that determines how well diabetes is being controlled. Normal A1c level is between 4% and 6%.

**CBPR** – Community **B**ased **P**ractice **R**esearch

**CDC** – Centers for **D**isease **C**ontrol

**CGDC** – Charleston and **G**eorgetown County **D**iabetes **C**oalition

**CHA** – Community **H**ealth **A**dvisor

**CORE** – Georgetown County Diabetes **C**ommunity **O**utreach **R**esources and **E**ducation

**NHDR** – National **H**ealthcare **D**isparities **R**eport

**NLM** – National **L**ibrary of **M**edicine

**REACH** – **R**acial and **E**thnic **A**pproaches to **C**ommunity **H**ealth

## **Chapter 1: Health Disparities**

Even after decades of research, very little is known about the factors that ensure the success of a health disparity intervention. Though millions of dollars and much time and effort have been spent on designing and implementing interventions, little evidence of an actual reduction in disparities exists. A recent paper by Voelker (2008) reported a dismal record of improving the health of vulnerable populations at the national and local levels; the impact of this dismal record was expensive in terms of unnecessary health care expenses as well as the unnecessary suffering of almost one of four people in the United States, due to the social assignment of race or ethnicity. On the hopeful side, Voelker mentioned one study showing actual success in reducing disparities; co-authored by a librarian, this intervention relied extensively on library resources and information services as part of a broad community partnership. My research project explored the methods and practices used by the community partners in this successful health disparities intervention. Detailing the methods and practices used by community partners enabled me to develop a model of best practice for subsequent interventions useful to community partners and those working in and researching the multidisciplinary fields of health disparities research.

A call has been made for scholarship that will enable better understanding of the effectiveness, and advantages or disadvantages of the policies, practices, and roles used in community-engaged health disparities intervention programs (Allison, 2007; Chin & Goldmann, 2011; Jones, Trivedi, & Ayanian, 2010). The lack of peer-reviewed

scholarship likely prevents needed progress toward the reduction or elimination of health disparities and is why studying a successful intervention may prove useful in finding the factors that improve the health of a targeted population within a community.

Braveman (2006) described the history of various definitions for health disparities and inequalities, and proposed the following definition, alluding to the social and political factors in the health and well-being between populations:

A health disparity/inequality is a particular type of difference in health or in the most important influences on health that could potentially be shaped by policies; it is a difference in which disadvantaged social groups (such as the poor, racial/ethnic minorities, women or other groups that have persistently experienced social disadvantage or discrimination) systematically experience worse health or greater health risks than more advantaged groups. (p.180)

In the following sections, I provide an overview of the background to the issue of health disparities, and discuss contributing systemic factors and resulting national costs, as well as the roles of libraries and librarians in an effective intervention. I delineate the purpose for conducting this study, the specific research question addressed, and my qualifications for undertaking the research. Finally, I conclude with relevant definitions.

### **Background**

In the United States, the extent and severity of health disparities have only recently become a national concern (Smedley, Stith, & Nelson, 2003). This recent interest is surprising because minority-based disparities in health care, and in the national

infrastructure and workforce composition, have been long known. For instance, as early as 1895, a race-based professional association called the National Medical Association was formed in response to the overt racism toward African American patients and professionals (National Medical Association, 2009). The new interest in addressing these long-term disparities appears to indicate that the medical establishment has only recently come to view them as unacceptable.

In almost all non-White groups, indicators of health status (e.g., longevity) and health care (e.g., access to insurance) are less optimal than for Whites. Consequently, most White populations can expect to have better health, receive better health care, and live longer lives than can those of equal education and socioeconomic status in minority populations (Adelman, 2008). This is true across all levels of the socioeconomic spectrum (i.e., wealthy Whites have better health and longer lives than do equally wealthy African Americans). When looking at Table 1, it is easy to see that 28% of the United States population consists of people who are not the majority population. People in these groups are more likely than are Whites to receive either suboptimal care (i.e., a health *care* disparity); suffer shorter life spans than do Whites (i.e., a health *status* disparity); or both.

Currently, disparities are so stark that public health professionals predict poorer health status simply by knowing the socioeconomic status, race, and geographic location in which the population resides.

### **Systemic Failures**

One of the difficulties with understanding the etiology of health disparities is the vast number of factors affecting outcomes of personal self-care and professional health care practices. Depending on the investigator's background and training, health

Table 1

*Population, by Race, From the United States Census 2010*

Demographic	Population	%
Total United States population, 2010	308,745,538	100.0%
White, Black, African American, American Indian, Alaskan Native, Asian, Native Hawaiian, or other.	299,736,465	97.1%
White	223,553,265	72.4%
Black	39,929,319	12.6%
American Indian and Alaska Native	2,932,248	0.9%
Asian	14,674,252	4.8%
Hawaiian and Pacific Islander	540,013	0.2%
Other race	19,107,368	6.2%
Two or more races	9,009,073	2.9%

*Note.* Adapted from Humes, Jones, & Ramirez, 2011, with ethnicity data excluded

disparities can be viewed as a systemic problem with many potential sources. Selected examples of factors contributing to health disparities are listed in the following sections.

**Medical education segregation.** Stelnick, Lee-Rey, Nivet, and Soto-Greene (2008) described the history that ended the possibility of medical education for African Americans when all but two Black medical colleges were closed in 1911. The restriction

that prevented African Americans from becoming physicians lasted through 1964, when 97% of new physicians were White. The modern-day implications of this loss of opportunity include an education culture that is still challenged to recognize the skills and leadership of African Americans.

**Lack of accuracy in government-produced reports.** Bloche (2004) described his experience with the Department of Health and Human Services (DHHS) when he was required by top officials to rewrite the conclusion that health care disparities are pervasive in our health care system. Bloche suggested the prevailing political direction was to shift the responsibility for health disparities to the individual, and away from the health system.

**Poverty.** Barr (2008) provided an overview of studies that showed across all racial and ethnic populations that longevity and health appeared to be positively correlated with socioeconomic status. The populations and groups who had the lowest incomes were the same populations with the worst health and shortest life-spans. The populations and groups with the highest incomes consistently had much longer lives, with higher quality health.

**Race as a social construct.** Fine, Ibrahim, and Thomas (2005) reported that health disparities research focused on “understanding the complex associations between race, health, and health care” (p. 2125). Many health professionals have come to view race as a social and cultural construct, largely controlled by the community and social structures. The implication of race as a social versus biologic or genetic construct is that

health outcomes are determined by the social status of skin hue (e.g., shades of black or brown) or socioeconomic indicator (e.g., perceived income or neighborhood lived in).

**Long-term physiological stress.** It is not known why skin hue and socioeconomic factors are strongly correlated with health disparities. One theory is that people of color and lower socioeconomic groups have fewer options when responding to everyday stress. They are less likely able to afford to attend a stress management program or take a vacation that more privileged groups routinely afford. People of color and lower socioeconomic groups have fewer choices in employment due to continued preference of hiring Whites for professional positions. These groups often have fewer choices and increased health hazards due to living in dangerous (e.g., violent) or unhealthy (e.g., polluted) neighborhoods (Brownson, Baker, Housemann, Brennan, & Bacak, 2001). The theory behind poorer health in these groups is that physical illness results from chronically high levels of cortisol, a stress-based hormone (Adler & Newman, 2002). Physiological research has shown that those on the lower end of the power spectrum (i.e., the dominance/subordinate status in non-humans, and the social-power status in humans) consistently had higher rates of cortisol than did those at the higher end. When experienced chronically, high levels of cortisol increased the incidence of chronic disease and shortened lives (Adelman, 2008).

**Persistence of health disparities.** Changing systemic practices that would increase effective options for handling stress (e.g., improving socioeconomic levels or moving people to healthier, safer neighborhoods) are beyond the scope of most

professionals. Despite the existing programs and interventions, a lack of knowledge remains about what works to reduce disparities. This lack of knowledge is apparent despite more than a century of knowing health and health care differences exist between privileged (White) and vulnerable (minority and lower socioeconomic) groups.

### **The Problem and its National Costs**

Lack of knowledge and the subsequent failure to reduce or eliminate disparities at a national level have dire consequences. Dire consequences include (a) the expectation of poorer health status in non-White and low-income populations, (b) the high cost of health care in the United States, and (c) lack of progress in the science of health care delivery.

Failure to reduce or eliminate health disparities in vulnerable populations is an expensive, complex national problem. LaVeist, Gaskin, and Richard (2009) reported 30% of medical expenditures for racially defined groups (e.g., African Americans and Asian Americans) were excess costs linked to health disparities, with a \$1.24 trillion impact on the U.S. economy. In terms of human suffering, more than one in four people are members of a vulnerable population and suffer from poorer health as a result of belonging to a non-White or low-income group.

This lack of knowledge concerning successful interventions is apparent in many ways. It is apparent in that I, as a medical librarian with 24/7 access to the best and most current medical, social science, and library literature, cannot find evidence to answer the simple question of *what works* to reduce a health disparity. This knowledge gap is

confirmed by others (see Beach et al., 2005; Chin, Walters, Cook, & Huang, 2007; Price et al., 2005).

The absence of useful knowledge to further the science of health care delivery is evident in the debate about using limited and competing health care resources. Allison (2007) suggested that not knowing what works to reduce health disparities slows the determination of whether limited funds and staffing should go toward quality improvement programs for all patients and practitioners regardless of race or income, or whether directing those limited funds to customized cultural interventions would provide more optimal results. Unfortunately, because literature on successful intervention outcomes is minimal, we are unable to address the quality versus cultural intervention debate and progress in the science of health care delivery is limited.

### **Introduction to Libraries and Library Services as a Factor**

Virtually all interventions intended to reduce health status and health care disparities address the information needs of many diverse adult learners (i.e., diverse in ethnic, racial, and socioeconomic categories as well as diverse in professional, academic, community, family, and personal roles). All are roles played by professionals, participants, and patients in optimizing community health.

Most health disparities interventions and programs have multiple partners working independently or interdependently and librarians are largely trusted resources of non-biased information. Adler (2006) reporting in the Institute of Medicine's health disparities literature, indicated that libraries as community partners enable the collective

efficacy of communities, thereby improving the health and satisfaction of the community as a whole (p. 147). Libraries, a fundamental and free service for most community and academic institution members, may become involved in health disparities projects due to their respective missions to preserve, organize, and transmit knowledge to and within their communities (Association of Academic Health Sciences Libraries, 2003; Basler, 2005). These missions are operationalized as:

- Advocating for and improving reading literacy within their community
- Advocating for and improving information technology literacy (e.g., learning how to search for health information on the Internet) within the community
- Advocating for and improving health literacy, including how to find and recognize the best information for personal and family member care
- Advocating and supporting improved professional literacy with the academic community, including teaching professionals how to find and manage the overload of information from the knowledge base for patient care, health promotion, and life-long learning

Medical librarians are relied upon by health care practitioners in all fields to further career and institutional goals. Medical librarians are used by patients to further health education for family or self-care needs. However, in spite of my expertise, I am at a loss when asked to support health disparities reduction programs because there appears to be no information about methods used by community partners, including libraries and librarians, to support a successful health disparities intervention. There is much literature

describing the existence of interventions, but most do not address the ultimate goal of improving the health of the vulnerable population for which they were intended, thereby leaving a knowledge gap for practitioners and researchers of what works when attempting to reduce or eliminate health disparities, or to understand the science of health care delivery for vulnerable populations. Consequently, librarians and other community partners striving to reduce or eliminate disparities have little information from which to build, plan, or improve methods that positively affect the health outcomes of a vulnerable population. Without knowledge of what works, it is difficult for the field to progress and for health disparities to be reduced.

### **The Purpose of This Study**

One efficient way to improve the field of health disparities research is to learn *what works in a successful intervention*. This research identifies methods, practices, and roles concomitant with an intervention that is successful in reducing or eliminating an actual health disparity. I have researched a rare case that has been reported in the peer-reviewed literature as having success in improving the health of vulnerable populations. I have asked what were the methods, practices, and roles undertaken within this intervention.

My definition of a “successful community-based program” is one that has been proven to reduce disparities in disease symptoms and adverse effects between a vulnerable and a socially dominant population. The word *concomitant* is used because community health disparities interventions generally have many community partners and

existing structures. Success in a complex dynamic community partnership likely has many vectors; it is plausible that understanding how some of these vectors affect partners and existing structures will prove invaluable in determining what is consistent with success in health disparity reductions.

### **Research Question**

To anchor my research, I confined it to the domain of community partners, including library staff, resources, and services in the successful intervention called Racial and Ethnic Approaches to Community Health 2010 Charleston and Georgetown Diabetes Coalition (hereafter referred to as REACH 2010 CGDC). REACH 2010 CGDC provides a case study of a health disparities intervention that produced measurable reductions in diabetes symptoms severity. Studying this case provided seminal knowledge with which to explore success in health disparities research so that knowledge may more quickly be applied to improve the health and reduce the health inequity of a vulnerable population. Discovering practices used to reduce the impacts of diabetes provided insights and knowledge useful to other practitioners, academics, librarians, and community members working to reduce health disparities. One project within REACH 2010 CGDC that was part of the overall mission was the Library Partnership. By interviewing Library Partnership members, I developed a model of best practices to share with the health and community-engaged research professions.

Using the REACH 2010 CGDC Library Partnership in an intrinsic case study, I explored the methods, including practices, policies, and roles, that were used by

community partners (see Figure 1) and that overall proved successful in reducing or eliminating several diabetes-related health disparities of a low-income, rural African American population. Specifically, I interviewed REACH 2010 CGDC community partners regarding:

1. Library staff roles, services, and resources that enabled a successful community-based diabetes-related health disparities intervention for a population with diabetes or learning new skills, behaviors, and attitudes.
  - What appear to be effective practices for library staff roles, services, and resources in a community-based diabetes-related health disparities intervention?
2. Innovative activities not traditionally thought of as library/librarian duties.
  - What were the non-traditional or innovative library roles, services, or resources used in the Charleston/Georgetown project?

Delimiter: I avoided the effects of “helicopter research,” whereby a researcher’s contact with the vulnerable population is transient and does not serve the members of the population. Helicopter research is a cause of distrust especially within African American communities (Hsin-hsin & Coker, 2010; Kennedy, Mathis, & Woods, 2007).

**Rationale for the study.** As a medical librarian and a student of adult education, I describe the problem as a lack of knowledge about the methods and roles used by community partners, including library staff, in the literature that are concomitant with successful health disparities reduction interventions. This lack of knowledge puts all

practitioners, academics, librarians, and community members at a disadvantage when trying to better understand, plan, implement, or improve a health disparity intervention in a population. Based on the success on REACH 2010 CGDC and its reliance on libraries, it seems that libraries and librarians may have a promising role to play in successful health disparities interventions.

**What is a successful intervention?** My definition of a successful intervention for this research is an intervention whose formal evaluation shows a quantitative improvement in a health measurement of a vulnerable population. An example is a pretest/posttest evaluation that shows a significant improvement in a physiological measurement (e.g., blood pressure level) or a reduction in adverse outcomes (e.g., amputation caused by chronic disease). One such intervention found to be effective in reducing disparities was REACH 2010 in Charleston and Georgetown counties in South Carolina, which I discuss later as an actual case on which my dissertation is based.

**Usefulness of identifying methods and practices.** Methods and practices around a successful health disparities intervention can fill in knowledge gaps for the field the health disparities. New knowledge about the practices of libraries concomitant with improvement of the health of a vulnerable population may be useful in planning future interventions. Gaining insight into these practices and values was essential, and is expected to be transferable to other projects, and re-contextualized for the many other disciplines working to reduce health disparities.

### **Qualifications of Researcher and Background**

I am a White professional female who works as a medical librarian in a well-known medical organization in Rochester, Minnesota. I have the honor of being a distinguished member in the Medical Library Association's Academy of Health Information Professionals, and I am an assistant professor of medical education in my employer's college of medicine. Additionally, I am a doctoral student of adult education in the University of Minnesota's Organizational Leadership and Policy Development program. In my role as an active community member and as a medical librarian, I recognize a lack in the knowledge needed by researchers, practitioners, and community members working toward reducing health disparities. Librarians are known to serve as discourse mediators (Simmons, 2005), and their roles seem aligned to address not only finding needed information for patrons, but also to alleviate knowledge gaps and thereby change structures and the status quo (e.g., by helping to create dialog on the current state of health disparities scholarship). My goal in this research was to identify community dynamics and methods that enabled reduction in a health disparity between African Americans and Whites.

### **Definitions of Terms**

**Health disparities.** To establish an area of disciplined study and research, there must be a shared understanding of the topic under consideration. However, health disparities definitions have been defined and redefined for decades; perhaps this hesitance to define this field (unlike other areas of medicine) is a consequence of having policymakers, government officials, and social and medical researchers as stakeholders.

“The definitions seem to move like the gradient in health status, up and down a ladder of ethnic, racial, and economic considerations,” as reported in *Health Affairs* (2008, p. 373).

The following definitions from several sources are presented in chronological order. From the Minority Health and Health Disparities Research and Education Act (2000):

A population is a health disparity population if, as determined by the Director of the Center after consultation with the Director of the Agency for Healthcare Research and Quality, there is a significant disparity in the overall rate of disease incidence, prevalence, morbidity, mortality or survival rates in the population as compared to the health status of the general population. (p. 2498)

Smedley, Stith, and Nelson (2003) described health care disparities as “racial or ethnic differences in the quality of health care that are not due to access-related factors or clinical needs, preferences, and appropriateness of intervention” (p. 32).

The Agency for Healthcare Research and Quality (AHRQ) defined disparities as any differences among populations that are statistically significant and differ from the reference group by at least 10% (cited in Hebert, Sisk, & Howell, 2008, p. 375).

Given the variety of definitions concerning health disparities, in this dissertation I use a frequently cited definition by Braveman (2006):

A health disparity/inequality is a particular type of difference in health or in the most important influences on health that could potentially be shaped by policies; it is a difference in which disadvantaged social groups (such as the low-income,

racial/ethnic minorities, women or other groups that have persistently experienced social disadvantage or discrimination) systematically experience worse health or greater health risks than more advantaged groups. (p.180).

**Library staff.** Staff include librarians (i.e., professionals with a master's degree) and other staff (i.e., technical and service staff with education of at least a high school diploma) who work within or between library systems that may include public, academic, or hospital libraries.

**Library services.** On- or off-site library services include instruction, checking in and out of materials, interlibrary loan, and facilities for community buildings (e.g., auditoriums and reading rooms).

**Successful intervention.** An intervention is deemed successful when a formal evaluation shows a measurable improvement in a health variable of a vulnerable population. An example is a pretest/posttest evaluation that shows significant improvement in a physiological measurement (e.g., decreased blood pressure level) or a reduction in an adverse outcome (e.g., blindness or amputation) following the intervention. One such intervention found to successfully reduce disparities in severity of diabetes symptoms and adverse effects was reported by Jenkins, Magwood, Carlson, Thomas, and Linnen (2010) and Jenkins, Myers, Heidari, Kelechi, and Buckner-Brown (2011).

## **Summary**

Measurement of health disparities at the national population level consistently shows that failure to improve the health of vulnerable populations is chronic and pervasive. Abouzaid and Maio (2009) and others (Berkman, 2009; Griffith, Yonas, Mason, & Havens, 2009; U.S. DHHS, 2012; Voelker, 2008; Williams, Costa, Odunlami, & Mohammed, 2008) who reviewed why the United States has made so little progress in reducing disparities found systematic issues adversely affect minority populations. For example, lack of insurance due to provider bias helps to inadvertently maintain disparities.

The research I undertook to identify what works (e.g., the methods) in a successful community intervention will:

- Add to the knowledge base for practitioners in community and clinical settings
- Add to the knowledge base for academics in education and research settings
- Provide a shared scholarship for practitioners, academics, and community members for research activities that fall under the concept of translation of practice into research
- Provide a shared scholarship so that practitioners and community members can choose from practices consistent with actual health disparities reductions

This approach seems novel in health disparities research, and therefore may have a potentially significant impact on future community-based intervention programs.

A detailed description of the REACH 2010 CGDC project is given at the start of chapter 3. An analysis of findings concerning what worked follows in chapter 4, together with the discussion as it relates to the literature in chapter 5. Chapter 6 addresses implications for future research.

## **Chapter 2: Review of the Literature**

This review focuses on several bodies of literature relevant to health disparities research. Health disparities for African Americans first were commented on in the scholarly literature in the late 1800s; this time period is consistent with the formation of the race-based National Medical Association. Subsequently, health disparities scholarship remained virtually nonexistent for almost 100 years. However, since the turn of the 21st century, when Congress directed the U.S. DHHS to address health disparities, the level of concern and resulting publications sky-rocketed (Adler, 2006). This chapter begins with an overview of the gray literature and obscure resources for public health; then reviews major trends of success and failure in health disparities research; and concludes with an examination of literature about successful interventions to reduce diabetes, including community-based participatory research.

### **Overview of the Gray Literature**

Although the body of journal literature is currently nascent, seminal works to support health disparities research have been provided in the gray literature. Gray literature is “that [information] which is produced by all levels of government, academics, business and industry in print and electronic formats, but which is not controlled by commercial publishers” (Third International Conference on Grey Literature, 1997, para. 2). This may be problematic when reviewing disparities research because this literature is not indexed in the routine portals to high-quality clinical and academic research information (e.g., Medline).

In 2000, a U.S. government plan called Healthy People 2010 established explicit goals to eliminate racial and ethnic disparities. The resulting report to eliminate disparities was created and sponsored by the U.S. DHHS (2000). The report provided a structure and plan to address social factors affecting the nation's most prevalent diseases and health risk factors (e.g., obesity, substance abuse, safe sex, environmental quality, mental health, and access to health care). The Centers for Disease Control (CDC) responded to the Healthy People's 2010 plan by creating the Racial Ethnic Approaches to Community Health (REACH) 2010 framework. In 2003, the Institute of Medicine's *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* provided an introduction to disparities from different perspectives, including those of the patient and the organization (Smedley et al., 2003).

### **Scholarship on Obscure Resources for Public Health**

Information needed to practice population health or public health existed in disparate and frequently obscure sources. Challenges faced by public health practitioners were addressed in a special issue of *The Journal of Urban Health* (Lasker, 1998):

The existing base of information can enhance decision making only if users are aware of what is available, can readily identify documents that are relevant and of sufficient quality to meet their needs, and can obtain that information in a timely manner. (p. 779)

Lasker outlined the advances in information technology and telecommunications for the biomedical literature, concluding, "Yet, while these activities are extremely valuable,

they are not sufficient to meet the information needs of two other sectors with functions that are essential to improving health: the public health and health policy communities” (p. 779).

Lasker (1998) reported that the diversity of disciplines affecting public health and public health policy required sources and bibliographic aids:

Professionals in public health and health policy seek statistical and epidemiological data, legal and legislative documents, information about community resources, and an amorphous, and sometimes ephemeral, “gray” literature, comprising reports, policy statements, articles, and newsletters from federal, state, and local governments, commissions and task forces, think tanks, academic institutions, foundations, professional and trade associations, and the trade and regular press. (p. 780).

Lasker’s statement addressed the professional problem of finding the most respected medical databases (e.g., Medline) to be inferior in readily identifying quality information about health disparities. The highest quality information concerning disparities comes from governmental and private nonprofit foundations (e.g., The Commonwealth Fund and the Robert Wood Johnson Foundation). Their reports and monographs are considered gray, and neither is readily identified nor accessible through the premier medical databases (e.g., Medline).

### **Scope of Initial Literature Review for Interventions With Libraries**

Although health disparities are evident in groups defined by sexual orientation, gender, and immigrant status, one could argue they affect fewer people than do those found in racial/ethnic groups. For this study, information was sought that addressed health disparities of race and ethnic groups from 2004 through 2009.

To identify interventions using library staff and resources, the following databases were used:

- Medline: The bibliographic database Medline was selected because it is the U.S. and international resource for biomedical literature and is produced by the National Library of Medicine. Medline indexes a set of 5,000 journals (most are peer-reviewed) in the medical, nursing, and dental sciences. It should be noted that not until 2008 did the National Library of Medicine (NLM) introduce two new subject headings into the subject heading (MeSH) database (NLM, 2009). *Healthcare disparities* was introduced to categorize articles addressing “those differences in access to or availability of facilities and services.” *Health status disparities* was introduced to identify articles addressing the “variation in rates of disease occurrence and disabilities between socioeconomic and/or geographically defined population groups.”
- CINAHL (Cumulative Index to Nursing and Allied Health Literature): CINAHL is a bibliographic database of English-language journal articles, books, book chapters, audio-visuals, and dissertations about nursing, allied health, biomedicine, and health care.

- LISTA (Library, Information Science & Technology Abstract): LISTA is a bibliographic database on subjects such as librarianship, classification, cataloging, bibliometrics online information retrieval, and information management. LISTA indexes nearly 600 periodicals plus books, research reports, and proceedings.

Bobal, Brown, Hartman, Magee, and Schmidt (2007) published *Navigating the US Health Care System: A Video Guide for Immigrant and Diverse Populations*. This article described the events that led to the production of a video by an academic library staff. This video was created to assist individuals from disadvantaged populations to navigate through the U.S. health care system. Librarians, in making the video, addressed 13 steps for moving through the health system, including making the doctor's appointment, getting access to health information, and how to be a good patient. Project evaluation indicated that more than 2,000 copies were distributed, enabling health professionals to show this video to patients who are immigrants.

This report described the realities of creating a health-promoting video to serve diverse and immigrant populations. The authors indicated that long-term evaluation would be published later. It was expected that further research would inquire how the viewers (i.e., immigrants and others from diverse populations) evaluated the video, and whether it was helpful to them.

Walker, Howard, Washington, and Godley (2007) published *Development of a Health Sciences Library at a Historically Black College and University HBCU: Laying the Foundation for Increased Minority Health and Health Disparities Research*. This

paper outlined the beginning of the partnership between the University of North Carolina Chapel-Hill (UNC-CH) and Shaw University for the development of a new health sciences collection to support disparities research and minority health outreach. Shaw University is a private, 4-year, Baptist-affiliated, historically Black college and university with a long history of addressing African American health disparities and serving communities through the role of churches. The partnership started in 2000 with funding from the National Center on Minority Health and Health Disparities and had the objective to “create and expand an inter-university center that explores the use of novel faith-based initiatives to address health disparities, to educate and train students in health disparities research, and to facilitate Shaw’s emergence as a research university” (p. 439). Shaw University’s need to emerge as a research university created the collaboration between Shaw’s academic library and the larger health sciences library at UNC-CH. Evaluation showed immediate results, which included:

- Acquiring 15 more medical journals (after starting with six journal titles)
- Acquiring more than 100 new books (after starting with few consumer health reference books)
- Acquiring five more databases (after starting with two)
- Hiring a health services research librarian who arranged for interlibrary loan, mediated literature searches, and library privileges with the larger UNC-CH library

This report potentially provided baseline data to identify significant initiatives; if an outcomes evaluation showed success in reducing disparities, a study of its methods might uncover insights into best practices within the field of health disparities research.

In *The Journey Project: A Case Study in Providing Health Information to Mitigate Health Disparities*, Leisey (2009) addressed how a new type of social worker, a social work informationist (SWI), filled both the informational and the emotional needs of cancer patients and their families at the Virginia Commonwealth University. The SWI, with a master's and doctorate in social work, originated from a project that merged social worker and consumer-health librarian skills. This project was to ensure cancer patients had access to and an understanding of health information. The project "focused on helping patients make sense of the vast quantities of information provided and offering a resource for dealing with difficult emotional health-related issues" (p. 30).

Leisey described how she took time to ensure patients' understanding of the health information. This was a meaningful difference in that the work of a librarian is to make information identifiable and accessible, but not to interpret the information for the patient or library user. (It is possible that the new role of information specialist in context [Davidoff & Miglus, 2011] will enable librarians to go beyond the scope of only providing information and begin to enable the transfer of knowledge through interpretation to patients.) Leisey learned that individuals from vulnerable populations may have distrust of the health care system. For example, an African American patient, citing the Tuskegee experiment, insisted on getting information only from a physician

who was African American. Leisey noted that librarians may be unaware of this phenomenon.

All the papers reviewed showed summary results, and those providing an evaluation did not address the health outcomes of the vulnerable population. Within these reports of specific interventions there was an absence of:

- Metrics showing an improved health outcome or a reduced disparity
- Correlations between improved access to health information and change in a health status indicator

The long-term health outcomes of specific interventions intended to reduce health disparities were mostly absent in the literature, raising the question: why is evaluation so rare in interventions? The barriers to evaluation of specific interventions are many.

Barriers include:

- The variables within health disparities intervention research are complex, and the politics of evaluation that occurs as part of a local community's effort can make evaluation difficult (Aldrich, Silva, Marable, Sandman, & Abraham, 2009).
- Qualitative methods that could be used to understand a lifestyle-related health problem are lacking. For example, in the early 1980s, relying on quantitative data, acquired immunodeficiency syndrome (AIDS) was thought to occur only in gay men and Haitian people. Little was known about the practices of sharing body fluids or the prevention practices needed to avoid spreading the human immunodeficiency virus (HIV) until qualitative interview data were studied.

- Researchers have avoided the political fray. Conclusions about health disparities findings have been fraught with political challenges, such as presenting results suggesting institutions have inadvertently sustained health disparities.
- Researchers have avoided ideological issues. The problem of health disparities has invoked justice and equity issues. Equity issues are founded in ideology, sense of fairness, and politics. Academics have maintained needed neutrality and avoided the charge of being ideological (Carter-Pokras, Offutt-Powell, Kaufman, Gils, & Mays, 2012).

### **The 20,000 Foot View**

Search statements on library-related health disparities interventions were broadened to find any success or failure in health disparities research. The search uncovered publications reporting trends of success and failure in health disparities at the national level. One such publication is published annually as the *National Healthcare Disparities Report* (NHDR). Since 2003, the NHDR has focused on “prevailing disparities in health care delivery as it relates to racial factors and socioeconomic factors in priority populations” (United States Code 42, 2003). The NHDR is published annually to report national trends and changes in health and health care disparities. Monitoring disparities at the national level is difficult because data were collected from many different databases, without coordination. Highlights on the trends in quality of and access to health care are presented in the following sections.

**Health care quality.** The most recent NHDR report (U.S. DHHS, 2012) showed that for all quality measures (e.g., receiving recommended vaccinations), Blacks, American Indian, and Alaskan Natives received suboptimal health care compared with that of Whites. Most noticeably, Blacks and lowest-income populations had the highest percentages of “worse” quality care. The report concluded there was no overall improvement in the quality of care, and the small number of disparities that were decreasing outnumbered those that were increasing (p. 7). Quality measures for diabetes care (e.g., feet checked for sores, and A1c test) were both listed under “rapidly worsening” quality measures (p. 10).

**Health care.** The NHDR report (U.S. DHHS, 2012) showed that for access measures (e.g., access to health insurance, perception of health needs), populations of color had worse access to health care than did Whites (p. 4). Of all the access measures, 50% showed no improvement, and 40% showed decline, indicating no overall improvement in access to health care. This lack of success at the national population level has occurred in spite of thousands of projects and millions of dollars spent to reduce or eliminate these disparities (Abouzaid & Maio, 2009; Berkman, 2009; Griffith et al., 2009; Voelker, 2008).

### **Identification of a Successful Intervention**

Few examples of successful interventions to reduce diabetes were found. One article, entitled “Decades of Work to Reduce Disparities in Health Care Produce Limited Success” (Voelker, 2008), summarized the failure of dozens of extensive disparities

reduction programs to affect population health. However, one exception to the limited success was described in the article “Reducing Disparities for African Americans with Diabetes: Progress made by the REACH 2010 Charleston and Georgetown Diabetes Coalition” (Jenkins et al., 2004). This report of a successful intervention, co-authored by a librarian, showed success in reducing diabetes severity in a low-income rural African American community in South Carolina. This paper reported not only a rare success in reducing a health disparity, but also that libraries and librarians were partners and played a significant role in the intervention’s success. Jenkins et al. described ways in which a public library network; a bookmobile; and a cyber-mobile (i.e., a traveling bus providing computers with satellite-supported Internet access to underserved communities) were used to improve access to health information in rural, low-income areas of South Carolina. The evaluation reported success as long-term elimination of disparities in diabetes management in this population (i.e., blood glucose control testing, lipid profile, kidney testing, eye exams, and blood pressure).

**Community-based participatory research.** The coalition called REACH 2010 CGDC is based on community-based participatory research (CBPR). This approach relies on community members to be leaders of and participants in a research study. This approach differs dramatically from traditional positivistic research. Positivistic research seeks universal laws by avoiding bias (e.g., using double blind techniques). Some bias may be avoided when neither the research subjects nor research associates are aware of the treatment group. Positivistic research is likely best suited for physical (not behavioral)

phenomena. CBPR is a research approach that can provide solutions and methods to community issues by supporting community-oriented development, programming, and learning. The community is the unit of study, and its members become researchers and subjects of the research program, and have access to study aspects (except patient data). Unlike positivistic research, which works to neutralize external influence (or human bias) on outcomes, CBPR values human influence, so the practices of transparency, trust, learning, power sharing, and change are always included. The key concepts of CPBR were defined by Israel, Schulz, Parker, Becker, Allen, and Guzman (2008):

- In CBPR, the unit of identity is the community. The community is a social construct and is formed by the people who feel connected to others through some aspect of shared values, such as family, lifestyle, or neighborhood. A community in CBPR is more than a group of people simply living in the same neighborhood.
- CBPR starts and builds on the existing resources and strengths within the community. These resources may be community members' skills, knowledge, networks, or institutional resources.
- CBPR produces and enables partnerships in all phases of the research. In the collaboration, power is shared as the CBPR project or intervention is planned and implemented.
- CBPR ensures that information and knowledge are used for the benefit of all community partners, as well as building upon the larger body of knowledge that enables community well-being.

- CBPR is heavily based on co-learning. Co-learning enables all partners to start in the same place and better understand social inequalities. Co-learning can inspire community partners to reflect on and acknowledge their privileged or vulnerable position in society, and consequently, be more sensitive to how that position may affect interactions, communication, and decision making.
- CBPR partnership development and research methods are continually being enabled, developed, and supported; the final protocol is not determined before the study begins.
- CBPR is holistic. Mental, physical, and environmental factors are addressed in the context of historical, cultural, and social determinants with the community and larger society.
- CBPR distributes its findings to all partners for sharing and for feedback. Findings are written in a respectful tone at a meaningful literacy level. Findings intended to be submitted to scholarly journals are reviewed by community members, and co-authorship is encouraged.
- CBPR requires a long-term process and sustainability. To keep and ensure trust, partners must be available for the long term to be involved in the process in an authentic way; partners need to find ways to continue even when funding goes away.

CBPR combines critical theory (i.e., addressing community power imbalance through learning and collaboration) with transformational learning (i.e., changing mental

constructs that form our reality through learning and experience). CBPR appears to be a viable alternative to top-down, positivist methods that have not yet improved the health of people of vulnerable populations.

**REACH 2010 CGDC.** The REACH *Fact Sheet* (2010) is one report of a successful community-based intervention focused on decreasing diabetes-related symptoms and adverse effects in a population of 12,000 low-income African Americans in South Carolina (Jenkins et al., 2004). Evaluation of an intervention is rare in health disparities, but REACH 2010 CGDC outcomes included:

- Improved annual testing for 13,000 African Americans on several health measures: A1c from 46% to 97%, lipids from 47% to 81%, kidney testing from 13% to 53%, and foot exams from 64% to 97%
- Improved diabetes control (A1c < 7%) from 11% to 48% for 13,000 African Americans
- Improved adherence to American Diabetes Association guidelines for diabetes education, with teaching provided at 94% of visits, up from 41%
- Decreased emergency room visits by about 50% for unfunded patients with diabetes
- Decreased lower extremity amputations in African American men, from 80 per 1,000 hospitalizations to 31 per 1,000 hospitalizations

This is an impressive list and an example of a successful intervention. This study provides the basis for this dissertation and is detailed later in the “The Intervention (Case)” section.

The value of the REACH 2010 CGDC intervention was the outcome of the improved health of a vulnerable population. Its evaluation report (Jenkins et al., 2004) may be a unique resource for future librarians and practitioners seeking to plan or participate in an intervention. REACH 2010 CGDC has great potential as a case study for the field of health disparities to find out what works to reduce the disparities of diabetes.

Subsequent library references to Jenkins et al. (2004) were identified using the citation databases Web of Science and Scopus. “Community Outreach Partnerships” written by Basler (2005), the director of the Medical University of South Carolina Medical Library (institutional home of the REACH 2010 CGDC principle investigator) reviewed the institutional, philosophical, and attitudinal barriers to academic librarians and libraries participation in community outreach projects. Basler’s leadership paper addressed the state of academic library practice in reducing health disparities and provided insights into partnerships between community projects and academic librarianship. Basler stated that for librarians who seek adventure, participation in community health projects is well worth its tremendous effort (p. 37).

### **Theoretical Background to Community-Based Health Partnerships**

CBPR incorporates a variety of theories that can be used to develop community-based public health interventions. These theories have roots in psychology, health

education, sociology, and adult education. For instance, adult education theories address patient education (Knowles, 1984); self-care (Maslow, 1970); and transformative learning (Mezirow & Associates, 2000). Theories concerning community growth and learning (e.g., Freire, 1970) also apply. Models available that provide useful visual tools for conceptualizing the field of health improvement through individual change include the transtheoretical model of change (Prochaska & DiClemente, 1983) and chronic disease care (Wagner, 1998). However, my research focused on best practices in health disparities reduction from a community-partner perspective, for which a paucity of research exists with which to identify an applicable theory. Because my research focused on policies, practices, and roles of community partners, including library staff, I anchored the theoretical background with Mezirow's theory of individual change, often identified as transformative learning theory (TLT). This theory posits that an adult perspective is constructed by meanings we apply to our experiences. Disorienting experiences can provide a critical point of reflection, leading to learning and empowerment (Merriam, Caffarella, & Baumgartner, 2007). Mezirow and Associates (2000) suggested a single disorientating experience may, after several stages of change, cause a transformation in a person's perceptions, outlook, and behavior.

TLT can be especially important in improving the health of a person with chronic disease (e.g., obesity, diabetes, and hypertension). These diseases are managed with changes (e.g., diet, exercise, and medication) to daily activities. Diabetes is an incurable serious chronic disease; unmanaged, it can lead to increasingly poorer health and

disability, including blindness, coma, limb loss, and death (Macleod, Murchison, Russell, & Dingwall-Fordyce, 1989). However, when a healthy lifestyle specifically addressing diabetes symptoms is adopted, the disease can have minimal impact on one's health (Mayo Clinic, 2009). Transitioning from unmanaged diabetes to well-managed diabetes requires a healthy diet, strict medication compliance, regular exercise, and infection prevention through self-care (American Academy of Family Physicians, 2009). For many patients diagnosed with diabetes, this transition requires the transformation of daily activities in order to remain healthy through the duration of their life.

In one early description of TLT, Mezirow (1978) described the long-term effects of experiences of adult women returning to community college. He described a process that started with a disorienting experience and proceeded to internal discourse, using new information. This process can end with a transformed perspective, which can lead to dramatic changes in attitude and lifestyle (Mezirow, 1997). For chronic disease, these steps can lead to significant and substantial changes in attitude, behavior, and health, leading to a lifestyle transformation:

1. A "disorienting" dilemma (e.g., individual gets a diabetes diagnosis)
2. Self-reflection that results in anger, fear, guilt, or shame (e.g., "I have a family that needs me to take care of myself.")
3. A critical assessment of one's assumptions (e.g., "My current lifestyle is not good or healthy.")

4. Recognition of a connection between one's discontent and the process of transformation (e.g., "My current lifestyle will lead me to become disabled or die sooner.")
5. Exploration and consideration of new roles, relationships, and actions (e.g., "I see that I could change my diet and exercise habits, which might enable me to live longer and with less disability.")
6. Planning a course of action (e.g., "I will attend community classes to learn more.")
7. Acquiring knowledge and skills to implement change (e.g., "I learned how to use the Internet to look up health information.")
8. Provisional trying of new roles (e.g., "I am trying out being enabled by looking up information that will lead me to healthy recipes and make me an informed patient.")
9. Building competence and self-confidence in new roles, skills, and relationships (e.g., "With my friends in my community classes, I have been successful in learning how to use the Internet, as well as learning how to make healthier meals.")
10. Reintegrating new knowledge and skills into one's life, dictated by the new perspective (e.g., "Now I exercise a lot, eat mostly healthy food, and am able to find information pretty quickly to take to my doctor; I am enabled now to be a healthy family member with diabetes.")

I selected Mezirow's (1978, 1997) theory for my study because professionals and community partners can transform their thinking and practice by reflecting on methods used in a successful health disparities intervention. This reflection can enable re-interpretation of existing knowledge, skills, and attitudes, resulting in individual and professional growth.

Although Mezirow (1978, 1997) is known for individual transformation and learning, TLT (similar to Freire's [1973] theory of emancipation) has been used to enable transformation within a community. It was used to build a learning sanctuary for a community to better understand sustainable living (Lange, 2009). A dramatic health-based example is the community-led transformation in Senegal, through which the engagement with community elders reduced the cultural practice of female genital cutting (Easton, Monkman, & Miles, 2009).

### **Improvement Needs Knowledge: A Call to Action**

Considering the lack of knowledge about what works to reduce disparities and the implication for rigor in health disparities research, Allison (2007) invited action to identify and to learn from successful (i.e., proven) interventions:

First, policy makers should support proven interventions and promote national data structures to monitor the impact of these interventions on health disparities.

Second, funding agencies should invest in expanded and coordinated research portfolios to better elucidate the causes and consequences of health disparities and develop interventions to promote equitable health outcomes for communities of

color, similar to the Robert Wood Johnson Foundation, which funds a network of innovative disparity programs such as Finding Answers. Finally, researchers should address known gaps in our understanding of the fundamental mechanisms through which disparities operate and test new interventions to move from understanding to change. (p. 6S)

Consistent with Allison's statement that "policy makers should support proven interventions and promote national data structures to monitor the impact of these interventions on health disparities" (p. 6S), this dissertation identified methods from a successful program so that usable knowledge can be shared with community partners; librarians; practitioners; and academics (i.e., university faculty and staff) working in the health disparities field. Again, successful inventions are those defined as achieving the defined goal of reducing a measurable health disparity.

### **The Need for This Case Study**

The need for this case study stems from the lack of described methods for this intervention. As excerpted from the section "Methods for Reducing Disparities," Jenkins et al. (2004) alluded to methods without going into detail (*italics added for emphasis*):

Concepts for action and related action steps have been identified for each of these foci. Corresponding activities are being coordinated by nurses with master's or doctoral degrees; by a *librarian*/health information specialist with a master's degree; and by Community Health Advisors (CHAs) who work within the communities in which they live. Diabetes activities are focused on building skills

to help people with diabetes practice improved diabetes self-management and to find answers to the questions: What do I need to do to take better care of my diabetes? How can I help my health provider or doctor take better care of my diabetes? Where do I turn to find resources to help me and my health provider take better care of my diabetes? (pp. 325–326)

The final three sentences, posed as questions, provide the conceptual framework for activities used in the REACH 2010 CGDC intervention, but do not detail how the activities were carried out. Addressing the issue of methods, Jenkins et al. (2004) wrote: “The Coalition’s interventions for reducing disparities will be presented in detail in a subsequent publication” (p. 325). Additional references to libraries and the provision of health information were provided (*italics added for emphasis*):

The Coalition has hired and trained an interdisciplinary staff including nurse specialists in diabetes, epidemiologist, health educator, *librarian*, nutritionist, resource coordinator, administrative specialists, and lay community health advisors/advocates who work to integrate the activities related to health systems change and community development, empowerment, and education. Community and systems changes to reduce the identified disparities include community networking and skill-building, *health information network* development including resources and linkages, diabetes education for self-management in clinical sites that is linked to community-based case management for high-risk clients,

continuous quality improvement teams, and expanded access to health services.

(p. 326)

and

Another component of community development is the establishment of the *Health Information Network*. As part of this effort, the Coalition's *librarian* has worked with *local libraries* to update diabetes-related materials. In addition, the *libraries* now use the bookmobile and the cyber mobile to take diabetes information to the communities. The CHAs work with community members in helping them to access and use diabetes-related information through partnered programs with *local libraries*. (p. 326)

These excerpts show considerable reliance on librarians and libraries in the intervention, but this reliance is not described in a way that is practical for further research or practice. In a more recent publication, Jenkins et al. (2010) stated, "REACH partnered with the National Network of Libraries of Medicine to develop, test, and now institutionalize a library-based program that teaches participants how to use diabetes information to learn about the Internet" (p. 248), which alluded to a potentially useful insight into how to initiate, plan, and improve a library role expected to ultimately reduce a health disparity. Additional searching did not find information, other than an award for the libraries' accomplishments in this intervention. Pointing out the absence of reported methods is not a criticism of REACH CGDC 2010 partnership research. Reporting in detail on the methods of 40 active community partners in the intervention would have

distracted the researchers from the primary goal: to reduce the diabetes health disparities in the community.

For this dissertation, the REACH CGDC 2010 intervention was a rich source of novel thinking and discovery for those seeking to partner on health disparities interventions, as well as to seek to better understand foundations for intervention success.

### **Summary**

It appears the health disparities literature has yet to establish itself in a way that is useful to practitioners who work toward improving the health of minority ethnic and racial populations. This lack of a useful body of literature likely has many causes, some of which may be intrinsic to our system of institutionalized racism and classism. Exploration of successful interventions (e.g., the REACH CGDC 2010 study) may yield invaluable insight into what contributes to reducing health disparities in racial and ethnic populations. In chapter 3, the research methodology, design, rationale, as well as data collection and analysis, are described for this study of practices in a multi-partnered health disparities intervention for a vulnerable population of low-income, rural African Americans with diabetes.

### **Chapter 3: Research Methods**

The interpretative, qualitative methodology selected for this study featured an intrinsic case study design. Interviews were completed by community partners from a successful multi-partnered, community-based, diabetes-related health disparities intervention that included librarians as community partners. This chapter describes the theoretical framework for the research, rationale for the case study design, and ethical concerns, and provides details about the specific methods used.

#### **Theoretical Background**

The theoretical framework for this research was Mezirow's TLT. This theory posits that adult perspective is constructed in part by the meaning we apply to our experiences, and that some experiences are a critical source for learning and growth (Merriam et al., 2007). Mezirow (2000, 2009) suggested a single experience or event may, after several stages of change, cause a person to transform his or her perceptions, outlook, and behavior. Diabetes is frequently a serious chronic and debilitating disease: unmanaged, diabetes can lead to serious complications, including blindness, coma, limb loss, and death (Macleod et al., 1989). If managed with a lifestyle that supports health, diabetes can have minimal impact. Transitioning from unmanaged diabetes to a well-managed lifestyle with diabetes requires adopting many new behaviors (e.g., a strictly maintained healthy diet, medication compliance, regular exercise, and infection prevention) through active self-care (American Academy of Family Physicians, 2009). The management regime requires people with diabetes to make a drastic transformation

of daily activities and lifestyle. In the case of the vulnerable population, these transformations often entail changes to a lifestyle learned from parents and grandparents, which are held dear.

### **Rationale for an Intrinsic Case Study**

The initial report of success by Jenkins et al. (2004), reviewed by Peek, Cargill, and Huang (2007) and Voelker (2008), and later reports (Jenkins et al., 2010) referred to librarians and libraries briefly, but did not detail intervention actions and methods in a way that would be helpful for future practitioners planning an intervention.

Whereas both intrinsic and instrumental case study designs were considered, the chosen intrinsic case study design focused on the inherent characteristics of unique events. REACH 2010 GCDC was unique for several reasons:

- A formal evaluation of the intervention's outcome was performed.
- Formal evaluation showed a significant reduction in the severity of diabetes complications
- Extensive library roles included instructors and a project manager.
- Library resources and services were integrally involved throughout the project.
- A credentialed librarian co-authored the publication reporting the project.

In contrast, an instrumental case study is appropriate if general understanding or a demonstration of issues related to the role of libraries in health disparities interventions is sought (Stake, 1995). Due to the paucity of scholarship on health disparities outcomes, it is premature to discuss a *general* understanding of specific roles in the successful

reduction of health disparities, and therefore an instrumental case study was inappropriate.

The design for this dissertation was exploratory in that the primary goal was to identify key variables, including the potential for individual and community transformation, in the REACH 2010 CGDC partnership's successful reduction of diabetes symptoms and adverse effects in South Carolina.

The method used to identify and describe library practices and roles concomitant with successful reduction in health disparities was "interpretive qualitative" (Creswell, 2007). Creswell stated that interpretive qualitative research

is an approach to qualitative research that has become interwoven into the core characteristics of qualitative research. It recognizes the self-reflective nature of qualitative research and emphasizes the role of the researcher as an interpreter of the data and an individual who represents information. (p. 248)

With this interpretative qualitative method, I sought to provide a "thick, rich description" of aspects of community partners' (including library staff's) roles in a known successful health disparities reduction intervention.

The case—or *unit of analysis*—was the successful health disparities intervention. Success was defined as peer-reviewed evidence of a statistically significant reduction of a health disparity between African Americans and Whites in a community suffering from diabetes.

For the purposes of data collection, this case was bounded by the significant documents, artifacts, and professionals of the geographic areas of Georgetown and Charleston counties in South Carolina.

### **Ethical Issues**

Ethical concerns related to privacy and confidentiality included consideration of use of the term *vulnerable population* with study participants (i.e., individuals from a low-income African American community), who may not view themselves as vulnerable. This label, although potentially useful in discussing non-majority populations experiencing health inequity, might be detrimental or damaging to a person's psychological health or pride in his or her ancestry if that person is determined to be a member of that population. Consequently, I used the term *low-income African American* for members of these communities. During the study, participants of the Georgetown African American community with whom I spoke readily identified their community as very low-income, very rural, and almost entirely African American.

For ethical reasons, individualized health information was generalized, anonymized, or excluded from the results.

Because the questionnaire (see Appendix B) focused on what happened during this successful intervention, the expected risk was considered minimal. The data were anonymized. Participants were asked for concerns about unrealized negative or embarrassing information, and no concerns were mentioned.

Given the several publications already written about this intervention, it is likely readers can deduce who participated in this study. Although many efforts were made to keep the participants' identities anonymous, identification of the participants is not considered to be potentially damaging due to the information already publically available through publications, newspaper interviews, and websites.

### **Research Methodology**

To anchor this intrinsic case study with an interpretive methodology, I confined the variables to the domain of key informants associated with a successful multi-partnered intervention that reduced health disparities. This successful case was used to gain insights into factors that are perhaps intrinsic to individual and community transformation, leading to health disparities reduction. Discovering practices used in a successful case provided rich insights and knowledge that are potentially useful to other practitioners, academics, librarians, and community members working to reduce health disparities. To that end, interviewing collaborating community partners, with a focus on libraries, enabled me to describe best practices to share with health disparities research professionals.

**Development of the research questionnaire.** The following questions were intended to uncover the information that would glean practices consistent with health disparities reduction. The initial questions were further developed and finalized with feedback from graduates of the University of Minnesota's Organizational Leadership and Policy Development program, and in consultation with the Center for Translational

Science Activities at Mayo Clinic. They then were piloted with library staff at the University of Minnesota, Rochester:

At the start of the interview, which was conducted over the phone, participants were informed that the purpose of the study was to learn: “What methods, including practices, policies, and roles, were used by collaboration community partners in the REACH 2010 CGDC intervention program that overall proved successful in reducing or eliminating several health disparities of a vulnerable African American population?” During the interview, participants were asked for their response to the following set of questions:

1. What is your title, official role in this intervention, and length of time on this project?
2. How did you initially get involved in this project (i.e., education, work or volunteer histories, as appropriate)?
3. Did any of your activities involve interactions with library staff, policies, services, or resources for this case or a related project?
4. If so, please describe the library staff, services, or resources that from your perspective impacted this intervention. What is your perception of what contributed to make this intervention successful?
5. From your experiences with this intervention what appear to be the most effective *practices* surrounding the library activities in the community-engaged diabetes intervention? (e.g., tasks, classes, projects, reports)

6. From your experience with this intervention, what appear to be the most effective *policies* (e.g., who was included, how were they included, planned timeline) concerning the library (e.g., university or public) in this community-engaged diabetes intervention?
7. Please describe for me any lessons learned on best practices that can be used in other community-engaged intervention studies. Feel free to mention things that would increase the chances of making a future project successful. These may include recommendations to avoid jeopardizing the success of future community partnerships addressing health issues.
8. Was there a particular library role, policy, procedure, or service that you felt was instrumental in the success of this program?
9. Explain the effectiveness of the library (e.g., academic or public) staff roles in this community diabetes intervention.
10. Was there an event or incident where you realized “This intervention is actually working” and we will be successful?
11. Were there aspects of your personality or work style that you feel enabled a better outcome that you would like to share?
12. Is there any additional information you would like to offer for this study?

**The selected intervention (case).** The REACH Charleston and Georgetown Diabetes Coalition is a community-university diabetes coalition that improved the health

of a population of 12,000 African Americans in two adjacent counties in South Carolina.

REACH 2010 CGDC described itself as:

An urban-rural, community-university diabetes coalition working in partnership to eliminate racial and ethnic health disparities of over 13,000 African Americans with diabetes in Charleston and Georgetown counties in South Carolina. We use effective, cultural approaches to building knowledge and skills to help people better manage their diabetes, to help health practitioners provide better diabetes care, and to build community advocacy and support to sustain these efforts. (para. 1)

Using the aforementioned questions with volunteers from an intrinsic case study, I elicited descriptions of the successful elements of the intervention.

**The community partners.** REACH 2010 CGDC relied on many community partners:

- Sororities (e.g., Alpha Kappa Alpha Omicron Rho Omega chapter)
- Health associations (e.g., Carolina's Center for Medical Excellence, Charleston Diabetes Coalition, Commun-I-Care, Diabetes Initiative of South Carolina, East Cooper Community Outreach, Franklin C. Fetter Family Health Center, Georgetown Diabetes Community Outreach and Education [CORE] Group)
- Academic health partners (e.g., Medical University of South Carolina, College of Nursing)

- Government agencies (e.g., South Carolina State Budget and Control Board, South Carolina Department of Environmental Control)
- Professional associations (e.g., Tri-County Black Nurses Association)
- Community institutions (e.g., local United Way, churches, community centers, worksites, and libraries)

This community-based intervention was considered appropriate for my research because of its partial reliance on library staff initiatives in delivering the intervention.

**Selection of participants.** After receiving Institutional Review Board (IRB) approval (Appendix A), participants (i.e., key informants, consisting of the volunteers and staff who participated in the REACH CGDC 2010 Library Partnership intervention) were selected. All participants had formal roles in this intervention. Community members for whom this intervention was intended were excluded to avoid distrust caused by “helicopter” research.

By agreement, the REACH 2010 CGDC principal investigator (PI) contacted potential participants with the letter of invitation and consent form. Fifteen participants consented to this study, and 11 were interviewed. Four who consented were not

Table 2: Study Participants

REACH 2010 CGDC Role 2006–2008	Race/ gender	Ed degree	Organization or institution
Founder of CORE/CHA	AA/F	none	Founder, Georgetown County Diabetes CORE Group

COMMUNITY PRACTICES

Founding member of CORE/CHA	AA/F	?	Georgetown County Diabetes CORE Group
CHA	AA/F	AA	Georgetown County Diabetes CORE Group
Board member of CORE	AA/M	?	Georgetown County Diabetes CORE Group
Public library director	W/M	MLS	Georgetown County Public Library
Community church pastor	AA/M	?	Greater St. Peters Church of Our Lord Jesus Christ, Palmetto Diocese
Librarian 1	AA/F	MLS	Charleston, John's Island Branch Library
Librarian 2	AA/F	MLS	Charleston, St. Paul's Branch Library
Librarian 3	AA/M	MLS	Charleston, reference librarian for Otranto Road Regional Library
Librarian 4	AA/M	MLS	Charleston County Public Library / Wiltown Community Center Cooper River Memorial Library

Project manager of Library Partnership	W/F	MLS	Medical University of South Carolina, CGDC 2010 Library Partnership coordinator
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interviewed due to schedule conflicts. Participants included the following: CHAs, library staff, librarians, Library Partnership project manager, a pastor, a steering committee board member, and the founder of the original grass roots outreach project established in 1997.

**Details of interviews.** All participants were interviewed by phone in the location of their choice (i.e., home, community center, or office) in South Carolina. All interviews were conducted with a long distance phone call made by the researcher in Rochester, Minnesota, to the participant in the spring of 2012. Eleven phone calls were made; each lasted 30 to 90 minutes. All interviews were recorded, 10 by audiotape and one by handwritten notes. All interviews were transcribed for this research.

Draft transcripts were sent to the respective participants for review and corrections. Two participants provided clarifying information to their transcript. Transcripts were analyzed for themes related to policies, practices, and insights, as described by the participants. One participant provided several formal documents, presentations, and publications related to the case. Also captured were unexpected

insights heard within interviews about how the program was actualized (e.g., selection of relatively unknown community members as leaders).

**Selection of documents.** The scope of documents used for data collection included:

- Peer-reviewed papers authored by REACH 2010 CGDC participants
- Gray literature documents and final reports submitted by the project manager
- Web pages from participating organizations

These documents were used to gain a deeper understanding about the case when questions occurred as themes were uncovered.

**Determining results and conclusions.** Identified themes are presented in chapter 4. The implications of these themes are discussed and interpreted through models being developed to better address effective community-based health disparities research.

**Triangulation.** I asked all the interviewees to read my results and conclusions and let me know if they agreed or had opposition to my findings before the dissertation was published. The five interviewees who responded were very positive about my findings and conclusions and especially positive at my emphasis on the CORE organization. Two interviewees responded with factual changes (e.g., location of their library at the time of the project), and one responded with requests to change a nuanced meaning about unknown leaders as well as a request not to use the word “poor” to describe the community’s low socioeconomic status, nor to use the word “diabetic” to

describe a person with diabetes. All changes requested by the interviewees were understood and their requests were completed.

### **Summary**

Chapter 3 provided details about the methodological design for the qualitative intrinsic case study used to determine the methods used in a successful intervention with multiple community partners in South Carolina. Chapter 4 provides details about the study participants and the themes that emerged from the interviews.

## Chapter 4: Results

The purpose of this study was to gain practical knowledge and insight into the roles, activities, and resources used in the REACH CGDC 2010 Library Partnership project and in related projects that were successful in reducing the severity of diabetes in an African American population living in a low-income and rural area of South Carolina. The previous chapter outlined the methods used to learn in more detail about the practices and methods in a community-based health care disparities intervention. Chapter 4 identifies themes found in the interview transcripts. Eleven participants involved in the REACH 2010 CGDC between the years 2004 and 2006 were interviewed with IRB-approved questions in a semi-structured interview.

Participants in this study included librarians, library assistants, a public library director, a pastor, the Library Partnership project manager (academic librarian), three CHAs, and a board member of the initial CORE Group. The participants' names are not reported, and their quotes are coded with a brief description of their role. Table 2 provides a key to those interviewed, with a brief description of their role and context.

### **Overall Philosophy and Themes**

The informal philosophy of the intervention seemed to underlay every decision and initiative within the intervention. In the words of the founder of CORE, who was also a CHA, "Death is due to lack of knowledge. I think of the knowledge that people need." A fundamental value concerning knowledge is expressed in this statement: knowledge saves lives. The statement is broad enough to inspire and enable all partners from diverse

organizations to work to bring needed information and skills to community members, wherever they are in terms of geographic location or literacy level. This philosophical statement provides room for almost any community group to contribute to the intervention. All themes and actions are grounded in the phenomenon that early death from diabetes is more likely when needed information is lacking than it would be if that information were available. Needed information can be of many types, ranging from knowing one's own glucose levels to knowing how to find high-quality information for self-care or family care.

This intervention occurred with many community members and many partnerships. Much of the information was integrated into many overlapping activities (e.g., diabetes education classes in the church, and cooking demonstrations in the library), and therefore activities and roles could not be seen as produced by only one partner. The themes that were most striking to me—either due to repetition across participants or to the appearance of passion as the theme was reported—are noted first. The major themes discovered from reviewing the transcripts were (a) autonomy, (b) community-based and community-led, (c) incentives, (d) a new role for professionals, (e) participants realizing success, (f) church participation, (g) transformation, and (h) perspective of the librarians.

### **Theme 1: Autonomy**

The first major theme was the autonomy of the incorporated two related subthemes: “we were just working on our own” and “they didn't tell us what to do.”

**We were just working on our own.** In this theme, participants described the establishment and ownership of the grassroots effort called CORE. This organization was described many times by the participants as the founding organization. The REACH 2010 CGDC project used CORE's capacity in the community without co-opting or changing community partners' mission or leadership. The values of independence and ownership of the initial grassroots organization were pervasive throughout the interviews, and led to extensive community change through the building of networks. A CHA who was and still is a member of the CORE organization said, "I know that we started the Diabetes Core Group in 1997. REACH 2010 has been with us, I can't remember how long, but anyway we started with nothing and then REACH 2010 brought money in a little bit later."

The inception of the REACH 2010 CGDC project grew from one person's successful grassroots effort in 1997. This person, the CORE founder, attended a workshop on diabetes in Myrtle Beach, South Carolina, and found the information learned in the workshop invaluable for herself. She brought the information back to her community, which led to the inception of CORE. CORE quickly experienced rapid success. The comments of other participants make clear that the founder of CORE was one of the most respected members of the community and the partnership. The CORE founder's comment that "death is due to lack of knowledge" is featured in the title of this dissertation. What follows is the founder's description of her realization, after attending the diabetes workshop in Myrtle Beach, about the need for a community outreach program:

We started with a meeting at my church....I found out we had 70 diabetics in my church alone. Then we set up a meeting at the Dickerson AME Church in Georgetown. Seventy-five people came out to that meeting. That meeting was a real boost, and we asked ourselves, "What's next?"

The initial and continuing members of the grassroots project were proud the Diabetes CORE Group was the originating organization, in the words of a founding member of CORE who was also a CHA:

We joined them, or rather they [CDC's REACH 2010] asked us to join them. We were there before REACH 2010 came. There is a program Diabetes Today, out of Columbia, and they came to Myrtle Beach, South Carolina, and they had a workshop and invited some of the community leaders to come. The [founder] went to that workshop and she came back..... I said, "Ms. \_\_\_\_\_, what did they want you to do?" She said, "They didn't tell me what they wanted to do, they just told me they wanted us to find out about diabetes and find a program to make people aware of diabetes and how to treat diabetes and what they should be looking out for." I said, "We can easily do that."

The benefits of working together often were expressed by the participants, who all were striving to meet shared goals. For instance, project ownership was evident in the recognition that REACH 2010 funds could not be used for all things needed (e.g., stethoscopes, and finger sticks in church sponsored events). The pastor discussed unfunded needs for the community members he was serving:

I've talked to a lot of people, I've talked to a lot of ministers, and the first thing out of their mouth is "Where they are going to get the money from?" It takes money to fund a program because you're going to need to have supplies. You ask people to come and volunteer, and they are nurses and they are people who work with people in that area. They will volunteer their time, [but] they're not going to give what you need. You need stethoscopes for blood pressure taking, you need the finger sticks and needles for diabetes, you need the strips. Sometimes you need to have things on hand.... When people come, they come to the program and they forget to take their medication. You need to be able to afford to have what's needed there, so that they will not go into a diabetic coma when their sugar drops. You need to have supplies to help with that. You need to be able to afford to buy the little necessary snacks, like [brand name] that you can give a person, learning how to use those things, and making those things available. To have those things takes a little bit of money, but people don't want to invest their money. The REACH program is good because it provides a little stipend; it doesn't provide care for the whole program, because there are only certain things that you could buy with the grant money that comes to you. You can buy material, like paper, but you can't get the medical supplies needed. You can get a camera, or they'll help you get a computer, or they'll pay for the phone bill so that you can be online to do things, but the other finances are crucial to the need. You have to find a way to do that.

The pastor described how other partners enabled acquisition of needed items not funded by the REACH 2010 CGDC grant.

Participants all reported the REACH 2010 CGDC program was embraced. However, being embraced did not mean a lack of attempts to broaden further the REACH 2010 CGDC scope. One of the CORE board members broadened the focus by successfully arguing for and expanding the scope of the REACH project to children, to enable early prevention of diabetes:

I think the best practices are the prevention standpoint. We started in Georgetown, and we looked at it. You need to look at the youth and the family structure. We cannot wait to talk for people to get diabetes to talk to them, we have to go into their homes before they get it. We were trying to teach them from the grave; I wanted to teach them from all stages, from the cradle to grave,.... teaching youth how to eat healthily, so the pattern would start early in life.

When the CORE board member who made that statement was asked if his initiative to address children with diabetes prevention was considered beyond the scope of the program, he responded, “That’s exactly what they said, but we pushed and pushed and pushed. We wanted to connect the dots with what is there—children with parents and children with grandparents.” Ultimately, this successful effort offered reinforcement so the individual felt further empowered, while building efficacy for the REACH 2010 CGDC partnership by including children and prevention into the focus.

**They didn't tell us what to do.** Another quality of the relationship between REACH 2010 and its partners was “they didn't tell us what to do.” A founding member of CORE, who was also a CHA, described how autonomy for the initial organization started at the very beginning (i.e., the founder's attendance at the Myrtle Beach workshop), and was valued and protected by the community partners.

Every time they go out there, they start fresh, but with REACH 2010. [The founder] did this workshop with Diabetes Today, and they didn't tell her what to do. That was the good part—that they didn't tell us what to do, so we went out there and we did all of the things that we knew were important to our area, which is out in the rural areas. It does not work like in the city.

One CHA, who was a founding member of CORE, mentioned the concern of not having autonomy when working with an outside institution, and that the lack of autonomy would likely bring unwanted instruction (e.g., cultural invasion). Although this CHA did not provide specific examples, she appeared to be aware of the possibility, and proactively preserved autonomy:

That has been the problem, that *is* the problem with so many government programs, that they try to do instead of, you know, if they would only take what other people have learned and then go from there, government programs would work a whole lot better. But they don't usually do that. They start fresh. Every time they go out there, they start fresh. But with REACH 2010, Ms. \_\_\_\_\_ did this workshop with Diabetes Today, and they didn't tell her what to do.

In very practical ways and using the examples of staff and leadership selection, autonomy was retained by design. The project manager, who was also a library partner, stated, “The community members on the steering committee chose the volunteers from their areas to be the trainers at the sites that would work with the public librarians and me.”

Distrust of White cultural invasion was an issue that was addressed and remedied early on. I did not hear examples of distrust that affected relationships, but this may have been because leaders prevented distrust before it took root. A founding member of CORE, who was also a CHA, described one example of how the threat to trust was addressed before problems occurred:

I used to tell [a researcher], “Look, if you take your White face into a Black community, the first thing you’re going to get is a whole lot of suspicion, and you’re not going to get any information.” It took me a while to make them understand that they wanted to see people that looked like them but talk like you, and they would most likely try to believe them, not that they are going to. I said, “Yes, you are going to have to take someone who looks like the people you are trying to serve.” And she finally got it. That’s how REACH 2010 got into communities in the rural areas out there, because they started trusting her. Because we trusted her and they know us. We know the people in the communities, so it worked out that way.

In a second example, this CORE founding member foresaw distrust by the community toward surveys and data collection, especially when the survey was presented by people outside the community:

A lot of times they go out and they want to do surveys stuff, they're [community members] not going to get the truth on their surveys because people will not tell them that. We will go out and get that information, and they will trust us more, and there are certain things they won't tell us because they think that if I say anything to this person, I'm going to lose a little bit of benefit that I have. And you have to make them believe that, no, you can't lose your benefit, we are trying to help you get more. (When you say benefit, what do you mean?) They think they finally got their Social Security and food stamps or something, and they think they are going to lose that if they talk to us.

### **Theme 2: Community-based and Community-led**

Three subthemes were identified within the general community theme: “just being grassroots,” “developing community leadership in a grassroots project,” and “developing trust in a grassroots project requires time and focus.”

**Just being grassroots.** In this subtheme, the primary value of the participants was to “meet the community members where they are.” This value seemed to drive all the decisions, which allowed for greater exposure and increased the opportunities for community members to learn, to share, and to be active—all factors enabling a new healthy lifestyle. Being a member of these communities meant one was very likely to be

exposed to an event sponsored by the REACH 2010 CGDC project. Sites included churches, community centers, people's homes, the radio station, libraries; even people shopping in the grocery store were exposed to diabetes education. A librarian stated that the larger goal was the grassroots exposure and the need to meet the community members in their community:

I think that was the big goal—just being grassroots, meeting people right where they are, and showing them that their quality of life—can be improved by using free library resources and by partnering with the medical community and the university community in a real way without judgment.

The CORE founder, who was also a CHA, explained the need for staying in touch with community members in order to plan a program people would attend:

It works, but the most important thing is to stay with the people. You have to know what they want; you can't just put a program together and think that it's going to work, because it does not work all of the time. You have to go and find out what the people want and then put your program together.

For the most part, the CHAs gave workshops to community members, while librarians worked with CHAs or responded to community members coming into the library. No matter their role, all participants expressed great satisfaction in interacting directly with the community. One librarian said, "I liked it. We went into the actual community, and the people actually saw us. We actually worked hands on with the individuals and I think that was great."

The Library Partnership project manager intentionally attended distant community events that were not library related:

I would show up for things in Georgetown two hours away for a walk at 7:00 a.m.

Going the extra mile and doing some community outreach was a pretty standard expectation. It may not have been library focused, but it was centered in the community, and it built relationships. You just have to kind of build that trust.

In some cases, passion for assistance and information was provided, even when not requested. The passion and dedication of the founder of CORE for saving people from the consequences of diabetes through education were evident in her story about a customer in the community grocery store:

New people, they seem to know me as the diabetes lady. I go up to new people. I went up to a man in the grocery store who had lots of different food in his cart. I hailed him. “Aren’t you a diabetic?” I said. “How are your numbers—your A1c level, blood pressure, cholesterol?” I said, “Brother, you are not doing fine, your sugar is too high, and your cholesterol is too high.” He was concerned, very concerned. My daughter, who was with me, and said, “Mom, you have no shame.” And I said, “Diabetes has no shame.” I feel everybody can live long as they can.

Through the many partners, community members were enabled to gain knowledge and skills for a healthy lifestyle, no matter their level of poverty or need for

diabetes education. One librarian recognized the success of the church in getting people to learn about to take care of themselves:

And then of course with the church, when you talk with [the pastor], they have a very successful program where people would come out and listen to information about a health talk basically about diabetes, or high blood pressure, or exercise, or nutrition or something, on a Saturday. They would get their numbers checked at that meeting. They would have their blood pressure taken, and each person would have a card, so it would be getting tracked for them on how they are doing. At the end of the talk and the checks, they would get a bag of groceries. So certainly that was a popular program. And that was a program where the libraries could also present some information, where we did a library card registration at an event like that. It built trust because you were able to meet people at their basic safety net level. Once you can show them that you care—I guess that was the old phrase—people don't care how much you know, until they know how much you care.

Many barriers needed to be addressed by participants working to enable improved health of community members. Barriers included distrust, not enough food, not enough money, and limited transportation. When a high percentage of community members are suffering from diabetes, the disease and its serious consequences likely seem normal because they are shared by many members. Community members may therefore normalize a life-threatening disease, which inhibits movement toward healthy choices. I

asked the founder of CORE how to get people to trust you when it may appear you will be telling them what they are doing is wrong, and she said:

You show people you care about their needs. You let them tell you. You work with them on their level—not what you think their needs are. You have no idea, poring over statistics, it doesn't build trust. You make a connection; you start by telling them your story. They can trust you, and if they don't trust you, you are not going to get to first base. We talked to them enough for them to tell us [what] their needs are. Then you are most likely going to get participation.

Along the same lines as the founder of CORE indicating work with the community members at their level, the church provided safety nets for community members who were participating in the program. As the pastor explained, many members of the community (who were not church members) came to the church's education sessions:

We invited them in because we had a program that was started during the same year that the Lord laid it upon my heart to consider the older people, that they would have to make a decision whether I'm going to get all of my medicine or part of my medicine this month, or am I going to buy the food to carry me on? The Lord gave it to me that if I could provide a bag of groceries a month, once a month for the people, it will help them in making that decision. If we provide them the staples of canned goods and macaroni, and provide them some meat, that way they could take over. And that would last them for a couple days. And it will

help them in making that decision about going on and getting their medicine, knowing that they would have enough to eat.

In addition to working with the community members on their level, one of the librarians responded to the recognition that “they can’t do what they can’t do” with enabling tactics. In her role as an educator, she enabled success through practical means, such as showing them how to shop for food using a list, how to apply for food stamps, and how to create a healthy food portion:

Once you could meet people where they are, that they are hungry, so they stretch their food. They are poor, so they cut their medicines. And this is what happens for real, so when you meet them right there, and then help them know better, then you help them do better later on. But you can’t tell someone who is hungry and without much financial resource that they can’t cut their medicine. They can’t do what they can’t do... We tell you that you should cook better. Well, cook better with what? Okay, so here’s how to apply for food stamps, let’s talk about that. Here’s how you go to the grocery store with a list so you don’t spend as much. Here’s what a portion should look like, and we can go through that using a computer.

**Developing community leadership in a grassroots project.** The Library Partnership project manager explained how volunteers were selected: “The community members on the steering committee chose the volunteers from their areas to be the trainers at the sites that would work with the public librarians and me.”

The administrators, the library director, and the project manager with whom I spoke were White professionals with one or more graduate degrees. Their role was to facilitate the intervention and not to lead it. They actively supported leadership development at the local level, and often by individuals who were not yet leaders:

What I learned in terms of the library component and also the REACH program, lots of times in a community outreach program, we would get known community leaders, but as it turns out, some of the best community leaders were those who were unknown. And they were the ones who took it and ran with it, people were very helpful and instrumental. But also connecting through different communities, finding unknown leaders was important. You need to ask through existing communities, taking recommendations, meeting them, and spending time with them. Just don't go with an advisory committee that has known names on it. When I read the literature, you get the same people turning up. And if you do get those, people may have burn out; they get turned off the project. You don't have the real wealth of the community.... When I reflect back on it, there is so much untapped community help and support for the community to have. You hear the most vocal advocates, but they may not be the foot soldiers or take a real leadership role. (Library Partnership project manager)

**Developing trust in a grass roots project requires time and focus.** The Library Partnership project manager, when offering advice for another similar project, indicated that time was an important factor:

A real lesson to understanding is that everything took longer than you would ordinarily think. Collaboration and building trust takes a long time. That's the main thing: trust and relationships. This is something people need to realize. This took over 10 years on the academic side and even the public library sides; there are so many different sides that pull on you. You need to focus on the outreach program, really kind of a struggle.

### **Theme 3: Incentives**

Getting participants "something they wanted," even when it appeared to have nothing to do with diabetes, was a key to success:

I think when we sat down and talked about it, I think that the cleverness of it all was to entice them with something that they wanted. See, along the way, we first kind of found out what it was that they wanted, so they were interested in it.

Email was key. The email was key more than anything else because they wanted a way to communicate with other family members, out of state family members. So that was their enticement and they knew that with the library being here they come to the library, so the email was key and the internet was key, but then they had to learn all the other skills in order to be able to do it. (librarian 1)

What they wanted was very varied and included being able to email their family; referring to email, the same librarian stated, "We didn't have anyone who didn't want it":

They [seniors] were excited because a lot of them had grandchildren and children who were computer savvy. And unfortunately they never really wanted to take the

time because they didn't think that they were interested. They just made the assumption that they are not really interested. So they were happy to have it so that they could first of all be able to contact other relatives in other places. They could communicate with them on that level because they were doing it with other family members, they were just left out of that loop. We didn't have anyone who didn't want it. Everyone was excited.

Other incentives to participate in difficult tasks were created by providing opportunities to strengthen community institutions and their networks. The most objective measure of success for the participants appeared to be only that a community member needed to show up and try something. I was intrigued with how they were able to get low-literacy adults to learn how to use a computer. My own experience as a professional academic librarian was that literate older adults are hesitant to learn the skills needed for computer literacy. I asked the CORE board member how they achieved success. He replied they used surprises (e.g., door prizes) as well as appealing to community spirit through strengthening a cherished institution:

For people at the churches, one incentive beside door prizes was if enough people learned how to use the computer, the church won a computer to have for its own use. For this, people really extended themselves. This got the churches involved.

You learn about the computer, and they were members of the church.

Additionally, networking in the community was fortified by hiring known people and overcoming barriers:

[\_\_\_\_\_] is such a great person to have as a Library Branch manager in the northwest section of the county. She is the daughter of a minister in that portion of the county; she comes from a family that is well respected, and also a family that cares about the people in that part of the county. She has many friends, so the program's success was heavily dependent upon that unique individual. (public library director)

And:

A lot of family members didn't finish high school, so they had to feel comfortable. And you have to have a personality, where you have an embracing personality, so that they would feel comfortable in letting you know that they are not educated. That in itself can be a big barrier. I think that just being open and friendly, and also the work style of your past and you're willing to try is an accomplishment. (librarian 1)

Additionally, this librarian suggested that celebrating even small accomplishments or just the effort was similar to having a party:

It wasn't whether I applauded them with positives, just verbal reinforcement of "Okay, if you are willing to try, then you've already won, so if you just simply try." And it worked because then they weren't afraid to try. And there was nothing, there was never a foolish question and not ever a bad move. And there was nothing they could ever do to hurt a computer. We applauded effort. The accomplishment level that was like a party, but just that we recognized the

willingness to try and to put themselves out there and to enter into a new territory.

Change is hard for all of us.

#### **Theme 4: A New Role for Professionals**

This theme about the role of professionals included three subthemes: “it was no ‘you’ and no ‘I,’” “the role of the Library Partnership project manager,” and “what the Library Partnership project manager thought was key.”

**It was no “you” and no “I.”** Forgoing traditional practice, public librarians trained the CHAs to provide information to community members. The positive impact of the public librarians and staff was often reported with appreciation:

To me, the biggest impact was of the library staff and their ability to teach you, to show you, how to get the resources. All of us grow up and we go through school and things, and we only use the library for research for papers for what we have to do in school. Very few of us get beyond those boundaries to look into other areas, unless you get involved and you have a person from the library to steer you in the right direction. It’s hard to really use the library and see how important it is to be able to use the library for the things that you need. (community church pastor)

One CHA cited the value of the Public Library director in allowing library staff to develop the curriculum for the program:

They [the library] even developed a curriculum for us. We found that we had some people who were not considered literate at all. You could not jump in and teach them about the Internet if they had never turned on a computer before. I’ve

dealt with enough. The libraries came together, providing the curriculum for us to follow, to help with the classes. And he allowed this on their work time. He was very supportive.

In developing the curriculum, the librarians identified nationally known and vetted resources for the CHAs to use with community members. These resources were selected for a low-literacy user group. Online videos were especially selected for low-literacy community members:

They had an interactive program... it actually talked to you. They were able to listen to what was being said. The computer could stop, and people asked questions. And it was more visual, as well. It was a good mechanism for teaching *older* seniors who were low literacy; it was very good mechanism for low literacy.  
(CHA)

The pastor indicated that the library staff's participation and showing up at community events helped ensure success of the whole project:

The interest of the library ensured to make the program successful. They came out and made themselves available, introducing people to things, and letting people know that these things are available. As we served people, they would come up and set up a table out there and just talk with people one-on-one and invite them to join the library, invite them to come and use the library, to learn what the library really has to offer them.

And:

I think that really just met people where they were, it gave them information and opened them up to resources, it was something where people would be willing to tell other people because they wouldn't be afraid if I tell somebody else there won't be enough for me. No, they needed to go ahead and tell somebody else they were sure there would be enough for everybody. People got information because that's what people do, people talk, and that's what changes their habits, what they know, what they talk about. (librarian 2)

In the academic and public library fields, a librarian normally would not turn over a curriculum to a paraprofessional. However, in this intervention, the CHAs were trained by the librarians to provide workshops to the community members. According to the CORE founder, who was also a CHA, the CHAs saw the library and library-sponsored training as instrumental:

We went to anyone that called us. We went to churches, we went to health fairs. We went to anyone that called us and wanted us to appear or bring some [of] our information and talk to them about diabetes, that's what we did. Sometimes we did one just about every day of the week. We went all over Georgetown County doing that.

One CHA said that the library staff and CHAs made this work by working together without a sense of "you" or "I":

The library was very instrumental because they opened the doors for the community to come in, and they were very receptive to the project. As I said

before, the branch managers [library staff] were trained. They were able to assist the people on the computers, as well, and they were able to distribute pamphlets with information. Yes... everybody came together and worked together.

Everybody was onboard with the idea, and everybody put in their part; it was no “you” and no “I.” Everybody came together, and this brought all the efforts together. And we were willing to work. A lot of relationships were developed. As of now, these relationships and partnerships are still working.

The pastor showed a realization about and then an appreciation for the library’s role:

That was one of the greatest things that ever happened to me. Because as I grew up, I understood that the only thing librarians did was put books together in the library, keep order. What I learned about the involvement of librarians are the things that they do, the research they do to make things available to the community. It really impressed me that we had staff from the John’s Island area and from Medical University.... The librarians have been a source of support and strength for the program.

The pastor described how the church enabled people to use a computer and look up information about prescribed medications. These sessions provided opportunities for the CHAs to help navigate to information for other serious and chronic health issues (e.g., hypertension):

We had a program at our local church where we would teach those that were not computer literates. We would teach them how to use a computer and how to go on

to, I think it's Medline Plus. We would let them get on there and look up the medications. We were not only concerned about the diabetes, but the part that high blood pressure played in this, because the two of them came together. Normally the people that have diabetes suffer from high blood pressure, as well. We would teach them how to go online, look up their medication, see if they needed [follow-up], talked to them about how they could control their diabetes by eating a certain way, the proper way to eat, and portions and the kind of things to avoid. In our area, we have a lot of people who have a lot of amputations and a lot of people who lose their sight because they don't take care of themselves because they are overweight, and they won't listen. There are just so many things that we discovered by getting involved with the REACH program and we were seeking ways to help. We found out one of the best ways to help is to have an educational program where we can educate the people on diabetes and what it does and the part they can play to help by doing different exercises and things to help them to maintain themselves.

**The role of the Library Partnership project manager.** The Library Partnership project manager was mentioned often and with considerable respect as a key asset to the creation of the partnership. The pastor provided insight into the project manager's role:

It was really instrumental. She brought the program to you and allowed you to have your input. She made you feel a part of what was going on. A lot of times, I've learned over the years, that you're invited to be in a program and remain as a

number there, but not really have input. Because it is already designed to go a certain way, and all they want is for you just to represent as a number so they can say they have X number of people working in a program. It wasn't so with the library project manager. She is the kind of person who got *you* interested. She wanted to know what *you* think. She would bring ideas and ask you, "How do you feel this is going to work? I want you to say what you feel." She really got you involved in it. She found ways to work them in, even though the program was kind of designed and they knew what they were looking for. She found a way to work things in to show you that your input was very important.

Similarly, when the Georgetown Library director was asked about the role of the project manager for the libraries, he responded:

The library project manager and I got a long famously. You know, we were of the same ilk, which can be dangerous, of course. But [she] loves to laugh, she's very much a people person, but she's organized, too, as I am. She is just a facilitator, so she and I worked so well together. There was no friction ever. I enjoyed working with her because I like things to be fun. In a way, life is a game, if you don't enjoy it, why do it? And that was [her] outlook, I think, too.

The Georgetown Library director described his very small role in facilitating access to library resources. After winning an award from the Public Library Directors Association, he gave the credit to the Library Partnership project manager:

The university may have worked directly with the Diabetes CORE Group, but this was the first time they had reached out to the library. They not only reached out to us, but also they reached out to the library in Charleston. And I remember because we all went to Columbia, and we actually got an award for this from the Public Library Directors Association at that time. And we were totally astounded, because I turned to my counterpart, the director of the Charleston County Library, and I said, “Did you do much on this?” She said, “No, I didn’t do much on this.” And I said, “Well, here we are getting an award for this.” I said, “This is rather astonishing, isn’t it?” And she said something like “[Library Partnership project manager’s name]!” It was that wonderful, energetic person who made this happen.

**What the Library Partnership project manager thought was key.** The role of the project manager for the Library Partnership had great potential for leadership; however, by her own initiative, her role was self-limiting. The project manager, a White professional who was not from the community, took a facilitative role. When asked what she thought was key to the program, she responded:

The whole willingness to do use CBPR community-based participatory research. The collaboration between the REACH program and the libraries, and the community, it seems like there was a lot of outreach with community members, to use voices, faces, desires, activities. A lot of effort was put into putting the

community first, and then let the community drive the process within a research framework. That's the key for where we ended up.

She accomplished this in part by not taking a leadership role. When asked how she accomplished this, the project manager stated:

One, not to make the community's decisions. I just tried to take a low profile, that was my approach. I was coordinating emails, meetings, and setting the agenda. I kind of ran the meetings, but it wasn't me talking all the while. I came up with the first drafts, and then everyone worked that over to change the words. They especially developed the needs assessment, and they pretested the instrument. It seemed like I might start an activity, or the idea, and however it developed, I did not direct. I was more of a facilitator. Probably an effective way to do it. Perhaps people from the academic side would say the science needs to drive this. Most of the decisions were left to evolve organically in the community, but within a scientific framework.

She also said, "I had to temper my opinion," and she reminded the community of her role in listening and recording things:

A lot of times, in the library piece, they wanted me to make some of the decisions. My role as administrator [is] to record things and get things coordinated. I am here to listen and record things. I had to temper my opinion so they would make the decision together and not depend on me.

The role of the project library manager was seen as critical to success in developing many partnerships. I asked her what she thought was critical to success, and she responded with information about the needs assessment:

The needs assessment applied for in 2003, when REACH was already underway, helped us visualize more what we could do in a grant.... The planning committee actually did the first grant together. Out of the planning proposal came the two other proposals, for the rural and the faith. The Planning Committee [for 9 months, Sept–May] really kicked it off. We were able to identify community needs and activities through the distinct decisions and actions of the planning committee, and open it up to 18 members to become the steering committee.

When asked if the rural and the faith projects (see Appendix C) were separate, the project manager stated:

Yes, they were contracted under NNLM; that moved into REACH in terms of working with the CHA. And I was working with REACH in terms of my other duties, so it kind of all integrated into one whole program.... It allowed us to get additional funding to support the library component, that we had librarians in the community. It kind of helped support that whole initiative. It was separate, but then it was integrated.

According to the project manager, the target audience in the library's outreach and outreach services changed from a focus on children to a focus on adults.

A public library, they do a lot of children's services, so they had to refocus on the [adult health] outreach—not as a policy change, but a refocus. But they wound up onboard with the academic group and the diabetes education, and doing more outreach.

### **Theme 5: Participants Realizing Success**

Reflections by the participants about the first time they thought the program was working were insightful and varied. The founder said that when so many people turned out for the first meeting to use the computer, she knew the program was working: “The very first meeting people came, when we had the computer. People learned to use the computer. Because of the turnout, I knew people were very interested.”

One librarian relayed the story of a woman, approximately 80-years-old, who suddenly realized she had the “power of information to talk with her doctors” and who then quickly shared this discovery with other participants:

You know, it was funny when you were saying that, one of our clientele, her face came to mind. What made me realize that it was going to work, she is—oh my gosh, probably at the time she was probably right at 80.... What made me realize that it was going to work was to see the light bulb go off for her that she could have the power of information to talk with her doctors. Because all along she felt that all she could do was just take a pill, whatever the doctor was giving her. And she wasn't really understanding, but from the old school. When I saw that connection, when she was reading the information that she was able to get to on

her own in the class, when I saw that—and I can still see her face—that is when I knew that it would not end there. Because that's what you want, you want the sustainability, you want each person themselves to become a walking advertisement, not for it to end just with them. And I knew that was that point and it was because she immediately turned to the person next to her afterwards and started talking about it. But to see her face, yes, that's when I knew that this was it. After so long you hope, you just hope, you keep working and just hoping, and pray that maybe you'll see it. That's when I knew.... I mean, she was old, and that's invaluable because you know she has children, grandchildren, she's involved with the church. But someone like that is highly respected in the community, who then becomes a very powerful messenger.

The public library director knew the program was working when he saw the very positive community response to a colorful poster advertising the program. When community members saw their own faces in the publicly available poster, they responded very positively, which attracted even more positive attention and community members:

I realized the joy of the project when [project manager] brought in that poster of the Diabetes Coalition and the library working together on this endeavor. And she had gone out and she had taken the photographs, and she put together this marvelous poster. And when we hung that in our different libraries, and we had multiple posters, and so we put those in each one of our libraries, and it just encapsulated, it just crystallized, it just showed vividly what this was all about.

And it was such a joyful poster. And it was a very clear view for the entire community to see that this was something that we were doing together, that we were reaching out to the public, and that we were teaching people about these very valuable resources.

When asked specifically what the poster looked like, the public library director described it as a very colorful poster. It had all of the players who were involved, and showed them doing different activities. A CORE board member described the empowerment that came from this project:

The people who were on the posters were the people in the community. The people in the community saw themselves in the posters. They saw themselves attending health classes. Grandkids saw their grandparents in the posters, and said, "She can do that." This kept the community interested; that really sparked interest. Kids walk in and say, "That's my mom. That's my grandma."

One librarian described seeing community members enjoy learning and then using email within the class. She said they were able to navigate information resources, which resulted in curiosity about their medical care as well as in more meaningful conversations with their physicians:

That's something that did happen, because they were just absolutely thrilled and it was a bonus for them to all of a sudden know about the computer, how to manipulate a mouse, sending an email. You should have seen some of the ladies in one of the sessions. They were sending emails to one another in the class as

they were learning. And then to be able to get the information on their own and to say, “You know what, I’m going to ask my doctor about this. He has me taking this type of medication, and look what it says. It says blah-blah-blah. I need to ask my doctor about that. And look how much I’m taking.” Those types of conversations occurred, so that was good. (It sounds like they got inspired to learn more and get more involved?) Yes, because they started looking at the side effects, saying that’s why I’m feeling like this. It was an awakening experience for them. So that part I would say—I would definitely, definitely say that’s a must have.

### **Theme 6: Church Participation**

The church played a critical role in extending trust to the program, thereby gaining access to the community. The church was heavily relied upon in the partnership, and participants articulated the strength they felt religious values brought to the community and to the partnership. The pastor as stated, “Our ministry is not just to the spiritual man, but to the whole man.” He further explained how this was manifested in the community:

The Lord has blessed us because our church has been able to provide the kind of funds that are needed for a continuing program through the [long term]. To get somebody to understand that this is an investment in life, it has great dividends, but the dividends are not coming back to you tangibly. If you can help people save their life, that’s worth more than any amount of money. We’ve had people

come and they didn't even know that they were diabetic; they knew they had high blood pressure, and they came and found out that they had diabetes type II. So we were able to steer them in the right direction.

As the librarians and the CHAs enabled community members to learn how to navigate to high quality information, the church enabled community members to make better decisions about taking care of their health:

If we provide them the staples of canned goods and macaroni, and provide them some meat that way they could take over and that would last them for a couple days, and it will help them in making that decision about going on and getting their medicine, knowing that they would have enough to eat. (Wow!) Now it's in its eighth year. What we do is get people to buy groceries and a package of chicken legs that's fresh from the grocery store. We do this one Saturday a month on the fourth Saturday of the month. We have an hour of education in regards to diabetes and how it would affect the people. We do educational time with professionals, we have dietitians come in, we have nurses come in, and we have doctors come in. We have people from the various areas come in, we have foot doctors come in to explain to them about the proper care of the feet, we have people from the Eye Institute come in to talk to them about taking care of their eyes and eyesight because we have people in the area that go blind from diabetes. We have a continuing program at different areas in the month that we target. This is one of the main months that we target in Stroke Awareness Month; we educate

the people about high blood pressure leading into strokes with diabetes. We try to bring in people that are able to educate the people in this area. (community church pastor)

When asked if the classes were made available to non-church members, as well, the pastor responded that most attendees are not church members. He stated that when the program started, more than 100 people came, but some came only for the groceries and not the classes. The church started a restriction that the groceries could be taken only if the education session was attended. The pastor said, "Our requirements are that we require those that participate in the program to come to the educational hour. We don't just give them the groceries."

When asked what he would do differently, the pastor said the church volunteers realized they did not have the basic health supplies (e.g., arm pressure cuff, stethoscope, or needles) to provide health assessments or replacement medicine in an emergency or for members who forget to bring theirs. He stated:

Emergency Preparedness gave us a nucleus of people who had an interest in people because we have had [broad] publication. We had an older mother there who at one time had a seizure, and because of the seizure that she had, our nurse [said], "We have got to do something to be prepared for something like this." Another time, we were in a meeting, and nobody had a blood pressure cuff and nobody had a meter, and a person who was diabetic and who was also on [medication] got sick. And they had to drive them a distance to have this looked

at. I said, “Oh man, this can’t happen. We are serving the Lord, it’s true, but we need to have the things.” I said, “You mean, with all of the nurses that we have here, nobody has a pressure cuff when they come to services?” Nobody did. So we pulled together and we decided that this is never going to happen again. We are going to always have a pressure cuff, we are going to always have the diabetes things. We are going to always have somebody on duty at the meetings, so that when we have a church service, if somebody gets sick in that church service, we will be able to sustain them until we get the EMS or somebody there. It’s important that you know when a person has diabetes and that when their sugar drops, that you have what it takes to kind of put them right back up until you can get all that is needed. This is one of the things that we had discussed, and Lord brought along REACH 2010. And we came together as a team to work on these things, discuss these things, and learned about these things.

### **Theme 7: Transformation**

This dissertation focuses specifically on the methods used within a health disparities reduction program. Although the characteristics of transformation within the community are not a method, transformation is reported as a theme to indicate the impact the methods have had.

In the spring of 2012, 6 years after REACH 2010 CGDC Library Partnership funding ended, participants reported sustained changed resulting from the synergy of the partnerships. The founder of CORE, who was also a CHA, said:

We've seen the community change. People know now what A1c levels are. They pay attention to what their doctor gives them. It used to be they would say "my white pill" or "my pink pill." Now they say, "I'm on this or that [brand name of medicine], etcetera." It has made a tremendous change in the community.

and she also stated:

The CORE group wants to show you can have diabetes and can be happy. We also have programs in the ball field, streets, church, diabetes gala, diabetes walk, boat rides, history walk. We had a health revival, brochure, speakers, whatever meant to get the message out is what we need. At the diabetes gala we honored 15 years of service to diabetes, and had 70 plus diabetes survivors. We had 108 people attend. We had the senator, mayor, representatives, and Dr. [Smith]. We brought people in from the outside for a diabetes jamboree, such as doctors, nurses, nutrition, cholesterol checks, and the National Kidney Foundation checked people for kidney disease.

As part of the transformation, a new clinic was established, which is now an active partnering organization. A founding member of CORE, who was also a CHA, described what happened:

They all got together, and that's how we got the clinic down in the Choppee area. And that's a really, really rural area, where people really needed that clinic because they have trouble with transportation and all of the different things to get to health services. So that service was there. I used it myself. It's a very good

service that we have down in that area that came out of the program Ms. \_\_\_\_\_

founded, which we called Georgetown County Diabetes CORE Group.

The clinic is not only within the community, but it contains many services, so community members can make one trip for several appointments in one day. In the words of the same founding member of CORE:

We have a program that we have that's gone to national recognition, just doing the simple things like getting people to services and not trying to bundle a whole lot of things. But then that's what happened with the program that we did with having alcohol and drug abuse and mental health, and all of them in the same building. Say the doctor needed that person to go and see any one of those entities, they could do all of that in one day instead of going home and having to come back to a different appointment on a different day.

### **Theme 8: Perspective of the Librarians**

The final theme, focused on the perspective of the librarians. The intervention enabled one librarian to respond to individual community members so they would change their meal planning and recipes:

By us being able to check out books to them that have recipes that are doable and still had some taste, introducing the concept of not just using seasoning salt, but using Mrs. Dash, or using some coarse sea salt and not being heavy-handed with it. If you are making red rice, don't use a whole third cup of sugar in it. Just be careful about what you are doing. We were able to show them this, or give them

the opportunity to take it home and feel that they were having a private opportunity to make these decisions, and to not feel scorned for how they were raised. It was an empowerment activity. Or we show them “Here are some exercises you can do right from your chair. We don’t expect you to go put on some tights and head to the gym or walk the bridge or run the pier at the beach, but if you are at home, here is what you can do.” And show them these with DVDs or websites that have the streaming examples of it. And have people come in and show them what they could do. I think that was the big goal, just being grassroots, meeting people right where they are, and showing them that their quality of life can be improved by using free library resources and by partnering with the medical community and the university community in a real way, without judgment. (librarian 2)

In most situations, librarians teach the courses they design. However, this was not the case in this grassroots partnership. The classes about how to search the web were taught via train-the-trainer style and included basic computer literacy (e.g., email, basic Internet concepts, and Microsoft Word).

One of the things that we found out that was very interesting was that a lot of the clients were computer illiterate. In order for them to be able to access the information themselves, we had to back up and we had to teach them basic computer skills. That’s where the Charleston County Public Library was really heavily involved because we pulled a lot of our basic class structure from our

Technology Learning Center, where classes are taught to the public and to other staff members. We provided the format for basic computer, how to use email, basic Internet, that sort of thing, and basic Word, which was like the next level, so that they would feel comfortable in manipulating the Internet, the web. That involved a series of trainings. And then it was shared through Georgetown and was implemented. We had volunteer teachers who actually taught the classes because it was train-the-trainer. We trained them, and they went out and were able to work with their clientele. (librarian 1)

Librarian 4 described how he had developed a program called

*LearnaboutDiabetes@YourLibrary*, and was approached by the project manager to use it for the intervention:

They wanted me to be involved in showing some of the people they were already working with, people that had diabetes, how to come into the public library. They wanted me to recommend websites, and that's how we did it. I called it Learn About Diabetes at Your Library, using the @ symbol that you would use in a website address. [The project manager] sort of took that, and when we got into this project with the rural communities, that sort of became our signature phrase. After doing a couple of meetings in the public library and some community sites, [project manager] came and said she had this grant and they wanted to take this to some of the rural areas that they were already dealing with.

Librarian 1 provided a rationale about why CHAs and not librarians were used in teaching the community members:

Some [community members] were embarrassed for their lack of education, so we had to give some more privacy than others as they whispered literally their particular issue or they felt that they were uneducated. Their literacy issue and the health part, and they would go as far as to bring something in if they couldn't pronounce it or whatever, and then shared that with us. So, overtime, it became really building up trust. That was what was important within the community, why we went for local teachers for that immediate interaction to work with them. Because you have to remember, the library was just opening, so we were still relatively new in the game in terms of them knowing us.

The Internet searching curriculum was developed by the librarians:

We picked out websites, like MedlinePlus.gov and the American Diabetes Association web page—things that we knew were not commercial sites. We taught people and we enabled them to be able to distinguish between what was a commercial site and what was a government funded site, what was sort of a nonprofit site, so that they would know how information is disseminated and what is actually valid and what is actually not valid. Essentially, we taught basic Internet search skills, and we tied in the whole research of diabetes information with that. (librarian 4)

Librarian 3 described how community-driven education with people from the community built trust:

We covered several communities with health surveys and focus groups. The process and progression of the REACH 2010 Project was well thought out. The activities involved a lot of community partners, which ultimately developed support. All the areas involved had buy in, it was really community-driven education. The information was placed where the people lived and worked. They had folks who they trusted and knew weren't just coming into their communities for a short while. Also, as Charleston County public librarians, we had a vested interest in the communities the project was serving, because we were a part of a long-standing educational institution within the county. The curriculum developed by the Charleston County Public Library's Technology Learning Center, which was incorporated into the REACH 2010 community education training, not only empowered the communities served with health information, but the computer courses also empowered the participants in their workplaces. This also led to a stronger level of independence by the individuals and trust in the REACH 2010 Project.

Librarian 1 described how she helped prepare the curriculum for the community members:

The educational component was a big component, so I got in touch with our Technology Learning Center to put together some of the packages to teach. We

taught the teachers. It was like a train-the-trainer type of program, so we trained the trainers at all of the various locations where computer classes were taught in order to get those with diabetes comfortable with accessing the information that they needed so they could learn more about the disease, and also things (like “What do you ask your doctor when you go in for a doctor visit?”) to empower them to feel free to ask questions, and to go to the doctor. What we did was we educated from a system-wide perspective from all of the branches who were kept abreast of what we were doing and with our particular branch, our area like us here at [branch library], all of the staff were kept abreast and my Reference Department, the reference manager in particular, was involved with helping to educate the branch so that we all knew what was occurring and where the materials were located.

Librarian 4 described how healthy meal cooking demonstrations were provided in the library, with supporting library materials made readily available to community members:

I introduced them to [people] from REACH 2010, and she was able to go there and do some diabetes education. She also did some things on healthy eating. Let me backtrack a minute and say one of the things that she did in the library that I really enjoyed was we had a cooking demonstration, where we prepared a meal, a healthy meal, and then we went back and we were able to tell the people how it was prepared, that kind of thing. I was able to pull books with the recipes and things from the Internet. There was a lady whose name I cannot think of, she is

nationally known with [national entertainment] and she did a cookbook or she did some things with some celebrities.

Librarians were involved in enabling a more effective medical appointment because “doctors go from room to room really quickly.” Physicians had not been mentioned in any of the planning meetings, so I was curious if physicians were involved at all. I learned that part of the program was to enable community members to use more effective communication between the community member and the physician:

We know that the health transaction is really quick. Doctors are going from room to room really quickly. The community members needed to try to get in as much information before they go to that doctor visit so that they would be ready for what was going to happen, in probably about 15 minutes, depending on what they are there for. (Was there any part of talking with physicians about what would be helpful to get community members to have a better interaction, I mean was physicians’ input used?) You know, I do believe there were some nurses because [project manager] was part of the College of Nursing. I do not know about that side of it. I was part of another side of things. There was a point where there was something brought up called Askme3. It is the National Patient Safety Foundation. Askme3 has good questions for your good health. The questions that you would ask your doctor, nurse, or pharmacist: (1) What is my main problem? (2) What do I need to do? (3) Why is this important for me to do this? If you just got those three in, because the transaction is pretty quick. (librarian 2)

To enable adherence to what was learned in the medical appointment, community members learned to look up medicines and other information provided by their physician:

We are not telling you to do anything different than what your personal primary care physician has not told you to do. We are just saying for your own research, if you want to know more about diabetes, if you want to look up some recipes on diabetic meals, or you want to find out about an exercise that you could do, these are the places where you can look online. We would tie it in with books, as well.

(librarian 4)

### **Summary**

Themes uncovered from the participants' transcripts stressed the origin of a community-based partnership effective in reducing the severity of diabetes in two counties of South Carolina. One theme addressed the autonomy of the originating community partner, who was able to extend its mission with external funds from the CDC REACH program. Another theme described the project decision making as being community-led and community-based. Much effort was expended by external and internal partners to keep the activities and roles within the community. The theme concerning a changed role for professionals described librarians creating, but not teaching, their tailor-made curriculum for the specific community suffering from a serious chronic disease called diabetes. The fifth theme revealed a point at which the participants realized what they were doing was going to be successful. The sixth theme, the role of the church, gave insights into new roles the church played in supporting a

community partnership to learn about diabetes self-care. The seventh theme provided insight into methods used by the partners in transforming the community. In the final theme, “perspective of the librarians,” evidence of the intentional community-based focus is most salient.

In this chapter, my findings were presented to gain and share practical knowledge and insight into what roles, activities, and resources used in the REACH 2010 CGDC Library Partnership project and its related interventions successful in reducing the severity of diabetes in a successful intervention.

### **Chapter 5: Discussion**

The paucity of knowledge about what works to reduce health disparities in the United States was described in chapters 1 and 2. As a medical librarian, I have been frustrated at the lack of published methods with which to make recommendations for health disparities reduction. As a librarian, I feel I should be able to support health care providers and researchers by being able to identify and provide peer-reviewed literature to help reduce disparities.

In this chapter, I review the themes found in the interviews with key informants and relate them to the overriding question driving this research. To identify and record potential best practice methods, I completed an intrinsic case study of a successful program called REACH 2010 CGDC Library Partnership, a health education intervention in which a community of low-income, rural African Americans reduced the severity of diabetes symptoms. This case was selected due to its documented success in reducing disparities of diabetes symptoms after formal evaluation. The interviews from 11 key informants were analyzed and salient themes were identified.

This chapter discusses the following two aspects of the findings:

1. Response to the research question about the methods used in a successful health disparities intervention, using several lenses of adult education theory
2. Interpretation of how the steps for transformation (Mezirow, 2000) were experienced by the community through this intervention

The research question was formulated to find insight into the methods of successful health disparities intervention:

What methods, including practices, policies, and roles, were used by collaboration community partners in the REACH 2010 CGDC intervention program that overall proved successful in reducing or eliminating several health disparities of a vulnerable African-American population?

Based on the interviews and published outcomes, transformation and empowerment occurred in the form of a community that was newly enabled by attending community-directed classes to improve health and technology literacy, as well as by attending social events to learn and experience the management aspects of diabetes.

### **Methods Used in a Successful Health Disparities Intervention**

Eight themes were identified to describe the methods used in a successful health disparities intervention.

**Theme 1: Autonomy.** Theme 1 describes how the program originated with complete community autonomy, and how that autonomy was maintained. In the mid-1990s, one community member, after attending a workshop in a nearby city, decided to bring the newfound knowledge back to her community. When she came back from the workshop, she asked for support from her community, and community colleagues quickly organized an initiative that would help reduce the severity of diabetes in order to save lives. To be clear: this initiative and its management were not instigated by a government or a health institution. The initial action, organization, and success of the community

members were completely the responsibility of the community members. My observation during the interviews was that autonomy was fiercely defended and was key to producing and maintaining community autonomy. Autonomy in this setting meant the ability to make one's own decisions and be responsible for their outcome. This fierce sense of autonomy was still energetically maintained even after getting support from and partnering with very large financial and political entities (e.g., the CDC REACH and the Medical University of South Carolina).

I conclude that what worked in maintaining autonomy was reliance and trust in the leadership of those originating the CORE program. The CORE originators were respected members of the community, and using respected members meant not having to face the significant long-term challenge of gaining the trust of an outsider. Using members of African American descent within the community avoided the detrimental legacy issues of Tuskegee and avoided helicopter research. These community leaders were already trusted and were inspired to take action to improve the health of their community. Compared with outsiders, they had more knowledge about their community and how to draw their community together to improve health.

The philosophies and actions of founding members of the CORE Group resonated with Freire's (1970) description of what it means to "fight at their side" (p. 39). In this case, fighting was not about conflict with a political or financial power, but fighting to maintain community autonomy and improve health while facing an adversary in the form of a chronic disease called diabetes. According to Freire,

The radical, committed to human liberation, does not become the prisoner of a “circle of certainty” within which reality is also imprisoned. On the contrary, the more radical the person is, the more fully he or she enters into reality so that, knowing it better, he or she can better transform it. This individual is not afraid to confront, to listen, to see the world unveiled. This person is not afraid to meet the people or enter into dialogue with them. This person not consider himself the proprietor of history or of all people, or the liberator of the oppressed; but he or she does commit himself or herself, within history, to fight at their side (p. 39).

In this case, the founders of CORE mirrored Freire’s description in that they were inspired to lead members within their own community to better health, through health and computer literacy as well as health literacy about diabetes. In their interviews, the founder, founding member, and board member were immediately inspired with the goal to improve the health of their community and were not afraid to confront others when they thought it necessary. Examples in the interviews were many, and include the founding member warning the REACH 2010 CGDC PI (who was White and from the academic community) not to come into the community without being vetted by the CORE founders. The founding member was concerned that the trust of the community members and the program would be lessened if she showed up without first being vetted.

**Theme 2: Community-based and community-led.** External and community-based participants maintained every aspect of the project within the community. These activities included selecting members from the community to work on the steering

committees. Examples included having events held only within the community, using only community members for the actors in a diabetes theater show, and selecting people with leadership potential only from the community. To improve the chances of success, many already known local leaders were not selected if they were perceived to be overcommitted to other projects.

The subtheme “just being grassroots” describes a method that worked because trust for this community project remained within the community and was not co-opted by one or more external partners (e.g., the university, public library, or the CDC). Furthermore, “just being grassroots” meant community members avoided the threat of cultural invasion, as described by Freire (1973). Cultural invasion is the occurrence of an outside culture bringing solutions to a community’s problem without an understanding of the community’s resources. Cultural invasion, especially when information or assistance is offered to a community that does not have the resources to best use the information, can be highly detrimental to intercultural trust and community empowerment (Travers, 1997).

**Theme 3: Incentives.** The partnerships were formed ultimately to focus on enabling a healthy lifestyle for people with diabetes. In spite of this intended focus on diabetes, the results of a needs analysis expanded the short-term goals to include broader, more holistic skills needed for functioning in the electronic age. Participants indicated that many community members were intrigued and drawn to these incentivized events, wherein they could gain skills on how to use email or other computer functions (e.g.,

word processing). Learning how to use email enabled some community members to stay in touch with their family, especially grandchildren, and enabled others to perform better at their job as they learned how to use email for the first time. The interviews revealed the great interest and satisfaction of community members in gaining skills that were unrelated to diabetes symptom reduction. Having the community produce a curriculum of short-term needs not related to diabetes likely helped build trust, flexibility, and personal autonomy that were ultimately needed to reduce the severity of symptoms due to diabetes in this community. Knowles' (1984) assumptions of life-centeredness and the importance of intrinsic motivation to improve job satisfaction and quality of life were evident in the subtheme "the cleverness of it all."

This theme describes a method that worked because the community members' most immediate needs were not always diabetes related. In the interviews, excitement about the skills they gained centered on the thrill of learning email or helping win a computer for the church. I did not hear the same excitement about gaining skills for self-management of diabetes. However, the skills of email and web searching likely brought interest and enthusiasm to subsequently learning about diabetes self-management. In other words, satisfying immediate skill-building needs led to the eventual success in addressing intermediate needs (e.g., searching the web for preventive care information), which eventually reduced the severity of a chronic disease in the population.

The theoretical basis for this is transformative learning (Mezirow, 1997), which suggests that addressing the more urgent needs of a learner generates greater confidence

in learning about the less urgent, but nonetheless critical, health needs of caring for diabetes; this confidence can come from changing the meaning scheme of “I won’t be able learn to search the Internet because I’ve never used a computer” to “I look forward to learning to search the Internet because I know how to use the computer for email.” These new skills illustrate the role of critical reflection in a person who realizes he or she has gained the capacity to search the Internet for diabetes information as a result of mastering emailing his or her grandchildren, and thus has been transformed. These new skills lead to the increased autonomy of the adult, which is an indicator of transformative learning (Mezirow, 1997).

**Theme 4: A new role for professionals.** Librarians in public services in academic and public libraries routinely teach the classes they design. In this intervention, the curriculum was provided by the librarians to the CHAs so the CHAs could in turn deliver it to community members. Although librarians normally teach community members inside the library, in this case they provided instruction to CHAs who would be considered professionally unqualified to engage in library instruction. Thus, the librarians played a role that different from that usually expected.

Most libraries provide administrative support for librarians to teach computer and Internet literacy for health (Zeisel, 2005). REACH 2010 CGDC librarians extended their professional tools by creating experts out of the CHAs. This theme expresses the CBPR principle of collaborative, equitable partnership, and involved an empowering and power-sharing process that avoided the inequalities expressed through social power, education

credentials, and life experiences. If the instructor is of the majority race, comes from a different socioeconomic background, or is more highly educated than they are, learning may be inhibited and resentment may grow (Minkler, 2004) due to power inequality. In this intervention, equitable partnership was expressed by the librarians sharing and trusting their expertise with the CHAs. This shared information enabled the community members to rely on the curriculum content, without the distracting intrusion of power differentials commonly caused by an instructor's race, neighborhood, socioeconomic, or education differences.

**Theme 5. Participants realizing success.** The participants were sensitive to or observed unsolicited feedback from community members about what was interesting or exciting about the program. These events (i.e., what was most interesting or exciting) fostered the community members' learning.

Transformative learning in the community, as described by Mezirow (1997), requires power sharing and rapport between the instructor and the community members. The identification of highlighted moments for the community members showed that the key informants were engaged with the community members' learning and were collecting informal data about what was engaging. In one example, the instructor identified a light bulb moment when she saw the joy on an older woman as she suddenly realized she could use the information she had learned to talk with her doctors. This woman was a grandmother and a respected community member. The instructor expected that the health disparities intervention could be sustainable if community members, such as this woman,

shared what they learned with their grandchildren and others in the community. This theme reflected elements of adult education theory, according to which instructors' should be engaged with and sensitive to the needs of learners (Knowles, 1984). This theme also reflected the CBPR principles, as described by Israel et al. (2008).

Empowering community members to share their new skills and knowledge with other community members is evidence of the CBPR principle about building on strengths and resources within the community. Additional individual and community recognition (e.g., through depictions on a large colorful poster) emboldened community members and was evidence that CBPR integrates and achieves a balance between research and action for mutual benefit and enablement.

**Theme 6: Church participation.** The role of the church was critical for many community members with diabetes to learn how to take better care of themselves and their family members. The pastor's comment that "Our ministry is not just to the spiritual man but to the whole man" was in line with Tisdell's (2008) description of spirituality as a journey toward a higher being (e.g., God or life force). Tisdell pointed out although spirituality currently is regarded by the academy as "marginal" (p. 27), the Christianity has had a strong presence in the lives of adult education emancipatory movement leaders. The presence of spirituality was more than significant in recent emancipators. Examples include Myles Horton, co-founder of the Highlander Folk School, who has been called the father of the civil rights movement. Horton studied under Reinhold Niebuhr, who founded the Presbyterian-based Union Theological Seminary. Paulo Freire, also a leader

of emancipatory education, strongly embraced Christianity in the form of Roman Catholicism. Freire (1970, 1973; Freire & Macedo, 1987) became a founder of modern thinking on community power building and community enablement through literacy and adult education. For people of color, Tisdell (2008) asserted that spirituality helps reclaim a stronger cultural identity.

Many traditional secular academic and research institutions divorce their worldviews from religion or spirituality, and most researchers avoid relying on religion or spirituality as a public part of their practice. I come from an academic and social culture in which churches have not always been seen as agents of change. However, adult education has traditionally recognized and engaged all community voices for success in the community.

REACH 2010 CGDC used a well-respected community institution in the form of a church. This particular church, although small, was selected because of the prior community outreach efforts of the pastor. Another CBPR principle (Israel et al., 2008) is to embrace the existing strengths and relationships within the community; in this case, an active, community-oriented church was identified and well used. For example, by providing groceries to attendees, this church was influential in getting community members to attend sessions and learn self-care for diabetes.

A comfortable and safe space is important to learners, especially when the space is the venue for an atmosphere of respect, dialogue, and accountability (Vella, 2000). Furthermore, for many Christian African Americans, churches serve not only as spiritual

centers, but are known as a keystone for “mobilization of networks and material resources” to support and enable community-building efforts (Pattillo-McCoy, 1998, p. 768). The REACH 2010 CGDC intervention’s heavy reliance on the church and its enthusiastic reception in supporting the library and literacy workshops was evidence that this church was a keystone as well as a critical partner in the successful grassroots intervention.

This theme describes a method that worked because, just as the individuals who were the founders of CORE were part of the community, this particular church and its pastor were embedded in and trusted by the community. The time needed to earn necessary trust and credibility was expended before the project started. In comparison, if an external organization were to seek to become a trusted and embedded community partner, it would need years to build trust, respect, and credible relationships. The basis of distrust is found in many recorded abuses of vulnerable populations; for example, breaking confidentiality and misuse of family members (Skloot, 2010); the long-term effects of the Tuskegee legacy (Bates & Harris, 2004); and most recently, the misuse of Havasupai tissue for research on mental diseases without consent (Santos, 2008).

When a trusted institution (e.g., this church) is involved, the potential for incorrect or inappropriate comments about the vulnerable population is lessened. If such comments occur within that culture, they may be more readily dismissed as incidental (i.e., when compared with the same comments made by a majority population member).

**Theme 7. Transformation.** Because the health of a community appears to be dependent on many factors, ranging from geographic to social, changes in the community are needed to sustain lifestyle changes in individuals. Although the goals of the intervention were focused on diabetes specifically, the community appeared to have changed in ways well beyond the scope of diabetes. The key informants were enthusiastic about reporting the changes they helped enable or observed.

The community now has more libraries, more health clinics, more people who can use email, and more people who know effective questions to ask their physician. More people in the community are connected with the church and the library. One library assistant went on to earn a master's degree in librarianship and applied for (and received) grants to further improve the library services to the community.

This theme describes a method that worked due to trust and autonomy. Trust was brought in from the beginning by having community members learn and then teach the computer and health literacy classes. By avoiding helicopter research and cultural invasion, the leaders quickly earned the trust of the community. Autonomy was maintained by the initial community-based CORE group retaining control despite the REACH 2010 CGDC grant funding by the CDC. Community-based power sharing and a level playing field appeared to give a foundation for confidence and ability for future endeavors for the community at all levels in the form of individuals, groups, and the community itself.

**Theme 8: Perspective of the librarians.** New roles for the librarians were grounded in the community centeredness of the intervention. These roles included:

- Establishment of the facilitator role of the program manager for the Library Partnership
- Collaboration with the CHAs to teach the community members how to use Internet resources to find health information
- Commitment of librarians to show support to the project by attending non-library oriented community events (e.g., community walks)
- Deference and interdependence of librarians and all other partners to maintain the autonomy and trust within the community

### **Interpretation of the Steps for Transformation**

To articulate an interpretation of how the steps for transformation were experienced by the community through this intervention, it is helpful to consider the contribution of the CBPR principles, Mezirow's (1978) TLT, and Freire's (1970) emancipatory learning.

**CBPR principles.** According to CBPR, the community is recognized as the unit of identity (Israel et al., 2008). The units of identity were the Charleston and Georgetown counties of South Carolina. The libraries and other partners were located within these counties, and provided services to the members of these communities.

CBPR starts by building on the existing resources and strengths within the community. In this case, the two public library systems were brought into the REACH

2010 CGDC partnership when they were already existent in the community, but through this partnership their strength harnessed.

CBPR produces and enables partnerships in all phases of the research. The library staff actively in this case submitted their ideas and gave their time to the project and throughout the project.

CBPR ensures that information and knowledge is used for the benefit of all community partners, as well as building upon the larger body of knowledge that enables growth or well-being. This was a perfect fit because the libraries in this case naturally served all members of the community.

CBPR is heavily based on co-learning. The project manager for the libraries said that she had been “yanked out of Technical Services” to learn about this new project. The project manager recognized, in this situation, she was learning along with African American community members. While possibly initially uncomfortable for the project manager, her new role resulted in co-learning that likely inspired mutual trust with a secondary effect of deflating the power differentials due to variance in education and race.

CBPR partnership development and research methods are continually being enabled, developed, and supported. The final protocol is never determined before the study begins. CBPR is holistic. Mental, physical, environmental aspects are addressed in the context of historical, cultural, and social determinants with the community and larger society. CBPR distributes its findings to all partners for sharing and for feedback.

Findings are written in a respectful tone at a meaningful literacy level. Findings intended to be submitted to scholarly journals are reviewed by community members, and co-authorship is encouraged. CBPR requires a long-term process and sustainability. To keep and ensure trust, partners must be available over the long term and be involved in the process in an authentic way. Partners need to find ways to continue even when funding goes away.

**Application of transformation through adult learning.** The conclusions about how the methods that worked in this intervention reflect the principles of CBPR are consistent with Mezirow's (1978) TLT and Freire's emancipatory learning. TLT was recognized by Mezirow after studying adult women attending community college. Although Mezirow studied transformation in individuals, other theorists have considered learning and reflection in groups and community settings. Kasl and Elias (2000) asserted that groups have the ability to learn just as individuals do; therefore, transformative learning can occur in groups and communities, as well. The community change (i.e., reduction of the severity of diabetes) observed in South Carolina in this intervention can be viewed through TLT's 10 phases (Mezirow, 2000).

***The "disorienting" dilemma.*** The disorienting dilemma for the community was found in the visit by the founder of CORE to Myrtle Beach in 1996. At Myrtle Beach, the founder attended a diabetes workshop and learned that life with diabetes, while causing much suffering and death in her community, was actually survivable with a high quality of life if a healthy lifestyle was obtained. During her interview with me, she indicated

that she realized the changes required for diabetes self-care were entirely possible for her as well as for the members of her community. She seemed to learn that the severity of the disease for her and her fellow community members was negotiable; that is, a changed lifestyle could lead to a healthier, longer-lasting, and enjoyable life. I propose that this was the disorienting experience that enabled the community's empowerment.

*Self-reflection that results in discomfort.* The original experience at the Myrtle Beach workshop appeared to energize the founder of CORE to instill knowledge and skills to improve health and prolong the lives of fellow community members with diabetes. One could argue that if she had not been energized to initiate a movement in her community, she would have believed the suffering and death from diabetes within her community had to continue. It could be argued also that enthusiasm for (or conversely the fear of regret) inspired the community members to learn the tools to change and support those changes newly instituted by their family and friends.

*A critical assessment of one's assumptions.* The assumptions that it is acceptable and the norm to suffer from diabetes symptoms throughout the community was challenged by the outspoken community leaders, who appealed to other community members to learn self-care. The assumptions of the community were challenged by the new information that they, too, could gain access to information resources, as well as gain the health care skills to have a healthier, longer life, resulting from actively addressing the self-care needs of diabetes. My study did not include community members

suffering from diabetes; therefore, indirect examples were used. Jenkins et al. (2010) described an epiphany for community members and stake holders at all levels:

The evidence included moving communities at risk, even stakeholders and gatekeepers, forward in realizing and espousing that diabetes mellitus is a killer, not “just a touch of sugar” or “oh, diabetes runs in the family.” This strategic movement from diabetes being a generation-to-generation family history an unwelcomed consequence of potentially preventable complications could be described as an epiphany. (p. 250)

Assumptions about the normalcy of diabetes and illiteracy in the community were also challenged when friends and family talked about enjoying learning about diabetes and computers as part of the intervention. Classes held in the community settings enabled access to many sources of information and skill-building, not just information on diabetes or skills for diabetes self-care.

***Recognition of connection between one’s discontent and the process of transformation.*** Community events related to the effects or self-care for diabetes included library classes, community theater, a celebration gala, and openings for the new library and clinic. Each of these events provided another opportunity for a community member’s recognition that discontent from diabetes (within oneself or a family member) could be transformed into fun events that led to reduced suffering from diabetes and its effects (e.g., limb loss, blindness, and death). Through learning about self-management, diabetes symptoms and their severity can be alleviated by the learner. After community

members learned that the skills to live a healthier life could be learned from people they trusted in places they trusted, then they may have felt an obligation to family and community members to provide and support care of self and others.

*Exploration and consideration of new roles, relationships and actions.* This step was evident in the new roles the partners held; that is, the librarians became instructors of CHAs, instead of directly instructing the community members about health literacy and diabetes. The pastor initiated and supported an ongoing series of community classes for health at his church. The program director for the Library Partnership was new to the position and became a learner in ways that were similar to the community learners she was serving. New roles also were described in the recommendation to select unknown leaders from the community to serve on steering committees and represent stakeholders. One of the advantages of considering unknown leaders was having persons who were very interested in participating, but not already so involved in other activities that their time and commitment were compromised.

Likely, community members with diabetes gained the new role of enabled persons. They had the knowledge through their newfound health literacy and Internet skills to maintain effective self-care. Enabled community members gained new roles by understanding and supporting other community and family members to manage their self-care.

*Planning a course of action.* Planning within the community was a strong component of this community's change. Steering committees were created several times

to plan for the long-term rollout of the intervention. The steering committees consisted of community members who represented the stakeholders. The committees performed needs assessments to obtain community input.

*Acquiring knowledge and skills to implement change.* Community health workers were enabled with knowledge for searching the Internet. Community members learned how to search the Internet for medical information.

*Provisional trying of new roles.* New roles were evident in community members as they learned computer skills. New roles also were evident as the CHAs provided library instruction to the community members. In addition, new roles were evident as the librarians attended community events as visitors to show support and to share curricula with the CHAs.

*Building competence and self-confidence.* The CHAs praised the community members, not just for accomplishments, but also for simply showing up and trying to accomplish the tasks.

*Integrating new knowledge and skills.* On a large scale, adults in the community learned about the self-care of diabetes, as well as about how to find new information. Through a large community effort, they came to view diabetes as manageable. Not only was the severity of diabetes decreased, but individuals gained the collateral benefits of using email; searching the Internet; and engaging in health and community building endeavors (e.g., health-related fairs, walks, and boat cruises).

**Application of Freire’s emancipatory learning approach.** The REACH 2010 CGDC initiative, as proudly acknowledged by all participants, came from grassroots community members envisioning a better and enabled community in the late 1990s. These initial community leaders decided that through community building, they would reduce the severity of diabetes effects on their members.

The CGDC sought to strengthen CORE and extended its mission by adding funds and resources, but not to change the power structure or mission in the community. That the power structure and mission did not change was evident in the interviews, as well as in the publications reporting on the progress of this community-institution collaboration.

### **Conclusions**

The overriding question driving this research was “What can we learn from a successful community-based health disparities intervention?” The findings show that effective practices are based in trusted institutions and community members. These institutions and community members provide leadership and training to the community members. This observation is consistent with Freire’s (1970) theory for emancipation (i.e., community members identify the need and teach themselves with the assistance, but not the control, of outsiders). The observations showed that emancipatory learning can occur when skills are gained, and a new foundation can create the realization and optimism for further growth and empowerment (Cranton, 2006).

To inform members of a culture that their diet, exercise, and thinking habits need to change to improve health is a daunting task, especially if proposed by a member of a

different community or culture. In general, few individuals seek to change their lifestyle because someone said it was a good idea. However, in the REACH 2010 CGDC Library Partnership project, as a result of the broad, community-based health literacy initiative, many individuals appeared to change the way they ate, exercised, and thought about their health and that of their community. I think one of the major components for change was trust—trust in the motivation of the CORE members and the community health advisory, and trust in the validity of the information being offered. If others from outside the community had engaged in instruction or leadership, distrust likely would have greatly reduced community participation and slowed the adoption of knowledge needed for self-care. Trust, already established by CORE, appeared to be maintained or strengthened through the use of community members as CHAs and library instructors. Trust appeared to be established by the external partners through excellent communication: keeping one's word, clearly defining the project boundaries, and being transparent when changes occurred.

### **Summary**

In summary, REACH 2010 CGDC is an excellent example of a community collaboration that successfully reduced a health disparity in a vulnerable population. When examining the methods (e.g., autonomy, community driven, church-based, with librarian participation) that brought the reduction of a diabetes health disparity, we also see the enhancement of the community. Through the lens of adult education, we can see the principles of Mezirow's (2000) TLT and Freire's (1970) emancipatory approach in

action. These principles resulted in improving health literacy, improving computer literacy, and improving access through literacy and physical resources to medical and information resources. The next chapter suggests the implications of using REACH 2010 CGDC to better understand and improve projects intended to reduce health disparities based on race and socioeconomic status.

In chapter 5, I examined the finding of chapter 4 in light of TLT and emancipation theories. Current CPBR methods and principles were supported by Knowles's (1984), Mezirow's (2000), and Freire's (1970, 1973) theories. Chapter 6 examines implications and future research.

### **Chapter 6: Implications and Future Research**

This chapter provides implications and personal reflections concerning this study. I interviewed 11 key informants in South Carolina who were active in providing services, education, and support toward reducing the severity of diabetes in their communities. This interpretive intrinsic case study of a successful health disparities reduction intervention is unique because few studies exist of methods to further the field of health disparities research. The intent of this dissertation was to begin to find out what works to inform academics, researchers, and community members for future intervention planning and research.

Limitations of the conclusion are specific to a socioeconomic group (i.e., low income); a race (i.e., African American); and a geographic area (i.e., rural South Carolina). One would expect that the themes found here would be found in similar community, race, and diabetes settings. In that light, recommended research could seek out themes of other successful interventions from the perspective not only of an academic librarian, but also by individuals from other professions who work as stakeholders. These stakeholders may include nurses, CHAs, ministers, and policy makers.

In spite of these limitations, insights from this research may inform future interventions for the following reasons:

- The seminal organization was community initiated and was successful.

- CDC's REACH 2010, a much larger political entity, became a partner with the existing CORE organization, extending CORE's influence by strengthening its services but not changing its mission.
- The initial community leaders were African Americans without advanced formal education. These characteristics made them peers with the community members most likely to benefit from CORE's services. Using peers who are community members reduced the chances of distrust and lack of credibility resulting from power imbalances through race, neighborhood, occupation, and education differences.
- The library directors (i.e., director of the Medical University of South Carolina, and the director of the public library) were very supportive of library staff involvement, and in staff being directed by community leaders. Both library directors made their staff's involvement a priority.
- The Library Partnership project manager was new to this community partnership process and learned alongside community leaders. An expert who already knows this process may not have earned the trust achieved in being a beginner in implementing CBPR.

### **My Reflections and Recommendations**

This case was intriguing to me not only because it was a successful intervention that reduced a disparity in a vulnerable population, but because its use of libraries and librarians made the multifaceted field disparities accessible from a professional and

personal perspective. That said, this dissertation was not written with the intent nor the conclusion that libraries are, or should be, the main focus of a disparities intervention.

Consistent with Freire's (1973) thoughts, a community can change when it is motivated and enabled to do so. Freire emphasized community enablement through reading literacy. I heard personal and community enablement in this REACH 2010 Program through improved computer literacy (e.g., email, word processing, and Internet navigation) and health literacy (e.g., "I know what pills I am taking and why I am taking them").

The eight themes I described showed how one particular community and its dynamic subjectivity made a successful change in its members. I wrote this from the perspective of a privileged outsider who was granted precious time from very busy and committed community members whose careers are defined by the improvement of health in their community members. As an outsider, I shared my insights with the objective of informing other researchers, community members, and academics to make a positive impact on future interventions.

**Future action goals.** In the future, when I am in a position of working with a community-based partnership to reduce disparities, (e.g., as an institutional partner), I plan to:

1. Identify a grassroots organization already existing within and trusted by the vulnerable community and consider the partnership opportunity

2. Minimize the impact on the grassroots organization's mission, autonomy, and power structure; the project will be successful if *their* (i.e., individuals within the grassroots organization) influence within the community is extended
3. Describe a defined plan, with all partners, of what my organization is planning on doing, and share that plan with the other partners, including the length of time involved; if or when plans must change, I will be transparent and communicate about when they will change and why
4. Ensure I partner with other local *community* institutions (e.g., churches and libraries); due to a difference in missions and goals, an academic library may not be able to keep needed long-term commitments in the same way a community-based public library or church would
5. Support community-leadership choices of "unknown potential" for leadership for committees and projects; avoid exclusively picking already known community leaders
6. Ensure humility and power sharing with selected community leaders, especially those who may not meet academic standards of expertise or the middle-class standards of successful
7. Defer to the community leaders on their choice of trainers and those who will interface with the community
8. Know that differences in race among vulnerable populations may have a much larger effect on feelings of safety and trust than many Whites suspect

9. Use community strengths, no matter where they are found

**Recommended research.** It seems the field of health disparities research is in dire need of specific cases of what works to improve the health of a vulnerable population. Using the insights gained from this intrinsic case study, I recommend that future health disparities interventions require evaluation of the long-term health care or health status outcomes of the vulnerable and majority population. Having additional examples of success will enable the themes I have identified to be examined for transferability into other cultural, ethnic, or geographically-based communities.

Additionally, future case studies should examine the role of active community based entities, such as churches, public libraries, and schools. Future case studies would find insights into how and when external academic libraries and researchers can optimize support of health disparities interventions without undermining the long-term relationships of trust and autonomy needed for the community to change. In the spirit of community-based partnerships, when health disparities research is performed, it seems paramount for researchers to respectfully include the community participants who are likely the only experts of what specifically will work to enable lifestyle changes in their community.

### **Conclusion**

In the 4 years that have passed since I started this research, awareness of the persistence of national health disparities has increased along with the awareness of incidence of diabetes at epidemic rates across the United States (Geiss, 2012). Newspaper

headlines concerning health disparities and diabetes are frequent. From my study, I can see we already have many trusted (but unsung) system and structural elements in place that are likely to aid in research interventions to improve health. For instance, the mission of the public library is to enable and encourage all community members (no matter the literacy or socioeconomic level) to further personal and community development, and this makes public libraries ideal partners in a health disparities intervention. Public libraries and churches, because of their focus on individual and community growth, are persistent and trusted institutions with many community contacts. Challenges to public libraries in accepting this role may include staffing decisions that send librarians outside the library for a majority of their time. Such changes will affect the services most commonly delivered inside a library, but would enable improvement at the community level.

Churches and other religious organizations may serve a similar purpose when they endeavor to serve a multifaceted community as was found in this case study. Religious organizations, when open to serve community needs, (in the name of their respective faiths) would, like libraries, serve as effective, trusted, long-term, community-based partners that could improve health of a vulnerable population.

### **My Culture**

My White middle-class culture, which values formal education credentials, looks beyond the local community for expertise and leadership. My perspective is challenged

when I see a successful program led by local community members who are not formally educated and their leadership comes from within their community.

My professional culture would likely seek more control over who became volunteers and also be concerned about the experiences and qualifications for such important volunteer work. However, I realized that by keeping the control within the group and keeping it grassroots, the intervention stayed empowered and owned by the community. Likely, this culture of which I am a part has disempowered interventions due to value for methods control based on the stance of positivistic science. I look forward to supporting future health disparities research with this new mindset.

The power of community partnerships has enabled me to bring change to my community of Rochester, Minnesota. In 2010, I was a charter members of a grassroots organization called Friends of Indian Heights. With the help of other community partners, Friends of Indian Heights successfully protected a parcel of native flora and fauna within Rochester city limits from becoming a sports park. Additionally, in 2011, I was a charter member of a Mayo Clinic employee group called Celebrate Dakota. This group, now 50 members strong, has welcomed exiled Dakota people back to Rochester. In addition, Celebrate Dakota created a community-wide group called Greater Rochester Area Dakota Supporters. These groups work together with already existing community partners, including the Rochester Public Library, the Native American Center of Southeast Minnesota, Rochester Department of Parks and Recreation, Audubon, Prairie Enthusiasts, and many more.

As a result of my academic study and community experiences, I now think and feel differently about my power as an individual. I have seen successful and dramatic change from the outside in (i.e., my study of the REACH intervention in South Carolina) and from the inside out (i.e., my involvement in chartering and partnering with community groups in Rochester, MN). In the American culture of individualism, this dynamic of community change through community partnering appears to be perhaps undervalued and misunderstood.

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**Appendix A: Institutional Review Board Letter**

12/01/2011

Dawn M Littleton

507 17th St. NW Rochester, MN 55901-2502

RE: "Discovering the Library Practices in the Successful Multi-partnered Community Based Health Disparities Intervention REACH2010 of Georgetown and Charleston Counties in South Carolina"

IRB Code Number: 1111P06484

Dear Dr. Littleton:

The Institutional Review Board (IRB) received your response to its stipulations. Since this information satisfies the federal criteria for approval at 45CFR46.111 and the requirements set by the IRB, final approval for the project is noted in our files.

Upon receipt of this letter, you may begin your research. IRB approval of this study includes the letter of invitation received November 4, 2011 and the consent form received November 28, 2011. The IRB would like to stress that subjects who go through the consent process are considered enrolled participants and are counted toward the total number of subjects, even if they have no further participation in the study. Please keep this in mind when calculating the number of subjects you request. This study is currently approved for 10 subjects. If you desire an increase in the number of approved subjects, you will need to make a formal request to the IRB. [Approved for increase to 25 subjects on 3/9/2012]

For your records and for grant certification purposes, the approval date for the referenced project is November 15, 2011 and the Assurance of Compliance number is FWA00000312 (Fairview Health Systems Research FWA00000325, Gillette Children's Specialty Healthcare FWA00004003). Research projects are subject to continuing review and renewal; approval will expire one year from that date.

You will receive a form two months before the expiration date. If you would like us to send certification of approval to a funding agency, please tell us the name and address of your contact person at the agency. As Principal Investigator of this project, you are required by federal regulations to inform the IRB of any proposed changes in your research that will affect human subjects. Changes should not be initiated until written IRB approval is received. Unanticipated problems or serious unexpected adverse events should be reported to the IRB as they occur. The IRB wishes you success with this research. If you have questions, please call the IRB office at 612-626-5654.

Sincerely,  
Christina Dobrovolny,  
CIP Research Compliance Supervisor

## Appendix B: Interview Questions

### Questions Used in Interviews

1. What is your title, official role in this intervention, and length of time on this project?
2. How did you initially get involved in this project (i.e., education, work or volunteer histories as appropriate)?
3. Did any of your activities involve interactions with library staff, policies, services or resources for this case or a related project?
4. If so, please describe the library staff, services, or resources that from your perspective impacted this intervention? What is your perception of what contributed to make this intervention successful?
5. From your experiences with this intervention what appear to be the most effective *practices* surrounding the library activities in the community-engaged diabetes intervention? (e.g., tasks, classes, projects, reports)
6. From your experience with this intervention, what appears to be the most effective *policies* (e.g., who was included, how were they included, planned timeline etc.) concerning the library (e.g., university or public) in this community-engaged diabetes intervention?
7. Please describe for me any lessons learned on best practices that can be used in other community-engaged intervention studies? Feel free to mention things that would increase the chances of making a future project successful. These may include recommendations to avoid jeopardizing the success of future community partnerships addressing health issues.
8. Was there a particular library role, policy, procedure or service that you felt was instrumental in the success of this program?
9. Explain the effectiveness of the library (e.g., academic or public) staff roles in this community diabetes intervention?
10. Was there an event or incident where you realized this intervention is actually working and we will be successful?
11. Were there aspects of your personality or work style that you feel enabled a better outcome that you would like to share?
12. Is there any additional information you would like to offer for this study?

**Appendix C: REACH 2010 Faith-in-Health Library Initiative**

Subcontract to NLM Contract No. N01-LM-1-3522

**Medical University of South Carolina  
Charleston, South Carolina**

Barbara Carlson, MLIS AHIP, Library Coordinator  
REACH 2010 Charleston and Georgetown Diabetes Coalition  
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**FINAL REPORT  
September 1, 2004-April 30, 2006**

Submitted May 30, 2006 to:

Janice Kelly jkelly@hshsl.umaryland.edu  
NN/LM SE/A Region

cc: Carolyn Jenkins, DrPH jenkinsc@musc.edu  
Gayenell Magwood, MSN, magwoodg@musc.edu  
Thomas G. Basler, PhD, basler@musc.edu

**REACH 2010 FAITH-IN-HEALTH LIBRARY INITIATIVE  
Subcontract to NLM Contract No. N01-LM-1-3522**

Quarter 7 Report February 1, 2006-April 30, 2006 is included as a separate report (REACH Faith Q7 Rep.doc), and submitted with this Final Report.

**FINAL REPORT****SUMMARY OF ACCOMPLISHMENTS AND INTRODUCTION:**

African Americans are leading the United States in deaths related to diabetes. Health disparities may be reduced if more African Americans, especially in the rural areas, get access to and learn how to use the Internet and libraries to get up-to-date, quality information on diabetes and related health issues to improve diabetes self-management skills.

**REACH 2010 Faith-in-Health Library Initiative Accomplishments and Plans for Sustainability and Expansion:**

- Brings together faith organizations, different types of libraries, and other community groups to help people learn more about diabetes by using the Internet and libraries. A diverse group of leaders developed into a working Steering Committee that focused on digital divide issues as factors related to health disparities.
- Installed and now maintains at least one new Internet computer in each of 2 faith organizations: Greater St. Peter's Church of Our Lord Jesus Christ, and Nazareth A.M.E. Church. Neither church had Internet access prior to this project. Likewise, the Choppee area where Nazareth A.M.E. Church is located in Georgetown had limited library services by a bookmobile and no library within 15 miles.
- Taught Steering Committee members and other influential leaders how to search for health information on the Internet and explored issues such as health literacy and how to judge the quality of health information at a day-long "model" health information workshop held at the Medical University of South Carolina's Library. This workshop serviced all project organizations, and was conducted in collaboration with staff from the NNLM SE/A Region.

- Developed and implemented an ongoing community-based train-the-trainer program to teach volunteers how to use Internet and library resources to access and spread quality diabetes information.
- Publicize the community-based training program and resources. A variety of activities promoted the project. Fliers were distributed to other churches in the areas and steering committee members promoted the program at different community meetings and events. Greater St. Peter's Church used paid radio announcements to publicize the program.
- Teach individuals at community sites and from other organizations about recommended diabetes resources.
- Kept records of training and other project activities through reports, logs, and journals.
- Designed and tried to use a pre-post test to evaluate the training programs and collection of digital diabetes resources.
- Participated in 2 focus groups in Charleston in March 2006 to help evaluate the entire process.
- U.S. National Commission on Libraries and Information Science (NCLIS) 2006 Health Award for Libraries Grand Prize Winner: This project was represented as part of the REACH 2010 Charleston and Georgetown Diabetes Coalition's Library Partnership that won the grand prize on May 3, 2006 in the NCLIS health award competition. Barbara Carlson, principal investigator, participated in a panel discussion on partnerships and outreach, and did a presentation (Appendix: NCLISCarlson2006.ppt). At the forum, Joyce Linnen (Nazareth A.M.E.), Pastor Carl Grant, and Jacqueline Grant (Greater St. Peter's Church) also represented both faith based program partners. The official NCLIS award announcement is in the Appendix as HealthAwardsWinner2006-07.pdf. This press release did not acknowledge the NNLM as a primary funding agency for the REACH Library Partnership, so Barbara Carlson on behalf of the REACH Library Partnership included the following statement in her thank you letter to Dr. Beth Fitzsimmons, NCLIS Chairperson:

“The National Library of Medicine, as host of the health information forum, Dr. Lindberg's remarks, and Dr. Angela Ruffin with the National Network of Libraries of Medicine, showed us that the NLM and NNLM offer outstanding and constant support. For many years, we have known them as partners, and our success is also their success. Our REACH Library Partnership and the work we do was made possible by bringing together funding opportunities from the National Network of Libraries of Medicine and the CDC, so the NNLM deserves to be acknowledged with all other major contributors.”

Church leaders, their diabetes Internet trainers, public librarians, other community leaders, a REACH 2010 community health advisor, and the REACH librarian worked together to design, implement, and evaluate the program. With Internet computers in the churches, librarians as trainers, skilled volunteer community-based instructors, and a shared vision for building community capacity, this project planned to train at least 120 community members over 18 months, and spread the word about diabetes resources to a minimum of 1,000 individuals.

**Geographic region/number of counties:** This project impacted African Americans in two South Carolina coastal counties: Charleston County and Georgetown County. The geographic area covered an area of 1,600 square miles along a 150-mile stretch of the South Carolina coast.

### **Collaborations/Partnerships**

Two faith-based organizations of different denominations are represented on the Steering Committee. Prior to this project, representatives of Greater St. Peter's Church served on the REACH NNLM Community Outreach Partnership Planning Committee from September 1, 2003-May 31, 2004, so this partnership has been building its relationships over a period of time. Before this project started, each of the two lead churches agreed to extend invitations of participation in the program to other churches of different denominations in their area. Below is a list of organizational partners that are the primary groups involved in this project, but activities have been held at other venues in conjunction with different organizations.

- Greater St. Peters Church of Our Lord Jesus Christ  
2062 Savage Road, Charleston, SC 29414 (843) 556-6568  
Contact: Pastor Carl Grant [pastorgrant@yahoo.com](mailto:pastorgrant@yahoo.com)

This Holiness church has an average Sunday attendance of 56 and is located in the West Ashley suburb of Charleston. Pastor Carl Grant served on the REACH 2010 Charleston and Georgetown Diabetes Coalition NNLM Community Outreach Partnership Planning Project, September 1, 2003-May 31, 2004. He is the inspiration and driving force behind this initiative. Pastor Grant is committed to working with neighboring churches: Graham AME, Community Baptist, Bibleway Assembly Deliverance, and Bibleway Baptist. Prior to this project, Greater St. Peters COOLJC had no Internet connectivity. This church received one new computer workstation, printer, and Internet service through Comcast cable modem. The Charleston County Public Library St. Andrews Regional Branch is within two miles of the church, and many church members are computer and health literate.

- Nazareth A.M.E Church

1500 Postfoot Circle, Georgetown, SC 29440, (843) 546-0907

Contact: Reverent Michael Frost

This African Methodist Episcopal (A.M.E.) Church has a congregation of 500 members with an average Sunday attendance of 150-175. The church is located in Choppee, a very rural area of Georgetown, and most members of the congregation live in Dunbar and Choppee. Reverend Michael Frost is an enthusiastic pastor, who works closely with the local grassroots diabetes community organization, the Georgetown County Diabetes CORE Group. One of his church members is Ms. Florene Linnen, founder of the Diabetes CORE Group, renowned diabetes community activist, and REACH 2010 Community Health Advisor (CHA). Nazareth was a participant in the *Learn About Diabetes @ the Library* Program and had members working on the earlier REACH NNLM Community Outreach Partnership Planning Project. There was no prior Internet access at the church, and it had only one non-Internet accessible computer for office use. Four other churches got involved in the training program. The closest Georgetown County library was over 15 miles away, but a new Carvers Bay Library Branch within 5 miles was opened May 13, 2006. This church received one new computer workstation, printer, and dial-up Internet service. It was anticipated that if training got underway within this community, the new public library would have a user population better able to use the library's resources.

Both churches have congregations that know first hand the burden and devastation caused by diabetes. Their pastoral and elder leadership continue to seek effective ways to fight diabetes, which calls home too soon many from their congregations. Besides being spiritual leaders of their churches, the pastors through this partnership have embraced the role of information innovators. They guide the training program, and ensure that it will blend with the socio-cultural environment of their churches. They select their members who deliver the training, and motivate the trainees to learn new skills and use new resources. The pastors work with other church leaders, encourage their congregants to share expertise and ideas, publicize the training program, and contribute content to the new faith-based diabetes web resource. They share the project's progress with other community organizations and welcome further interdenominational collaboration to enhance resource sharing.

Each of the two churches above received:

- New computer and printer, as well as computer supplies and software
- Internet access for the site's computer
- Technical support to maintain the computer, printer, and network connections
- Assistance from a public librarian and REACH librarian
- Free attendance at a day-long "model" health information workshop
- Funds to help support participation in the Steering Committee meetings, training sessions, and community-based instructors

Each of the two faith leaders or their representatives participated in steering committee meetings recruited 1-2 lead diabetes Internet trainers, co-designed an Internet training program, motivated and recruited community members to participate in the health information technology training program, collaborated with other leaders to learn about electronic diabetes resources, promoted the recommended digital diabetes resources, and worked with other Steering Committee members, technical experts, and the community to help the REACH 2010 Faith-in-Health Library Initiative make progress.

Other partnered organizations are listed below:

- The REACH 2010 Charleston and Georgetown Diabetes Coalition aims to eliminate disparities for more than 12,000 African Americans diagnosed with diabetes by improving self-management and care. The Coalition is the umbrella organization for the library program and includes over 16 organizations and people with diabetes. The Coalition is funded by the CDC, and the principal investigator is Dr. Carolyn Jenkins. Activities happen where people live, work, worship, play, and seek health care. The Coalition improves access, care, education, and outcomes within health care systems, enhances community development, empowerment and education for African Americans with diabetes, and builds coalition power, advocacy and sustainability. The REACH 2010 Diabetes Coalition's health sciences librarian serves as director of the REACH library program and works closely with REACH community health advisors (lay diabetes educators/advocates) to liaison with community organizations.
- The Charleston County Public Library (CCPL) System serves over 300,000 people through 16 branches and a bookmobile. The Johns Island Regional Branch opened in October 2004. This project afforded collaborative opportunities to build bridges in the community with this new library. Seven public librarians from this system were directly involved in serving on the Steering Committee, developing the curriculum, and training volunteer instructors. CCPL administrative support came directly from the Extensions Manager in charge of all branch libraries in the system. The library manager from the St. Paul's/Hollywood Branch worked closely with Greater St. Peter's Church.
- The Georgetown County Public Library (GCPL) System had 3 libraries and a bookmobile when this project started. A new Carvers Bay Branch in the Choppee area opened on May 13, 2006. This project helped introduce the community to the value of libraries and plan health information as an ongoing service by this new library. The Carvers Bay library manager serves on the steering committee and provides health information instruction at the Choppee Health Center and in other areas. Library administrative support came directly from GCPL director.

- Wadmalaw Island Community Center addresses quality of life for all residents of Wadmalaw and preserves the unique history of the island. The Center runs a senior exercise, nutrition, and recreation program.
- Wiltown Community Center strives to address the welfare, recreation, health, and education needs of 5 rural communities, and holds after-school and adult education programs that teach life-enhancement strategies.
- wired.MD is a company that offers Web based patient and consumer health education videos and print handouts for use at the point of care and beyond. It has donated its products to the REACH library program for a year.

The REACH library partnership remains a close working group of organizations that are committed to health information outreach. As in any collaborative effort, some organizations and individuals have gone above and beyond outlined contractual agreements, while others barely met or failed to meet minimal expectations. Both faith based organizations performed at a high level to accomplish this project. The library partnership has grown in its relationship with the faith community, and they remain vital and strong partners who focus on existing and future activities. Finding strong community leaders who provide a community with positive, futuristic vision, and who commit time and energy to mobilizing community resources are key to success.

**Training:**

The selected diabetes Internet trainers from Greater St. Peter's Church worked closely with a Charleston County Public library manager to become comfortable using the curriculum. From October 2005, there were 13 persons who got hands-on training through 30 classes, each at least 1-hour in duration. Participants used MedlinePlus to search for prescription drug information, got diabetes and other health information from the American Diabetes Association, CCPL, REACH, Hands-on-Health-SC and wired.MD websites, and learned basic computer skills. Participants' questions drove class content into other computer skill areas. During the 4<sup>th</sup> Saturday Community Health Day at the Church each month, registered nurses from the Medical University of South Carolina and Bon Secours-St. Francis Hospital System and librarians shared health information with attendees that numbered over 175 monthly.

Training at Nazareth A.M.E. Church involves four other churches. Coordinated by a member of Nazareth A.M.E., they use and distribute the teaching curriculum and have agreed to scheduled class times at Nazareth. The trainers from five different churches are educators with good skills in computer and Internet use. They have the experience and expertise needed for teaching others new skills. Nazareth's lead trainer is enthusiastic about the program and has taken MedlinePlus training into daycare centers for staff training, and into several schools to share information with administrators, teachers, and students.

Only some training activities and demonstrations have online records completed in the outreach activity reporting system. There were other promotional and hands-on training sessions that were not recorded officially in the online system, but are reflected in the statistics below, accumulated from the logs and reports. Based on these and other activities' attendance, the totals are recorded below.

#### Summary of Training Activities and Participants:

- a. Total number of sessions conducted as part of the project: **83**
- b. Total number of sessions in which half or more than half of participants were from minority populations: **83**
- c. Total number of participants in the project's sessions: **1,069**
- d. Breakdown by participants by
  - i. Health care or service provider: **20**
  - ii. Health sciences library state member: **5**
  - iii. Public/other library staff member: **9**
  - iv. Member of the general public: **1,035**

#### Training Sites:

- Greater St. Peters Church of Our Lord Jesus Christ  
2062 Savage Road, Charleston, SC 29414  
Greater St. Peter's Church is a church facility, which consists of only a sanctuary in the West Ashley suburb of Charleston. Internet access to one computer housed in the church's sanctuary is via Comcast cable modem. The church facility is small, but even before the computer was purchased, Pastor Grant had a computer desk custom-made along side the pew area. The congregation numbers just over 50 individuals, but the church provides at no charge health care screenings and health information services to over 175 persons from across five counties on the fourth Saturday of each month. The Saturday health program runs from 9:00am – 2:00pm. Guest speakers provide health educational sessions on various topics and registered nurses from the congregation offer free blood pressure and blood glucose screenings. At its own expense, the Church supplies participants with free bags of healthy food to encourage healthy eating and nutrition.

- Nazareth A.M.E Church  
1500 Postfoot Circle, Georgetown, SC 29440  
Nazareth set up its computer in its fellowship hall. Dial-up Internet access was all that was available and affordable in this rural area. Technical support was provided for this public workstation by this project. Nazareth A.M.E. Church members and other rural residents had no library within 15 miles at the start of this project, but the new Carvers Bay Branch Library opened May 13, 2006 within 5 miles of the church. The GCPL staff

member who conducts a health information class at the Choppee Health Center less than a mile down the road is the new Carvers Bay Library manager. The potential for further collaboration in the Choppee, Dunbar and Plantersville areas is strong, so there are plans to expand the REACH library program into these remote rural areas of Georgetown County.

**Exhibits:**

No designated conference exhibits were done in connection with this program. However, non-technical promotional outreach displays were done at various health fairs, the Black Expo (10,000 visitors), and professional organizations' events.

**Resource Materials Developed for Training or Promotion:**

A REACH library program's teaching curriculum was developed for use by all affiliated training sites and organizations. Two basic components were developed: The Basics: a Diabetes and Health information module required of all participants, and the Options: four basic computer skills modules (Keyboard Basics, Computer Basics, Internet Basics, and WORD Basics) for use based on skill-levels and needs of participants. Teaching materials for use by instructors and participants are included in the curriculum.

A copy of the full curriculum is enclosed on CD, and the Diabetes and Health Information Module is also included in the Appendix (Diabetes Health.doc). Websites recommended in the Diabetes and Health Information module may become more tailored to African Americans, based on a fine collection of resources compiled by Becky Hebert of the NN/LM SE/A Region. The curriculum offers talking points for outreach presentations that can be tailored to audiences.

A PowerPoint show that provides a comprehensive view of the library program is available on the REACH web site [www.musc.edu/reach](http://www.musc.edu/reach) by clicking on REACH 2010 and scrolling down. (Appendix: SCLA Oct2005.ppt). Top priorities will continue to be to promote MedlinePlus and Hands-on-Health-SC (a Go Local site for SC). Generally, health information needs are met by MedlinePlus, and it has a growing fan club of users in Charleston and Georgetown counties because of this project. As Hands-on-Health-SC links a greater number of local resources through MedlinePlus and people learn more about their public libraries, our community will have easier access to quality health information.

**Web sites:**

A website that addresses diabetes patient concerns within a faith context is still under construction.

**Document delivery and reference services:**

As public librarians train volunteer diabetes Internet trainers and do outreach services promoting the REACH library program, they inform people about the statewide electronic full-text databases available for health information, interlibrary loan, and other reference services. The Georgetown County Library System has more library card owners as a result of the project.

### **Approaches and Interventions Used:**

#### *Partnership Development:*

The REACH staff facilitates a community-based participatory research approach (CBPR) to program planning, design, implementation, and evaluation. The program started by building a partnership from organizational contacts familiar to REACH faculty and staff. REACH community health advisors, program director, and librarian were all connected to groups and individual leaders from their ongoing work in the community. An earlier NNLM-funded Community Outreach Partnership Planning Project, which worked through a 9-member planning committee, formed the foundation of the current partnership and formalized a committee structure and operational processes. This project implements the plans of the planning committee, which expanded and became a steering committee for actions in this project. Community members are the driving force, and all partners contribute to community action plans. The 9-member steering committee for this project held joint meetings with 9 committee members from the REACH 2010 Rural Health eAccess Project to further build collaboration and experience from different perspectives.

Steering committee meetings were held October 5, 2004, November 13, 2004, January 4, 2005, February 17, 2005, May 3, 2005, July 16, 2005, November 10, 2005, and March 7, 2006. Meeting locations took place mainly in the East Cooper area of Charleston County to split the geographic distance members had to travel. Public libraries were often the meetings' locales, but other meeting sites were used based on availability and location. Attendance by these churches at Steering Committee meetings ran 100% and at several meetings other interested community members accompanied their official representatives. At the July 16, 2005 meeting held in Georgetown, several community members from an entirely different area came and inquired about getting the program in their area. In between these meetings, librarian subcommittees met to work on the curriculum and web site, and individual training sites held meetings with their designated librarian trainers and volunteers. Steering Committee members stayed connected by email and phone calls.

#### *Train-the-Trainer:*

Community leaders, their diabetes Internet trainers, REACH community health advisors, public librarians, technical experts, and the REACH 2010/MUSC health sciences librarian collaborated to design, implement, and evaluate a train-the-trainer program to spread quality diabetes and other health information resources within the

community. All members of the Steering Committee attended a “model” health information workshop held on a Saturday in a computer classroom at the Medical University of South Carolina’s Library during the third month of the project. Topics included information on the NNLM and its online resources, how to judge health information on the Internet, how librarians conduct a health reference interview, health literacy issues, and a review of key health resources available through local public libraries. A health sciences librarian from the NNLM Southeastern/Atlantic Region was a guest instructor, and several Steering Committee members also presented different topics.

This train-the-trainer program was designed to target current Internet users, who in turn would teach novices, as well as experienced users to judge the quality of health information on the Internet and use a digital collection of diabetes resources. After follow-up Steering Committee meetings, each of the two sites selected lead diabetes Internet trainers with existing computer skills and a willingness to work with the Steering Committee.

The public librarians served as the initial team of core trainers, since they developed the teaching curriculum. At least two librarians, including the REACH librarian, were matched geographically with the lead diabetes Internet trainers at each of the sites and trained them to use the curriculum. Depending on the skill level of the site trainers, the librarians would co-teach and provide backup teaching services. The librarians also got involved in each community’s outreach activities. A good deal of co-teaching and collaboration took place at the Greater St. Peter’s Church. The Nazareth A.M.E. Church relied on a skilled church member to teach their members as well as train six other persons from 4 neighboring churches of different denominations. Each church received initial training from the librarians. Greater St. Peter’s did more co-teaching with librarians, probably because of the suburban locale and close proximity. Now, trained and knowledgeable community members teach other community members including their own church’s leaders, neighbors, friends, and family.

#### *Teaching Curriculum Development:*

The Steering Committee charged the librarians on the committee with developing the curriculum. The Charleston County public librarians took the lead and met as a subcommittee to consider instructional methods and content. The Johns Island Regional Library’s manager chaired the 5-librarian subcommittee, and involved another librarian on her staff who had expertise developed in the Technology Learning Center (TLC) at CCPL’s Main Library. The group concentrated on building basic computer skills to address digital divide issues.

After reviewing the computer skills modules, a 3-member subcommittee including the REACH health sciences librarian created the Diabetes and Health Information module. Emphasis was placed on building computer skills, and the original order of module presentation was designed to step participants through the computer basics to the diabetes/health module. Based on project goals and objectives, the order of presentation changed to require teaching the diabetes/health module first to be followed

by whichever computer skills module was needed by participants. Much discussion happened prior to this agreement. The public librarians' initial focus was on helping people build computer skills, since they felt people could not use Internet resources without knowing how to use computers. The health sciences librarian's approach was on fast-tracking health information services by the teaching only minimal computer skills, such as pointing, clicking, scrolling, and basic web browser navigation. She suggested that many Web-based multimedia resources require users to have a minimal skill-level in order to use them, and if people got part way through the computer training, they may not reach the health information training. Actual implementation often meant combining the two approaches with teaching basic computer skills using health information resources. Sometimes participants' limited mobility or interest did not permit use of the complete curriculum. The Interactive Tutorials on MedlinePlus proved to be popular resources, and often demonstrations to groups were deemed more appropriate than hands-on instruction.

After the librarian subcommittees completed their curriculum work, the curriculum was formally presented to the Steering Committee at its May 3, 2005 meeting. Steering Committee representatives from all sites voted to accept and implement the curriculum. Site representatives received copies of the curriculum in both print and CD-ROM for use at their sites, and duplication was encouraged to spread training beyond the designated sites. For this project, librarians were assigned to each church as lead trainers of the community volunteer trainers, who were identified by their faith leaders. Over the next couple of months, the librarians and volunteers became familiar with the training curriculum materials and worked collaboratively at site locales. Some volunteer trainers had better computer skills than others, so the church sites developed their training programs according to their own pace and based on their community's needs. Each church established its own schedule of classes and activities to best fit the needs of their area's participants.

*Web site Development:*

Both pastors are particularly mindful of the need for quality health information and commit resources and their congregations to helping people with diabetes. Pastor Grant tells of how several members of his congregation on different occasions "fell out" suffering hypoglycemia while at church and wound up in the emergency room. He, as pastor, and other church leaders including RNs and physicians, were ill-equipped to assist without basic supplies available at the church (e.g., glucometer, blood pressure cuff, orange juice, etc.). Similar episodes happen with regularity in other African American churches. For Pastor Grant, these experiences served as 'wakeup calls' for readying church homes to better help their members with diabetes. His aim to help other pastors and churches avoid similar episodes through planned prevention is what this library initiative has taken on as a cause for action—information for better diabetes care and self-management addressed through a fundamental social and cultural institution--the church. Reverend Michael Frost tells the story of his mother-in-law and how she almost lost a leg to diabetes. He and his family have given permission to write, tell, and share her story

with others, so that people will understand that it is best to be active participants in their own and their family's health care decisions.

Greater St. Peter's Church is taking the lead on the web site construction. Its pastor, 2 church members, a public librarian, and the REACH librarian form a small working subcommittee constructing the web site. A web master, who works primarily with non-profits was recommended by the public librarian, and is the project's web master. The web master has secured a domain name and is constructing the site as subcommittee members provide content. The site still requires major work and organization of its content. Building a good web site is time-consuming project in itself, and work will resume after this report is written. When all initial content is complete, the web master will work with a church member to transition responsibility for the site to the church and REACH affiliates. As a result of the transition, the church member will get new skills and will be able to act as a resource to other community organizations wishing to build web sites. This is an ongoing part of this project that will not stop although NNLM funding has stopped.

**Evaluation:**

The original objectives were to hold 9 steering committee meetings, establish 2 new Internet access points, develop and implement a community based train-the-trainer program, reach a minimum of 120 community members with health information training opportunities, promote quality health information resources to about 1,000 individuals across the two counties, develop a web site for diabetes patient support, and set in place plans to sustain these efforts.

The success of the project was evaluated by:

- participation in Steering Committee meetings,
- establishment and maintenance of 2 Internet access sites,
- creation of a training curriculum,
- implementation of a training program at each site,
- total number of training activities and total number of persons reached by the program from trainers' logs and activities' attendance records,
- pre-post tests to judge the effectiveness of training,
- development of a web site for diabetes patient support and,
- focus group participation of steering committee members (trainees from Georgetown, and trainees from Charleston)—all to evaluate program impact.

Eight steering committee meetings were held with attendance at 100% for each of the two churches. At the May 3<sup>rd</sup> meeting Greater St. Peter's had 6 representatives and at the November 13<sup>th</sup> meeting, they had 4 representatives participate. From the first meeting when not all members knew each other to the last well-attended March 7, 2006 meeting the group grew together and shared information and outreach program ideas on planned activities and other forms of outreach. Now there is a real sense that people care about

each other and their organizations, and will continue working together on these important issues.

Concerning the numbers of persons and activities, this project exceeded its goal of spreading information on quality diabetes Internet resources to over 1,000 individuals; however, actual hands-on training sessions were far fewer than anticipated. Training sessions didn't start until October 2005, because of the delay in getting technical support established for this project, which delayed the installation of Internet workstations, which in turn delayed construction of the curriculum and implementation of training activities. As a result this project was set back about 5 months in its timeline. Please see the Problems and Barriers Encountered section of this report for a detailed explanation of technical support issues.

Trainers kept logs and journals of their sessions, but did not always report results back to the principal investigator. There was an understanding from the beginning and throughout the project that if it wasn't written down and documented, it didn't happen. The challenge of getting operational buy-in of documentation for evaluation exists, especially in community-based projects. Part of our challenge is to educate community members about the research process, so we must find ways to assist community members with documentation. In hindsight, we should have had a subcommittee create a form for trainers to document their activities. We relied on general guidelines without posing enough structure.

Pre-post tests were to evaluate the effectiveness of the training and measure the following:

- At least 50% of community members trained by community trainers will be able to identify MedlinePlus and one other quality electronic diabetes resource of preference from the suite of recommended resources
- At least 30% will rate one recommended electronic diabetes resource as a product to recommend to another community member

We found the pre-post tests difficult to implement within the community (Appendix: Evaluate.doc). Although we are not completely certain of the reasons why, we can suggest possible ones. The pre-post test was introduced after the training got underway, and trainers could not introduce it until new trainees started the classes. When new trainees started, trainers may have forgotten about using it. Also, there seemed to be reluctance to "test" participants' knowledge of the resources, since community members did not want to scare participants away from training. In addition, the instrument was developed solely by the principal investigator and then reviewed by the REACH evaluator/epidemiologist, but was not pilot tested within the community. We plan to revisit this evaluation tool to better understand its failure to work. Literacy issues are always a concern when working with our REACH population, so pilot testing and engaging the trainers in the process of the pre-post test development may provide some answers to developing an effective tool.

Focus Group Participation Results:

Participants from this project joined participants from the REACH 2010 Rural Health eAccess Project in focus groups held during March 2006: one in Charleston for 13 Steering Committee members and one in Charleston for 6 program participants/trainees who attended the hands-on training.

One finding from the trainee/participants in Charleston and Georgetown was that that people wanted to have longer sessions and access to more computers. Most sessions only lasted an hour or 1.5 hours, and people expressed a desire for more time to practice. Also, a general concern was the need for handouts. Although MedlinePlus bookmarks and other materials were distributed, simplified “how to” tip-sheets for basic steps on accessing resources were requested. Time and again people would claim “senior moments” prevented them from remembering what to do the next time they attended the hands-on sessions. The majority enjoyed learning new skills and particularly liked looking up their medications on MedlinePlus. Several participants passed the information to family members either through printouts or email.

Below are representative comments from the participant groups:

“I got into the class to learn how to do the computer. Once I got into the program, I log on to Medline[Plus] and I found the subject that was presenting to me which was high blood pressure and hypertension. I got all the information through that. I printed from that information, so I could study on it. All information covered me, because I take pills and pressure pills and stuff.”

“I am trying to get my brother now to come. He really needs, because he lives alone. He does not get too much information. I really am pulling on him to come, because he will be so amazed with the information that he gets. He accepts what the doctors say and don’t question. I say that is not good. You need to know. You need to understand. I am working on him.”

“For me, I have family members who are diabetics, cancer, and I have hypertension myself and glaucoma so Medline[Plus] was very informative. It gave a lot of information especially with glaucoma. I was able to print out a whole section on glaucoma and stuff like that. It was very good information. Because diabetes is in my family, I am interested in the information in there too. Since you know that it is there, you need to know the signs. The church also has medical information that you do once a month and I make sure that I go and I have my pressure and my sugar checked. That was very good. It is all connected so I think it was a very good service. “

Below are representative comments from the steering committee group:

“Whenever I go to the doctor now, and they give me a prescription. I get right on MedlinePlus and look up that prescription in detail so I can find out about side effects that the doctors did not even mention to me. It is more thorough and more detailed. Even when they give some type of diagnoses with me, my children or anyone in my family, I go right to MedlinePlus to see what this is and how it is going to affect me. From a personal stand point again, I have a grandmother who is a diabetic. She has taken about 3 or 4 different types of medicines. Every time the doctors switch one, I say let me see how this is going to counteract with some of the other medicines. Now I am more secure about stuff the doctor gives me, because now it is information there. If she or he does not tell me what I need to know, I can always pull it up and go back and say, “Hey this is what I see on Medline Plus and this is what it saying.”

“I think as a librarian, I use it [MedlinePlus] more with my patrons I come into interactions with every day whereas before I may not have. I would have gone to my resources that I have in my books on the shelves. I may have not turned to the computer and say here let’s look at MedlinePlus, let’s do what this says about your condition or whatever and guide them to that point. I am using it more in my daily interactions with my patrons.”

“I agree with what everyone has said, and personally I have found that MedlinePlus has helped me with medication that I have been on. If you take it properly, the doctor just said that take this one per day and now I find that one medicine specifically I needed to take first thing in the morning and with a lot of water and it really has helped me. I feel better. It has been helpful.”

“With me, I have never used the internet a whole lot to find health information, but when I was introduced to MedlinePlus, MedlinePlus is where I go all the time and if someone comes into the library and wants information on any type of health problem or diseases or wants to know about a procedure... I asked if you ever seen MedlinePlus? Let me show it to you. That is how I relate and that is my experience with MedlinePlus. I love it and I will take it wherever I go.”

“It [MedlinePlus] is valid, user friendly and the tutorials are excellent. It is very user friendly so people who may be afraid otherwise, they find it very helpful.”

“One of my students, she has glaucoma and her husband has hypertension and people in her family has diabetes. They were able to print the information after they watched the tutorial. They printed the information, and they took it back to family members, especially the ones with diabetes. She kind of guards them when they eat. A lot of people don’t like that, but she has it in her hand and says this is not good for you. She tells them, especially her brother who has diabetes what he needs to find out when he

goes to the doctor what his numbers are. She said that he usually says, “The doctor says that I am fine.” Well what is your sugar level, what are your high blood pressure and that kind of information? She takes it to her family members and shares it with them.”

“I think that I have learned a lot from this project. It has really broadened my horizon as well as me reaching out to others around me. That is how I rate it, A excellent, very good. Wow! I really enjoyed it. I really appreciated the opportunity to work with such a... I will call it a prestigious project to have my name associated with it and to be a part of the community. It has given me ideas about what I want to do later on in life. I want to open a center that teaches computers to the elderly. That is one thing that I am looking forward to doing. I just appreciate this opportunity.”

“It was definitely a learning experience for me. I got to meet very nice individuals in the group here, and also I got to learn more about controlling my health and my diabetes.”

“This project has far reaching effects and it is truly about that whole thing about a drop creating a ripple. We have touched some people who might not have ever been touched with literally life changing information and that is so powerful. It could have just been one article or one definition, one prescription, something, and then they said something to somebody else and it has possibly impacted hundreds, generations that will be here when we are gone because they will keep talking about it. That is awesome!”

“I have learned a lot from being on this steering committee myself. Being that I am a diabetic myself, and I have learned a lot of helpful things to keep me fairly healthy in controlling my diabetes. I want to thank the group for that. I am not a professional. I am just a volunteer in the community, but I learned a lot and spread the word with everybody who I come in contact with. It was a good experience.”

“It has been a very positive experience for me. You know sometimes I have been doing this for almost 20 years now teaching people how to use the library materials and stuff. It made me thankful because [I] realize that I am doing something that is important. Sometimes we forget that when we get bog down in the things that the world brings to us. So it renewed my spirit, and I really thank you for that opportunity.”

“From the point of library and keeping up with your community, this is the same for Charleston and Georgetown. Your library is your institution. Anytime you need us, we are available to you. It is not always you coming into our doors. We are always willing to go to your doors, like we say with this project. We have all gone and done outreach. You have heard of some of the things that we have done. We are always open and willing to come to you and you come to us, because we are a part of your community so that is where you have some more sustainability. That is important.”

**Problems and Barriers Encountered:**

*Going Down the Road Less Taken Had More Bumps But Has Made a Difference:*

*Technical Support –*

The aim of this project was to establish technical support from within the community rather than provide it from IT experts affiliated with the medical university. This approach is critical to sustainability beyond the life of this subcontract.

Establishing technical support services for the Internet computers was a challenge that brought the reality of this high-cost service up against the low line-item amount in the budget. Each site had a different Internet service need and Internet service configuration/provider. Project technical service cost-quotes varied widely and reconciling timely quotes with the service needs of each individual site required estimations and explanations of unknown detailed services for cost quotations. With a 30-day limit on the life of cost-quotations, one quote went cold by the time the third quote was received, delaying the process further. We attempted to work primarily with small minority owned businesses, since they represented the target population for this project. One company owner cringed when he was told new Internet users would be using the sites and that the sites to be serviced were over 80 miles apart across two counties. He suggested not using the Internet and instead CD products, but eventually provided a cost estimate. Getting a technical service provider seemed nearly impossible into January 2005 and delayed installation of the computers 4-5 months beyond our initial timeline. Fortunately for this project, one particular small business owner provided a low-cost quote based on the fact that he had an affinity for helping people with diabetes, since diabetes had affected his family. As it turned out, the actual subcontractor who provided the technical support had opportunities to get better known in the community, and he might get additional business opportunities with other organizations as a result. What started out as a time-consuming very cumbersome administrative problem resulted in reliable community-based services that provide sustainable support through relationships lasting beyond the life of this project's funded timeline.

Both sites were established and maintained with minimal problems. Minor issues reported to the technician generally required only telephone or email troubleshooting assistance. The quality of the products used, the friendliness of the site managers and staff, and the general setup of each of the sites provided a pleasant environment for the work that needed to be accomplished. One recommendation for future project planning is to consult technical partners at the earliest possible point during the planning phase, to avoid unnecessary delays or conflicts of actual versus assumed technology capabilities of project sites.

*Telecommunications:*

A lesson learned is that there continues to be limited Internet service provider options in some rural areas. Nazareth A.M.E. Church had to rely on dial-up service, even though DSL service was available less than 1-mile away.

*Exceptional Partners Make Exceptional Outcomes*

When working within the community, personal relationships impact project plans and progress. Programs built on partnerships among professionals and community organizations' dedicated leaders will sustain positive results and influence community development. These faith leaders and their designated representatives are exemplary partners. They are true community leaders who very much include the health of their communities in their organizations' work without interference from doctrine or creed. When presented with the challenge of going outside their denominational community, both embraced the idea and made it work. These faith leaders and the librarians who live and work within the community are stakeholders and champions of health information outreach and remain supportive of this project's goals and objectives.

*Never Let the Other Fellow Set the Agenda.* (quote from James Baker, former U.S. secretary of state). *Flip the Curriculum and Set the Agenda.*

All partners came to the project with different expectations and organizational agendas, yet they folded the project's purpose into their programs and moved the entire process along. An open and honest dialogue among partners brought different approaches to the steering committee's work. These faith organizations embraced teaching about quality health information as the program's primary purpose, while some affiliated secular organizations on the Steering Committee just wanted to use health information to teach computer skills.

In developing the teaching curriculum, the librarians had lots of discussion about what should come first, teaching people computer skills or health information resources. The public librarians, who have assumed the responsibility of teaching computer skills set the curriculum to address basic computer skills first and then health information skills last. The REACH health sciences librarian, understanding that health information might not happen for some participants flipped the curriculum to have health information resources be taught or demonstrated first as the "required" Basics and then computer skills as the Options. The order might have seemed backwards to some trainers, but the outcome is that MedlinePlus is now a community resource, whereas this project might have produced only more email users. In the end, it succeeded in doing both. Trainers use health information resources while teaching computer skills, as well as the opposite. The public librarians associated with this program understood their responsibility as subcontractors and trained people based on this objective.

**Continuation Plans:**

This project is organic and was designed to be self-sustaining. From the beginning, community members were engaged in shared responsibilities with the

understanding that all participants would take credit for its success or failure. Through written sub-contractual agreements, community organizations took ownership of the program and agreed to help design, implement, and evaluate the program. The organizations agreed to participate in Steering Committee Meetings over 18 months, recruit program coordinators, co-design an Internet training program, motivate and recruit community members to participate in the training, collaborate with other community groups to learn about quality health information resources, build a web site, and work in collaboration on all aspects of the program. As a CBPR program, decision-making was shared and drove all processes. Ownership of the program was a built-in process.

The program will be sustained on a less formal basis, because organizations' inter-relationships and connections are now stronger. However, expansion not maintenance is our intent. Because of the NCLIS 2006 Health Award for Libraries grand prize of \$20,000.00 and its publicity, the program can reach into other geographic areas that requested the program and partner with other interested entities.

Greater St. Peter's Church plans to continue the program by using volunteers as trainers. The group is also planning to engage young people with family members with health issues, so they can learn how to find quality health information on the Internet on behalf of their relatives.

The Nazareth AME Church plans to continue its program through collaboration with the church's Health Ministry and its Library. The majority of the diabetes Internet instructors agreed to continue to volunteer their services and work in the churches along with their health ministry. The Church is going to make the Internet computer available twice a week, instead of once a week. The lead diabetes Internet trainer has also agreed to be available on an emergency basis, since Nazareth has a partner with another church in the area, who will continue the training classes.

**Impact:**

*Change Agents Change Communities and Communities Change the Change Agents:*

*Change in librarians and libraries:*

There are a greater number of public library card owners as a result of this project. At one community event, the library gained over 20 new library cardholders and thanked the librarian for taking time to participate and explain library services and resources. A public librarian has suggested that there has been increased use of new diabetes resources. Currently, this suggestion is undocumented. However, the REACH library program has baseline data on the number of print and video diabetes resources available prior to this project and several "snapshot" measurements of circulation on the two library systems' collections. Data will be collected within the next six months to compare with this baseline data. REACH faculty plan to submit for publication these results in the journal literature within 12 months and show the program's impact.

During the focus group and at other times, public librarians working on this project said that they are now more likely to use MedlinePlus and other authoritative health related websites as reference sources when helping library users. Prior to working with this project, they relied on print and specific statewide database resources. There is also a greater comfort level on the part of the librarians to teach people about health resources. When several of them were asked by the project director to demonstrate a health information resource as part of the Health Information Workshop held in November 2004, they declined. Now they are very willing to promote health information resources and instruct individuals and groups on their use.

Health information outreach is good for librarianship. One significant outcome is that an African American public library manager, who has worked with REACH from an earlier planning project through this project, is now enrolled in library school and has a strong interest in public health. Although the REACH library program cannot take full credit for this interest in health sciences librarianship, the library manager has indicated that the informal mentoring by this project's director has influenced her career path. One 20+ year public librarian veteran expressed how participation in this project provided renewed professional energy and reaffirmation in the value of their service. This project director, a veteran of 21 years in health sciences librarianship with a total of 34 years in academic, public, school and medical libraries (11 of the last dedicated to outreach within the African American community) has learned many lessons from working with public library colleagues and community leaders. This outreach project, which is community driven, feels very different than the university driven outreach of 11 years ago. The lessons of shared success have lasting impact.

*Change in perspective of community about libraries:*

Comments collected during the planning project for this program indicated that many middle aged and older African Americans with limited formal education felt that libraries were for young people and have little relevance to their own well-being. They did not realize the general value of libraries to communities, and were unaware of the information technology resources libraries offer or the high service orientation and skill level of librarians. As a result of this project and the overall REACH library program, community leaders and volunteers have an increased appreciation of library involvement in the communities they serve. Relationships between librarians and community organizations that were either non-existent or limited in scope were transformed into a working and growing partnership.

**Recommendations for Improvement:**

A suggestion that the project director has heard several times is that there is a need for simple, step-by-step instructional handouts. Participants in the hands-on training sessions from a couple of sites expressed this need in order to retain and continue learning. The curriculum materials that were distributed had some handout materials that were meant for participants, but either the materials were not utilized by the trainers or

were not appropriate for the trainees. This suggestion will be addressed as we continue our work. Trainees also wanted longer than 1-1.5 hour sessions. Each site determined its own schedule and format for training, so it will be up to the particular sites as to how to resolve this issue with support from the librarians.

**Responses to follow-up questions (attached):**

**FOLLOW-UP QUESTIONS**

**1. Were your original goals and objectives met? If not, why not?**

All goals and objectives were met or exceeded except completion of the web site. This program's reach did suffer from the delay in establishing technical support. Both church sites performed beyond their targeted goals, and emerged as solid partners for future collaboration.

**2. What significant lessons were learned which would be of interest or use to others conducting outreach projects? Which strategies were the most effective in implementing the project?**

Significant lessons learned are scattered throughout this report. The best strategy for implementation of this program is to build strong relationships among partnering organizations. Personal relationships within these organizations are the foundations of the institutional relationships. Honest and open communication is crucial to all working relationships that have lasting value. Communication takes time and commitment by all partners. Listening to one another and providing equal opportunities for all to make decisions and take actions is fundamental to building trust. The project must operate with the understanding that accountability matters, and that all will share in failed or successful outcomes.

The great general apprehension about working with faith organizations is the question of the separation of church and state. These issues were never of real concern, because of the clear directive and emphasis on non-denominational outreach. In fact, the personal integrity of faith leaders and the forthrightness in their organizations are the foundation of a strong partnership. They have proven to be more reliable than some secular community organizations founded on personal and political agendas. This experience with faith leaders encourages further collaboration.

**3. If you were to start all over again, what, if anything, would you change about your goals, project plans, etc.?**

Initially, the project proposal did not include any travel/mileage support for project staff, which placed an undue burden on personnel assisting community organizations in rural areas. This oversight required a re-budget request and follow-up

communications, which should have been done earlier in the administrative process. However, with all the other administrative duties, it is difficult to see how it could have happened any earlier. This project carried a large administrative load with responsibility for all of its aspects. A great emphasis was placed on submitting a proposal with the maximum amount of funding going to community groups, which resulted in a shortage of resources for project staff. A better balance of resources between all partners needs to be established from the start.

**4. What advice or recommendations would you give to anyone considering a similar outreach effort?**

Select partners carefully. Expect the unexpected. Communication must be open and honest, and is the most important factor, which determines what happens. Listening and sharing control is just as important as talking and directing the process.

Allow time to engage all partners in all aspects of the program. Eighteen months is not enough time to build good working relationships, so plan to do a “series of projects” in building a program to determine what partners have the commitment and staying power for positive outcomes. As each project ends, the lessons learned will help build better processes, stronger partnerships, and greater successes. Funding agencies and funded organizations must not think only in “project” terms but in “program” terms. Library outreach efforts take time to develop an experiential track record and knowledge base for community driven solutions.

Appendix (All files are included with mailed print and electronic CD copies; emailed files exclude PPT files)

REACH Faith Q7 Rep.doc

Internet report NAZ.doc

REACH GSP Report May 2006.doc

SCLA Oct2005.ppt

Diabetes Health.doc

NCLISCarlson2006.ppt

HealthAwardsWinner2006-07.pdf

Evaluate.doc

Curriculum on CD

Figure 1. Community Partners in REACH 2010 CGDC

