BUILDING RELATIONSHIPS BETWEEN A FREE CLINIC AND ITS DONORS

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This thesis presents qualitative research conducted in summer 2017 at the Finger Lakes Free Clinic, which provides free medical and holistic care to people without insurance in upstate New York. The primary goal of this research was to strengthen the relationship between a free clinic and its donors by gathering donor concerns and perceptions regarding federal healthcare policy. Data from 32 interviews with donors, staff, board members, and volunteers, along with 100 hours of participant observation revealed that donors to this clinic were concerned about the potential impact of Congressional healthcare reform yet did not consider federal policy a strong influence on their donations. Rather, donors cited dedication to local giving and personal connections with the clinic as their primary motivations. These motivations suggest the value of viewing the clinic-donor relationship as a relationship of reciprocity. From this framework, the research identifies opportunities for the clinic to reciprocate donor generosity while expanding services in response to a growing need. Insights from the research will guide the clinic's response to federal policy changes and support the clinic's vision of becoming a national model for integrative care.

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CHAPTER 1

INTRODUCTION

When then-President Barack Obama signed the Affordable Care Act into law in 2010, the public health community was quick to estimate potential positive effects for healthcare access, quality, and efficiency. Although implementation would require a realignment of the entire healthcare system, the outcome would ultimately benefit the public.

While making substantial progress in expanding coverage to millions of previously uninsured Americans, the Affordable Care Act has not ushered in the era of market stability and seamless coverage that some had envisioned. Before the law was implemented, there were estimates suggesting 25 million people would remain uninsured (Rosenbaum 2011). Conservative efforts to undermine the law have since shortened enrollment windows and repealed the individual mandate, a necessary pillar of the law's stability. At the other end of the political spectrum, new healthcare reform has been considered, notably a Medicare-for-all proposal that would drastically change the health insurance landscape. The future of American healthcare may be nebulous, but the tasks at hand for healthcare providers and paraprofessionals cannot wait. In times of transition and uncertainty, community supports are more important than ever.

The primary goal of this research is to strengthen the relationship between a free clinic and its donors by gathering donor concerns and perceptions regarding federal healthcare policy. Free clinics for the uninsured comprise part of the "healthcare safety net" that catches populations underserved by larger institutions. Other safety net providers might include local health departments, school clinics, public hospitals, and community health centers. These providers are committed to providing care regardless of a person's ability to pay; government

subsidies offset costs for some of these providers, but not all (Chokshi, Chang, and Wilson 2012). Though a valuable component of healthcare infrastructure, this safety net demonstrates variable quality and is far from comprehensive. Uninsured patients who rely on safety-net-type healthcare within the existing system report delays due to cost, lack of access to medication, discrimination, and alienation (Becker 2004). This experience reveals the presence of a de facto two-tiered healthcare system in which people with insurance are treated significantly better and receive higher quality care than the uninsured at major hospitals and private practices. The two-tiered system contributes to health disparities between insured and uninsured people. The resulting poor health among the uninsured increases stress on the local healthcare infrastructure, which must absorb any uncompensated costs for care that exceed government subsidies. The existence and mission of free clinics oriented solely toward the needs of the uninsured helps to mitigate these effects at both the individual and community levels.

In summer 2017, Congress debated a series of healthcare bills meant to "repeal and replace" the Affordable Care Act of 2010. Each twist and turn in the events that unfolded became a national headline, and many worried that what they saw as substantial gains in coverage and healthcare access would be lost. This was especially true in New York, which had chosen to expand Medicaid under the ACA and risked losing that funding.

It was in this climate that I approached the Finger Lakes Free Clinic (FFC),[1] offering to help them navigate this uncertain time by gathering ideas and perspectives from their donors and volunteers. The clinic wanted to know if donors' anxiety about healthcare policy at the federal level would have financial effects on the clinic. Beyond that, how would donors feel about the

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[1] Pseudonym.

clinic taking a political stand? What kinds of messages and information were the donors looking for the clinic to provide?

The research project developed from a series of meetings between the Executive Director, my site supervisor (also a board member), and the volunteer coordinator at the time. These three key figures facilitated my access to the clinic while communicating clearly to me what they wanted to gain from the research. I presented them with three possible projects, and they chose the one they were most interested in: investigating donors' feelings about federal policy. I conducted 100 hours of participant observation, 32 interviews, and attended 7 board and committee meetings from May to August 2017. The products of the research ("deliverables") that we agreed I would provide included a full report of findings and recommendations for internal use, an external report of findings relevant to donors and volunteers, and an informal report to the clinic operations committee with my observations of the day-to-day workflow.

In Chapter 2, I describe the research site and its major programs. FFC began as a grassroots collaboration and remains central to the surrounding community. In Chapter 3, I review components of the Affordable Care Act, then explain the sequence of repeal attempts that occurred during the summer of 2017. These policy proposals overlapped with the research period such that participants could communicate their reactions to me in real time. Chapter 4, the literature review, takes literally the phrase "charitable giving" to mean that donations can be understood as gifts in the anthropological sense, building donors' relationship with the clinic through reciprocity (Mauss 1925/2002). In this framework, reciprocity describes the exchange of resources, knowledge, and power so that a relationship can be established and maintained (Sahlins 1972, Gregory 1982, Carrier 1991). These key concepts—gifts and reciprocal relationships—guided the research design, prompting a focus on actions the clinic could take to

symbolically reciprocate donors' monetary gifts. In this chapter, I also present the foundational

public health concept of social determinants of health: the aspects of life that influence health

beyond direct medical care. Social determinants are especially important in the case of FFC

because the clinic serves a vulnerable population of people without health insurance. Finally, I

present background literature on FFC's integrative care model and Chronic Care Program. The

Chronic Care Program demonstrates the potential for conventional and holistic medicine to work

together to promote health in the uninsured population. Chapter 5 describes the methodology for

this qualitative research study, along with theoretical influences from the anthropology of policy.

In Chapter 6, I present results from fieldwork grouped into sections based on themes that arose

from interviews and observations. The three major themes that led to recommendations were

donor communication, policy response, and growth. In every interview, I asked participants what

their ideal vision for the clinic would be, five years from that day. The components of the five-

year vision are also presented in this chapter. Chapter 7 begins by revisiting giving and

reciprocity in the context of FFC. I then present my design for an evaluation of the Chronic Care

Program, an essential activity to bring FFC closer to its vision of becoming a national model for

integrative care. This design incorporates principles of utilization-focused evaluation with

insights from the fieldwork to propose a comprehensive evaluation, tailored to fit the needs and

capabilities of the clinic. In Chapter 8, I address the limitations of my research and call attention

to a new method for studying policy impacts. Chapter 9 contains my personal reflection on the

value of this research experience.

CHAPTER 2

SITE

This chapter describes the mission, structure, and operations of the Finger Lakes Health Alliance (FHA) and introduces its major programs: the free clinic, the health fund, community health education, and the Chronic Care Program. The Chronic Care Program is described in the most depth because, as a public health intervention, it is the subject of a major product of the research: a proposal for evaluation (Chapter 7).

2.1   The Finger Lakes Free Clinic

The Finger Lakes Free Clinic (FFC) in upstate NY has operated as a program of the Finger Lakes Health Alliance since 2006. Staffed by volunteer practitioners, this clinic offers both conventional and complementary medicine on a walk-in basis to people without health insurance (Lynch and Davis, 2012). The interior of the building blends traditional layout of a healthcare provider's office with elements meant to put people at ease: plants, brightly painted walls, and a small play area for children (Figures 2.1 and 2.2).

Figure 2.1: Intake window with filing cabinets and plants

Figure 2.2: Play area in the waiting room with cheerful rug and books.

The Finger Lakes Free Clinic's target population is broad, as services are available to all uninsured and underinsured patients living in the region. Uninsured patients do not have any kind of health insurance; underinsured patients have some sort of insurance, but it does not cover the services they need. These patients might have high-deductible catastrophic coverage or plans that do not cover holistic treatment. The mission, goals, and objectives of the Finger Lakes Health Alliance are presented in Table 2.1. The mission in particular reflects a holistic and collaborative approach to healthcare.

Table 2.1: Mission, goal, and objectives adapted from information on the clinic website.

Mission: To empower a healthy community, cultivate humanistic collaboration, and support access to medical and holistic care
Goal: To facilitate access to healthcare for all, with a focus on the un- and underinsured
Objectives: • Provide regular walk-in clinic hours   • Support long-term health through the Chronic Care Program   • Provide emergency assistance with medical expenses through the Finger Lakes Health Fund   • Educate about healthcare access—insurance, integrative medicine, policy, available community resources

2.1.1 Personnel

FFC has undergone staff turnover and restructuring in the past five years. In summer 2017, the clinic had five paid staff members:

1. Executive Director, who focuses on grant writing, development, and public outreach

2. Clinic Coordinator, who oversees the clinic's day-to-day operations and manages advanced cases, e.g. clients presenting a combination of medical and social needs or needing a referral to other community support organizations

3. Administrative Coordinator, who organizes the volunteers, maintains the website, and handles other logistics

4. Volunteer Coordinator, who recruits and schedules volunteer administrative staff and healthcare providers

5. Chronic Care Program Director, who provides case management for the Chronic Care Program

During the research period, the volunteer coordinator left, and that position was absorbed by other staff. Because there are so few staff, each operates as the authority in their own sphere. The executive director is accountable to the Board of Directors. The Board of Directors currently consists of eight directors whose purpose is to ensure the organization's financial well-being and adherence to the mission. Directors are not paid; they are expected to contribute to fundraising activities. Some directors have clinical backgrounds while others bring experience from the business or nonprofit sectors. Prospective board members are chosen through the nominating committee, one of four board committees: nominating, steering, finance, and development. Committees must include three directors and could additionally include community members and other interested volunteers. Clinic operations committee advises the board, although it is not an official board committee. As a result of past conflict between the staff and the board, the staff are represented by a union.

FFC relies on volunteers for its day-to-day operations. The FFC's biomedical and holistic

staff are all volunteers. On a walk-in clinic evening, there are two volunteer nurses and one or more volunteer doctors. Volunteer practitioners of other kinds (herbalist, chiropractic, Reiki, acupuncture) have their own schedule of appointments, but usually practice during walk-in hours as well. In addition, most of the administrative work is done by volunteers. Volunteers handle intake and scheduling, as well as inputting case notes into the database. FFC also uses volunteers for outreach events and fundraisers. FFC is funded through the following major sources:

- Foundations and community organizations: Park Foundation, United Way, Community Foundation of Tompkins County, Legacy Foundation of Tompkins County, CVS Caremark

- Tompkins County

- Local business sponsorships

- Individual donors

2.1.2 Community Support

FFC began as a grassroots organization and retains strong ties to the surrounding community of Ithaca, NY. Among the people it serves, the clinic has an extremely good reputation. Ithaca is predominantly socially liberal, so the community supports the mission of the organization to advance healthcare for all. Recently, the clinic has struggled to find the personnel to conduct outreach activities. As a result, their profile in the community is less than it was; the board and staff continue to strategize possible improvements.

2.1.3 Overcoming Obstacles

The main obstacle the clinic faces is sustaining funding, particularly in the case of the Chronic Care Program. Chronic Care was funded as a pilot, and the clinic has had trouble finding the money to keep it going in its post-pilot state. The second large obstacle is the lack of

volunteer providers. Due to a shortage of primary care doctors and the fee-for-service model of compensation, these providers feel pressured to shrink appointment windows and serve a higher volume of patients in their regular practice. It is difficult to incentivize these already-overworked providers to then donate their time and energy after hours.

Funding for the Chronic Care Program is being addressed through targeted grant-writing.

The problem of too few providers will hopefully be solved through future collaboration with nearby Cornell University, which is in the process of implementing a new rural medicine rotation based in Ithaca. Both of these obstacles are high priorities for the Board of Directors, who are developing solutions through the development committee and clinic operations committee.

2.1.4   Integrated Care Model

As mentioned above, what makes this clinic unique among free clinics is its dedication to providing both complementary and conventional medical care. The National Center for Complementary and Integrative Health (NCCIH) categorizes complementary and alternative medicine (CAM) practices into two subgroups: Natural Products, such as herbs and vitamins, and Mind and Body Practices, such as yoga, chiropractic therapy, meditation, and acupuncture (National Center for Complementary and Integrative Health [NCCIH] 2016). Both types are available at FFC.

Social attitudes toward CAM are often skeptical, in part because physicians are reluctant to bring up the subject with their patients (Dew et al. 2008). These ambivalent social attitudes may not, however, translate to non-use. A study of college students at Columbia University suggests that despite overall attitudes toward CAM being slightly negative, over 77% of

respondents agreed that it is good to have different types of therapies available, and nearly 82% of respondents reported using CAM in the last year (Versnik Nowak et al. 2015). In a different study, college students with a history of previous medical conditions had more positive opinions of CAM practitioners (Synovitz et al. 2006). In the United States, more than 30% of adults and about 12% of children use CAM as part of their healthcare (NCCIH 2016).

Despite widespread use, CAM still occupies a subordinate position to Western biomedicine in the United States for a variety of reasons. Some popular CAM practices have not yet scientifically demonstrated effectiveness; many CAM practitioners have no licensing requirements to ensure quality; CAM practices with roots in indigenous cultures are subject to colonial prejudices. As a result, patients may be disinclined to discuss CAM with their biomedical healthcare providers, who may neglect to bring up the topic or come across as judgmental (Shelley et al. 2009). Many patients choose instead to navigate both systems in parallel, demonstrating active engagement in their healthcare yet risking harm from unintended drug interactions or under-researched treatments (Ge et al. 2013, Adler et al. 2009). In physician communities, there has been increasing focus on conversing effectively with patients about CAM with the goal of reducing potential harm and maximizing potential benefit (Blackman 2007, Shelley et al. 2009). The National Center for Complementary and Integrative Health has attempted to bridge some of the ideological distance by promoting the idea of "Complementary" and "Integrative" medicine over that of "Alternative" (NCCIH 2016).

These efforts seem to be effective, as complementary practices have been increasingly used alongside conventional medicine in systems of integrated healthcare. Integrated medicine[2]

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[2] This paper uses the term integrated (or integrative) medicine to refer specifically to the combination of biomedical and CAM practice. This phrase has also been used to describe holistic, patient-centered approaches to care, regardless of whether CAM use is involved; the underlying philosophy is the same in both cases.

can involve collaboration not only between CAM and conventional biomedicine, but with psychological therapies as well, where the addition of CAM enhances the holistic capacity of service (Singer and Adams 2014). Furthermore, the rising popularity of integrative medicine has coincided with an increased focus on disease prevention—thus disrupting the narrative that complementary medicine is subordinate to biomedicine and a treatment of last resort. Integrated medicine and preventive medicine have compatible principles: strengthen health and well-being in a holistic sense, educate patients to make informed choices, and—most relevantly—offer the patients a wide variety of options. Integrated medicine could be employed effectively at all levels of prevention: Primary (preventing new problems), Secondary (screening for problems), and Tertiary (management of a problem) (Ali and Katz 2015). Populations with financial or cultural barriers to accessing healthcare have fewer options, which decreases individual agency and contributes to population-level health disparities. To increase underserved populations' options for care, integrated medicine must be built into the existing systems that target these populations (Berz et al. 2015).

At FFC, integrated medicine is most visible in the Chronic Care Program, a long-term case management program for people with chronic conditions (described below). Integrated care is facilitated by consultation and referrals between providers of different modalities. For example, a walk-in patient who sees the doctor for stress-induced gastrointestinal distress might receive conventional consultation followed by a referral to the herbalist. This model disrupts the conventional supremacy of Western biomedicine over other modalities in the United States, so its success depends on ongoing communication and mutual respect between biomedical and holistic practitioners.

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2.2   Addressing Immediate Needs: The Walk-in Clinic

The FHA operates a walk-in clinic (the Finger Lakes Free Clinic) two evenings per week, depending on provider availability. People are seen on a first-come first-served basis, regardless of whether they are a new or returning patient. Typically, there are one or two primary care providers (doctor, nurse practitioner, or physician's assistant) supported by two nurses. As in a regular doctor's office, nurses do a preliminary screen before patients are seen by the primary care provider. When they first arrive, patients sign in and, if new, receive intake paperwork to fill out. Intake forms include basic demographic information, optional information on race and ethnicity, and a scan of a photo ID. Patients are verbally asked to confirm their uninsured status. Due to high volume and limited staff, patients may sign in several hours before they are seen. Providers must balance the high volume of patients with the opportunity to take more time in consultations than they could in their regular practice. The clinic coordinator monitors the list and closes the doors when there are enough patients to fill up the clinic hours for that evening.

The attitude of the waiting room alternates between hectic and bored, usually depending whether there are children present. A play area in the corner offers a box of toys and a donated Bright Red Bookshelf from the Family Reading Partnership. Clinic policies and patients' rights are posted prominently on the wall, alongside awards, flyers, and a dry-erase board listing that day's staff. The walls are brightly colored and there is a plant hanging in the window. The front table has literature on a variety of health topics: HIV, healthy eating, alcohol recovery, sex education for the elderly. One week, there appears a squadron of tiny rubber ducks in scrubs: "Take one for free" (Figure 2.3).

Figure 2.3: Literature table with ducks.

Patients bring family members and caregivers; people talk on the phone socially or to arrange transportation. In such a compact space, privacy is limited. Some people make small talk—regulars know the front desk volunteers—while others spend their wait staring at a phone or magazine. After all of the patients have been seen, volunteers stay even later to schedule appointments, organize paper case files, and retype provider case notes into the online database. The on-the-ground operations of the walk-in clinic represent an enormous coordinated effort; the result is a smooth and systematic—if time-intensive—experience for patients.

2.3   Addressing Financial Barriers to Care: The Finger Lakes Health Fund

For treatment and diagnostic services that the walk-in clinic does not provide, the FHA provides emergency financial assistance through the Health Fund. When the FHA first began, allied members contributed to the health fund and could request financial assistance with medical expenses from the fund. The fund was not available to non-members, i.e. those who had not contributed to the fund. The Internal Revenue Service determined this setup to be a type of

health insurance and would have required FHA to operate as an insurance provider. In response, FHA restructured the system to work more like a charitable grant. Now, the Health Fund is a pool of donations from which anyone can apply for funding based on financial and medical need.

2.4   Addressing Information Access: Community Health Education

The FHA is committed to providing free information on health conditions, preventive care, and navigating local healthcare systems. On some walk-in clinic days, a volunteer social worker is available to work one-on-one with patients who need help understanding insurance coverage and accessing services. On the clinical side, the clinic provides space for a school of herbal medicine. Patients learn herbal medicine during treatment, leading some to become practitioners. Community health education brings information to the surrounding community, not just to patients. Student presentations on herbal medicine are open to the public. FHA partners with local organizations to bring in speakers and address local health concerns. In summer 2017, the board discussed coordinating a Lyme disease informational panel to answer people's questions about prevention, scope, and chronic symptoms. There was some interest among leadership to expand Community Health Education to include the effects of healthcare policy on the local level. Some results from this study include donors' reactions and suggestions to policy-related messaging (Chapter 6).

2.5   Addressing Chronic Disease: The Chronic Care Program

Patients in rural areas such as upstate New York face barriers to insurance coverage including cost and in-network provider availability, and often lack infrastructural and financial access to continuous care (Foutz, Artiga, and Garfield 2017, Wong and Regan 2009). Continuity

of care is especially important for treating chronic conditions such as cancer, diabetes, chronic obstructive pulmonary disease (COPD), and hypertension.

In Tompkins County, where the FFC is located, the top three causes of death are chronic diseases: cancer, heart disease, and chronic lower respiratory diseases (Tompkins County Health Department [TCHD] 2017a). Increased access to evidence-based interventions targeting chronic disease was identified as one of three community health improvement goals alongside promoting mental health and preventing substance abuse (TCHD 2017b). In adults ages 18-64, 86.5% report having some form of health insurance. This high rate can be attributed to both the college student population and the Affordable Care Act's Medicaid expansion, which decreased the rate of uninsured patients in New York State by 40% (TCHD 2017a, Kaiser Family Foundation 2017). After adjusting for the population of college students, the poverty rate in the county is 11.5% (TCHD 2017a). The majority of FFC patients make less than the median income for the county, and the clinic estimates that about half of the walk-in visitors have a chronic condition (Larsen 2017). Long-term management of chronic conditions for the rural uninsured is difficult to achieve under the free clinic model, which operates based on walk-in appointments; even if a patient visits more than once, they may not see the same provider and they may not be able to schedule regular visits. Despite the need, the clinic had no specific program for chronic care prior to 2015 (Larsen 2017).

In 2015, volunteer practitioner William Larsen, DNP, developed a pilot program for addressing chronic conditions within the FFC's patient population (Larsen 2017). The FFC Chronic Care Program (CCP) is a 6-month program that adapts the chronic care model (CCM) to integrate conventional and complementary medicine while making efficient use of FFC's existing resources.

The chronic care model (CCM) is an evidence-based system for promoting self-management and productive interactions between patients and providers with the ultimate goal of reorienting medicine toward planned care rather than reactive care (Wagner et al. 2001). The CCM was developed in 1998 at the MacColl Institute for Healthcare Innovation (Wagner 1998, McEvoy and Barnes 2007). This model provides the underlying theoretical framework for Larsen's CCP intervention. The six elements that comprise the model are the following:

1. *Health care organization*, particularly the structure, culture, and characteristics of the practice organization that impact patient care

2. *Community resources* that contribute to an environment in which a chronic care patient can thrive (e.g. peer support groups available outside the clinic)

3. *Self-Management support* that emphasizes patients' goal setting and action plans over the typical one-way transmission of education from provider to patient

4. *Delivery system design*, coordinating multiple caregivers through case management

5. *Decision support* that institutionalizes guidelines into provider behavior

6. *Clinical information system* that is regularly updated and can generate reports for patient and provider use.

CCM-based interventions have shown a consistently positive effect on patient satisfaction and mental health of individuals with a comorbid physical condition (Coleman et al. 1999, McEvoy and Barnes 2007). CCM has also been implemented successfully in a Minnesota Salvation Army Free Clinic for the uninsured (Stroebel et al. 2005). These examples are explored in more depth in Chapter 4 to inform the CCP evaluation proposal located in Chapter 7, a product of this research.

During the CCP, patients meet every month with at least one member of their care team, a group of practitioners from multiple modalities. FFC uses "modality" to refer to the different types of care that patients can choose to access, biomedical or otherwise. Chronic care patients are given priority on waiting lists for complementary therapies such as acupuncture, massage,

and herbal medicine. They also schedule appointments outside of regular walk-in clinic hours to ensure regularity and accommodate longer appointments. This structure allows for continuity of care in addition to making good use of limited clinic space (Figure 2.4).

Figure 2.4: Doctor's station in one of four exam rooms.

Outside of patient appointments, the care team meets periodically to review each case and make referrals to other modalities if needed. The creators of the program estimate that for every half-hour of direct care to the patient, the care team provides two to three hours of coordination work (Larsen 2017). In consultation with the care team, patients develop a personalized chronic disease self-management plan. Patients receive a booklet outlining their care plan in which they can record basic lifestyle factors and behaviors (e.g. sleep, pain, physical activity). Larsen and his team acknowledge that this program is not a replacement for regular primary care; built into the program are efforts to sign people up for health insurance (Larsen 2017). Insurance enrollment is an attainable path out of the program for many patients due to New York State's Medicaid expansion.

The Chronic Care Program is popular among the staff, board, and patients. Patients report

high satisfaction with the program, which operates at capacity (Larsen 2017). Although

volunteers only interact with the program sporadically, they understand and support the core

concept: "I think the Chronic Care Program that's been started in the last couple, last year or so,

is huge because there's continuity of care." This participant identifies the CCP as one of the

clinic's biggest strengths. Finding funding for the program post-pilot has been a source of

tension during board meetings. At a crucial board meeting discussing the fate of the program, an

impassioned board member brought in a printout of an article detailing the benefits of chronic

care for everyone to read. Board members with a clinical background argue for CCP's efficacy

and importance to the organization's mission, while board members from the business sector are

concerned about the program's impact on the budget; all agree that the program ideally would

continue, but the source of funding remains uncertain.

CHAPTER 3

POLITICAL CONTEXT

This section provides a brief explanation of the Affordable Care Act (ACA) and

subsequent attempts to repeal it. Healthcare reform is an enormous area for scholarship; this

summary will focus primarily on parts of the ACA that affect community healthcare and

Congressional healthcare proposals from the summer of 2017.

3.1   Unpacking the ACA

The Patient Protection and Affordable Care Act of 2010 sought to provide affordable

health insurance options to low- and middle-income people. The law's content can be grouped

roughly into three categories. First, Medicaid would be expanded so that people up to 138% of

the poverty line could apply for Medicaid. For middle-income households, subsidies would be

provided to offset the cost of premiums. Second, state governments would set up insurance

exchanges—specific websites where people could go to compare and choose an insurance plan.

Some options would be private, while other options would be government plans. All plans would

cover essential benefits, including screening and preventive healthcare, and prices could not

discriminate based on most pre-existing conditions (excluding, for example, high risk behaviors

such as smoking). This provision was popular across the board. Less popular was the third major

part of the law: the individual mandate. People must enroll in health insurance or they risk

paying a fine. This provision was generally unpopular; healthy people are not otherwise

incentivized to pay for health insurance, and some view this as a government infringement on

personal freedom. However, this part of the law is instrumental to the stability of the market. A

pool of insured consisting only of unhealthy people leads to high-cost plans, since insurance

companies would be paying a lot of money for a small number of people. A pool of insured

consisting of both healthy and unhealthy individuals spreads out the cost, lowering the price tag

for each insured person. This provision was meant to facilitate insurance companies' compliance

with the essential benefits requirement. There would be more services covered, but also more

people buying insurance.

Sources of Health Insurance Coverage in 2016 (Millions of Persons)

- Population Sum: 340* Actual: 324
  - 65+ yrs. Medicare 53
  - Under 65 yrs. Non-Institutional 272*
    - Employer-Based 155
    - Other Coverage 90
      - Medicaid & CHIP 57
      - ACA Medicaid 11
      - ACA Exchange 12
      - Other** 10
    - Uninsured 27
  - Military 15

*Note: Due to multiple sources of coverage for some individuals, there is some double-counting in the components. The actual U.S. population in December 2016 was approximately 324m.
**Other: The 10m was reduced to tie to the total for "Other Coverage" of 90m. "Other" includes 23m persons (9m non-ACA marketplaces, 9m disabled in Medicare, 5m other).

Source data:
CBO "Federal Subsidies for Health Insurance Coverage for People Under Age 65: 2016 to 2026" (March 2016)
Census Bureau "Health Insurance Coverage in the United States: 2015 (September 2016)

Figure 3.1: Health insurance coverage post-ACA. Health Insurance Coverage in the U.S. 2016 - v1 by Farcaster. Used under CC BY-SA 4.0.

Early challenges to the law resulted in a partial implementation. The individual mandate

was (until recently) upheld, exchanges were created, and subsidies were offered. However,

Medicaid expansion was left up to the states, resulting in 33 states expanding Medicaid

(including the District of Columbia) and 18 states not expanding Medicaid. This discrepancy

created a large gap in non-expansion states between the Medicaid-eligible and those who could

afford non-Medicaid plans. Many of these people remained uninsured, paying a penalty that was

less expensive than the cost of being covered. New York State did expand Medicaid, resulting in

40% decrease in uninsurance in the state (Kaiser Family Foundation 2017). In the U.S., over 22

million previously uninsured had some sort of health insurance coverage by 2016. However, uninsured people still exist—people who are not aware they qualify for Medicaid or a subsidy, or people who cannot or will not interact with institutional systems. The breakdown of coverage sources as measured in 2016 can be found in Figure 3.1, from the Congressional Budget Office. Orange boxes indicate coverage directly related to ACA Medicaid expansion and ACA-established marketplaces, totaling 23 million newly insured. The red box of 27 million remaining uninsured represents the population targeted by safety-net clinics.

In 2016, Donald Trump was elected President of the United States, in part due to his endorsement of Republican healthcare reform. Two important takeaways from the election for this discussion are:

1. Rhetoric to "repeal and replace" the ACA from the Republican side

2. Strong support for universal healthcare and a single-payer system, championed by Democratic primary candidate Senator Bernie Sanders (VT)

Although the prevailing side was anti-ACA, the introduction of the concept of universal healthcare into mainstream U.S. politics changed the dialogue about what healthcare reform could be. The impact of universal healthcare rhetoric is discussed later in this chapter.

3.2   Summer of 2017

By summer 2017, the GOP-majority Congress was actively working to "repeal and replace" the Affordable Care Act. This process overlapped with the research period such that participants were able to express their reactions to the bills as they were proposed. The timeline in Figure 3.2 shows the research period as it relates to the series of proposals.

These proposals were announced (or leaked) to great consternation and drama among liberal factions of the American public. Repeal-only bills were especially feared, as the gains in

coverage due to Medicaid expansion and subsidies would be lost—some 22 million people might

find themselves without coverage again.
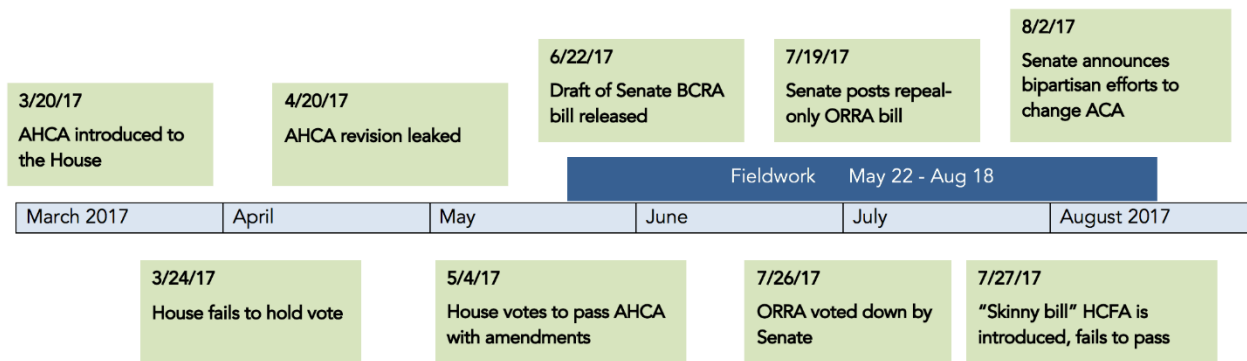
Figure 3.2: Timeline of proposed legislation relative to the research period.

The first "repeal and replace" bill, H.R. 1628 or the American Health Care Act (AHCA)

(U.S. Congress 2017), was introduced to the House in March 2017. The bill passed with

amendments in May under budget reconciliation rules, intended to smooth the bill's passage

through the Senate. This bill was to repeal the individual mandate, employer mandate, and many

of the taxes that were meant to pay for different parts of the ACA. Changes to Medicaid

expansion included work requirements for eligible enrollees and spending caps for the states. A

RAND Corporation report estimated that the AHCA in its original form would reduce insurance

coverage by 14.2 million in 2020, increasing to just under 20 million in 2026 (Eibner, Liu, and

Nowack 2017). Younger people with incomes above 200% of the Federal Poverty Line (FPL)

would see an improvement in policy prices in 2020. However, the number of people with better

rates under AHCA than ACA would decrease by 2026 as the growing cost of premiums outpaced

AHCA tax credits. Lower-income, older, and less healthy people would be disproportionately

worse off under AHCA, with uninsurance rates growing 119% for people ages 50-64, 80% for

people at or below 200% FPL, and 99% among people self-reporting poor or fair health (Eibner,

Liu, and Nowack 2017). In the words of one of the FFC's donors, "I think the President summed

it up pretty well when he called it mean-spirited…To me it's an absurd political thing, why anyone would say we have to repeal something rather than fix it, change it, make it better so that more people were getting decent coverage."

After arriving in the Senate, the bill was renamed the Better Care Reconciliation Act (BRCA). BRCA included a more aggressive timeline for ending Medicaid expansion and allowed states to opt-out of several popular parts of the ACA: allowing young people to stay on parents' insurance until age 26; essential benefits such as maternity, mental health, and prescription coverage; and prohibiting discrimination based on pre-existing conditions.[3] The Congressional Budget Office estimated that the number of uninsured people by 2020 would be 22 million more than projected under ACA (Congressional Budget Office 2017). A letter from the American Medical Association criticized BRCA as violating the spirit of the Hippocratic Oath, to "do no harm" (Abadi 2017). The BRCA did not gain enough support, and the Senate posted a repeal-only bill, Obama Repeal Reconciliation Act (ORRA), in late July. Senate Majority Leader Mitch McConnell's idea was to revive a bill that repealed ACA as promised, with a two-year delay to come up with something to replace it. The original bill passed Congress in 2015 and was vetoed by then-President Barack Obama. The ORRA was voted down just over a week later.

The final attempt in summer 2017 was the Health Care Freedom Act (HCFA), known as the "skinny bill" for addressing only the parts of the ACA that Republicans found most objectionable. The bill most notably removed the individual and employer mandates, cut federal funding to abortion providers for a year, allowed state waivers for a variety of ACA regulations,

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[3] For an excellent infographic comparing the ACA, AHCA, BRCA, and repeal-only Senate bill, see Gisele Grayson, Alyson Hurt, and Alison Kodjak of NPR's article from June 22, 2017, "CHART: Who Wins, Who Loses With Senate Health Care Bill."

and cut a fund designated for the CDC. HCFA did not pass, as Sen. John McCain (AZ) cast the decisive vote with a dramatic thumbs-down on July 27, 2017.

This entire process took place in the span of four months. After the summer, there was one final gasp for the Republican "repeal and replace" effort: the Graham-Cassidy bill, an amendment that turned federal funding for Medicaid expansion and insurance subsidies into block grants, allowing states to fund their health system of choice and opt out of ACA regulations. This amendment gained some press but never made it to a vote.

3.3   Future Possibilities

During the research period, it was striking how many participants brought up universal healthcare or single-payer as the ideal system. The connection of the popularity of this idea to the local culture is discussed in the results section (Chapter 6). Several participants spoke about single payer and universal healthcare as if they were the same idea: government-run healthcare. However, there is a meaningful distinction between the two. Universal healthcare is the principle that all people have insurance coverage, regardless of who is providing it. In single payer, the one insurance provider is the government, who, as the payer, can negotiate prices and quality controls.

These ideas were considered radical until they entered mainstream dialogue during the 2016 election. This was largely due to the charismatic leadership of Sen. Bernie Sanders (VT) who gained immense popular support despite losing the Democratic primary. Since then, conversations about universal healthcare have become more common; Medicare-for-all is a viable Democratic platform in the 2018 midterms and has already made some headway in primary elections (Newkirk 2017, Pew Research Center 2018, Jackson 2018 re: Alexandria

Ocasio-Cortez's primary win). Support for universal and single-payer healthcare has emerged within the American Medical Association. The AMA medical student caucus successfully pressured senior leadership to reconsider their traditional opposition, citing access to health insurance as a social determinant of health (Luthra 2018). In July 2018, Democrats in the House of Representatives launched a "Medicare for All" caucus of over 60 members (Weixel 2018). As of September 2018, Pew Research Center reports that 60% of Americans view healthcare coverage as a government responsibility. Of these, more support a single insurance system over a private-public combination (Kiley 2018). Policy historians have suggested that the ACA was the largest reform of the healthcare system since the creation of Medicare and Medicaid in 1965; perhaps a move toward a universal coverage system would be the next.

CHAPTER 4

LITERATURE REVIEW

4.1   Donations as Gifts

Charitable giving puts on display the complex interactions among personal values, social power, and interpersonal expectations. A nonprofit that understands and skillfully navigates these interactions can benefit from fruitful relationships with their donor base. This section will examine philanthropic donations through the lens of anthropological scholarship on gifts, illuminating unspoken influences on donor behavior.

In *The Gift* (1925/2002), Marcel Mauss develops the anthropological notion of the gift by analyzing pre-modern systems of gift-giving that contrast with the modern transactional economy. In Polynesia, Melanesia, and the American Northwest, Mauss identifies systems of gift-giving in which gifts carry moral obligations and have serious implications for the relationship of giver and receiver. Power relationships are defined, maintained, or subverted as the individuals involved are pressured to give, receive, and reciprocate. These relationships then affect all aspects of social life. In Mauss's example from the American Northwest, leaders hold extravagant feasts called potlatches, showering rival guests with gifts and destroying goods to assert dominance of wealth. The rival guest then must hold a larger potlatch of his own, giving to the first host in greater measure and destroying even more goods. Within the framework of this cultural logic, this competitive relationship is difficult to break once the expectation of exchange has begun. Mauss calls this obligation the spirit of the gift—the Maori term is *hau*—which creates social obligations for the giver and recipient (Mauss 1925/2002, 15). When the gift passes from giver to recipient, the spirit of the gift now has a hold on the recipient, beginning a relationship of indebtedness.

Post-structural French philosopher Jacques Derrida rejects Mauss's use of the word "gift" to describe these mutually-entangling relationships in the first installment of his lecture series on gifts, *Given Time: I. Counterfeit Money* (1992). Derrida asserts that gifts should be transformative, breaking the cycle of reciprocity, and any reciprocation, exchange, or counter-gift "annuls" the gift (Derrida 1992, 12). When giving a pure gift, the giver severs their relationship with the gift and the receiver by relinquishing any claim to how the gift is used. Derrida argues that binding a gift to any sort of obligation turns it into a kind of distributive justice, governed by laws (Derrida 1992, 138). A cross-cultural example of Derrida's view of gift-giving can be found in New Delhi, where philanthropists give *dān*—a "disinterested gift, a gift without expectation of return"—as a religious act, uncompensated by tax benefits (Bornstein 2009, 624). Derrida's definition of a gift does not describe philanthropic practices in the United States, where donors care very much how their donations are used and highly publicized fraud cases affect the reputation of the whole nonprofit sector (Greenlee et al. 2007, Gibelman and Gelman 2004). The pure altruism of the *dān* might parallel an anonymous donation, for which the donor intentionally gives up any social recognition associated with giving. However, in most cases, when attaching a name to the gift, donors intentionally enter into a relationship with the recipient organization. The use of donations to wield power is discussed later in this section; at present, this discussion returns to the use of gifts to establish relationships.

Similar to Mauss, Christopher A. Gregory equates the gift economy with a debt economy, with the important distinction that participants are more concerned with the personal relationships than the material gifts themselves. Gregory (1982) places gifts opposite commodities on a spectrum spanning the diversity of transactional relationships. Commodity exchange includes buying, selling, and bartering, in which all objects and services are first

reduced to monetary value, then are exchanged for items or money of equal value. For Gregory, the factor motivating movement toward either end of the spectrum is the degree of kinship between exchanging parties (Gregory 1982, 23). To illustrate the contrast between gift and commodity relationships, Gregory presents two diagrams: a chain of object movement that characterizes gift exchange (Figure 4.1) and a closed, singular transaction of commodity exchange (Figure 4.2).

$$A \xrightarrow{\ x\ } B \xrightarrow{\ y\ } A$$
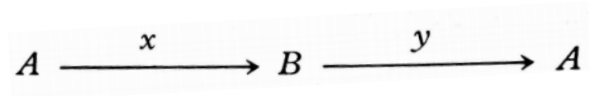
Figure 4.1: Gift exchange as a chain of object movement (Gregory 1982).

$$A \overset{x}{\underset{y}{\rightleftarrows}} B$$
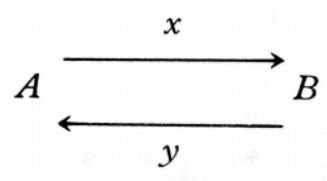
Figure 4.2: Commodity exchange as a closed transaction (Gregory 1982).

Although both transactions end with Group A in possession of Object y and Group B in possession of Object x, the fundamental understanding of the role of objects between both parties is clearly different in each case. Reciprocated gifts do not close a relationship the way reciprocated commodities do. A series of gift exchanges renews—and often redefines—a relationship, setting up an expectation for the exchange to continue. Mauss's original characterization of the gift relationship as a series of necessarily unequal transactions is now expanded to include complementary transactions between groups in a long-term relationship.[4]

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[4] Claude Levi-Strauss explored exchange between groups in his work *The Elementary Structures of Kinship* (1949), which developed theories of Restricted and Generalized Exchange to describe bride-exchange patterns around the world. Since the donor relationships examined in this project took place between individuals and the clinic (and not multiple organizations), this foundational work on exchange is acknowledged but omitted from the literature review.

James Carrier (1991) also addresses the continuum between gifts and commodities, narrowing the scope of the discussion from large kinship groups to personal relationships. As in Gregory, placement on the spectrum is determined by the degree of interpersonal entanglement. Because Mauss proposed the gift system as an evolutionary stage that has disappeared from Western society, part of Carrier's analysis is the reapplication of Mauss's model to modern transactions. Carrier identifies three primary components in Mauss's definition of the gift that differentiate gifts from commodities: first, gift transfer is obligatory; second, gifts are inalienable from the giver and receiver; and third, the giver and receiver ("transactors") form a lasting relationship and become mutually obligated to the exchange (Carrier 1991, 122). The obligation attached to gifts—the spirit of the gift, the *hau*—is an extension of an expectation, within relationships, that mutually beneficial patterns of behavior will continue. This expectation provides the foundation for the chain of gifts in Gregory (1982). Because obligation is created by the first debt, Carrier considers the opening gift of a relationship as the most voluntary; the relationship is not yet defined, but has just been created (Carrier 1991, 123).

The gift exchange model inextricably links the gift to the identity of the giver and receiver. This Mauss refers to as the "inalienable" nature of the gift (Carrier 1991, 122). Contributing to transactors' identity are social factors including rank, wealth, and kinship, all of which inevitably translate to power. Michel Foucault (1980) introduces power as a relation of force, rather than of economy or society, with two possible interpretations: power as repression, and power as war. The promotion of a just and peaceful society, then, must arise from the strategic control of power. Marshall Sahlins (1972) asserts that control of power, especially in the political realm, happens through exchange. When considering philanthropic gift-giving, the effects of force, as well as the capacity to wield force through gifts, must be acknowledged. The

acceptance or rejection of the gift is discussed extensively by William I. Miller (1995), who suggests that reciprocity or lack thereof reflects not only the desirability of the relationship to each transactor, but also the power dynamic between them. Through the acceptance, rejection, or reciprocity of a gift, transactors can attempt to influence the balance of social power. Returning to Mauss's potlatch example, it is clear that reciprocation in the form of competitive gift-giving serves to assert dominance of leaders over rivals, witnessed by the community. This example, in light of Miller's claim that relationships can be manipulated by gift-giving, challenges Carrier's earlier statement, that the opening gift of a relationship is altruistic. Considering power, it is plausible that the initial gift is meant to preemptively establish influence—not in response to a gift, but to ensure future control over the actions of the receiver.

Elite philanthropists use charitable giving to wield their power. Literature from applied anthropology has extensively critiqued international aid efforts as culturally incompetent at best and a veiled expression of colonial power at worst (e.g., HIV/AIDS relief in West Africa: Nguyen 2010, Post-WWII Latin America: Escobar 1995, human rights in South Asia: Visweswaran 2004, Cornell Vicos Project: Doughty 2002). This important body of work focuses on the social effects of large-scale development policies and projects. John H. Hanson (2015) narrows the focus to individual people—the philanthropic elites—who use charitable giving to create identity, generate symbolic capital, and maintain the socioeconomic status quo. Philanthropists give self-referentially—that is, to causes that directly uphold the institutions from which they benefit. Hanson offers the example of college alumni networks that funnel money back into the school they attended. This is also an example of class solidarity, in which philanthropists use charitable giving to align themselves with other elites. Hanson argues that philanthropists signal leadership and dominance by performing acts of "conspicuous

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compassion" which both excuse and reinforce elite status (Hanson 2015, 504). Donations are finite and tend to be earmarked for existing institutions. Donations do not upset the structural imbalances of wealth. Hanson suggests that elites are motivated to donate to causes that demonstrate their compassion without upsetting the underlying structures of inequality that keep them wealthy. This scathing critique of philanthropy paints donors as opportunistic, scheming to consolidate power while maintaining public sympathy.

The critical analysis of philanthropy can be softened by considering the perspective of the donors themselves, especially those that could not be categorized as elites. What do donors think motivates them, and how do donors form relationships with the organizations they support? What about middle- and low-income donors? Using an experiment informed by evolutionary theory and economic anthropology, Scaggs et al. (2017) demonstrate that donors are motivated by relationships and social cues. They identify "generalized trust" that others will replicate the philanthropic behavior along with "frequent volunteering" as indicators of higher generosity. The study also suggested that people with low levels of community engagement tend to direct excess funds to family and close friends, while people with high levels of community engagement (e.g. time spent volunteering, viewing their own involvement as important) were more likely to allocate to a local nonprofit.

This preference for local giving also emerged in a study on donors' use (or non-use, as it turned out) of information regarding charities' participation in regulatory programs. Charities participate in voluntary regulatory programs to signal transparency and inspire trust in donors. Tremblay-Boire and Prakash's survey experiment (2017) suggested that voluntary participation actually does not significantly impact donors' willingness to give. Instead, the location of the charity's operations was a significant influence.

Further research is required to definitively establish the importance of location. A study by Indiana University's Center on Philanthropy attempted to find differences in donor motivation based on region, but the only statistically significant indicators they found were income and education. High income and education were associated with motivators "for equity" and "making the world/community a better place" while low income and education were associated with motivators "meeting basic needs" or "helping people help themselves" (Center on Philanthropy 2009). These differences can guide outreach efforts so that charities build relationships with different donor groups based on shared values.

Local charities serving local populations are better situated to form long-term, ethically responsible relationships of reciprocity. The framework of reciprocity as a method of anthropological fieldwork, introduced by Maiter et al. (2008), can also inform the clinic's interactions with the community. The clinic is providing an expert service (medical care) within a community, with the intent to strengthen social and medical health of the community. This service could be delivered prescriptively—"Our specialty is serving the uninsured and this is how we're going to do it."—or collaboratively—"Our community is facing a problem; how can we mobilize our skills and resources to address it?" The former approach closes the door to financial support; the latter approach builds financial support into a team effort. Maiter et al. suggest that each project or goal should be viewed as one part of a much longer relationship, with all parties maintaining an obligation to one another and to the relationship. This perspective is a good fit for a community-based organization and would facilitate the ongoing collaboration, trust, and information exchange among stakeholders that reciprocity requires.

With this framework in mind, we will explore further the underlying issues that FFC is trying to address—not just medical outcomes, but the social determinants of health.

4.2   Social Determinants of Health

Donations support the FFC, which supports the health and social well-being of the community. To understand the importance of the clinic for its target population, a connection must be made between the conditions of life (broadly construed from the prenatal environment to housing situation to wealth over a lifetime) and health outcomes. This section will introduce the key concept of social determinants of health, which links federal policies and resource flow to local effects.

The World Health Organization (WHO) defines social determinants as the conditions in which people "are born, grow up, live, work, and age," along with the systems of healthcare delivery. These determinants contribute to risk and outcomes over a person's lifetime; the determinants themselves are influenced by economics, politics, and policy (World Health Organization 2018).[5] The concept suggests that there are other influences on a person's health aside from direct medical care. These influences—income, wealth, race, education, the built environment, environmental factors, etc.—are measurable and documented across multiple health outcomes, patient groups, and localities (Braveman and Gottlieb 2014). For example, health outcomes show a gradient along the socioeconomic spectrum, even when controlled for confounding factors such as race or location; wealthy people have the best outcomes, middle-income people have mid-level outcomes, and low-income people have poor outcomes. Because social determinants may only show effects on health after long periods of time (e.g. through generations or over the development of a chronic condition), measurement of directly-attributable health outcomes can be complicated (Braveman and Gottlieb 2014). There has been

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[5] For further reading, see the WHO's Commission on Social Determinants of Health final report from 2008, titled "Closing the gap in a generation: Health equity through action on the social determinants of health."

a strong effort to fund long-term cross-sector studies exploring social determinants and finding ways to address disparities among social groups. New York State's health improvement plan for 2013-2018, the Prevention Agenda, suggests a "Health in All Policies" approach as an overarching goal for addressing social determinants while recommending relevant evidence-based programs and policies (New York State Department of Health 2015). The state-level Prevention Agenda aligns with the priorities of the federal-level health improvement plan, Healthy People 2020. Objectives in Healthy People 2020 address social determinants of health in the areas of economic stability, e.g. employment and housing; education; access to healthcare, e.g. insurance and use of primary care; neighborhood safety and infrastructure; and social and community context, e.g. incarcerated parents, voter participation, and support for people with disabilities (Office of Disease Prevention and Health Promotion 2018). These objectives are varied in scope, reflecting the interconnected and far-reaching nature of social determinants. The ultimate purpose of addressing social determinants is to promote health equity—equal opportunity for all people to pursue a healthy life.

As identified above by the WHO, policy is an upstream influence on social determinants of health, especially policies that impact people's daily lives. Hahn et al. (2017) argue that civil rights laws are particularly important social determinants of health because they affect so many intermediate factors to health outcomes: the criminal justice system, housing, job opportunities, education, environmental equity, and transportation, among others. The authors cite research indicating that the Civil Rights Act of 1964 had a significant impact on black infants' health for the next two generations (Hahn et al. 2017 in reference to Chay and Greenstone 2000). These improved outcomes, however, depend on proper implementation and enforcement of civil rights and regulations, not just the passage of the law. A parallel can be drawn to the Affordable Care

Act, whose effect on health outcomes has undoubtedly been diminished by states' ability to opt out of Medicaid expansion.

Regarding health insurance, it has been established that the Affordable Care Act had a substantial impact on the newly-insured's health access and utilization, though the long-term impact on health outcomes remains to be seen (Kominski, Nonzee, and Sorenson 2017). Less intuitive, however, is the positive effect that the ACA has on people who are already insured. The effects of uninsurance on other members of the community (i.e. the insured) are referred to as "spillover effects," which include impacts on access and quality of care. In a simplified example, expenses absorbed by a hospital for an uninsured patient's preventable ER visit are ultimately paid by the community through tax-funded state grants, limiting resources for other programs. Social spillover effects also exist. Data from the Los Angeles Family Neighborhood Survey demonstrate an association between high levels of uninsurance and lower social cohesion pre-ACA (McKay and Timmermans 2017). In this study, social cohesion was operationalized as "perceptions of trust, sharing, support, and obligation"; these perceptions weakened among communities with more uninsured people, regardless of other individual and neighborhood factors. There are not only individual health benefits, but also broader community-wide benefits to offering insurance and healthcare to the uninsured. Thus, it is both useful and necessary to maintain a community-wide view when considering the role of FFC and the potential effects of federal policy, beyond the clinic's target patient population.

4.3   Evidence for the Chronic Care Model

As described in Chapter 2, FFC's Chronic Care Program (CCP) was developed based on the chronic care model for managing chronic conditions. The chronic care model (CCM) was

developed in 1998 by researchers from the MacColl Institute for Health Care Innovation as part of the Improving Chronic Illness Care program, funded by the Robert Wood Johnson Foundation (Wagner 1998). The CCM has inspired interventions for a variety of different chronic diseases and related symptoms. In this section, I present implementations and evaluations of CCM-based interventions that informed the evaluation proposal located in Chapter 7. I outline the limitations of the available literature and suggest areas of further study for CCM-based interventions.

4.3.1   Implementations of CCM

For older adults, CCM-based interventions have shown a consistently positive effect on patient satisfaction and mental health of individuals with a comorbid physical condition (Coleman et al. 1999, McEvoy and Barnes 2007). CCM has been implemented in rural practice to address diabetes management and education, with positive results for provider adherence to standards of care as well as for patients' empowerment, knowledge, and diabetes management (Siminerio, Piatt, and Zgibor 2005). Most relevantly, the CCM has been implemented in a Salvation Army Free Clinic (SAFC) for the uninsured in a prospective cohort study of 149 patients. SAFC has similar limitations to the FFC: transient patient population, difficulty ensuring continuity of care, and limited staff and resources (Stroebel et al. 2005). SAFC used the CCM to address these limitations to some extent. For example, SAFC addressed the CCM component "delivery system design" by organizing patients in a chronic disease registry, which facilitated coordination of care for a medically diverse population. The registry (an Excel spreadsheet) combined the usual demographic information with disease-specific guidelines for each patient so that progress on all cases was visible in one document. This allowed SAFC to address another component of the CCM: "decision support" for the healthcare providers. Cells

were highlighted to mark tests that needed to be done or results that needed to be addressed, allowing providers to prepare for appointments and prioritize follow-ups at a glance. The researchers attribute the low dropout rate (17% lost to follow-up as opposed to >40% in similar studies) in part to this strategy. Additionally, SAFC delivered chronic care in nurse-led teams, which increased the chance that the patient would see a familiar practitioner at every visit (Stroebel et al. 2005). As a feasibility pilot, the SAFC chronic care plan did not contain concrete recommendations for sustaining the program. The FFC faces the same challenge as it seeks to continue the CCP pilot. The biggest difference between the SAFC and the FFC is that FFC provides integrative medicine; the possibility of adapting the CCM to integrative medicine will be discussed later in this section.

Barr et al. (2003) expanded the CCM to include population health promotion strategies, which add community participation and attention to the social determinants of health, both of which are relevant in the case of community clinics. This expanded chronic care model (ECCM) has been used for diverse purposes, such as analyzing physician approaches toward obesity prevention in Texas and guiding pediatric asthma interventions in American cities (Hong et al. 2012, Viswanathan et al. 2011a). In the latter example, a broad initiative by the Merck Children's Asthma Network, Inc., encouraged healthcare organizations in areas of high pediatric asthma morbidity to translate evidence-based interventions that follow the theoretical trajectory of the ECCM to their communities (Viswanathan et al. 2011a). The mixed-methods evaluation of this initiative included ongoing process monitoring and feedback; pooled individual and site-specific reporting on asthma outcomes from baseline to 12-month follow up; and pre-/post-intervention interviews, focus groups, and site visits (Viswanathan et al. 2011b). In keeping with the initiative's focus on translation, the community organizations were permitted to use MCAN's

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standardized instruments (e.g. surveys) within different plans for implementing the evaluation, which the sites developed for themselves (Mansfield et al. 2011).

The MCAN research team states that the evaluation methodology was specifically chosen to measure how the implementation processes worked and what reasons there might be for failure or success (Viswanathan et al. 2011b). This offers a valuable guiding framework for evaluation of the FFC CCP, which also must balance fidelity with adaptation when translating the CCM to the integrative free clinic context. In both cases, the community setting is an essential factor to the implementation, so a controlled trial would be inappropriate for evaluating program effectiveness. One substantial difference between this study and the FFC CCP is that MCAN's chosen sites were well-resourced, urban, long-established organizations with existing funding, which allowed more flexibility in tailoring the interventions and evaluations to the sites (Viswanathan et al. 2011a). FFC is operating under less fortunate conditions, and therefore must find creative ways to implement and evaluate CCM interventions cost-effectively.

4.3.2   Integrated Medicine for Chronic Care

When chronic conditions do not have clear solutions, patients turn to options outside of conventional biomedicine. Chronic pain is one example of a persistent, complex symptom that decreases quality of life but does not always respond to conventional care. Patients who do not wish to use opioids to treat pain might choose an integrative care plan that incorporates biomedical treatment with complementary and alternative medicine (CAM) if such a choice is available (Eaton et al. 2018). In a similar way, people living with chronic disease who have tried multiple different treatment options might turn to integrative care to manage symptoms. Specialized CAM practices such as acupuncture, however, are often not covered by insurance,

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prohibitively expensive, and inaccessible in many rural areas. FFC has a specific policy against prescribing controlled substances, so opioid pain relief is not an option for FFC patients. FFC's commitment to making integrated medicine available to un- and under-insured people is a significant advantage in the clinic's treatment of chronic conditions.

Many studies and meta-analyses have evaluated the use and effectiveness of CAM or integrated medicine for patients living with chronic diseases (e.g., Falci et al. 2016; Lee, Bhowmick, and Wachholtz 2016; Deng et al. 2013; Vickers et al. 2012; Niazi and Niazi 2011; Rosenzweig et al. 2010). The most commonly encountered form of integrative care in intervention literature seems to be Mindfulness-Based Stress Reduction (MBSR) therapy, in which patients attend group trainings on mindfulness meditation, with a focus on managing stress and pain during daily life. In conjunction with regular treatment, MBSR improves health-related quality of life, bodily pain, and psychological distress to the greatest extent in patients with arthritis, back/neck pain, or multiple comorbid pain conditions (Rosenzweig et al. 2010). The indicators used in this study to evaluate the effectiveness of MBSR could also be used to evaluate outcomes of the FFC CCP. Health-related quality of life, bodily pain, and psychological distress are all relevant factors to the chronic disease experience. Positive changes in these areas are likely to support longer-term disease management. For example, in an inpatient setting, Cramer et al. (2013) found that an integrative program of such activities as meditation and relaxation improved the likelihood of positive health behavior change. This suggests that even without direct causal relationships established between certain complementary practices and health outcomes, integrative medicine can still reinforce the benefits of conventional health interventions. The MBSR study results support the CCP model, but exact replication of Rosenzweig et al.'s intervention would not be feasible for the FFC, which does not have the

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personnel or resources for eight intensive weekly meetings, weekend activities, and training-related materials.

Less academic attention has been devoted to integrated medicine in the context of the CCM. This is surprising, considering that the CCM's core components are already set up to incorporate integrated medicine without substantial organizational change. In the CCM, care is delivered in teams that might include medical specialists; in integrated medicine, biomedical practitioners collaborate with CAM specialists to create a treatment plan. Similarly, the self-management support element of the CCM aligns with integrated medicine's commitment to providing a variety of options for patients to consider. One possible direction for the evaluation of the CCP would be to find out the extent to which integrative medicine is part of the organizational culture, since the healthcare organization itself is one element of the CCM.

A review of available research indicates that the chronic care model has been tested and implemented in diverse contexts. FFC CCP is the first such implementation that attempts to accommodate such complicated factors as inconsistency in staffing, integrative care model, and the transient uninsured population. An evaluation of this program is necessary to determine the feasibility of this model beyond the pilot stage for chronic care delivery in an integrative free clinic. I describe my design for such an evaluation in Chapter 7.

4.3.3   Limitations and Applications

One potential limitation of the current research is the lack of tested strategies for ensuring the sustainability of such a program in a low-budget community clinic setting. Chronic disease management can be expensive; the CDC reported that in 2010, chronic conditions were responsible for 86% of all healthcare spending in the United States (Centers for Disease Control

and Prevention [CDC] 2017). Attention to chronic care and the positioning of community clinics as patient-centered medical homes has been shown to decrease Medicaid claims and non-urgent emergency department visits—both valuable cost-savings to healthcare infrastructure (Fillmore et al. 2014, Agee and Gates 2014). Ideally, publicizing community-specific cost-saving statistics would inspire support and sponsorship from local hospitals. A further limitation is that there has not been sufficient research on the effect of electronic health records (EHR) and the recent telehealth trend on delivery of the chronic care model. As clinics adopt these techniques, it would be instructive to track any changes in the way communication with chronic care patients is maintained.

Lessons from the available literature can be applied to the FFC's Chronic Care Program. Team-based care can mitigate the problem of continuity (Stroebel et al. 2005). Integration of mindfulness techniques into the care plan can promote positive health behavior change (Cramer et al. 2013). A controlled trial might not be applicable for evaluating the CCP, since community resources and situational context are essential components of the CCM (Viswanathan et al. 2011a). There is potential for future research using the results of an FFC CCP evaluation. In the MCAN initiative, the researchers developed a new model for the chronic care of pediatric asthma based on the ECCM (Findley et al. 2011). This demonstrates the potential for FFC's integrative chronic care model to make new contributions to the field.

CHAPTER 5

METHODS

5.1   Framework for Methodology

While the framework for data analysis has been described extensively in the literature

review (Chapter 4), this research owes its methodological framework to previous anthropological

scholarship on policy, briefly outlined here.

A foundational text for studying large organizations (e.g., the United States government)

comes from Laura Nader (1972), who encouraged anthropologists to "study up" at the cultures of

people in power. The sources of money and influence are essential components of any local

phenomenon that an anthropologist might wish to study.

As an instrument of political power, policy provides a narrowed unit for anthropological

analysis. The creation, content, and reception of policy reveals much about the culture of

policymaking. In the case of healthcare reform, the proposals that made it to the public eye (and

even more so, to the vote) reflected a hodgepodge of political agendas and bargaining rather than

a cohesive plan for improving the nation. One of the aims of this research was to measure the

extent to which local people followed and reacted to this process.

Anthropology of policy seeks to describe the experience of policy on different social

levels, thus revealing a holistic picture of a policy's effect. Key to this analysis is the practice of

"studying through," first introduced by Reinhold (1994) in reference to the effects of policy on

homosexual couples in the United Kingdom. This method involves in-depth study of not just

individuals, but also their relationships with others as they participate in an influential network.

The result is a macro-level understanding enhanced by micro-level ethnographic richness. This

type of analysis has been used to uncover conflicts of interest in international aid (Wedel 2004).

With this framework in mind, the research design incorporates inquiry at amplifying social levels from individual donors to the clinic's organizational structure to national healthcare policy. The remainder of this section will present the guiding questions, research activities, and a description of participants.

5.2   Research Questions

These research questions were developed in collaboration with FFC to guide this study in measuring the effect of federal policy on donors.

1. In what ways and to what extent is FFC engaged with its donors?

2. What concerns do donors have regarding the current healthcare climate?

3. How can FFC respond effectively to these concerns?

4. How can effective responses to donor perceptions of healthcare policy be incorporated into FFC's plans for eventual expansion?

5.3   Research Activities

The research results, analysis, and discussion draw on data from the following activities:

• 32 semi-structured interviews with donors, volunteers, staff, and board members

• 100 hours of observation at the clinic

• 7 board and committee meetings

The semi-structured interviews took the form of guided yet participant-centered conversations about the clinic's activities and policy on the federal level. Since the study's aim was to hear from the participants, it would have been too restrictive to conduct structured interviews or surveys with a pre-determined set of questions. The semi-structured format allowed participants to bring up their own priorities and suggestions while remaining within the topics of policy and clinic activities. Interviews were audio-recorded, usually lasting between 45 and 80

minutes. Interview guides for the semi-structured interviews are available in Appendix B. Donor recruitment was conducted by the clinic through email communication and snowball sampling. Volunteers, staff, and board members were approached by the researcher to participate in the study. This recruitment occurred with the knowledge and support of the clinic's leadership. Interviewees are sorted by their relationship to the clinic in Table 5.1.

Table 5.1: Interviewees by relationship to the clinic.

	Donors	Volunteers (incl. providers)	Staff and Board
Participants	22*	13	6

*This number includes participants that are also counted in the other two categories.

All interviewees were oriented to the study through an informed consent process. I explained the purpose of the study, my relationship to the clinic as a volunteer researcher, and their rights as participants. Each interviewee was given the opportunity to ask questions about the study. They then signed a paper informed consent form that had been approved by the UNT Institutional Review Board and received a copy for their records. Participants were given pseudonyms for all deliverables. The clinic was given a pseudonym suggested by the site supervisor and agreed upon by the Board of Directors. The clinic pseudonym is used in this publication as well as in all conference presentations so as not to complicate the public narrative and branding process that had already begun.

On walk-in clinic evenings, I observed the waiting room and the administrative staff, taking field notes on workflow, atmosphere, and use of space. I did not record the waiting room through audio or video so as to preserve patient privacy. For this same reason, my field notes do not contain names or identifying characteristics of any patients. The purpose of this observation was to identify procedural activities that were particularly efficient or inefficient, especially

those that impacted patient experience. I learned from staff and board members that in the past, staff perceived the board to be disconnected from the day-to-day clinic activities; this perception was a source of conflict. As a board-sponsored researcher, it was important for me to be present during the walk-in clinic to ensure that my recommendations would fit into the workflow and not overburden the staff. I varied my location, beginning seated behind the sign-in desk, at the discharge window, and among patients in the waiting room. I did not observe patients as they received clinical services, as that was not relevant to my research questions; I only observed patients when they interacted with administrative staff. In accordance with IRB guidelines, I posted a notice that administrative activities were under observation. On one occasion, the acupuncture provider for the evening had no clients scheduled due to a miscommunication. With the approval of clinic staff, I participated in one 30-minute session of acupuncture as though I were a regular patient. I had not experienced this therapy before. Although the session did not immediately resolve my presenting complaint (a headache), the provider was welcoming and professional, patiently answering my questions about acupuncture, its popularity in Ithaca, and her previous experience. By participating in this therapy, I had the opportunity to view the clinic from the patients' perspective.

In addition to observing workflow and operations during walk-in clinic hours, I sat in on a total of seven board and committee meetings to get a sense of the clinic's higher-level priorities. Monthly board meetings took place in the evening in the large room at the back of the clinic that serves a multitude of purposes: conference room, storage space, and overflow clinic space. Development and finance committee meetings took place in this room or in the waiting room. I observed these meetings while taking field notes on the topics of discussion and the interactions between board members, only occasionally participating to introduce myself and my

45

research. Meetings generally lasted 90 to 120 minutes and were organized into an agenda with designated time allotments, which were usually followed. Attendance for board meetings was high; attendance for committee meetings was low. Topics of discussion included negotiations between the board and the staff's union, fundraising efforts requiring limited manpower, and the funding of the Chronic Care Program. Board and committee members seemed comfortable voicing a variety of opinions with each other, each coming from a different background (e.g. clinical, business, other nonprofits). With added insight from these observations, I was able to gather together the ideas I heard into the final report while anticipating board members' responses to my findings.

5.4   Analysis and Reporting

Handwritten field notes were typed; audio-recorded interviews were transcribed using oTranscribe. This process yielded more than 350 typed pages of interviews and 50 typed pages of field notes. The first round of analysis consisted of open coding. I annotated relevant instances in the notes and transcripts with phrases such as "staff-board relationship," "not enough providers," "local-mindedness," "outreach activities," and "what the donors want." Many of these initial codes varied in wording and overlapped. I then grouped these annotations into larger categories based on the main research questions, choosing a key phrase (in qualitative methods, an "axial code") to refer to these groups of ideas. For example, instances where interviewees noticed the lack of providers, the need for supplies, or the potential for collaboration were grouped into an axial code called "areas for growth." From the axial codes, I identified key themes to report to the FFC. These themes became the different sections of the client deliverable: donor communication, policy response, growth, and a vision for the future. This inductive

analytical process ensured that the findings reported to the client were grounded in the reality of the interviewees' words. I chose not to use an analytical software to analyze this data, as I was not intending to demonstrate statistical significance for my results (e.g., providing evidence for political lean as an indicator of donating). The small sample size yielded an amount of data that was manageable to work with without the help of advanced software. In fact, without the convenience of a "excerpt" tool, I listened and read through the entire body of data multiple times during analysis, ensuring a deep familiarity with the data. Limitations of the small sample size are discussed in Chapter 8.

5.5   Description of Participants

I conducted thirty-two interviews with donors, volunteers, staff, and board members, with some people falling into two or more of those categories. The twenty-two donors who chose to participate in this study are mostly of retirement age. Many of these donors have been socially connected or personally involved with the Finger Lakes Health Alliance (FHA), the parent organization of FFC, since it began. Participants gave three main reasons for supporting FFC: firsthand experience with FFC's work, preference to give locally, and knowledge of the healthcare system's shortcomings. Nine participants connected their support of FHA to their familiarity with the free clinic's work. These participants are volunteers or former volunteers who have seen day-to-day clinic activities and can visualize how their donations are being used. Nine participants emphasized that FHA is a local organization, so they are confident that their donation impacts their community. Participants also donate to a variety of other healthcare causes including the Cancer Resource Center and Planned Parenthood of the Southern Finger Lakes—both local organizations. Five participants mentioned that they donate to FHA because

they support healthcare for the marginalized. These participants are aware that people are not

served by the current system and are invested in improving healthcare access for all

The following four donor profiles demonstrate the range of experiences and backgrounds

present in the sample. These examples introduce some of the main themes that are further

explored in the results chapter (Chapter 6).

5.5.1   Donor Profile: Susan

After a long career with Cornell Cooperative Extension, Susan is now retired and actively

involved in nonprofit organizations. She serves on the board of the Family Reading Partnership

and is a member of P.E.O. Sisterhood, which supports women's education internationally. She

first heard about the clinic from a fellow member of P.E.O., whose husband was a well-respected

physician volunteer at FFC. After hearing this physician speak passionately about the importance

of the work, Susan became a donor.

Susan is optimistic about the future of healthcare in America, despite her knowledge of

current shortcomings. She has read about the difference in outcomes between the United States

and other developed countries. Susan would like to see a single-payer system, but does not

believe the current partisan political climate will allow it. Even so, she says:

> It's gotta get better [laughs]. I'm always optimistic. It can always get better, we're going
> to do better. And, and part of it, the reason I think that is because people who got
> coverage under Obamacare now realize what they've been missing. And so it, it's just
> gotta get better.

When asked what "better" would look like, Susan focuses on educating people about healthcare

costs, the effects of prevention, and appropriate use of the healthcare delivery system.

> I'll speculate in terms of what I'd like it to be. And that would be that people would be
> knowledgeable about healthcare costs. If a lot of people would get basic healthcare, they
> would not end up in the emergency room. I would love to see emergency rooms really for

emergencies in the future. If we could have that…that would be much improvement…So, um, what else would I like in five years? [pause] Just that Americans become better educated and convinced that taking care of themselves makes a difference in their life. The rate of diabetics as a result of poor eating habits is outrageous. I would really like to see that improve in five years. That's where I'm at, at the moment.

In Ithaca, Susan sees Cornell University as a large draw for highly educated healthcare professionals, specifically pointing out female physicians whose husbands are employed by Cornell. She describes her involvement with the clinic as "hands-off"; she supports the mission, but is not well-informed of personnel structure or finances, and has never been invited to visit. Susan would like to receive more information from the clinic as a response to her donation:

> I don't need a lot of accolades…. Some of the organizations have these lists of people in categories and what they gave and all that and it's like, I would rather you didn't use my name but I, just, in terms of appreciation, just sharing more information would be helpful to me. I would appreciate it that you trust me when you tell me some things…some statistics on how many people you've been able to serve, how many volunteer hours go-, and the value of those volunteer hours is a lot. And then just some stories of people that have been helped. Stories are always, you know, and I know you have to protect people's confidentiality, but you can generalize things, and, and tell a story.

5.5.2   Donor Profile: John

John and his wife have lived in Ithaca since 1992. They have three children around the age of 30. Although John has donated to FFC annually for the past few years, he describes his engagement with the clinic as "nil." This interview was the first time he had been invited to the clinic, and he is not aware of any social connections to clinic board, staff, or volunteers. He originally heard about FFC through his daughter. John's children influence his philanthropic giving. He describes them as "sensitive to the needs of people in this community. They're progressive young people and they influence in many ways who we should consider giving to. We talk about it as a family." John's extended family has a philanthropic foundation, and they discuss giving at family gatherings to instill an ethic of charity in the younger generation. During

one such discussion, a question was posed to a younger group, ages 5 to 22: Why do people

give? John described responses such as an alumni connection or a church connection. His idea is

different:

> There were all kinds of answers that were spewed forth that we've all heard before, but I found myself raising my hand and saying, because they're asked…It's been my own experience that sometimes all it takes is an ask, and you become aware of something, and you become aware of a need, and you say "Hey, we can do that." So we do.

> John sees the importance not only of communication, but also the local impact of his

donations. He says that he specifically does not give to national-level organization such as the

American Cancer Society and the American Lung Association because he feels that those

donations "get blown away in the wind." He prefers to give to local organizations, such as the

Cancer Resource Center and the local chapter of Planned Parenthood. He notices the many

organizations and health resources available to people in Ithaca and supports New York State's

progressive Medicaid expansion. Despite these assets, John is concerned about the future. He

describes the AHCA as an "abomination" and points to the poor health outcomes America faces

in comparison to other developed countries who spend less money.

> I've always believed that our healthcare system is, it was a, a result of unintended consequences of insurance companies in the 1950s or 40s, whenever it started, coming up with what seemed like a good idea at that time. And it has grown into this, into this thing where employer-sponsored healthcare paid for by insurance companies is the tail wagging the whole dog. And here we are.

5.5.3 Donor Profile: Donna

Donna moved to Ithaca from California six years ago. At the time, her daughter was nine

months old, and Donna was concerned about maintaining routine medical care for her through

the move. She describes her discovery of FFC:

> Before we moved to this area I was just looking around for different healthcare options and I was searching online and the clinic popped up. And just, immediately, even before

we moved here, I felt very relieved that no matter what happened, when we moved across the country to this new place, that I would have a place to go for healthcare or just help getting connected with what's available in this community.

Once she arrived, Donna remained interested in FFC, seeking out more information about the health alliance. She was interested in joining the board of a nonprofit, so she submitted her application and joined the FHA Board of Directors. She has held officer positions and serves on multiple committees.

Donna owns a small business and has a background in healthcare information technology. She considers herself well informed about the structure of healthcare delivery, but only somewhat informed of proposed legislation. She supports a universal healthcare coverage system "along the lines of single-payer" and would like to see proposals that directly address the poor health outcomes. To sum up in a word, she wants the future of healthcare to be more "reasonable":

> I can understand the need to rein in healthcare costs. But at the same time, I think it's hard to swallow some of the cuts that are being proposed, with the repeal and the new act, because it's not helping to improve any of those outcomes…I think what we have now [the ACA] is reasonable, I think what's being proposed is not reasonable—just to get to universal coverage would definitely be reasonable. You've got, you've got this minimum level. You know, lots of other countries have similar setup and it works.

As a well-informed board member, Donna has a detailed vision for what the clinic could be in the future. When asked about what she would like to see in five years, she responds:

> I would like to see the clinic still be around. I think that what it does and the services it offers will likely shift. There's a number of things that the board would like to do that just haven't been possible. And from talking to people…who have been around since the beginning, these are the things that people back then were hoping the clinic would come to do. The biggest thing that's coming to mind is a dental program…. Lots of other free clinics, they do medical, dental, vision, kind of your standard stuff. I would like to see us do more of those standard things and at the same time keep the integrated component in some way….Being more responsive to community needs, because there's still gaps.

One of Donna's goals is to see the clinic remain an active participant in conversations about

healthcare. FFC has the opportunity to share humanizing stories:

> D: I don't know if you read the Stanford Social Innovation Review, there's an [article](#) that published recently talking about healthcare and how the conversation about healthcare policy would be totally different if we stopped referring to things like preexisting conditions and all the legalese and instead talked about, let's talk about my son who's been diagnosed with whatever and it's costing us this much every month for his medication and if we lose our health insurance, this is what it's gonna mean for my family. Can you help me?
>
> E: Putting the human face on it.
>
> D: Mmhmm. And I think the clinic it's just like a trove of all of that, you know? Everybody who comes through this door has been failed by the system in one way or another. So I think we could do a much better job of supporting those who are fighting for things like single payer and just, you know, a more reasonable health policy. Being one of the voices in that mix.

5.5.4 Donor Profile: Brian

Brian is a self-described third-career Physician's Assistant, having worked previously as

an engineer and "hippie craftsman." His medical research on HIV/AIDS took him from Harlem

to Kosovo to South Africa, where he helped to start an HIV clinic in an area with limited access

to doctors. Upon retirement, Brian volunteered for about three years with the FFC and now

supports the clinic as a donor. He describes the atmosphere of learning and collaboration at FFC:

> One of the things that was very hard to me right at the beginning was the fact that this is primary care, and I have never done primary care, so it was learning a new set of medicine. I would go in to [the supervising physician] and say, "What's the treatment for gout?" And he would laugh and he would blrrrp [give the answer] out of his head. He'd done it a hundred times. I had never done it, I had never seen a case of gout at Harlem Hospital HIV clinic.

Similar collaboration would occur between Brian (a provider of conventional medicine) and the

holistic providers. Brian describes his attitude toward herbal medicine, along with that of his own

primary care doctor:

> The herbalist would come across the way and…ask me this, and I would refer people to him. I take some herbs. There is a chemical that I could buy or there's an herb I could use, and I do that. And I said this to my primary care doctor and he said, "Yeah, it works, doesn't it!"

He describes the clinic as "hippie" in the sense that it accepts multiple methods of looking at wellness and medicine, but also committed to quality: "That's part of it here, is, we do good medicine. We don't do half-assed stuff here. It's never been the way it is done here."

On the topic of healthcare policy, Brian is in favor of a Medicare-for-all system. To him, the greatest barrier to such a system is the ideological and cultural divide between the country's liberal coasts and conservative heartland. More dialogue resolving misunderstandings and ideological prejudice would allow a better system to arise. He traces the divide back to protests of the Vietnam War and arguments over Social Security:

> B: Well it's, there's always been a piece there, you can go back to the America First Party and the ones that didn't want to get into the First World War, I mean there's lots of that, but there was a particular division that happened there [around the Vietnam War].
>
> E: And how would repairing that division lead to universal care?
>
> B: Then, it would be that people on the, from the quote-unquote Red States, would see, Oh, there's value in this, it's not just a hippie proposal that won't work. And it's not socialism and it's not, you know, but it's work-, I mean, the roads are socialism, okay? [laughs] You have a better, once you can bridge that divide then you have people going back and forth.
>
> E: So, more dialogue?
>
> B: Any dialogue.

One of Brian's ideas for the future is to reconnect the clinic with the nearby hospital system. From his son, who lives in Pennsylvania, Brian has learned that the free clinic there is located within the hospital, fully supported by lab tests and personnel. Based on his experience as a FFC volunteer, Brian estimates that the pricing structure for FFC patients needing blood work was five times higher than for insured patients and eight or nine times higher than for Medicare patients. He is frustrated that such seemingly arbitrary differences exist and would like to see some sort of resolution.

These four cases demonstrate the variety of issues that are important to FFC's donors and their ideas for how FFC could respond. In the following chapter, I present the main findings from the research, many of which have been illustrated in these donors' stories.

CHAPTER 6

RESULTS

This section presents the main findings from the research as presented in the client

deliverable. The chapter is organized into sections based on the following themes that emerged

from interviews and observation:

1. Donor Communication

2. Policy Response

3. Growth

A fourth theme, regarding relationships within the organization, was included in the final internal

deliverable but omitted here and in all external dissemination at the request of the board.

Recommendations to strengthen relationships within the organization were useful to clinic

leadership as they planned for the future. However, the donors were largely unaware of internal

relationships, so those findings were not ultimately relevant to this donor-focused study.

For each of the three themes, aggregate findings are presented alongside illustrative

participant quotes, followed by recommendations for the clinic. These recommendations are

summarized in Appendix A. Following these themes is a section on participants' visions for what

the clinic would ideally look like, five years into the future. As anticipated, many of the topics

brought up in this section also came up in the section on areas for growth. The five-year vision is

presented as its own section because it reflects more broadly the participants' highest hopes, not

just their suggestions.

The main deliverable to the client was a comprehensive internal report of aggregate

findings and recommendations from the research. I presented the key findings to the clinic's

Board of Directors in person at their October 2017 meeting. I prepared a condensed report for

participants and other external audiences, which was delivered electronically in November 2017. At that time, I also sent an informal report of my observations of day-to-day clinic operations to the clinic operations committee chair.

6.1   Donor Communication

6.1.1   Findings

6.1.1.1   Frequency of Communication

In general, donors are looking for more communication from the clinic (Figure 6.1). The most popular frequency was quarterly communication, which includes both appeals for support and clinic news. No participants wished for communication more frequent than monthly. It is also worth noting that participants did not agree on how much the clinic communicates with them now. This may be a result of appearing on multiple donor lists or none at all. One donor expressed: "Don't send me stuff all the time, but maybe quarterly…post an annual report."
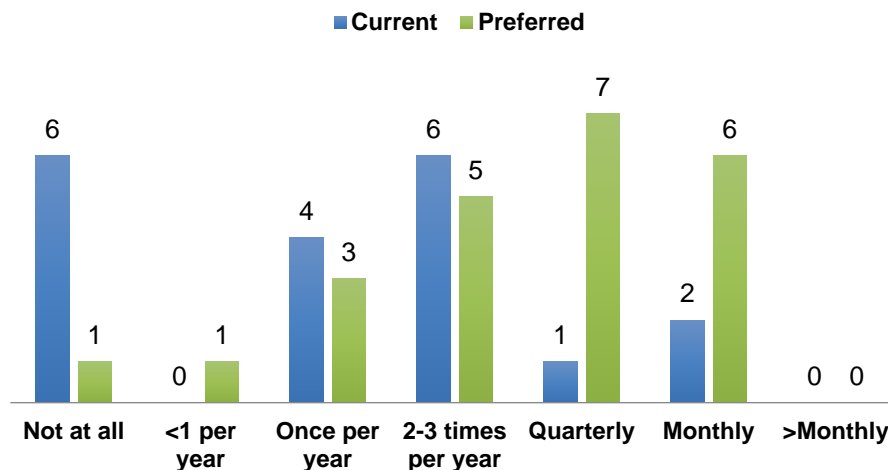
Figure 6.1: Clinic's current frequency of communication with donors versus donor preferences.

6.1.1.2   Content of Communication

Mailed appeals for donations still seem to be an effective way to reach the donors who participated in this study. Two donors asked specifically for the annual report to be included in these mailings. In addition to regular appeals, seventeen participants expressed interest in a clinic newsletter. Suggestions for content include budgetary information, clinic-sponsored events, staff and board introductions, and statistics of patients served and the popularity of different services. Participants suggested that the newsletter be sent quarterly by email and not exceed one page.

6.1.1.3   Social Media

Five of the twenty-two donors mentioned that they could be engaged through social media, although that was not their primary method of keeping up with the clinic. Three donors were aware that the clinic was on social media already. Three donors responded that they do not interact with social media, so the clinic's social media presence was irrelevant to them.

6.1.2   Recommendations

6.1.2.1   Newsletter

A brief quarterly e-newsletter would effectively respond to the donors' request for more information while providing talking points for publicizing the clinic. In this newsletter, the clinic could provide basic statistics (patients served, holistic services used, etc.) and financial information to donors. The newsletter could also highlight a volunteer practitioner with further information about their area of expertise. The newsletter should announce events or one-time volunteer opportunities that donors who are seeking more involvement might attend. The

purpose of the newsletter should not be an appeal, but information for donating online or by mail could be included.

6.1.2.2   Attracting New Donors

The donors who chose to participate in this study are mostly of retirement age. The findings for donor engagement reflect their preferences, and the recommendations focus on strengthening communication with this dedicated group.

FFC could also consider increasing engagement with a younger generation of donors. Enthusiastic young donors could help raise awareness among potential patients of their age group through peer interaction. One idea that arose at a board meeting was to engage nearby colleges' Greek communities by presenting FFC as a site for philanthropy. The clinic could gather data on this population's preferences for engagement by selectively surveying university students who already volunteer at the clinic.

Current donors support FFC in part because they can be sure their donation stays within their community. One volunteer provider donates her time and money because: "I feel incapacitated to have any effect on the federal level, and so I act locally." In this case, discomfort with federal actions can actually be an encouragement to donate. FFC could draw on its history as a local institution and emphasize community impacts to attract locally-minded donors.

Another option for engaging new donors of any age is increasing FFC's internet presence, which currently consists of a website, Wikipedia page, and social media accounts. Social media marketing is now considered a job-related skill; the clinic could recruit a student volunteer to manage the social media accounts consistently, who could then put that skill on their resume.

6.2   Policy Response

6.2.1   Findings

6.2.1.1   Policy Information

Most participants described themselves as somewhat- or well-informed about federal healthcare policy, largely in the context of disagreeing with the proposed American Health Care Act (AHCA) (Figure 6.2). Participants named the *New York Times*, NPR, and national TV networks including ABC, CBS, NBC, and CNN as their sources of information on healthcare reform, in addition to the local *Ithaca Times* and *Ithaca Journal*. Six participants cited peer and personal experience with the health insurance market or healthcare delivery systems as sources of information about policy. One participant described the reasons she feels compelled to be informed:

> J: If I am not able to get health insurance that covers my prescriptions because they're pre-existing conditions, I would not be able to be healthy enough to attend school.
>
> E: So this is very personal to you.
>
> J: Yeah. And because I know so many people that are broke and sick. And not for lack of trying. Like, my friend is a tattoo artist and it took her years to get through her apprenticeship working full time …and raising a son, all by herself…And now, if she weren't, if she didn't have access to Medicaid, …she wouldn't be able to work. Like she, she and her son would lose their house. It's…[sighs]. I know very few people that are well off enough to not know anyone who would be affected.

These issues affect this participant as well as the people she cares about. She keeps up with the proposed changes not only to be knowledgeable, but also to prepare for the impact they might have on her life.

Three participants seek out information from organizations they were previously involved in, such as the League of Women Voters. One participant joked that others may deny it, but he gets his information from talk-show hosts Jimmy Fallon, Trevor Noah, and Stephen Colbert.

How informed do you feel about federal healthcare policy?
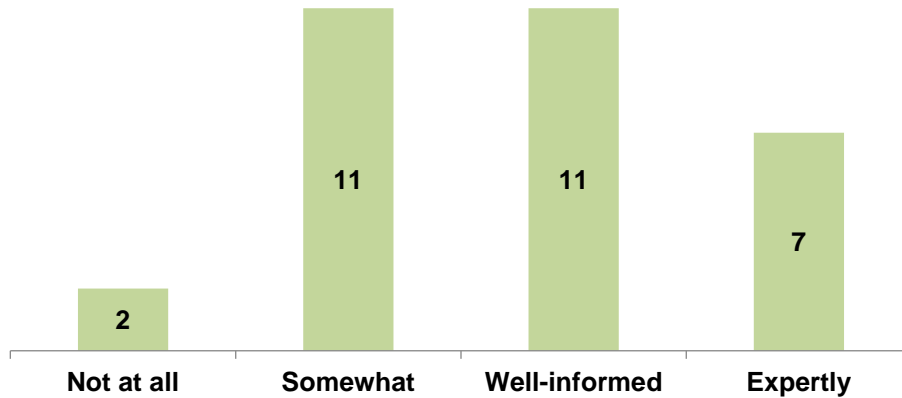
Figure 6.2: Self-reported level of knowledge among participants.

6.2.1.2   Attitudes toward Policy

All participants ($n = 31$) were opposed to the Congressional healthcare bills proposed in summer 2017. The bills were described as "dreadful," "terrifying," and "disastrous." This outcome was relatively unsurprising, considering Ithaca's liberal reputation and the participants' support of a free clinic.

Twenty-three participants expressed without prompting that they are in favor of a universal or single-payer healthcare system. This demonstrates donors' familiarity with these terms and that they thought these were important concepts to bring up in our conversation. The current support for a Medicare-for-all system in Congress indicates the acceptability of universal coverage rhetoric for policymakers; this finding suggests that this specific language has also entered mainstream discourse. Based on donor responses that conflated the two concepts, it is possible that "universal healthcare" and "single-payer" have become buzz words for the general public, meant to signal liberal political lean and communicate concern for the uninsured without requiring an in-depth understanding of how such systems work.

6.2.1.3   Effect of Policy on Donor Engagement

Donors indicated that the uncertainty surrounding federal healthcare policy would not negatively affect their commitment to the clinic. Responses generally fell into one of three categories: the federal policy does not affect donations, federal policy could prompt continued or increased support, or federal policy guaranteeing coverage could cause rescinded support if the clinic were no longer needed (Table 6.1). Ten donors did not connect federal policy to their philanthropic behavior at all; more compelling motivations to donate included belief in the FHA mission, social connections to the clinic, and involvement as a volunteer. These convictions were not swayed by uncertainty on the federal level.

Table 6.1: Reactions to federal policy.

	Increase or reinforce donation	Policy has no effect on donation	Would rescind support if no longer needed
Donors	33%	56%	11%
n=18	6	10	2

Some donors' motivations blended personal experience with knowledge of the larger system. A volunteer nurse who dedicates four to seven hours of time to the clinic per week considers firsthand experience with patients more of a motivation than federal policy. However, it is through these experiences that she understands the effects of policy:

> My husband and my decision to donate is more based on what I see here firsthand than healthcare policy. I'm learning about healthcare policy through our patients and that's what's really influenced us, realizing how many people don't have basic healthcare. And where would they go if the clinic wasn't here? They'd be in debt for little things like employment physicals and TB tests, all that costs money.

This participant connects policy and its effects—i.e., lack of access to basic healthcare—to the needs and concerns of the patients she sees during the week.

Two donors did suggest that if federal policy (e.g., universal healthcare) rendered the

clinic unnecessary, they would no longer support the clinic. This thought was expressed in

several interviews and informal conversations with clinic donors, volunteers, board, and staff. If

everyone had healthcare coverage, would the clinic still have a purpose? Thirteen participants

suggested that ideally, there would be no need for this clinic. On the other hand, eight

participants pointed out that the clinic would continue providing alternative medicine, as holistic

services are unlikely to be covered by insurance. Eleven participants mentioned that the clinic

could still offer advocacy, health education, and preventive care. Four participants, including the

nurse above, emphasized that even with universal coverage, people would slip through the

cracks—non-citizens, the undocumented, homeless, and other populations that avoid or cannot

access established systems—and still need the FFC. From the nurse's perspective:

> I think there's gonna always be a need. There's always gonna be a need. There's always
> people that are homeless, in between jobs, minimum wage jobs that you know don't offer
> health insurance, people, part time work, we also see a lot, a lot of international people
> that are visiting their children for six months and they don't have healthcare insurance, so
> they need their prescriptions. They become ill, and they often come here.

Another volunteer provider shared the story of a patient he had worked with who said he

was uninsured because he was reluctant to attract attention from the government. The reason?

Unpaid student loans from decades prior. The reasons are as complex and varied as the patients

themselves, and the strength of these reasons in the patient's mind forms a substantial barrier to

healthcare access. When working with uninsured people, education is important; compassion is

essential.

6.2.2   Recommendations

6.2.2.1   Response from the Clinic

As many participants pointed out, the clinic's response to uncertainty in policy can be simple: no matter what happens on the federal level, the free clinic will still be needed, and therefore will still need support.

One of the FHA's goals is to provide advocacy and education. At this time, healthcare policy is prominent in the public consciousness. The clinic's advocacy and educational services should include providing information about the healthcare system on a larger scale while helping patients navigate any new regulations that might arise.

Regarding public statements, nine participants suggested that the FFC focus on the specific impacts that policy would have on the clinic. FFC could publicize statistics about uninsured patients before and after the ACA passed, as well as projections for the impact of other proposals like the AHCA. These statements would have even more impact if they were localized to the state or county level.

6.2.2.2   Political Activism

There was no consensus among participants regarding whether FFC should take a political stance in the current healthcare debate (Table 6.2).

Table 6.2: Participant opinions on the clinic taking a political stance.

	Clinic should take a political stance	Political stance is risky but ultimately positive	Remaining neutral is best
Participants	38%	21%	41%
n=29	11	6	12

Two participants said that the existence of the clinic is already a political stance, so opposition to AHCA and similar proposals would be both expected and accepted. One participant objected to my use of the phrase "political stance," demonstrating the strength of his feelings around the issue: "It's a stand for human rights, and those aren't political stands." Eight participants answered that the clinic could comment about policies or encourage people to contact Congress, but should avoid directly naming candidates or politicians. One participant was strongly against any political involvement, saying that the clinic should stay out of the political dialogue and focus on the patients:

> Yeah, should the clinic get involved in the politics? [laughs] I'm not sure they should. Because it's like taking sides and there's already too many sides and, and they're, they're here to serve everybody. There's, I, you could get into a whining battle, uh, we can't do our job because you don't have adeq- healthcare and all that. But it doesn't, I don't think it serves anybody well at this point. I think there's lots of people around here who have opinions on healthcare and...Let the clinic really focus on helping people with their care.

This opinion seems to come from her exhaustion with the political debates around healthcare—"there's already too many sides" and "I don't think it serves anybody well at this point." This participant was not the only person to express frustration with talking about politics; the divisive 2016 election season and the drama around proposed bills were tiresome to many. However, participants were generally in favor of a non-partisan public response that focuses on policy's direct impact on the clinic.

6.3   Growth

6.3.1   Findings

The three groups of participants—donors, volunteers, staff/board—expressed different priorities for the clinic's growth. Figure 6.3 presents the seven topics that arose most often when identifying areas for the clinic to expand, along with percentages of each participant category

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that mentioned them. Among volunteers, the staff, and the board, the highest perceived needs were the need for more healthcare providers and the need for more outreach, to increase awareness of clinic activities in the community. To a lesser extent, staff saw a need to maintain current hours of operation for the walk-in clinic, and perhaps expand in the future. The lack of outreach was also visible to donors, followed by the need to provide more educational services to the public. Both of these are external areas for growth, so it makes sense that the donors would acknowledge these more often. The need for more space or better infrastructure did not come up often, in part because volunteers who had been there longer remembered the previous facility, which they did not prefer. Finally, about half of all participant categories identified data collection as an area for growth. Priorities for data collection for staff included patient outcomes and referrals; for donors, priorities were volume of service and financial data.
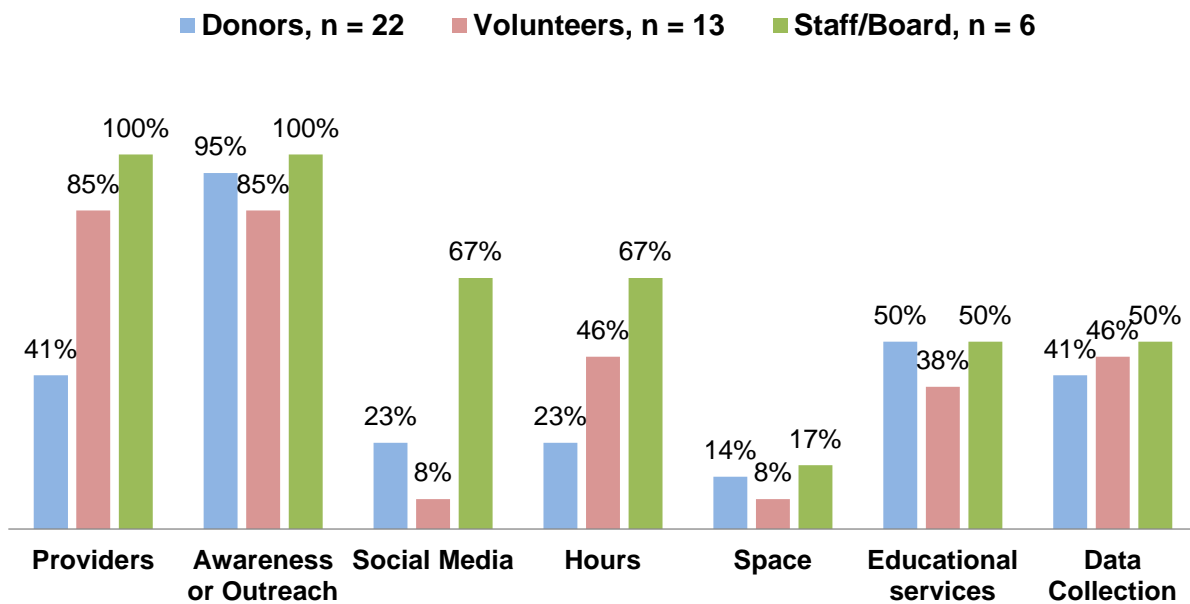
Figure 6.3: Areas of need for the clinic as expressed by different participant categories.

Differences between groups can be explained by differences in knowledge about the clinic's needs. For example, this subset of FFC's donor base was not strongly connected via

social media, and the volunteers were unaware that efforts to ramp up social media were in progress. The staff, on the other hand, were directly involved in the social media initiative, so the need came up more often. Another example is the lack of healthcare providers, which staff and volunteers experience firsthand, but donors rarely see. One board member offered her perspective on the difficulty of bringing in new providers and her suggestion for improvement:

> Every time I see my doctor I say, hey, would you be interested in volunteering at the clinic? And he's like, no, I don't have time, I'm too busy. Which he is, you know, that's a valid objection to raise, but at the same time, you know, everyone's busy. So I don't know that the clinic has done a great job of articulating the benefit to the provider when they volunteer here. Particularly for the M.D.s. With nurses, nurse practitioners, it's a different kind of sell….I think you need an M.D. to talk to an M.D.

She goes on to suggest that one selling point would be the potential for free clinic work to mitigate physician burnout, a primary concern of medical centers.

In addition to these topics, 87% of all participants mentioned a need for collaboration with area organizations. Collaboration could take the form of services, shared space, volunteer recruitment, or referrals. Suggested organizations included:

- Cayuga Medical Center (CMC)
- Cornell University
- Board of Cooperative Educational Services
- Planned Parenthood
- Greater Ithaca Activities Center
- Cancer Resource Center
- Addiction support groups
- Food pantries
- Department of Social Services
- Tompkins County Legislature

Eight participants suggested that partnerships with area organizations could lead to expansion of services including dental, vision, pediatrics, mental health, and social work. Three participants expressed interest in starting a mobile clinic to reach farm workers and rural populations. Collaboration would allow greater capacity to provide these services or referrals to organizations that already perform these services in the community. The need for a physician

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spokesperson to reach out to other potential volunteer physicians was echoed by another participant when describing collaborative opportunities at Cayuga Medical Center. A long-time donor with experience on the hospital's committees stated that the best person to put pressure on the hospital for support would be a physician, especially one already "highly-regarded."

6.3.2   Recommendations

6.3.2.1   Community Awareness

One participant described the FFC as an "undiscovered gem" in the community that could have even more scope if people knew about it. Participants mentioned the Family Reading Partnership as well as the Cancer Resource Center as good examples of becoming publicly known. Family Reading Partnership in particular is hard to miss—signs and murals encouraging caregivers to read to "every baby, every day" are common sights around town.

Part of the challenge for this organization is branding. Because of the organization's history, early supporters are committed to the "Finger Lakes Health Alliance" of which the "Finger Lakes Free Clinic" is a program. This is the case for most of the donors in this study, who have been with the organization from the beginning. Complicating this problem is the existence of several different logos and color schemes for the FHA and the FFC. By consolidating the organization's name and brand, there is an opportunity to re-focus community awareness on FHA's current priorities. These decisions can then be incorporated into other awareness efforts, particularly in the new website and the social media accounts.

The most pragmatic suggestion from a participant for increasing community awareness was to put a bigger sign on the building. This is something to consider if the branding changes

and a new sign is needed. On a related topic, participants also suggested that enhancing the exterior of the building could improve community perception of the organization.

6.3.2.2   Outreach

Twenty-eight participants identified outreach among the areas in which FFC could grow. As mentioned in the above section, participants do not perceive FFC to have a strong community presence despite its long local history. While raising awareness for the clinic focuses mainly on volunteers and donors, outreach is needed to reach patients. One participant called outreach the "street presence" and suggested that we use a mobile clinic to bring healthcare to rural farmworkers. Until such an undertaking is a financial option, the clinic should still make an effort to be present at community events, partner with organizations like GIAC and the Department of Social Services for referrals, and find other ways of being present and visible to people who may need the clinic.

6.3.2.3   Collaboration

Collaboration with other area organizations will likely help increase community awareness of FFC. In addition, forming partnerships with other organizations may allow FFC to broaden its donor base. Two promising opportunities for collaboration are Cornell University's new residency program and Cayuga Medical Center, which could be a source of both monetary support and volunteer practitioners. As two participants suggested, collaborations might be facilitated by a physician who is comfortable reaching out to clinical partners on FFC's behalf.

6.4   Vision for the Future

All participants were asked to describe their five-year vision for the future of the clinic. Several times, this question was met with the hope that the clinic would no longer need to exist. Upon further prompting, participants' most common responses included having enough providers to expand hours and increasing the clinic's presence in the community. Other top priorities included building relationships with area organizations and reintroducing the health education program.

The process of envisioning the future brought out the specific improvements and goals that the participants thought were most important. Most of the hopes are logistical: more providers, hours, and space. Others were more complex: outreach, education, and collaboration. Beyond the five-year vision, some participants also saw potential for the clinic's role in the healthcare system to expand. Participant responses are presented here as a roadmap for the clinic as it grows and changes. The community-wide benefits of working toward this vision is explored in the discussion.

6.4.1   Providers

Nineteen participants mentioned having a consistent schedule of providers as an essential part of their 5-year vision for the clinic. Insight from the staff suggested that this is especially important for the holistic providers: "A lot of people have lost faith in it because wait lists are so long. People are on the wait list for massage for a year or more." The loss of faith that she describes bespeaks the importance of consistency in maintaining trust.

6.4.2 Hours

Twelve participants included maintaining or expanding walk-in clinic hours as part of their 5-year vision for the clinic. The expansion of hours is linked to maintaining a schedule of providers. Without a medical provider, the walk-in clinic must close, often on short notice. A volunteer offered her take on inconsistent hours:

> If you're a person from the community and you come once, you get it together to come once and there's no one here even though we advertise that there's people here, the likelihood of you getting it together a second time to come back is not real great. I think it affects the patients, I think it affects the morale of the volunteers, I think it affects our image in the community, and it also affects people donating because they think Oh, this is kind of a sinking ship, why would I donate to this?

The effects of inconsistency are felt among multiple stakeholder groups: patients, volunteers, donors, and the larger community. Ideally, the walk-in clinic could staff not only its posted hours, but also expand to more nights of the week to offer patients more opportunities to receive care.

6.4.3 Outreach

Twelve participants mentioned increased community outreach as part of their 5-year vision for the clinic. A common thread through most interviews was that, while the free clinic is available for those who need it, FHA is not as well-known in the community as it should be, given its history. Staff also brought up the barriers that patients might have preventing them from using the clinic's services. One is distance, which really highlights the lack of free clinic infrastructure in the region. A staff member shared that "People are willing to drive hours and hours and hours if they can, but a lot of them have to cancel a lot of appointments because they're in such pain they can't make it here. And that's, that's now. That's with the ACA still in effect." These observations are immediately tied to policy; clearly the policy-related barriers are

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linked to the health-related barriers in this individual's mind. Outreach is needed not only to find potential patients and donors, but also to establish FHA as an important voice in conversations about healthcare and policy.

6.4.4   Space

Eleven participants spoke of the clinic's infrastructure in their 5-year vision. Responses included having enough space for an increased number of providers, as well as separating the clinic into administrative and clinical floors. Volunteers and staff were particularly attentive to patient flow. While waiting to discharge, patients sit in chairs in a heavily-trafficked hallway that connects the waiting room to the administrative office and conference room in the back of the building (Figure 6.4).
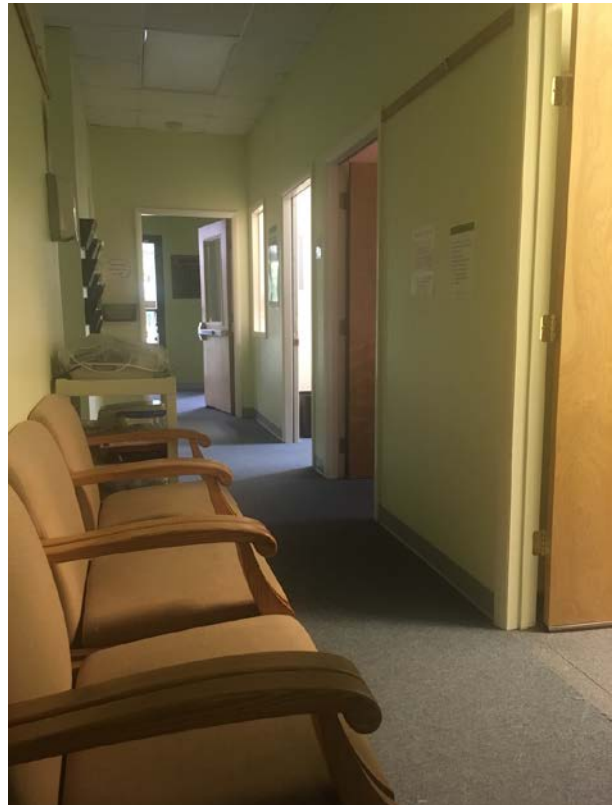
Figure 6.4: Discharge hallway and exit.

If patients use walkers, wheelchairs, or other medical assistive devices, or if a parent comes in with a stroller, this hallway becomes even more difficult to navigate. In addition, participants noted that having patients leave through the same door they came in might not be ideal for patient privacy or efficiency. One participant would like to see a design similar to the local Planned Parenthood, where patients enter through the waiting room, progress in a circle through the clinical area, and discharge through a separate

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vestibule. In this way, patients never return in the direction they came from, but follow one continuous path.

Despite shortcomings in the current space, staff and volunteers who had worked in the old building were quick to point out how much of an improvement this building is, especially in terms of accessibility. The previous clinic was located at the intersection of two busy roads and required patients to climb stairs to enter. These observations highlight the importance of adapting the size and design of the space as the organization scales up.

6.4.5 Collaboration

Eight participants specifically mentioned building relationships with area organizations as part of their 5-year vision. These participants hope to see FHA be recognized as a significant part of the region's healthcare delivery infrastructure.

6.4.6 Education

Eight participants included the addition or revival of community health education programs to their 5-year vision for the clinic.

6.4.7 FFC as a National Example

Two volunteer practitioners emphasized the integrative care model as one of the clinic's greatest strengths. Both suggested that this model could be an example across the country of biomedicine and holistic medicine coexisting and collaborating to the benefit of patients.

The integrative model of FFC is clearly visible in the Chronic Care Program, which enjoyed popularity as a pilot program and now seeks additional funding. Nine participants

specifically mentioned the Chronic Care Program when asked about the clinic's selling points. Chronic Care was often named during informal conversations between volunteers and patients, especially when patients asked about other services that FFC offers. If the FHA were to pursue national attention for the integrative care model, the Chronic Care Program would likely be at the center of the conversation. Building long-term sustainability for the Chronic Care Program now could open future opportunities.

FFC is already a member of the National Association of Free and Charitable Clinics and has sent board members and practitioner representatives to the NAFC conference in the past. If FFC chooses to promote itself as a national example, NAFC might be a good place to start. Even without ambitions of national attention, FFC could explore other benefits of membership.

6.5   Reception of Results

During the presentation to the Board of Directors, it was clear that these findings and recommendations did not come as a huge surprise. After all, their own interviews and meetings were part of the data. Many of the recommendations sound like common sense—if you want to be better known, ramp up social media; if you want to attract funding, communicate positive outcomes. The value of the client deliverable should be that it gathers together so many good ideas from people who care about the clinic into one place for future planning. By demonstrating where the different participant groups' knowledge and support overlap, the clinic can prioritize initiatives that will provide the most benefit, most efficiently.

CHAPTER 7

DISCUSSION

This chapter first considers how data gathered from FFC's donors fits into anthropological discourse on gifts. I then present my design for an evaluation of the Chronic Care Program, a future activity that would support the clinic's long-term vision of becoming a national model for integrative care. Finally, I describe how the clinic's work strengthens social cohesion, which yields local financial support.

7.1   Building Relationships of Reciprocity

The results of this research study align with the theoretical discussion in Chapter 4 in a broad sense. Donors operate as though their charitable giving were a reciprocal relationship, with donors providing financial support and the clinic providing information and community-strengthening outcomes. At the Finger Lakes Free Clinic, donors are also seeking evidence of stability for the clinic's future, just as the clinic is seeking financial support to remain stable in a time of uncertainty. The relationship only works if both parties are invested.

Reciprocity, with the goal of equal footing in the relationship, is an interesting concept to introduce to healthcare, since the existing institutions rely heavily on an organizational hierarchy of doctors and other staff above patients. This hierarchy is complicated in the case of donors, who lack medical expertise, but hold power over necessary resources.

The donors' expectations for reciprocity help to classify these gifts as Mauss would describe them—intentionally building relationships. Contrary to this perspective, Derrida writes that gifts bound by expectations and laws cannot be called gifts but are instead tools of distributive justice (Derrida 1992). The idea of distributive justice aligns with the viewpoint of

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the clinic's supporters, who describe healthcare as a human right. In the case of FFC, the flow of resources from people who can donate to uninsured people can be viewed as a form of distributive justice. Clinic activities affect social determinants of health (community education, insurance enrollment, social work), which moves the community toward health equity. Through philanthropic giving, the donors participate in distributive justice.

Despite broad agreement with the literature, it would be difficult to generalize these findings as characteristic of all donors to free clinics. Donors in this study had diverse perspectives regarding their motives and expectations for a charitable giving relationship. For example, some of the older participants donate because they knew the founders when the clinic first began. This shows a strong relationship with this particular clinic's history that might not translate to other locations. Although they are interested in knowing how the clinic is doing now (reciprocation of information), the relationship has already been built and more time can elapse between moments of contact. This underscores the need for different types of reciprocity for different types of donors.

The findings' departure from the literature can be attributed to the scale of giving at the FFC. FFC is a small, local nonprofit. Although donors are understandably curious about how their money is being used, there is less concern about the large-scale corruption seen in major NGOs. In fact, donors cited the fact that they could see the local effects of their donation as a reason to donate. Being right there in the community, it would be easy to see if FFC was not translating resources into positive outcomes. In a similar vein, the act of giving to FFC is less of a social symbol than it is a quiet investment in the community. It would be difficult for donors to wield power and social influence through these donations because of the organization's scale.

The case of FFC challenges Hanson's critique (2015) that donations are used by elites to

reinforce their position and avoid larger social responsibility. Ithaca's history of grassroots organizing has created a culture of "both-and" rather than "either-or" in regard to charity and advocacy. Not only do these donors give to FFC and other health equity causes (e.g. Planned Parenthood, Cancer Resource Center, United Way), but they also advocate for universal healthcare and other structural changes at the same time. I argue that part of the difference between the elites Hanson describes and FFC's donors is the personal connection donors maintain with the clinic. The same stories, awareness, and experiences that motivate their donation to FFC demand that they also engage the root causes. Identification of root causes might also come more easily to the highly educated Ithaca population, who might already be aware of concepts like "social determinants of health" and the structural inequalities in the United States.

7.2   Supporting the Vision: CCP Evaluation Proposal

Many of the goals outlined in the above section require long-term monitoring through targeted data collection. Fourteen participants identified data collection as one of the clinic's needs. With access to accurate data, the FHA can evaluate its programs for quality, growth, and sustainability.

Program evaluations allow organizations to measure success while providing evidence for implementation in other locations. To become a national model for integrative care, the FHA would need to provide statistics that support the success of the integrative care model. The evidence-based intervention is the gold standard of public health programs, but there is no single type of evaluation that validates every type of intervention perfectly (Patton 2012). Evaluation methods are tailored to fit context; anthropological data is valuable to the design. Although

implementing an evaluation of the Chronic Care Program was beyond the scope of my project, I did have the opportunity to create a plan for a future evaluation during my public health coursework, which I present in this section.

While designing the evaluation, I was heavily influenced by Michael Q. Patton's principles of Utilization-Focused Evaluation (UFE) (2012). Due to the FFC's limited resources and personnel, it was especially important that all parts of the evaluation be relevant to stakeholder questions and the presentation of findings be optimized for ease of use. Patton's concept of the "personal factor" was particularly applicable in this case, as the FFC's new executive director is a charismatic leader with strong ties to powerful community organizations such as the United Way and the local hospital system (Patton 2012, 63). During my fieldwork in the clinic, the executive director expressed his preference for robust data and enthusiasm to see the CCP continue past the pilot stage. Interviewees expressed their support of the executive director, recognizing his experience in leading other nonprofits and ability to speak expressively about the clinic. With the executive director's support of this evaluation, the findings would be more likely to be used. To that end, I designed questions that would provide him with the information he needs in many different forms to communicate effectively with partners. The hospital cost-savings estimate and the various measurements of program effectiveness are two examples of this design choice.

This evaluation responds to the program design and goals set in Larsen's CCP pilot (2017). In the pilot phase, Larsen conducted a pretest-posttest reflexive study that assessed self-efficacy and satisfaction in the patients while pretest-posttest chart reviews assessed quality of care and impact on clinic procedures (Larsen 2017). Based on the Chronic Care literature presented in Chapter 4, this section will outline a plan for further evaluation of this program in its

post-pilot state, with attention to how these evaluation measurements can be compared to the pilot pretest-posttest results. It is my hope that the FFC will use this tool as a starting point for future evaluation.

7.2.1 Program Description

Larsen's pilot study had two main research priorities: measuring patient self-efficacy and satisfaction and measuring the impact of implementing CCP on clinic process and structure (Larsen 2017). Since the pilot, CCP has become institutionalized; this evaluation will focus on the program's patient-centered objectives rather than its impact on clinic procedures.[6] This evaluation will measure the effectiveness of the team-based care model on patient outcomes and experience. The overall goal of the program is to increase patients' self-efficacy in managing their chronic conditions while demonstrating excellence in patient-centered integrative care delivery. This goal will be achieved through meeting the following objectives.

- Process Objectives:
  1. Patients will develop a management plan in conjunction with the care team within one month of signing up for the program.
  2. Based on the Patient Assessment of Care for Chronic Conditions (PACIC) instrument, 75% of patients will significantly favor the intervention overall at 6 months.
  3. 75% of patients enrolled at the beginning of the program will finish the 6-month unit, excluding losses to mortality.

- Outcome Objectives:
  1. 50% of patients will demonstrate improved self-management in relevant biological tests at 6 months. 75% of patients will have done the same by 12-month follow up.
  2. Based on the Stanford Self-Efficacy for Managing Chronic Disease 6-Item Scale,

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[6] Before evaluation, it seems that the CCP's biggest limitation is that there is no plan to transition patients out of the program—or assess their preparedness for that transition—after the 6-month program unit. Without this key mechanism, the CCP will reach fewer patients overall and struggle to maintain sustainability as patients remain in the program indefinitely. Although modifying the program in such a significant way is not the goal of this evaluation, evaluators will consider the possible use of their results by program planners to develop an exit strategy.

more than 50% of patients will show a statistically significant increase in overall self-efficacy at 6 months, maintained at 12 months.

3. Based on the RAND Short-Form 36 Health Survey (SF-36), the average score per condition will have significantly increased at 6 months, maintained at 12 months, indicating higher long-term mental and physical well-being.

7.2.2   Evaluation Methods

The CCP will be evaluated using a mixed-methods approach, incorporating survey instruments, lab test data, case reports, interviews, and observation. The evaluation plan consists of a process evaluation at three months (mid-intervention) and an ongoing outcome evaluation with measurements at baseline, 6 months (at the end of the intervention), and 12-months (6 months after the intervention's conclusion).

The process evaluation is intended to measure the degree of integration among multiple healing modalities as well as the successful transition from pilot to present. This will be measured through provider interviews and observation of clinic activities surrounding the CCP at 3 months (mid-intervention). Providers will be asked about their experience on the care team as well as their suggestions and vision for the future (Appendix C). Observations will allow evaluators to triangulate providers' responses; it would be a significant finding if discrepancies between internal perception of the program and real-life implementation were uncovered. After iterative coding of interview data and field notes, themes from providers' perceptions of the program will facilitate a comparison of pilot activities with current activities. This will be supported by a review of case reports to track the number of referrals between modalities as well as the number of patients developing management plans and remaining enrolled in the program.

In addition, the process evaluation will include measurements of patients' perceived quality of care using the Patient Assessment of Care for Chronic Conditions (PACIC) instrument. This survey includes questions about patient input on the management plan,

connection to other resources, and perceptions of the providers' attention and cultural

competence. A high score on this instrument would indicate that patients perceive the program

the way FFC intends: as patient-centered integrative care. The PACIC measures patients'

perceptions of care from the past six months, so the measurement will be administered at

baseline, 6-months and 12-months. Changes in the patients' scores over time will be analyzed for

significance using Wilcoxon signed-rank tests. Seventy-five percent of patients should

significantly favor the intervention overall at 6 months, with maintenance or improvement at 12

months, to achieve Process Objective 1.

Patient outcomes regarding self-efficacy and self-management of their chronic conditions

will be assessed through two survey instruments, interviews, and biological tests. Patients' self-

efficacy will be measured using the Stanford Self-Efficacy for Managing Chronic Disease 6-item

scale. This scale asks patients to rate how confident they are in managing various aspects of their

condition, from physical discomfort to emotional distress. Changes in the patients' scores over

time will be analyzed for significance using Wilcoxon signed-rank tests. 50% of patients should

demonstrate a statistically significant increase in overall self-efficacy at 6 months, with

maintenance or improvement at 12 months, to achieve Outcome Objective 2. This instrument

and the PACIC instrument were used in the pilot test, so results can be compared to the pilot

results.[7]

The evaluation will add a third instrument, the RAND 36-Item Short Form Health Survey

(SF-36), to measure health-related quality of life. Due to the varied structure of survey

questions—scales of different lengths, yes/no questions—individuals' overall scores will be

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[7] On the PACIC, pilot participants significantly favored the intervention in all sub-categories in addition to overall. On the Stanford Self-Efficacy scale, pilot participants' responses to Q3 regarding management of emotional distress significantly favored the intervention.

grouped by condition, then the average score per condition will be tested for change over time using paired samples t-tests. To achieve Outcome Objective 3, average scores should increase at 6 months with maintenance or improvement at 12 months, indicating improved quality of life.

Although these survey instruments have demonstrated effectiveness in evaluating chronic disease patients and complementary therapies (Larson 2017, Schmittdiel et al 2007, Rosenzweig et al. 2010), surveys alone do not offer a holistic picture of patient experience. This evaluation will make use of semi-structured patient interviews at baseline, 6 months, and 12 months to better understand the survey instrument results. Patients will be asked about their experience in the program (Appendix C); responses will be coded and analyzed using the same method as the provider interviews.

To measure a biological component of self-management success, patients will undergo relevant lab tests at each outcome data collection period (baseline, 6 months, 12 months). These tests will be specific to the chronic condition that the patient has. For example, the effectiveness of the program for a patient with diabetes might be determined using HbA1c levels. To achieve Outcome Objective 1, 75% of patients should demonstrate improvement or maintenance at a healthy level at 6 months, maintained at 12 months. Appropriate measures—that is, the definition of "self-management" and "healthy"—will be determined by the care team for each patient in consultation with medical literature and best practices.

Finally, to support the program's sustainability, evaluators will estimate the cost avoided by local healthcare infrastructure through the CCP's treatment of uninsured chronic disease patients. This estimate will be calculated at the 12-month mark. Actual costs for chronic disease patients in the ER for the previous three years will be compared with projected costs for additional uninsured chronic disease patients.

Table 7.1: Summary of evaluation methods.

Purpose	Evaluation question	Source of data	Variable	Analytic strategy	Timeline
Process evaluation assessing the transition from pilot to full program	How well does the current program maintain fidelity while improving and expanding upon the CCP pilot?	Case reports	Percent of patients who have developed management plan within 1 month of program start	Descriptive statistics - % with plan	1 month
		Provider interviews, observation	Fidelity - Which elements have been kept/dropped, and why? Have limitations identified in the pilot been addressed? (e.g. introducing "volunteer navigators" to connect pre-med students [Larson, 2017])	Qualitative – reporting on the current status of the program in relation to the pilot	3 months
		Completion rate of program	Percent of patients enrolled at the beginning of the program who finish the 6-month unit, excluding losses to mortality	Descriptive statistics - % who finish	6 months
Process evaluation assessing degree of integration and patient perception of quality of care	How well does the integrative model support chronic disease management in this setting?	Case reports	Number of referrals to alternative modalities	Descriptive statistics – compare numbers of referrals for each modality	3 months
		Provider interviews	What feedback do providers have about the feasibility of integrative chronic care at FFC?	Qualitative - identifying themes through iterative coding	3 months
		Patient Assessment of Care for Chronic Conditions (PACIC) instrument	Change in individual patients' scores	Wilcoxon signed-rank test	Baseline, 6 months, 12 months
Outcome evaluation assessing the effectiveness of intervention on self-management, self-efficacy and health-related quality of life	Are patients in the Chronic Care Program able to self-manage their conditions within one year of beginning the program?	Biological tests relevant to the chronic condition	Change in average results for each type of chronic condition	Depends on the type of test, but likely paired samples t-test	Baseline, 6 months, 12 months
		Stanford Self-efficacy for Managing Chronic Disease 6-item scale	Change in individual patients' scores over time	Wilcoxon signed-rank test	Baseline, 6 months, 12 months
		RAND Short-Form 36 Health Survey (SF-36) instrument	Change in average score for the whole group	Paired samples t-test	Baseline, 6 months, 12 months
		Patient interviews	What feedback do patients have about the effectiveness of the program for their condition?	Qualitative - identifying themes through iterative coding	Baseline, 6 months, 12 months
Outcome evaluation assessing effect of intervention on local infrastructure	Does the CCP decrease the cost burden of uninsured patients with chronic conditions on the local health infrastructure?	Local hospital ER utilization and cost data	Estimated amount of money that hospitals would spend on uninsured ER visits from chronic care patients	Cost-savings calculated based on actual versus projected costs for three complete years since the pilot began	12 months, with data from 3 years prior
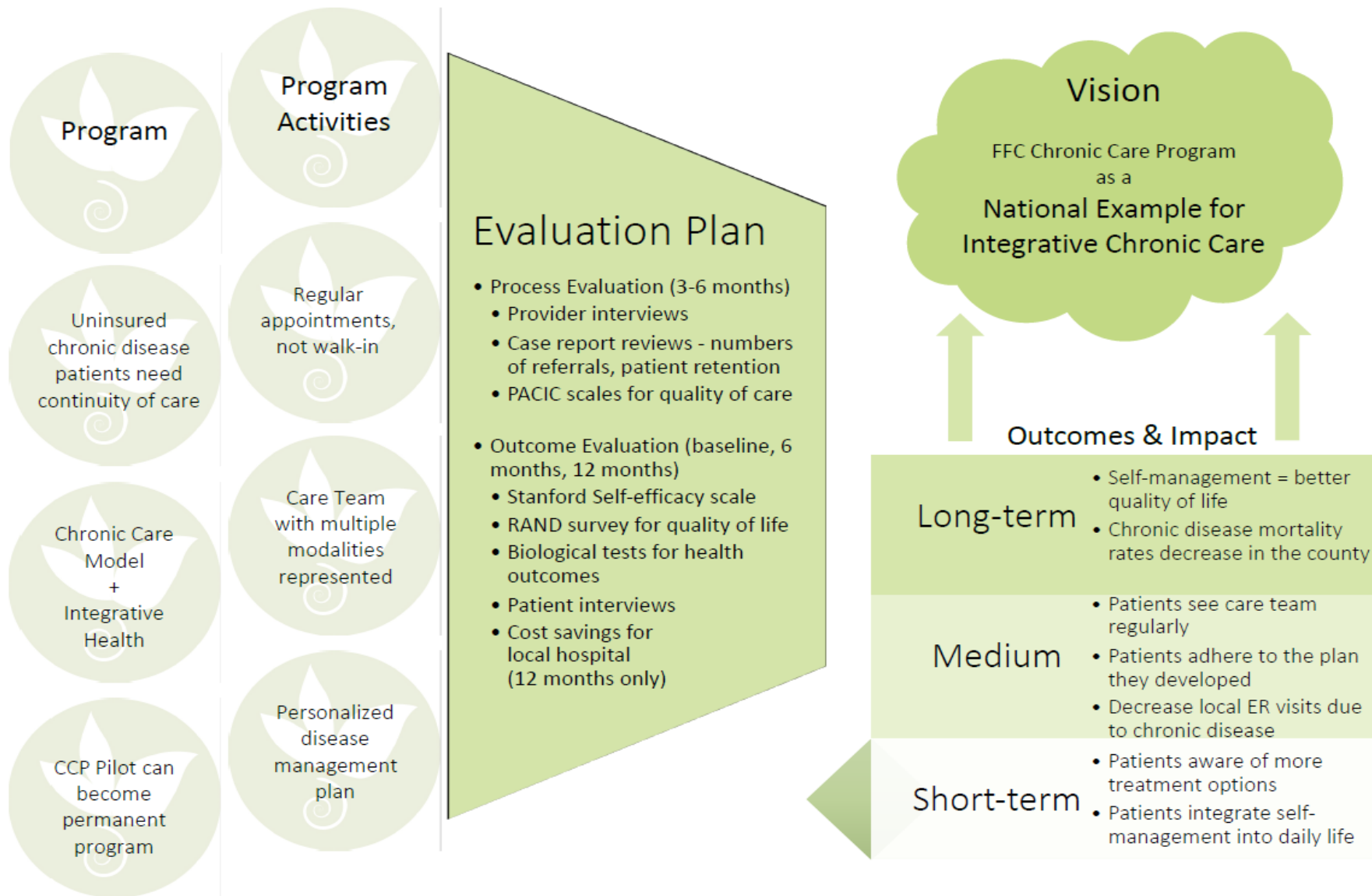
Figure 7.1: Logic model.

Projected costs will be calculated based on existing hospital utilization data and the average cost of ER treatment in the region. To indicate a substantial impact on ER costs, the actual cost of chronic disease visits would have to be about 23% less than projected (Steiner et al. 2008).

The evaluation methods outlined in this section are summarized in Table 7.1. The table operationalizes the process and outcome evaluation objectives into measurable variables, then indicates how and when those variables will be measured. In utilization-focused evaluation, each line of inquiry must have a clear purpose that aligns with the goals agreed upon by the stakeholders. This internal consistency adds to the face validity of the results, which stakeholders will then be more inclined to use. The methods table is followed by the evaluation proposal's logic model (Figure 7.1), a graphical representation of the evaluation's role in supporting both program goals and long-term vision. Through the evaluation, the program components are revealed to have individual outcomes and long-term impacts that strengthen FFC's case as a national example.

7.2.3 Dissemination

Results will be shared at three critical junctures during the evaluation process at 3, 6, and 12 months. Preliminary and process results will be shared with internal stakeholders at the 3-month mark. This report will focus on patient progress in the program, fidelity to the pilot model, degree of integration in care modalities, and feedback from the care team. Based on this data, the program team will determine what, if any, changes need to be made as the program continues. At the 3-month mark, evaluators will hold workshops to simulate use of fabricated findings. This practice is useful when working with diverse stakeholder groups. Workshops with fabricated

findings help stakeholders gain familiarity with the process of turning evaluation data into decisions, preparing them to engage meaningfully with the actual results at a later date.

After the 6-month CCP unit, results from PACIC instrument and patient interviews will be shared with FFC staff, board members, and the care team in a similar workshop format. Information will consist of data visualizations of PACIC results and salient quotes from the interviews. FFC's outreach volunteers will be able to use this deliverable to increase community support and seek donor buy-in for the program.

After the 12-month follow-up, aggregated and de-identified results from the biological tests, all survey instruments, interviews, and the cost-savings estimate will be shared in a written report with the board, FFC staff, and the care team. These results will be used to support grant writing to sustain or expand the program. The evaluation team will make a presentation to the Board of Directors during one of the monthly board meetings upon completion of the evaluation. An executive summary of the report will be distributed one week before the meeting to facilitate discussion after the presentation. The full report will be made available to future staff and board members in the organization's archives; information from the report can be released to other stakeholders or to the public at the board and staff's discretion. To promote the FFC's use of the findings, a representative from the evaluation team will continue to attend board meetings for 6 months following the end of the evaluation. This representative will be available to answer questions and make suggestions about the appropriate use of findings.

7.2.4   Feasibility

The evaluation proposal outlines a best-case scenario in which FFC can mobilize a team of personnel to carry out the evaluation activities (surveys, interviews, analysis). It is possible

that there would be some resistance to the idea of evaluation due to cost and time burden, in addition to the effort of coordination. To fit into FFC's budget, the team would be comprised of volunteers; the best source of skilled volunteers would be the nearby colleges: Cornell University, Ithaca College, and Tompkins Cortland Community College. If a group of motivated students could be found, the activities of this evaluation would be feasible for the clinic to complete over a year-long period. A successful evaluation of this particular program would strengthen the FFC's case as a national model for integrative care.

This proposal for evaluation is presented here to demonstrate the type of data collection that would best support the future vision for the clinic: rigorous evaluation of existing programs, encompassing patient outcomes, community impact, and operational efficiency. Beyond the pragmatics of data collection, support for the clinic's future comes from its community. The FHA began as a grassroots organization and continues to play a vital role in the local healthcare infrastructure. By mobilizing the support of volunteers, donors, staff, board, and practitioners, FFC can meet long-term goals while sustaining activities into the future.

7.3   Sustainability: The Mission Supports Itself

FFC provides care to the uninsured while decreasing the rate of uninsurance, a mutually-reinforcing set of activities that promotes the organization's sustainability. Treating an uninsured person is an episodic moment with community-wide effects. The negative spillover effects on access and quality of care for people with insurance are less likely to occur if the uninsured are getting the preventive and primary care they need in a community clinic rather than in the ER. Insurance navigation is an important component of the Chronic Care Program. FFC also helps the uninsured complete pre-employment physicals, which could lead to employer-supported

insurance. These activities are supplemented by community education, which could be expanded to include information about navigating the system and addressing social determinants of health. The treatment and the navigation are connected; together they provide not only individual benefits for the people involved, but also community-wide benefits, namely improved social cohesion. The link between uninsurance and decreased perceptions of trust, sharing, support, and obligation among community members was demonstrated by McKay and Timmermans (2017). They posit that uncompensated hospital treatment of the uninsured creates tension in a community as competing goals arise, and higher healthcare costs for uninsured families widens social distance. "Social cohesiveness, trust, and reciprocity among community members" breaks down as different interest groups try to direct money toward the uninsured or some other social need (McKay and Timmermans 2017, 58). By placing reciprocity right alongside cohesion and trust, the authors highlight, perhaps unintentionally, Mauss's insight about charity-related relationships. Reciprocity and trust bolster social cohesion. Considering the emphasis donors placed on local support and community-mindedness as motives for donating, social cohesion, trust, and reciprocity are all vital to the clinic's financial support. In this way, the FFC is working indirectly toward financial stability every time they see a patient or enroll someone in insurance because they are working to build up social cohesion.

7.4   Implications for the Field

This research adds to the body of literature on free clinics and the relationships they build with their communities in two ways. First, this discussion illuminates the need for further applied anthropology work on charity and reciprocity on a smaller scale to further reveal the additional responsibilities and relationships involved in local nonprofit work. In this study, the importance

of locality surfaced repeatedly. Donors were glad to know that their philanthropy had effects on their immediate surroundings. It would be worth exploring further the effect of proximity on the strength of the gift relationship.

This research adds to public health scholarship by demonstrating a connection between community resilience and support of health-promoting organizations. Donors' dedication to their local free clinic seemed to be unaffected by the threat of federal changes, suggesting resilience to national-scale issues. Community resilience has been discussed in public health as a component of disaster response (Morton and Lurie 2013). There is an opportunity, in the light of these findings, to theorize community resilience with added insights from applied anthropology—what cultural forms and practices contribute to resilience, and how could a culture of resilience mitigate (potentially disastrous) policy effects on population health?

CHAPTER 8

CONCLUSION

8.1   Limitations

This study is limited by the lack of existing anthropological studies on small-scale local

philanthropy in the United States. The bulk of the literature on charity focuses on large NGOs

and critiques of international aid. Without applied anthropology literature to build upon, the

connection between the theoretical analysis (donations as gifts) and the practical knowledge

gained (effects and perceptions of policy) is less established.

The research methods are limited by the small sample size, which is tied in part to the

size of the clinic and the network of donors. Participants were self-selected to some extent, so the

people I spoke to were already the most engaged with the clinic (reading the recruitment emails,

taking the initiative to reach out and participate). While this is a limitation to the generalizability

of the study, the findings can still be helpful to the clinic, which now has a sense of the opinions

of the most engaged and vocal part of their donor base.

Similarly, it is unclear whether this study comprised a representative sample of all

donors. Many of the people who responded chose to meet during business hours and were of

retirement age, suggesting that this study may have unintentionally excluded donors who are

busy or working. Conducting a longer study with more research personnel might have facilitated

the recruitment of other donors, who also would have provided valuable information.

8.2   Future Research

Due to the timing of the research and the failure of all Republican-proposed healthcare

reform in summer 2017, it was impossible to measure the direct effects of a policy change on the

local level. Measuring these effects is a difficult task, since most federal policy extends into multiple areas of influence. Future research should make use of new methods for analyzing policy effects—particularly the method outlined by Basu, Meghani, and Siddiqi (2017): constructing a control group. So far, there have been two primary methods for measuring policy effects on health. The first is the pre- and post- comparison of a single group affected by the policy. The limitation of this method is that it does not control for unrelated, natural trends that the group may already have experienced in the absence of the policy. The second method is the difference-in-differences comparison, which selects a comparison population based on similarity to the treatment group. This method assumes that the two groups are following the same general trends before the policy and that the policy would affect each group equally. Both of these methods have limitations that can be mitigated by constructing the comparison group. Basu et al.'s method selects subgroups of policy-exposed and policy-unexposed people, then matches them based on similar characteristics (age, income, location, etc.). Such a method, used in a mixed-methods study, could offer statistical evidence of the link between policy and outcomes.

CHAPTER 9

REFLECTION

This project has personal significance to me because at the time of the project, I was in the planning stages of relocating permanently to Ithaca. I wanted to get to know the community that would be my community, in a way that was useful to them. A year later, I have officially moved to the area, and I continue to feel a connection to the city, the region, and the local healthcare infrastructure. In addition, this was my first health-related research experience that I was entirely responsible and accountable for executing well. There was added pressure knowing that, as I plan to remain in the health sector in this region, I would certainly be working with these people again. Lastly and most importantly, the FFC embodies a cause that I am passionate about: making it easier for people to get the care they need. This project is an intersection of many interests, old and new: repairing the healthcare system, coordinating integrative medicine, analyzing government policy, listening to people's stories, understanding local culture and community cohesion—and this was even before I met the extraordinary individuals involved with the FFC.

Over the course of the project, I met people from all walks of life. During interviews, I got to know some of the local social elite—business owners, Cornell professors, and others. My participant observation at the clinic made clear to me the depth of the community's need for the FFC. Conversations with the clinic staff and board provided a middle ground—many were involved because they or someone they knew had needed the clinic in the past. One of my favorite parts of the experience was uncovering a similarity: all were extremely dedicated and enthusiastic about the mission. This is one of the strengths of having so many volunteers built

into the operating structure. It was inspiring to hear donors speak in support of the clinic, to hear staff speak in support of volunteers, and to hear providers speak in support of their patients.

Most of the differences between myself and the people I worked alongside came from my anthropological training. While the public health practitioners I talked to were largely focused on the individual level (e.g. case management) or the system level (e.g. advocacy), I have been trained to address both simultaneously. There is a danger there of bouncing back and forth from the big to the small picture without actually getting anything done. It was very instructive to see people working at each end of the spectrum efficiently. I did see a strong parallel between FFC's balance of the biomedical and holistic medicine with my own in-between state of public health and anthropology. As both FFC and I can attest, it is possible to do both well.

During fieldwork, I learned an enormous amount about how small nonprofits operate. I went in largely unaware of the potential financial difficulties, the strength of the volunteer corps, and the constant need to strategize around development. I also got to see firsthand a high-functioning free clinic practicing both biomedicine and holistic medicine—a rarity among community clinics. This is all useful information to bring back to the academic world. As we address real-world problems in applied research, it will be important to maintain an on-the-ground view of the effects on individuals and the healthcare delivery system.

Most of what I brought to the project from my classwork was methodology, with a hefty dash of theoretical grounding. It was much easier to converse with behavioral health providers when we could talk about the different models of care; it was necessary to understand social determinants of health and the power structures inherent to the system to speak intelligently about access for uninsured patients. The project's design as applied anthropology research allowed me to gather ethnographic data not only to describe what was going on, but also to make

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meaningful suggestions. Anthropology also offers a longer history of criticism than does public health. While public health has wholeheartedly embraced the concept of social determinants of health, anthropology targets for criticism the unequal social systems that determine the determinants.

The project provided many opportunities for growth, which were easy to spot as the times I felt the least sure of myself. Toward the end of data collection, one participant rather bluntly told me that the connections I was trying to make between policy and donations probably did not exist, and I would be better off researching another topic. Though unsettling at the time, such moments are valuable reminders to interrogate the value of research to the participants. The most practical area for growth was research methods. Though I conducted previous anthropological research, I did forget how uneventful day-to-day observation could get—not to mention how exhausting back-to-back interviews could become. My fieldnotes became steadily more relevant and detailed over the course of the project.

Overall, my perspective on public health practice has shifted from a transactional approach to a transformational approach. This change has been facilitated by my coursework in spring 2018, particularly Dr. Emily Spence-Almaguer's evaluation class and Dr. Marcy Paul's community-engaged research class. I came into the project with a problem-solving mindset; the clinic needed information, and I was going to gather it. Looking back, I realize that public health practitioners need to be more flexible and holistic. It is good to be the person with the answers, but it is better to build the community's capacity to find or make their own answers.

In graduate school, and in part because of this project, I have become even more critical of the health system in this country and its uneven approach to care. Supported by the data on health disparities, I have learned to point out injustice. More importantly, graduate school has

given me new tools to fight injustice—in this case by using my skills to support a nonprofit whose cause resonates with my values. FFC serves the people at the margins and in the gaps. By the time they get to the free clinic, just about every patient has a story of how the current system is failing to serve them the way it should. Working with FFC, I have learned that the short-term fix of free walk-in care can occur simultaneously to the long-term fix on the system level; we do not have to choose one path toward health equity.

I currently find myself working in nearby Broome County helping rural Medicaid enrollees to identify and access available community resources. From here, I can see a broader picture of the health delivery system in which the Finger Lakes Free Clinic plays a part. My experience at FFC not only enhanced my credibility as a candidate but reminds me on a daily basis of the ability of communities to provide care where the system fails. My future research interests remain in the same sphere—redesigning current systems to break down the barriers to healthcare access.

APPENDIX A

SUMMARY OF RECOMMENDATIONS

Resources and Strengths

Participants were asked about the resources and strengths that the clinic already possesses. These strengths can be leveraged toward the achievement of the goals outlined in this section. Assets are listed here with the number of participants who suggested them in parentheses.

Resources:
- Volunteer corps (6)
- Practitioners and collaborative organizations (5)
- Clinic location and facility (2)

Strengths:
- Integrative care model, particularly in the Chronic Care Program (9)
- Service-oriented mission and work ethic (6)
- Community and patient trust (3)
- Ability to humanize the healthcare discussion (3)
- Independence from some government regulation (2)

Short-term actions
- Plan and distribute a quarterly newsletter
- Pursue Cornell residency – FFC partnership
- Support sustainability of the Chronic Care Program
- Collect and manage data

Medium-term actions
- Advertise social media management volunteer position to students
- Consolidate brand
- Update internet presence
- Broaden donor base through collaborating with other organizations, business sponsorships, attracting younger generation of donors

Long-term actions
- Prepare persuasive case for ongoing partnership with Cayuga Medical Center
- Participate in local government and remain involved in healthcare policy issues
- Establish FFC model as a national example through evaluation and publicity

APPENDIX B

INTERVIEW GUIDES

Internal (staff, board, volunteers)

1. How informed do you feel about federal healthcare policy?
    a. Probe: Where do you get your information about healthcare policy?
2. How do you feel about the recent changes to American healthcare policy?
    a. Probe: Specific policy changes like the proposed AHCA?
3. How would you describe the future of healthcare in America? In your community?
    a. Probe: What about in terms of support for community clinics? Federal support? State support? Local/community support?
    b. Probe: What specific impacts do you expect healthcare policy changes to have on your community?
    c. Follow-up: How would you describe your attitude toward this future?
        i. Probe: How does this possible future differ from what you would hope for from the healthcare system?
4. What is the role of FFC in the community?
    a. Rephrase: How would you describe community support of FFC?
    b. Follow-up: What is your long-term vision for the clinic?
        i. Probe: How does your vision for the future compare to other leaders'?
        ii. Probe: What impact do you expect federal policies to have on FFC and your vision for its future?
    c. Follow-up: How has this vision developed over time among clinic leaders and the board?
5. From what you've heard, how does the Ithaca community feel about the future of healthcare in America?
    a. Probe: Specific policy changes like AHCA?
    b. Follow-up: Donors' feelings, specifically?
6. Describe FFC's current efforts to engage with donors?
    a. Rephrase: What strategies does the clinic currently use to strengthen donor engagement or recruit new donors?
    b. Probe: What challenges does the clinic face, with regard to donor engagement?
    c. Probe: What are the clinic's strengths when it comes to donor engagement?
        i. Rephrase: What are the clinic's major selling points that you want to be sure to communicate to donors/potential donors?
7. In your opinion, what sort of communication from the clinic to donors or to the public would be an appropriate response to the current healthcare situation?
8. Do you have any recommendations of other people I should talk to for this study?

External (donors)

1. How informed do you feel about federal healthcare policy?
    a. Probe: Where do you get your information about healthcare policy?
2. How do you feel about the recent changes to American healthcare policy?
    a. Probe: Specific policy changes like the proposed AHCA?
3. How would you describe the future of healthcare in America? In your community?

a. Probe: What about in terms of support for community clinics? Federal support? State support? Local/community support?
    b. Probe: What specific impacts do you expect healthcare policy changes to have on your community?
    c. Follow-up: How would you describe your attitude toward this future?
        i. Probe: How does this possible future differ from what you would hope for from the healthcare system?
4. What is the role of FFC in the community?
    a. Rephrase: How would you describe community support of FFC?
    b. Follow-up: What is your long-term vision for the clinic?
        i. Probe: How does your vision for the future compare to other leaders'?
        ii. Probe: What impact do you expect federal policies to have on FFC and your vision for its future?
    c. Follow-up: How has this vision developed over time among clinic leaders and the board?
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        i. Rephrase: What are the clinic's major selling points that you want to be sure to communicate to donors/potential donors?
7. In your opinion, what sort of communication from the clinic to donors or to the public would be an appropriate response to the current healthcare situation?
8. Do you have any recommendations of other people I should talk to for this study?

APPENDIX C

CCP EVALUATION PROPOSAL: SAMPLE QUESTIONS

FOR PROVIDER AND PATIENT INTERVIEWS

Sample questions for provider interviews

1. Could you speak generally about how the Chronic Care Program is going?

    a. On a scale of one to ten, with one being not so great and ten being perfect, where would you put the CCP?

    b. What could raise that number by 2?

    c. What keeps that number from being lower?

2. What changes have you noticed since the pilot became a full program?

3. Has anything surprised you about the program?

4. Do you have any suggestions for changes that could be made to the program before the end of the 6-month unit?

    a. Is there anything that could be done to make your job easier?

5. What is your ideal vision for the program?

    a. Hypothetically, if the program were to get a $100,000 grant tomorrow, how would you put that money to use?

    b. Hypothetically, when this evaluation is finished in a year and the team is

    c. presenting the results, what do you want to see in the presentation?

Sample questions for patient interviews

1. Could you speak generally about your experience in the Chronic Care Program?

    a. On a scale of one to ten, with one being not so great and ten being perfect, where would you put the CCP?

    b. What could raise that number by 2?

    c. What keeps that number from being lower?

2. Can you talk about how you manage your chronic condition?

    a. What has changed for you since entering the program?

3. Has anything surprised you about the program?

    a. Is there anything that could be done to make the program more convenient or helpful for you?

4. What is your ideal vision for the program?

    a. Hypothetically, if the program were to get a $100,000 grant tomorrow, how do you think the clinic should put that money to use?

    b. Hypothetically, when this evaluation is finished in a year and the team is presenting the results, what results would be most interesting to you?

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