Bridging the Gaps in HIV Care: The Translation of PACT in New York City And the Politics of Scaling Up

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ABSTRACT

In New York City, an innovative nonprofit and the department of health are joining forces to rescue the city’s most vulnerable HIV patients and reform the system of urban HIV care. In 2005, the City of New York approached PACT (Prevention and Access to Care and Treatment) – an affiliate of Partners In Health – to set in motion the replication of the PACT model in 28 health centers throughout the city. In the process that ensued, the PACT model lifted out of any single actors’ hands and was swept up by currents of institutional priorities, capacity limitations, and interpersonal negotiations. This thesis will explore the PACT story: the conditions, interests, and limitations that shaped this process of translation. It will uncover possible causal factors in the catalysis and transformation of the PACT model, contributing a single case analysis to a critical issue: the transformation of NGO models into the public sector without the erosion of their social good.

Uniting community mobilization and public-sector resources, nonprofit-government partnerships harness complementary strengths. Beneath an infallible surface, they are profoundly political phenomena. Partnership is a process of translation in which diverse actors negotiate the transformation of a model to meet a new constellation of interests. The resulting project reflects the priorities and power asymmetries of those involved, and if left unexamined, these evolutions in program design can carry undefined implications for those meant to be served.

This thesis examines the New York events through the lens of translation theory. To do so, it leverages the framework of Michel Callon’s actor-network theory. Callon examines the power-laden process by which core actors define the interests of others and draw them into an alliance. Key actors align diverse groups behind spokespeople and speak on these representatives’ behalf, becoming the gatekeepers of information and the guardians of translation.

In New York City, an office director selected and pursued an innovative model that would resonate with the Department of Health’s cultural history and methodical future. Politicians signed off from a distance, once they were blocked from the lobbies of New York nonprofits that felt threatened by case management reform. Cash-strapped public hospitals accepted the model to receive funding. As acceptors, they bore no power of assessment, and thus their defiance of the model was interpreted as resistance to change. Finally, disadvantaged HIV-positive New Yorkers are channeled into representatives who bear token witness to an intricate process of translation.

While the relevance of this thesis to development studies is limited by its U.S. focus, it addresses a far-reaching issue: the transformation of an innovation across borders and settings. This core mission of development studies is gathering urgency in a rapidly shrinking world.
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ACRONYMS

AIDS: Acquired Immune Deficiency Syndrome
ART: Antiretroviral therapy for the treatment of HIV/AIDS
CBO: Community-Based Organization
CHW: Community Health Worker
CTH: Office of Care, Treatment, and Housing of the New York City Bureau of HIV Services
DOHMH: Department of Health and Mental Hygiene, New York City
DOT: Directly Observed Therapy
HIV: Human Immunodeficiency Virus
MOU: Memorandum of Understanding
NGO: Non-governmental Organization
PACT: Prevention and Access to Care and Treatment, Boston, MA
PIH: Partners In Health, the institutional parent of PACT
PLWHA: People Living with HIV/AIDS
RFP: Request For Proposals
STS: Science and Technology Studies, pioneered by Michel Callon and Bruno Latour
TB: Tuberculosis
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CHAPTER 1

1

In inner-city Boston, an innovative community health worker program is bringing HIV care to the most vulnerable and catching the eyes of academics and policy-makers alike. Operating in a neighborhood where a black woman is 15 times more likely to die from AIDS than a white man, the health workers of Prevention and Access to Care and Treatment (PACT) – an affiliate of Partners In Health, modeled after its operations in Haiti – are targeting the social barriers that block destitute multi-drug-resistant HIV patients from traditional care.

In 2005 PACT’s director, Dr. Heidi Behforouz, received a startling phone call. Dr. Daniel Weglein, the director of New York City’s Bureau of HIV Services, wanted to explore the possibility of replication. The PACT model was still in its adolescence and was changing rapidly. Could it entrust its patient empowerment model to the largest health bureaucracy in the nation? Would it be hollowed of the elements that captured its social good? These questions were overshadowed by another: how on earth could PACT ever refuse?

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Dr. Weglein entered the imposing Manhattan office of Commissioner of Health Tom Frieden to pitch a cross-sector initiative of unprecedented scale: the $26 million replication of an HIV care model with roots in Boston and Haiti. Called a “data fanatic” in his profile as a 2005 Public Official of the Year, Frieden had furthered New York City’s reputation as home to the nation’s most data-driven health department. Frieden’s attention was captured, first, by PACT’s scientific evidence-basis; and second, by PACT’s use of directly observed therapy (DOT), in which health workers watch patients take a dose of medication each day. Frieden had used DOT to spectacular
effect during New York’s tuberculosis epidemic of the 1990s. He gave the PACT replication a green light.

Frieden would make his own unlikely mark on the model: “he kept talking about Malawi,” Weglein would later recall. The commissioner had recently read and cited a Malawi-based public health study, which employed a specific health indicator for HIV\(^1\). Weglein and his team eagerly swept it into the PACT model.

3

Weglein presented the PACT model to a conference room packed with heated hospital administrators. Weglein, who is a Boston native, recalls, “there I was, talking about Boston with a Boston accent in New York, and that’s about the worst thing you can do.” A well-respected New York medical director, who was a staunch Yankees fan, interrupted the meeting to argue about the Yankees and the Red Sox. “This became such a city issue: ‘our city’s better than your city, don’t tell us how to do things. Everyone’s always talking about Harvard, Harvard, Harvard, but we have good institutions in this city too.’ And there was this tremendous push-back that had to do with, ‘please respect what we’ve developed here.’” The poorest city hospitals would be the first to accept Weglein’s offer of grant money for HIV case management reform. Tension would define every step of their relationship with the department of health, as they sought to loosen the PACT-inspired protocol that the city had designed and enforced.

In the replication process launched by Weglein, the PACT model lifted out of any single actors’ hands and was swept up by currents of institutional priorities, capacity limitations, and interpersonal negotiations. An alliance of diverse actors would harness the model to a new

\(^1\) Frieden (2005) cited Libamba (2005), and was impressed by their use of body weight as an indicator for HIV treatment efficacy.
constellation of interests, and recreate it almost beyond recognition. This thesis will explore the PACT story: the conditions, interests, and limitations that shaped this process of translation. It will uncover possible causal factors in the catalysis of replication and the transformation of the PACT model, contributing a single case analysis to a critical issue: the translation of NGO models into the public sector without the erosion of their social good.

**Overview**

This thesis chronicles the replication of PACT in New York City as a window into the translation of an innovation across settings. In an age of globalization, new forms of collaboration are bridging the gap between the public and private sectors. Understanding the translation of a model across jurisdictions can cast light upon the resulting program and its impact. For a health care innovation that targets America’s most vulnerable patients, an awareness of impact is vital.

To illuminate the recent events in New York City, I employ Michel Callon’s actor network theory, a subfield of translation theory. Translation is the formation of an alliance in support of an innovation’s adoption, and the rewriting of the innovation to meet a new and ever-changing network of interests. Groups are channeled into spokespeople, and power is linked to the production and communication of knowledge. “To speak for others is first to silence those in whose name we speak” (Callon, 1986: 14).

The story chronicled by this thesis has as its protagonists a celebrated but politically disempowered HIV program in Boston; cash-strapped public hospitals; image-conscious city representatives during an election year; New York’s existing HIV nonprofits, which bear the political mandate of minority communities; and New York City’s community of people living
with HIV/AIDS (PLWHA). The relationships in the network are continually redefined, as actors defy their spokespeople and seize greater agency in the process of translation that envelops them.

A translation analysis of the PACT replication illuminates the process by which innovative health care devices are taken to scale in the public sector. Here, I will present three general findings, and two additional phenomena that a translation framework cannot easily accommodate.

First, training and evaluation are the prerogatives of the powerful. New York City’s Department of Health retained control of events, first, by developing a training plan that excluded the innovators of PACT; and second, by designing the voices and timeline of the program’s evaluation. The DOH developed a scheme of evaluative forms, collected them from replication sites, and held them until they decided to initiate an assessment. This was the only channel for replication sites. The hospitals’ criticisms of the replication protocol were easily dismissed as institutional inertia or inadequate training of staff.

Secondly, even when mechanisms exist to draw disenfranchised groups into a decision-making process, unstated power imbalances can easily undercut their real involvement. In the case of New York City, the HIV Planning Council is mandated to have a third of its seats filled by New York patients. However, these few New Yorkers are unelected and dismissed by many civil servants as rowdy and unproductive, in search of attention and a free metro card. The same few New Yorkers volunteer for numerous committees and are sometimes referred to as “professional patients.” Thus, while the HIV community is mandated to have spokespeople, their non-expert voices are silenced in a room of policy specialists and hospital administrators.

Thirdly, the sale of a model through the signing of a contract is the crucial juncture when agency passes from the innovator from the adopter. PACT was heavily involved in the training
and operations of pilot programs in three New York City hospitals. After a contract was signed, however, PACT was effectively reduced to the paper curriculum which it had sold to the New York Department of Health. It was stripped of its authority to train or to evaluate, and stood by as Weglein’s team took over design and troubleshooting in the interest of efficiency, uniformity, and cost efficacy.

This thesis also examines two phenomena that a translation framework cannot explain. The first is the theme of rigidity. Each actor in the story has different incentives to seek or eschew rigidity to the model, and different powers to do so. The New York Office of Care, Treatment, and Housing (CTH) seeks rigidity in order to maintain order, treat each site fairly, and more easily evaluate the model’s results and recreate the excellent Boston outcomes. PACT desires faithfulness to their original innovation, rather than CTH’s heavily adapted protocols, in the hope of preserving the essential components of their best practice. At the same time, both CTH and PACT acknowledge that rigidity can sabotage the model’s success in new environments. Finally, hospitals and health centers battle the rigid expectations and impositions of CTH’s model. Their ideal was the situation before reform, in which they were awarded grants to perform case management however they saw fit.

Secondly, it is argued that familiarity played a crucial role in the initiation of the replication process. Actor-network analysis limits itself to forces identified by the protagonists, without interrogating the actors’ preferences or the environmental factors behind them. However, the PACT model was remarkably resonant with CTH’s history and position in a complex web of funding structures. NYC Commissioner of Health Tom Frieden had employed a similar model to swiftly curb the tuberculosis epidemic of the 1990s, and readily approved the replication. By
taking charge of case management reform, the city could bring state-funded programs under its own supervision.

In this vein, it is argued here that characteristics of the PACT model guide its replication, and their exclusion from analysis overlooks an influential force in the translation process. For example, the PACT model brings legibility to diverse and overlapping programs, by emphasizing concrete solutions such as directly observed therapy and a health education workbook.

Translation theory does not interrogate the relationship between the translator and their choice of innovation. Focusing on the resolution of shared problems, the solution is irrelevant as long as it is interpreted through the translators. If these contextual factors are overlooked, an opportunity is lost to predict a replicated program’s trajectory and ultimate outcomes.

These findings are rooted in the recent groundbreaking events of New York, which are bringing nonprofit-government collaboration for HIV care to unprecedented scale. More broadly, however, this thesis studies the adaptation of an innovation across jurisdictions, an urgent mission of development studies in a globalizing world. While the relevance of this thesis to development studies is limited by its placement in an advanced industrial democracy, its findings can inform the future replication of PACT and the scaling-up of U.S.-based health innovations without the erosion of their social good.

**Research Question**

In an age of expanding nonprofit-government collaboration, methods to chart the transformation of a model through replication are crucial. Without them, a program bearing a stamp of nonprofit legitimacy can lose the core elements that allow it to serve patient needs.  

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2 Researchers detected this trajectory with hospital case management in the 1970s: case managers were initially patient advocates who connected clients with services, but as budgets
This thesis explores the relevance and utility of translation theory, a new movement in sociology pioneered by sociologists Michel Callon and Bruno Latour.

This thesis asks whether the New York replication of the PACT model can be productively framed by translation theory. It thus poses three questions. First, what does orthodox diffusion theory illuminate and what does it leave in the dark? Second, can translation theory shine a light into these corners? To answer this, the thesis will seek direct correspondences between the PACT events and the template translation narrative published by Michel Callon in 1987. Finally, what are the points of disjuncture between the PACT story and a translation framework?

This chapter will proceed with, first, a brief overview of medical case management and the Boston PACT project; second, a review of the literature on diffusion and translation; third, the presentation of the analytical framework, case selection, and methodology; and finally, an overview of the thesis’ structure.

**Background**

This section introduces medical case management, New York’s HIV epidemic, and PACT’s work to bring health care to Boston’s most vulnerable patients.

New York City is home to one in six of the country’s AIDS patients (Frieden, 2005). The city has committed to making health care available to all New Yorkers, and $2 billion per year is spent on HIV/AIDS in the city. New York State benefits from an ample pool of Medicaid funding,\(^3\) and while this is sufficient for most patients, there is an access gap for two groups of patients: first, those who earn just enough to be barred from Medicaid; and second, those who are failed by traditional medical systems due to barriers of homelessness, drug use, or food tightened, their role was reversed from advocacy to rationing. Molding to meet the needs of their institution, they become a service stop-gap to all but the most destitute (Mechanic, 1977).\(^3\)

\(^3\) Medicaid funding is unevenly distributed between states. Even after adjusting for cost of living, New York City enrollees receive twice the payout as in other cities such as Columbus (Villarreal, 2006).\(^3\)
insecurity. It is for these patients that the Federal government passed the Ryan White CARE Act, which created annual grants for cities to distribute as the “payers of last resort.” New York City receives $110 million in Ryan White funding per year, and grants are disbursed by the Office of Care, Treatment, and Housing located in the Bureau of HIV/AIDS.

With a tradition of HIV advocacy born in the East Village in the early 1980s, the city is densely populated with HIV-related community-based organizations (CBOs). These organizations perform the lion’s share of a key component of HIV care: medical case management. Case management makes up a key service category of Ryan White funding.

HIV case management programs are nationally prevalent despite a lack of consensus on what they should entail. Their mission is to provide a “human link” between patients and health services in order to improve patient quality of life and reduce medical expenditure (Sowell, 1995; Piette et al, 1990). Case managers assess patient needs, develop a plan of care, and connect patients to needed medical services. As the epidemic has migrated to poor, predominantly minority communities, there has been increasing demand for assistance with transportation, food, housing, and addiction problems. While many studies find case management to be cost-effective (Gardner, 2005), there are no widely adopted standards for evaluation.

The variation in case management programs reflects the diversity of their institutional homes. Piette et al (2005) have studied the dichotomy between CBO and hospital-based case management programs. Citing James Wilson’s landmark *Bureaucracy* (1989), Piette et al

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4 Ryan White funding is partitioned into service categories including housing assistance, the AIDS Drug Assistance Program (ADAP), and mental health services. The allotment is decided in each city by an HIV Planning Council, composed predominantly of community service providers, hospital representatives and HIV patients.

5 Certain components of case management reimbursable by Medicaid, and thus will not be paid for by Ryan White, the Payer of Last Resort. These include treatment adherence assistance, navigation, and accompaniment at doctors’ appointments. Ryan White-funded case management programs must bring something else to the table, such as patient education and counseling.

6 Additionally, Sowell (2005) warns that the case management banner is vulnerable to misappropriation by insurance companies and health clinics as a tool for preauthorization and service rationing.
suggest that the “dramatic differences in structure, mission, and size of public hospitals and CBOs” translate into different capabilities, which in turn shape their case managers’ perceptions of client needs and understanding of their role.\(^7\)

There is demand for an evidence-based model to become standard practice for HIV case management. At the cutting edge of this research is the Boston PACT project.

The PACT project is based in inner-city Boston, where a black woman with HIV is 15 times more likely to die from AIDS than a white man. PACT trains community health workers (CHWs) to provide home-based medical and social support to HIV patients who have been failed by traditional medicine. Most of these patients have had the virus for over 12 years and have developed a multiple drug resistance. In addition to traditional case management services, PACT’s CHWs provide health education, treatment adherence counseling, and directly observed therapy (DOT) for the most vulnerable patients. Founded in 1998 by Dr. Heidi Behforouz, PACT has published in the field’s leading journals and benefits from its affiliation with Partners In Health and Brigham and Women’s Hospital\(^8\). PACT has created a home education workbook and sets concrete milestones for its patients, offering a crisp and compelling model for expanding access to care. While costly up front, by targeting the most expensive patients and radically reducing their frequency of hospitalization, PACT has demonstrated considerable savings.

\(^7\) Piette et al found that hospital-based case managers are more likely to hold an advanced degree (64% of hospital case managers held a Masters in Social Work and 15.2% had a nursing degree; 68% of CBO case managers had neither). They also work much more closely with medical providers, and rarely work outside of the hospital. They operate exclusively within the hospital. By contrast, CBO case managers are more likely to provide home care; however, they are less likely to have a clinical background, tend to be more focused on developing community-wide services despite funding limitations, and report greater difficulty connecting their clients with services (CBO case managers are 2.7 times more likely to report extreme difficulty securing outpatient drug treatment, as well as home health care and help with insurance. Hospitals seem to benefit from their larger staff and their long-standing institutional partnerships with large social service providers.) Hospital case managers have an “agent” relationship, while CBO case managers are more focused on bolstering client independence and encourage them to take an active role in their relationship with their medical provider (Piette et al, 1990).

\(^8\) Clinical Infectious Diseases (Behforouz, 2004); Journal of AIDS (Behforouz, 2004); Annals of the New York Academy of Sciences (Furin, 2008).
Directly observed therapy holds great traction in New York City. From 1992-1996, Health Commissioner Tom Frieden responded to the city’s multidrug-resistant tuberculosis outbreak with case management and DOT and achieved an 80% reduction in cases. The success brought Frieden into the national spotlight, and in 2009 he became the director of the Centers for Disease Control in Washington, D.C. 40% of New York’s tuberculosis patients were also infected with HIV, and the program was funded by Ryan White. When Dr. Daniel Weglein, the Director of Public Health Practice for HIV Care at the Bureau of HIV Services, approached Commissioner Frieden about a similar application of case management and DOT for New York’s most vulnerable HIV patients, the Commissioner was all ears.

**Review of the Literature**

Diverse bodies of literature inform this story. There is a danger that the analysis be colored by preconceived roles, with PACT as a grassroots champion and New York City agencies co-starring as impersonal bureaucracies. This tendency must be countered using two tools found in the literature that follow: politicization and translation theory. These bodies of literature frame NGO-government partnerships as power-laden interactions between interested actors. Much NGO politicization literature is mono-directional, focusing on one unusual condition while “default” nonprofits retain infallibility. To navigate the asymmetry of NGO-government partnership literature, we turn to translation theory. By consciously limiting its scope to a narrowly defined network, it allows the scholar to consider each actor in the political process of translation. We can thus weave diverse bodies of literature into analysis of the decision to replicate PACT and the actors and factors in its hybridization.

**NATURAL SELECTION IN GOVERNMENT DECISION-MAKING**

A landmark work on policy decision-making is John Kingdon’s *Agendas, Alternatives, and Public Policies*
Kingdon’s decision-makers choose from ideas floating in a “policy primeval soup,” comprising the opinions of respected specialists in a given policy area such as urban HIV control. The ideas that survive this natural selection process meet certain criteria, including cost effectiveness, technical feasibility and value acceptability. The health policy community is particularly “inbred.” Huge, foundation-funded conferences bring civil servants, nonprofit entrepreneurs and academics together (Kingdon 1984: 123-4). Within the health field, the HIV management community is particularly visible. Dr. Daniel Weglein of the Bureau of HIV Services became a “policy entrepreneur”: an individual who invests their resources to promote a position in return for anticipated future success (Kingdon 1984: 188).

Since the Reagan presidency, the privatization and devolution of government services has been a growing national trend (Marwell, 2004; Smith, 2006). The U.S. is characterized by a public fear that government enterprises – unless partnered with a private element – crowd out initiatives in both the market and nonprofit sectors (Smith 2006: 228). In this climate, partnerships between government agencies and private actors are proliferating. This trend is reflected in the New York City Department of Health’s search for locally legitimate solutions. Brinkerhoff (2002) studies the considerable PR incentives to partnership. Agency reports often describe partnership “in glowing terms in an attempt to counter criticism of the past,” such that “it is difficult to distinguish the public relations objectives from actual practice” (Brinkerhoff 2002: 21).

**SCALING UP** Critics and champions of U.S. nonprofits agree on their limited scope: the network of NGO services is fragmented and conditional. In response, a body of literature has emerged that casts NGOs as laboratories that incubate best practices and inform government policy. PACT shares its parent organization Partners In Health’s commitment to serve the poor...
through the public sector: “while nongovernmental organizations have a valuable role to play in developing new approaches to treating disease, successful models must be implemented and expanded through the public sector to assure universal and sustained access” (PIH, 2010).

According to Uvin (2000), “becoming large” can be described as “expanding impact” only if an NGO moves beyond the nonprofit sector and catalyzes policy change. Annis (1988) was a seminal theorist in the translation of small-scale development into large-scale policy. The implications of this role can be complex: with the focus on NGOs as breakthrough projects, “time, funds, and imagination are poured into new programs that at best reinvent the wheel, while the potential of programs that have already proven their effectiveness remains sadly underdeveloped” (Bradach 2003: 19). Bradach encourages philanthropists learn from the business world, where franchises are twice as likely to succeed as start-ups. Given that private donors are less likely to fund old news, the responsibility to replicate best practice shifts to government. The reality of this achievement will be explored through the PACT story.

The transformation of the PACT model can be informed by the sociology of the diffusion of ideas. Two approaches stand out: orthodox diffusion of innovations theory and the new wave of translation theory.

**ORTHODOX DIFFUSION THEORY** Diffusion of innovations theory was pioneered by Everett Rogers in the 1960s, following turn-of-the-century work by French sociologist Gabriel Tarde. Diffusion is thought to occur when top-level actors invest catalytic energy to overcome an idea’s inertia. New audiences meet this idea with resistance, but may be persuaded to adopt it (Rogers 1962: 79). Ideas are packaged entities, and certain characteristics – such as simplicity and communicability – make make them easiest to diffuse. The diffusion model is attractive in part because it implies control over the diffusion process. The power of actors to achieve
adoption through persuasion makes this theory a favorite of consulting companies (Czarniawaska, 2008). An innovation package is relatively static; in a critique of diffusion theory, Bockman (2002) suggests that this can only occur if some mechanism exists to protect the model in its original form.

Acharya (2004) refers to Rogers’ diffusion theory as the “first wave” of norm diffusion scholarship. To these theorists, an idea’s acceptance or rejection is dependent only upon Rogers’ five factors and the amount of catalytic energy invested at the top. Second-wave theorists reject the distinction between active diffusers and passive acceptors, arguing that an idea’s acceptance depends on the opportunity for active, creative localization by its “recipients.” To understand this localization, we must turn to translation theory.

**TRANSLATION THEORY** A translation approach to the study of idea diffusion was pioneered by Bruno Latour and Michel Callon. According to Latour, “the spread in time and space of anything – claims, orders, artifacts, goods – is in the hands of the people” (Latour 1986: 267). Ideas are localized according to actors’ diverse frames of reference, and translation is “seen as a collective act of creation, and not as a bothersome impediment of a swift diffusion” (Czarniawska 2008: 88). Two key approaches to translation are social systems theory and actor network theory.

A social systems approach to translation is based on the work of Niklas Luhmann (1987) and Theo Hermans (1999), and focuses on the internal landscape of organizations. Translation is orchestrated by systems that operate based on their functional differentiation (Wolf and Fukari 2007: 24). As “structures of expectation,” these systems shape the actions of individuals and the

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[9] In James Ferguson’s discussion of a 1970’s intervention in Lesotho, the World Bank transported a package of agricultural practices into a community (Ferguson, 1990). These misplaced recommendations were transformed by political processes and localized until they were unrecognizable.
spread of ideas (Luhmann 1987: 362). Given the organizational complexity of actors in the
PACT replication, encompassing city, state, and federal levels of government, the systems theory
approach is ill suited to this thesis’s preliminary case analysis. The testimonies of key individuals
can be better employed by second approach: actor network theory.

Actor network theory was created by Science and Technology Studies (STS) scholars Bruno
Latour (1987) and Michel Callon (1986). Translation becomes power relations theory: a
mechanism for understanding how core actors define the interests of stakeholders, negotiate
alliances and become the spokesperson for many groups. The key act is displacement: actors are
drawn into complicit interest groups and mobilized behind representatives. These representatives
then lend their support to the central translator, who becomes the “obligatory passage point” and
the gatekeeper of information. In the French bay that inspired Callon, a group of scallop
researchers gained the power to speak for the scientific community, the fishermen, and the
scallops themselves. By the ANT tenet of symmetry, the scholar considers human and non-
human actors, judging the intentions of neither. Environmental forces outside the network are
discounted.

A strength of ANT is its rigor within a consciously bounded scope: it lends itself well to
process tracing based on network actors’ testimonies. The PACT story is one of who can speak
and who must fight to be heard. DOHMH decision-makers and academically celebrated PACT
organizers came to speak for the HIV community, as well as taxpayers and the HIV case
management academics. Callon’s final stage is dissidence, and we will see that the New York
City HIV community broke their silence: when they were not consulted on the city’s proposal,
they protested the PACT model vehemently and made its unadulterated adoption impossible.
This group disavowed its spokesman, claiming an active role in a new wave of transformation.
In the words of Ban (2010), “ideas cannot be signed for like a FedEx package.” The reconstitution of ideas is mutual and is shared throughout the network. Fourcade (2010, working document) suggests that marginal ideas rise in conjunction with individual social trajectories. Her examination of the changing culture of corporate governance exemplifies ANT “black box” theory: an idea is socially protected as incontestable truth, encased within a black box, until this box is opened and one accepted truth is replaced by another. How did black-boxed truths in the PACT story – such as adamancy by the DOHMH that New York City is too dangerous for home health visits – impact the translation of the PACT model? The protection of certain ideas, and the turnover of others, uncovers the balance of power and tools of persuasion.

**ACTOR NETWORK THEORY AND NGO-GOVERNMENT RELATIONS** A key perspective on NGO-government partnerships invokes ANT by analyzing the actors, stakeholders, and strategies involved in scaling up into the public sector. It fills a gap left by “instrumental” partnership literature, which lauds the complementary strengths of government agencies and nonprofits without interrogating the integrity of joint programs (Paul, 1989; Salomon, 1987). To Brinkerhoff (2002), the term “partnership” is overused and abused. It can gloss over power imbalances, falsely conveying local legitimacy on programs far removed from the NGO innovator’s mission. Partnership becomes a black box (Latour, 1987): a depoliticized arena in which programs drift to meet a new constellation of interests. Mechanic (1977) observes this trajectory in hospital case managers: they were initially patient advocates who connected clients with services, but as budgets tightened, their role was reversed from advocacy to rationing and they become a service stop-gap to all but the most destitute.

Brinkerhoff assesses NGO-government collaboration on two axes: mutuality and the maintenance of organizational identity. Weakness in both suggests “co-optation,” which can be
defined as “similar means and dissimilar ends” between the NGO and government (Najam 2000: 389). The extent of this dissonance is correlated to the power asymmetry between the policy initiator and receiver. By this framework, the diffusion of PACT’s curriculum is high-risk: after New York purchases the PACT curriculum, mutuality is lost and there is no mechanism to tie the replicated programs to PACT’s organizational identity. The project can freely drift to meet new stakeholder interests. Bradach (2003) suggests that for successful replication, NGOs must define a minimal package of elements that convey their social good. These elements are often tangential to stakeholder interests, and thus at risk of being lost in translation. The dangers of cost-efficacy rhetoric are discussed by Backman and Smith (2000), who argue that commercialization of U.S. NGOs detracts from their contribution to community capital.

Simmons (2007) describes the strategic trade-offs faced by NGOs in a network, presenting key dilemmas of scaling up. Should an NGO-government partnership be phased, or rapidly capitalize on a brief policy window? Should the intervention package be locally adaptive, or highly standardized in order to maintain key elements and counteract the shift from “effectiveness to efficiency” (Bradach, 2003)? Simmons raises particular concerns around ministries of health, which have limited capacity for community mobilization.

This literature demarcates trade-offs, but offers few guidelines for successfully navigating stakeholder interests and partnering in a network environment. Brinkerhoff’s “mutuality” and “organizational identity maintenance” are highly subjective, and are difficult tools for visualizing the already-elusive threat of mission drift. Additionally, this literature is mono-directional. It focuses almost exclusively on policy entrepreneurship by NGOs, and fails to address the alternate story: a government approaching a successful NGO model, as was the case with New York City’s health department approaching PACT.
These strains of literature politicize the depoliticized: nonprofits, government partnerships, and the power-laden reconstitution of a best-practice model. Their weaknesses are their limited foci: as they critique a set of actors and interests, limits of scope require that they apply normative generalizations to others. “Default” domestic NGOs retain such normative qualities as flexibility, community empowerment, and legitimacy, and by extension, these assumed powers are conveyed upon joint NGO-government programs. By invoking the symmetry of actor network theory, we can navigate from one literature strand to another according to their arenas of critical focus. Each will be a tool as we chronicle the factors that transformed the PACT model. The boundaries of network-theory analysis will limit this thesis’ speculation on out-of-network factors, and the testimonies of the translators will guide its results.

**Analytical Framework**

The empirical chapters will begin by explaining the PACT events through Everett Rogers’ orthodox Diffusion of Innovations theory. After identifying strengths and shortcomings in its application to PACT, I will advance to the main project of the thesis: casting further light on the recent PACT events using actor network theory. For maximum analytical leverage, Michel Callon’s narrative and framework will be discussed in parallel with the replication in New York. In this section, I will briefly elaborate on the two theoretical structures that will be used: Rogers’ Diffusion of Innovations theory and Michel Callon’s iteration of actor network theory. Both were first introduced in the literature review, and will be discussed in greater depth in the ensuing chapters.

**Everett Rogers’ Diffusion of Innovations**

Everett Rogers’ orthodox diffusion of innovations theory has been a favorite analytical tool for studying the diffusion of health care advances (Ferguson, 2002). Roger describes the
interaction between an adopter and an innovation in five stages: awareness, persuasion, decision, implementation, and confirmation. He analyzes the rate of diffusion of innovations and the characteristics of ideas that affect the ease with which they travel. In a form of cost-benefit analysis, Rogers’ actors seek to relieve the dissonance caused by uncertainty and by an awareness of a superior alternative (Tatnall, 2007). “Change agents” are powerful actors that persuade others to adopt a model whole-sale. New ideas are met with friction, and a model’s likelihood of being accepted or rejected is directly related to the energy invested by the change agent (Rogers, 1995).

In the PACT story, the Bureau of HIV Services’ Office of Care, Treatment, and Housing (CTH) finds itself in a state of dissonance. New York City has a chaotic network of overlapping case management organizations, none of which are directly accountable to CTH. They search for a model that will bring case management under a new order, and a literature review of the best journals leads them to the PACT model.

According to Rogers, the rate of adoption is influenced by 5 characteristics of the innovation itself: relative advantage, compatability, simplicity, trialability, and observability. In Chapter 2, I will discuss how these characteristics appear to CTH in the PACT model. All five are supported by a powerful undercurrent: familiarity. When Dr. Daniel Weglein pitched the model to Commissioner of Health Tom Frieden, the model’s directly observed therapy (DOT) captured his attention as a tool that he had employed to great effect against the New York tuberculosis epidemic.

Rogers’ theory has elements of concreteness that separate it from actor-network theory and, I argue, undercut its explanation of the PACT events. Rogers’ innovations are well-defined packages, which change only when adopters modify them for local fit. In New York City, the
PACT innovation is not a defined package, but rather, a reflection of diverse intentions and the relative power behind them. As the ensuing chapters will discuss, the Department of Health changes the model thoroughly in order to satisfy the HIV grassroots community, local politicians, and the City of New York’s bottom line. Then, the innovation’s true adopters – the 28 health center replication sites – lack the power to make the local modifications that Rogers alludes to. Chapter 2 will begin by applying Rogers’ theory in greater depth, and will conclude that PACT events are laced with political power in a way that Rogers’ theory cannot fully account for. The thesis will move on to its primary analytical framework: Callon’s translation theory.

**Translation Theory**

Michel Callon explores the passage of an innovation across jurisdictions and the organic, evolving relationships that recreate, rather than replicate, the innovation. Callon presents an arc with four stages: *problematization, interessement, enrolment,* and *mobilization.* Through these four stages, group interests are defined and channeled into spokespeople, and these spokespeople are channeled into an alliance behind the central translating group. Callon studies the power dynamics of this process regardless of the motivations behind it: “to speak for others is first to silence those in whose name we speak” (Callon, 1986: 14). The next chapters will locate the PACT events within these four stages in parallel with Callon’s own narrative, which chronicles the power dynamics of scholars and fishermen in St. Brieuc’s Bay, France. In this section, I will briefly present the four stages with examples from the PACT replication.

Callon’s first stage, *problematization,* is a stage of definition: in New York, Dr. Weglein and his team delineate a set of actors and characterize their goals. They thus organize a constellation of interests into an alliance, forging connections in support of their project. The Office of Care,
Treatment, and Housing becomes the “obligatory passage point,” or central conduit of information, linking alliance members to each other and to the shared project. New York City hospitals, for example, are defined by CTH to have chaotic, overlapping case management systems in need of a sweeping reform. These hospitals drawn by grant money into CTH’s alliance. CTH becomes the sole interpreter between replication sites and the original PACT model, and denies the hospitals’ requests to depart from the CTH protocol.

Next, the stage of *interessement* stabilizes the identity of the actors and locks them into roles. Employing such mechanisms as force, seduction, or solicitation, a group imposes tests on the limits of other actors’ commitment. The translating entities build devices between the relevant actors and rival projects, weakening or dismantling their links to others. In New York, the PACT staff is drawn behind the replication process through their great authority in the pilot process. In three New York City hospitals, the PACT staff is given full rein to train health workers and troubleshoot the implementation of their model. Upon these pilot sites’ success, PACT signs a contract that sells New York City their model, and alongside it, all authority over the implementation process.

Callon’s third stage, *enrolment*, describes the negotiations and trials by which the roles suggested in *interessement* are hammered into a reality. It is the solidification of shared goals into a seaworthy alliance. In the case of PACT, the contract signed during their *interessement* relegates them into a two-dimensional model that CTH can access and control. Their curriculum is lifted out of their hands, and their two-week health worker training is compressed into a two-day crash course performed 16 times by a private contracting company.

The fourth stage is *mobilization*. It is the process of reducing enrolled groups to individual spokespeople, and thus translating *enrolment* into active support. PACT is condensed into its
paper curriculum, and thus mobilized for CTH: unlike a team of opinionated PACT staff, a two-dimensional curriculum can be reinterpreted, repackaged, and shipped to each replication site.

Callon’s fifth and final stage is dissidence: the authority of the spokesman is questioned, rejected, and renegotiated. In the words of Callon, “translation becomes treason” (1986:15). As the 2011-2012 contract cycle approached, fearing poor outcomes at the poorly trained and hollowed-out replication sites, PACT took action to throw off their mobilization into a purchased curriculum. Director Heidi Behforouz and program manager Jessica Aguilera-Steinert drove to New York and met with the director of the Bureau of HIV Services. Capitalizing on a large turnover in Bureau staff and anxiety about the program’s success, PACT reclaimed authority over training and troubleshooting in the 2011 contract. In the new *modus operandi*, PACT’s silent representative – its curriculum – was replaced by its vocal and active outreach team.

This section has introduced orthodox diffusion theory and actor-network theory. Chapter 2 will begin with an orthodox explanation of PACT, and then turn to the main project of the thesis: the illumination of the New York events through Callon’s framework.

**Case Selection**

I chose PACT for my analysis of scaling-up for five reasons. First, the replication is in its first year of implementation. Troubleshooting teams in New York and Boston are now addressing the issues of mission drift and adaptation that will guide the course of the translation. The majority of nonprofit-government collaborations, such as Planned Parenthood and City Year, are distanced from this early stage. Secondly, while nonprofit-government collaboration is proliferating, replication at this scale is rare and understudied. Actors in New York and Boston are reaching across sectors in order to unlock HIV care for the nation’s most vulnerable patients. Thirdly, my research is motivated not by a general interest in NGO-government relations, but
rather, in their specific potential to narrow the health access gap in urban America. New York City is home to the nation’s largest HIV epidemic, and thousands of New Yorkers will ultimately be affected by the program. Fourthly, the location of officials in New York City and Boston made it possible for me to conduct in-person interviews. Over the course of three trips to Boston and two to New York City, I conducted over fifteen hours of interviews with stakeholders in the translation process.

Finally, the academics and doctors in the PACT story are well-suited to Callon’s and Bruno Latour’s Science and Technology Studies (STS) framework. STS seeks to uncover the political processes through which science is produced and conjecture becomes fact. The academic paper and accredited expertise are two mechanisms through which knowledge is established. In the PACT replication, city politicians meet Callon’s politicians of science: the doctors, academics, and public health experts who stand behind the PACT model as best practice.

**Data and Methods**

This thesis is a case study for the analysis of nonprofit-government replication through translation theory. It can be categorized as a disciplined interpretive case study, defined by J.S. Odell (2001) as the systematic application of a known theory to a recent and significant event.\(^\text{10}\) A disciplined interpretive case study has two purposes: first, demonstrating that a theory can be extended to explain a new event; and second, illuminating the theory’s strengths and weaknesses as its relevance to a new event is tested.

I conducted in-person interviews with 7 officials at the New York City Bureau of HIV Services, and interviews with the Founder and the Director of Client Services of the PACT

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\(^{10}\) Odell (2001) identifies six varieties of case study: single; disciplined interpretive; hypothesis-generating; least-likely; most-likely; and deviant. Odell’s disciplined interpretive category best describes the project of this thesis.
Project in Boston. Interviews were recorded on a personal device and transcribed by the researcher.\textsuperscript{11}

To operationalize actor-network theory, I draw explicit correspondences between the PACT story and Callon’s template narrative in St. Brieuc’s Bay. This exercise follows Callon’s principles of generalized symmetry and free association: ANT does not differentiate between natural and non-natural actors, and employs the same vocabulary for actors from diverse backgrounds. Just as Callon incorporates fishermen and scallops in a single actor-network, the thesis draws the narratives of St. Brieuc’s Bay and New York City into conversation.

\textit{Limitations of the Study}

Four limitations of this study must be considered. First and most critically, its task is inherently prescriptive. Academic integrity is endangered when empirical data is positioned against a pre-conceived model. The exercise is performed because, first, its poses theoretical challenges to the PACT events that open avenues for further analysis; and second, it highlights events that current actor-network theory cannot explain.

The second limitation of this study is that key voices are absent. Due to time constraints and the diversity of opinions in each group, it was not possible to interview hospital administrators or unaffiliated New Yorkers living with HIV/AIDS. Their direct statements would provide a counterpoint to the views ascribed to them by CTH officials.

Thirdly, this thesis applies actor network theory thinly. There is limited consideration of non-human actors, and Callon’s commitment to agnosticism is blurred by my exploration of the past experiences and funding structures that may have drawn CTH to PACT.

\textsuperscript{11}Full transcripts are included in the appendix. The exception is my unrecorded discussion with Dr. Heidi Behforouz at PACT, for which a summary is provided.
Finally, this thesis does not assess the programs’ impact. Callon’s principle of agnosticism demands impartiality towards actors and nonjudgmental consideration of their claims. This constriction undercuts the researcher’s ability to recognize mission drift and to map the program’s commitment to social good. In other words, the actors’ impact is kept in a black box. Outcome data is now being gathered in New York. Its analysis will demand a theoretical framework distinct from actor network theory, which disregards the destination of translation in order to bear witness to the elaborate negotiations involved.

**Relevance for Development Studies**

This thesis studies the adaptation of an innovation across jurisdictions, an urgent mission of development studies in a globalizing world. The relevance of this thesis is limited by its context in an advanced industrial democracy, which distinguishes it from research focusing on the global south. The events it examines are rooted in bureaucratic structures, and its findings cannot be easily rerouted from New York City to a developing country context.

Actor network theory is gathering momentum in the study of international politics and economic development. Since its publication in 1986, Callon’s “*Some Elements of a Sociology of Translation*” has been cited by nearly 3000 works and is being applied internationally to such cases as wetland conservation in England and psychiatric rehabilitation in Sweden (Burgess, 2000; Timpka, 2007). While actor-network theory has been applied to the diffusion of medical innovations (Prout, 1996; Gomart, 2002; Fitzgerald, 2002), it has not shed light on public replication of nonprofit best practices.

The PACT replication itself captures two national trends: first, increasing nonprofit-government collaboration; and secondly, growing attention to health care “hot spots,” or sets of

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12 During the time of interviews, the first chart review was underway at CTH.
highly vulnerable patients who are lost through the cracks of primary care and incur great costs in emergency room visits.

By interrogating the process through which a best practice is re-invented, this research can increase awareness of mission drift and help ensure that the needs of New York HIV patients are being effectively met. Already, Departments of Health across the country are following New York City and pursuing a replication contract with PACT. In addition to illuminating its unfolding implementation in 28 health centers, greater understanding of the New York events will contribute to a larger conversation on the challenges and strategies of nonprofits scaling up in the public sector.

The thesis will test the applicability of translation theory through an artificial exercise: they will draw direct correspondences between the PACT events and Callon’s template narrative, set in St. Brieuc’s Bay, France. In so doing, the thesis risks molding the empirical story to an arbitrarily selected arc. Yet, by uncovering elements of the PACT story that map to Callon’s story, it serves a dual purpose. First, it illuminates the PACT replication not as a recipe for social justice, but as a political terrain in which each actor’s pursuit of community health is tempered by familiarities and capacities. Secondly, it illuminates the need for translation theory that can encompass the complex history that drew the City of New York to PACT, and predict the integrity of the resulting program to its original mission.

**Thesis Structure**

The next four chapters will embed the PACT story into Callon’s four stages: *problematization, interessement, enrolment*, and *mobilization*. They will explore the use of a translation approach to illuminate political undercurrents in the PACT story that are hidden to orthodox diffusion of innovations theory. Particular attention will be paid to points of disjuncture
between the PACT and Callon narratives. In the sixth and final chapter, the thesis will draw conclusions on the relevance on translation theory and the components that it fails to explain. Based on this preliminary case study, I will reflect on the value of translation theory for analysis of future nonprofit-government collaborations and their contribution to social justice.
CHAPTER 2

Chapter 2 begins with an orthodox explanation of the replication of PACT in New York City. After a brief narrative, the thesis will assess the relevance of this theory and present questions that it does not address. The remainder of chapters 2 through 5 will apply actor-network theory to the replication of PACT in New York City. The chapters will invoke Callon’s framework by casting a direct analogy between actors in Callon’s narrative and in New York City. They will also seek points of disjuncture, and thus test the relevance of Callon’s theory in the PACT context.

**PACT Travels to New York: An Orthodox Explanation**

This section will present the PACT replication through Everett Rogers’ orthodox diffusion of innovations theory, which has been a preferred analytical tool for studying the diffusion of health care advances (Ferguson, 2002). The section will then consider which facets of the story can be illuminated by this explanation and which are overlooked.

Roger describes the interaction between an adopter and an innovation in five stages: awareness, persuasion, decision, implementation, and confirmation. He analyzes the rate of diffusion of innovations and the characteristics of ideas that affect the ease with which they travel. In a form of cost-benefit analysis, Rogers’ actors seek to relieve the dissonance caused by uncertainty and by an awareness of a superior alternative (Tatnall, 2007). “Change agents” are powerful actors that persuade others to adopt a model whole-sale. New ideas are met with friction, and a model’s likelihood of being accepted or rejected is directly related to the energy invested by the change agent (Rogers, 1995).
This section argues that three important characteristics of the PACT story will be lost in this
telling. First, the PACT innovation is not a defined package, but rather, a reflection of diverse
intentions and the relative power behind them. Secondly, rather than actors with steady
identities, the events in New York City are guided by the ways in which identities are perceived
by key decision-makers. Thirdly, the replication is not a linear tale of change-agents and
adopters: CTH selects the model, health providers are driven to accept it because they need grant
money, and CTH spends little time bringing them on board and more time obtaining approval
from politicians. The right to adapt the model is reserved to CTH’s central authority.

In the PACT story, the Bureau of HIV Services’ Office of Care, Treatment, and Housing
(CTH) finds itself in a state of dissonance. New York City has a chaotic network of overlapping
case management organizations, none of which are directly accountable to CTH. They search for
a model that will bring case management under a new order, and a literature review of the best
journals leads them to the PACT model.

According to Rogers, the rate of adoption is influenced by 5 characteristics of the innovation
itself: relative advantage, compatibility, simplicity, trialability, and observability. The next
paragraphs investigate the ways in which CTH perceives these characteristics in the PACT
model.

PACT’s relative advantage to CTH is clear: it has demonstrated its success in reducing
vulnerable patients’ viral loads and the great cost of their emergency room care. PACT embeds
case management into the medical infrastructure, relieving the dissonance of myriad unaffiliated
case management organizations. By drawing these Medicaid-funded organizations under CTH’s
purview, CTH can leverage state funding to realize the city’s vision. Less certain is the relative
advantage to replication sites: they must forgo open-ended grants for adherence to an imported model. The need for funding pushes public hospitals and CBOs to accept.

Rogers’ second characteristic is compatibility, defined as consistency with values and past experiences. Here, PACT hits the jackpot: its emphasis on directly observed therapy (DOT) recalls New York City’s swift control of the tuberculosis outbreak of the 1990s, which was heavily co-morbid with HIV and which brought international acclaim to Commissioner of Health Tom Frieden and the DOHMH. PACT’s commitment to evidence basis also holds traction with the country’s most research-focused department of health.

Thirdly, Rogers links the rate of diffusion to simplicity. The PACT home care model is difficult to execute, but it grounds the amorphous task of health education through the use of a workbook with checklists. By tying diverse community programs to hospitals, the PACT reform renders case management legible to CTH.

Fourthly, adopted innovations are easily piloted. This is especially important for early adopters, and New York City’s DOHMH has a reputation for staying at the cutting edge of the public health field. CTH ran pilot programs at two city hospitals, with extensive involvement of the PACT staff.

Finally, successful innovations are observable and communicable. PACT gains visibility from its affiliation with Partners In Health, and has published its findings in leading public health journals. The public health field has long had a reputation for having strong communication channels for dominant ideas (Kingdon 1984: 123-4).

By virtue of these five characteristics, PACT promises to relieve the dissonance of New York case management and Rogers’ five-stage diffusion process begins. In Rogers’ first stage, awareness, CTH identifies the PACT model in a literature review. In the second stage, rising
interest, the CTH’s behavior becomes purposive as it seeks more information from PACT.

Thirdly, in the trial stage, CTH sets up pilot programs in two hospitals and relies heavily on the PACT staff for troubleshooting. These pilots were a success, and the CTH project officers involved in them would have a durable faith in the model unmatched by those who joined the office later. Rogers’ final stage is rejection or adoption, the decision to pursue “100% utilization” of the innovation. It is here that the comparison first breaks down: the New York events offer no such absolutes. When CTH transforms into a change-agent and exports a PACT-inspired protocol to financially pressed health centers and CBOs, it has reinvented the model as its own. The health centers and CBOs do not follow Rogers’ progression from awareness to pursuit: rather than exploring a model that piques their interest, they are pushed by financial need to accept protocol that constricts their previous practices.

Rogers defines an “authority innovation-decision”\(^{13}\) to be one in which a small number of powerful individuals make a decision that others in a social system must implement. This yields the fastest rate of adoption, and is often favored by formal organizations such as government agencies despite a risk of being “circumvented” during implementation (Rogers 1995: 29). Rogers introduces the concept only in the 1995 edition of his book, 33 years after it was first released, and speaks little of the politics of this process.

Reinvention, also an addition of the 1995 edition, is defined to be "the degree to which an innovation is changed or modified by the user in the process of its adoption and implementation" (Rogers 1995: 175). To the innovators, re-invention is often considered “a distortion of their original technology.” With extensive re-invention, the rate of adoption becomes an ambiguous index and it is difficult for change agents to assess their performance. As a result, they may

\(^{13}\) Rogers defines three types of innovation-decision: individual, in which each member of a social system chooses independently of the rest; collective, in which a decision is made by consensus of the system’s members; and authority, in which the few decide on behalf of the many (Rogers 1995: 29).
attempt some form of “re-invention proofing” (Rogers 1995: 176-77). In light of the New York experience, PACT’s director of client services Jessica Aguilera-Steinert is “re-invention proofing” by preparing a rigid package of services and qualifications that future replication sites must commit to.

For adopters, re-invention can improve the model’s fit and local standing. Writes Rogers, "an innovation may be somewhat like a toothbrush in that people do not like to borrow it from someone else” (Rogers 1995: 175, 177). In light of re-invention, adoption must be understood as a process of social construction. An innovation is given new meaning by adopters as they learn to use it and localize it to their surroundings. Rogers does not cite Callon and Latour in his 1995 edition, but the addition of “re-invention” may be in part Rogers’ response to translation literature, which was released in the late 1980s.

Re-invention was the right of CTH and was denied to the replication sites, who received a rigid protocol repackaging the PACT model. CTH defended this rigidity as a mechanism of consistent service quality, easy evaluation, and minimizing unfairness by denying exceptions to individual sites. The sites’ demands for modification were sympathized with, but declined, by CTH project officers. Rogers describes a phenomenon in which change agents hold competing commitments to their bureaucracy and to the clients that they serve. In this way, CTH’s project officers are “subjected to various role conflicts” (Rogers 1962: 256).

While hospitals and CBOs are not recognized as architects of re-invention, the model certainly changes at their hands. They perform a type of re-invention that Rogers predicts when a model is complex or the implementers are inadequately trained. New York community health workers are trained by private contractors who condense the two-week PACT curriculum into two days and repeat the training 16 times.
CTH is in constant negotiation with replication sites, but not, as Rogers describes, to enhance the rate of adoption. Rather, they are troubleshooting the implementation of their protocol package. Most persuasion took place in the offices of New York City politicians, while hospital administrators were driven by financial need to accept the case management grant and its stipulations.

This is one example of a broader shortfall: Rogers cannot describe the political turf war of the PACT replication. Contents of the innovation package are fluid and contested, re-invention serves an uncertain mix of social good and institutional good, and power dynamics suffuse decision-making. Rogers describes identities as constant, but this is confused in the PACT story. Is the initial case management situation a chaotic mess, as CTH believes, or 25 years of experience that should not be meddled with, as the hospitals protest? Because CTH hold the power of the purse, their perception guides the course of events. A method of analysis is needed that prioritizes CTH’s perceptions and recruitment of stakeholders to the replication process. Such a method of analysis can be found in translation theory.

This section applied Everett Rogers’ landmark Diffusion of Innovations theory to the PACT story. Rogers’ theory illuminated attractive characteristics of the PACT model and introduced the concept of re-invention, by which the adopters of an idea recreate it to suit a new environment.

Much of the PACT story, however, was lost in this telling. Politics of identity were suppressed: the PACT model is not a concrete innovation package, but a loose and contested set of policies that found a new manifestation in New York City. Re-invention was explicitly performed by CTH in the creation of rigid NYC protocols, and implicitly enacted by hospitals and health centers when they could not implement these protocols to the letter.
To recapture the politics of the PACT story, I turn now to Michel Callon and Bruno Latour’s innovation translation theory. In his 1987 work, Callon narrates a process of translation which provides a template for the definition of stakeholder groups, their enrolment into an alliance, and their reduction to key spokespeople.

Chapter 1 presented Michel Callon’s four stages of translation: problematization, interessement, enrolment, and mobilization. Though these stages overlap, they can be considered sequentially as they follow the formation, rupture, and renegotiation of alliances. The next section presents Callon’s narrative, which will anchor an actor-network analysis of the PACT story.

**Callon’s Narrative: the Scallops of St. Brieuc’s Bay**

Callon’s study takes us to St. Brieuc’s Bay, France, in 1972. The bay’s stock of scallops was dwindling, putting the livelihood of its community of fishermen at risk. A group of three researchers had witnessed a Japanese technique for cultivating scallops: providing an artificial support for the larvae to anchor to. It was unclear if in the Japanese method was translatable to St. Brieuc’s Bay, which cultivated a different species, *Pectus Maximus*. There was a dearth of research on scallops; the decline was already apparent, and would soon become disastrous.

In Callon’s first stage, problematization, the three researchers defined a set of stakeholders and drew them into an alliance around their project. The fishermen were drawn by the short-term gains of continuing to fish, but to preserve their long-term interests they needed the solution sought by the researchers. For the scallops, the Japanese anchor system could be the best possibility for survival.

Next, the stage of *interessement* stabilizes the identity of the actors and locks them into roles. Employing such mechanisms as force, seduction, or solicitation, a group imposes tests on the
limits of other actors’ commitment. The translating entities build devices between the relevant actors and rival projects, weakening or dismantling their links to others. In St. Brieuc’s Bay, the scallops are solicited through the experimental apparatus: a device that protects the vulnerable larvae from predators, and provides an anchor for them. The larvae are thus extracted from their context and shielded in exchange for anchoring. Connections are broken between the scallops and competitive forces: the scallops are physically dissociated from predators and currents that would draw them down different pathways. Secondly, to interest the fishermen, the three researchers persuade a small set of representatives. By drawing graphs on a chalkboard and discussing spectacular results in Japan, they draw the fishermen into their alliance. Thirdly, the three researchers engage their scientific colleagues through conferences and publications. An exhaustive literature review has produced no knowledge of scallops, and their proposal alone can save a dying species and advance science.

Callon’s third stage, enrolment, describes the negotiations and trials by which the roles suggested in interessement are hammered into a reality. It is the solidification of shared goals into a seaworthy alliance. Callon’s scallops are successfully enrolled when they physically anchor to the nets, and their compliance is no longer hypothesized, but demonstrated. Enrollment is a process of negotiation and compromise. In St. Brieuc’s Bay, “a veritable battle” is fought to induce the scallops to anchor: the researchers make concessions, such as reconstructing the nets from different materials and repositioning them throughout the bay, until the scallops are at last satisfied. Through a series of transactions, “a modus vivendi is progressively arranged” (Callon, 1986: 11).

Another transaction is performed to enroll the researcher’s scientific colleagues. In the preceding stage of interessement, these colleagues tentatively lent support of the project. In the
enrollment stage, this support becomes a contract: the researchers commit to acknowledging their colleagues’ past work, and “it is at this price that the number of anchorages claimed by the researchers will be judged as sufficient” (Callon, 1986: 12).

By contrast, transactions with St. Brieuc’s fishermen are non-existent. The fishermen’s representatives can only “watch like amused spectators and wait for the final verdict” (Callon, 1986: 12). They lack the power to make demands; their voice has already been wholly passed on to the three researchers.

The fourth and final stage is mobilization. It is the process of reducing enrolled groups to individual spokespeople, and thus translating enrolment into active support. Callon’s model of mobilization shows fascinating symmetry between the scallops and the fishermen. The fishermen cast their ballots to select a representative; this official spokesman’s views are recorded by the researchers, and are voiced by the researchers when they present their results at Brest. Similarly, the scallops are represented by their larvae; by deciding to anchor or not, each casts a “ballot” and is converted into a statistic. This becomes a set of tables and curves on sheets of paper, carried by the researchers and presented at Brest. Thus, each party is displaced through a series of equivalencies and thus rendered both mobile. Their final form is interpretable by the researchers alone, who are thus empowered to communicate on both populations’ behalf.

The alliance crafted by the three researchers is delicate: members can reject the consensus and the alliances which it implies at any moment. “Translation becomes treason” (Callon, 1986: 15). The final stage is controversy: the authority of the spokesmen is questioned, rejected, and renegotiated. In this process, identities are reconstituted along with beliefs: where do the actors’ true interests lie?
The three researchers’ findings are followed by catastrophe. A few years after the scallops’ successful enrolment as an anchoring species, they reject the researchers’ findings: the repeat experiment finds all the anchors empty. As the scallops become dissidents, “the larvae which complied are betrayed by those they were thought to represent” (Callon, 1986: 16). The fishermen, too, break the vows of their representatives. One fateful night, they give in to temptation and fish the scallop population to devastation. “Brutally, and without a word, they disavowed their spokesmen and long term plans.” In light of these ruptures, the scientific colleagues become skeptical: is the scallops’ anchorage truly an obligatory passage point, satisfying the interests of the defined groups? “What do the fishermen really want? How does Pectin maximus behave?” (Callon, 1986: 16).

The controversy is closed when new spokespeople are validated. The three researchers engage in desperate renegotiations, “undertaking a vast campaign to educate and inform (i.e. form) the fishermen to choose other intermediaries” and adjusting the anchoring apparatus in the hopes of reclaiming success (Callon, 1986: 16).

Over the course of ten years, the three researchers became the locus of a process of translation. A new knowledge was produce and validated, fishermen were drawn together into a social group, and a community of specialists was entrusted with scientific authority over Pectus Maximus. There was simultaneously the production of knowledge and the construction of a network of relationships, in which “social and natural entities mutually controlled who they were and what they wanted” (Callon, 1986: 6).

Like the events of St. Brieuc’s Bay, the PACT replication story is one of who can speak and who must fight to be heard. DOHMH decision-makers and academically celebrated PACT organizers speak for the HIV community, as well as taxpayers and the HIV case management
field. Callon’s final stage is dissidence, and we will see that the New York City’s grassroots 
HIV-care community broke their silence: when they were not consulted on the city’s proposal, 
they protested the PACT model vehemently and made its unadulterated adoption impossible. 
This group disavowed its spokesman, claiming an active role in a new wave of transformation. 

**New York City and St. Brieuc’s Bay**

As an exercise to explore the application of translation theory to the PACT events, this thesis 
will identify the main elements of correspondence between the events of St. Brieuc’s Bay and the 
replication of PACT. Five players in Callon’s translation will be compared to radically different 
analogs: Callon’s three researchers with New York City’s Office of Care, Treatment, and 
Housing; Callon’s scientific community with city politicians; the Japanese anchors with the 
PACT model itself; the scallops with the hospitals and health centers; and finally, Callon’s 
fishermen with New York’s population of people living with HIV/AIDS. I will introduce these 
correspondences below. In future sections, I will elaborate in greater detail on these 
correspondences as they relate to each of Callon’s four stages.

Through the exercise of mapping the PACT story to Callon’s narrative, I have found that the fit is not perfect and there are a number of critical divergences from the translation framework. After presenting the five correspondences, this chapter will introduce major points of divergence between the PACT events and Callon’s framework. Finally, this chapter will advance the New York City story through Callon’s first stage, *problematization.*

First, the correspondences are introduced. The first comparison is drawn between Callon’s three researchers and the New York City Bureau of HIV/AIDS’ Office of Care, Treatment, and Housing (CTH). Dr. Daniel Weglein, former director and still member of the office, is the architect of the translation process. The three researchers bring the Japanese anchor model to St.
Brieuc’s Bay; Dr. Weglein channels the PACT model in New York City. Both are policy entrepreneurs who undertake the rescue of populations in disarray. The scallops’ numbers are dwindling; case management’s numbers are gorged. They draw diverse actors into an alliance, and translate a solution to the actors who will implement it. They are an “obligatory passage point”: only Callon’s researchers can convey the Japanese anchor innovation, and only CTH can convey its repackaged version of the PACT model. As the center of translation, CTH undertakes the negotiations and transactions involved in establishing an alliance of politicians, doctors, and administrators.

Secondly, the thesis draws a correspondence between Callon’s scientific community and New York City politicians. New York doctors may seem to be a more natural analogue; however, while doctors are passive observers of case management reform, politicians are gatekeepers. Similarly, Callon’s researchers proceed with their project only once their scientific colleagues have given a green light. The politics of science are the central subject of Science and Technology Studies, which encompasses translation theory. Both Callon’s scientists and New York’s politicians lend their distant but necessary support to the translation project on two conditions. For the scientists, first, scientific knowledge must be advanced; and second, their previous research must not be invalidated. For the politicians, first, community health must be advanced; and second, their credibility as supporters of minority rights must not be invalidated. This credibility is seated in community-based case management organizations, which were created in the 1980s to improve HIV care in poor, predominantly minority communities.

Thirdly, the Japanese anchor model will be compared to the Boston-based, and originally Haiti-based, PACT model. Each model becomes the intellectual property of the translator. Callon’s three researchers absorb the Japanese model, retool it, and convey it to St. Brieuc’s Bay.
New York’s Office of Care, Treatment, and Housing absorbs the PACT model, repackages it, and conveys it to 28 hospitals and health centers. But unlike the Japanese inventors, the innovators at PACT play an active role: they are closely involved in the pilot projects, become dissatisfied with the appropriation of their model, and ultimately take the project’s rocky beginnings as an opportunity to reclaim a management role.

Fourthly, Callon’s scallops find their counterpart in the New York hospitals and health centers that are recruited to replicate the PACT model. The scallops either accept or deny the anchor; those that accept it receive protection from tides and predators, and negotiate adjustments in anchor material and placement. New York health centers either accept or reject the repackaged PACT model; those that accept it receive Ryan White funding, and negotiate adjustments with CTH troubleshooting team (Project Officers). A tiered reimbursement structure based on patient targets pressures them to implement the model faithfully.

Finally, the fishermen find their counterpart in people living with HIV/AIDS. Initially, both groups are sacrificing their long term interests for critical short-term needs: the fishermen are fishing the last scallops from a dwindling population, and high-risk PLWHA are missing doctor’s appointments and doses of antiretroviral therapy due to crippling social obstacles. In the reform process, both groups become represented by a few spokesmen: fishermen elect their delegates, while 15 PLWHA volunteer for a seat in New York’s HIV Planning Council. In part because the PLWHA spokesmen are unelected, they are considered token and given relatively little weight on the HIV Planning Council.

In the French bay that inspired Callon, a group of scallop researchers gained the power to speak for the scientific community, the fishermen, and the scallops themselves. In New York City, an office director selects and pursues an innovative model that will resonate with the
DOH’s cultural history and methodical future. Politicians sign off from a distance once they are convinced of the invalidity of CBO protests. The replication sites latch on to the model to receive funding, just as Callon’s scallops anchor to the nets to escape the ravages of current and attack. As acceptors, they have no power of assessment, and thus their defiance of the model is interpreted as resistance to change. Finally, like Callon’s fishermen, disadvantaged HIV-positive New Yorkers are channeled into representatives who bear token witness to an intricate process of translation.

**Major Points of Disjuncture**

In mapping the PACT and Callon translation stories, I encountered two recurring points of disjuncture. These are presented as a weak link in translation theory, which can be explored in future research.

First of all, Callon’s analysis does not appreciate the role of familiarity in the selection of an innovation. To Callon, the innovation is an interchangeable place-holder, interesting for the eddies of negotiations and alliances that surround it. However, characteristics of the PACT model are central to the initiation and success of the translation process. Specifically, its familiarity to the translator was a crucial step in its selection as best practice. Elements of the PACT model mirrored a tuberculosis intervention of the 1990s that brought national acclaim to Commissioner of Health Tom Frieden, who was an enthusiastic supporter of the PACT replication.

Secondly, Callon provides little insight into the role of rigidity in the story. The rigidity of the model is a complex issue for each individual actor, and this complexity is multiplied in the translation alliance. The PACT project desires rigid replication of its own innovation; CTH reinvents it, to the displeasure of PACT, and imposes rigid replication of their own package upon
replication sites. At the same time, PACT and CTH acknowledge that flexibility will lessen the risk of rejection, a danger that accompanies any transplant. The hospitals and CBOs petition their project officers for exceptions and adaptations, and are almost universally denied. However, even when rigidity is prioritized, the model is diversified by the very process of translation. Rather than PACT directly providing its three-week training to the replication sites, a separately contracted company performs a two-day training sixteen times, garbling parts of the model. Then, each implementation site makes diverse ground-level decisions and faces different institutional requirements that make complete homogeneity impossible.

In the following section and the ensuing chapters, I will turn to a more detailed analysis of the correspondences as they appear in Callon’s four stages. Under Problematization, I will discuss CTH’s perception of stakeholders and their interests. Under Chapter 3’s Interessement, I will introduce the persuasive devices through which each actor is drawn into an alliance around case management reform. Under Chapter 4’s Enrolment, I will discuss the transactions through which actors renegotiate their roles and the stipulations of the reform. Chapter 5’s Mobilization examines the displacement of group identities into spokespeople, and the transfer of authority from these spokespeople to CTH. Finally, it examines the dissidence and controversy that reverse certain steps in the translation process.

**PROBLEMATIZATION**

“If we were going to put our money into something that we thought there would be a lot of support for, we thought PACT was a great place to start.”

– Dr. Daniel Weglein, NYC Director of Public Health Practice for HIV Care
The first of Callon’s four stages is problematization. It is a stage of definition: Callon’s three researchers delineate a set of actors and characterize their goals. They thus organize a constellation of interests into an alliance, forging connections in support of their project. The researchers become the “obligatory passage point,” or central conduit of information, linking alliance members to each other and to the shared project.

Callon’s story contains four principle actors: the fishermen; the scientific community; the scallops; and the researchers themselves. Unlike the PACT innovation, the innovation itself – a Japanese anchor system – is not an actor. It is unchanging and tangential to the course of the translation process. Callon’s disinterest in the innovation itself as an actor in translation is the first of two major failures in the application of translation theory to the PACT events. This and the second failure, regarding the issue of rigidity, will be explored in detail in ensuing sections.

**Problematization in St. Brieuc’s Bay**

*Problematization* is performed in Callon’s narrative by the three researchers, who define the identities of each group in such a way that will support their project. What follows are the researcher’s observations on these four actors and their goals.

First are the fishermen: a homogeneous group of individuals driven by profits. If they do not slow down their fishing practices, they will ruin themselves. However, their long-term interests hinge on restocking the bay. Second are the researchers’ scientific colleagues. They have done no research on scallops, but wish for knowledge to be advanced in such a way that their own findings are respected. Third are the scallops themselves, which have never been seen in larval form. They are the center of the question: will *Pectimus Maximus* anchor? Their goal is safety from predators and perpetuation of their species. Finally, the researchers themselves are attempting to illuminate an unstudied species and save the livelihood of St. Brieuc’s Bay.
Inspired by the achievement in Japan, they hope to assist the struggling fishermen and increase the stock of scallops.

Thus, each group is defined in such a way that its own needs align with the researchers’ endeavor. The researchers become the obligatory passage point, connecting isolated actors with a shared solution. If fishermen hope to preserve their income, if scientific colleagues want to advance knowledge, if scallops want to survive, “a Holy Alliance must be formed in order to induce the scallops of St. Brieuc Bay to multiply” (Callon, 1986, 7-8).

In New York City, the Office of Care, Treatment, and Housing (CTH) delineates groups and defines their goals. Each group finds an analogy in Callon’s story. CTH’s interpretation of five stakeholder groups and their correspondences with St. Brieuc’s Bay are summarized here. In the following five subsections, the first stage of translation in New York is presented in great empirical detail. The points of correspondence in the problematization of groups in St. Brieuc’s Bay and in New York City are introduced below, and illustrated in Figure 1.

First, like the fishermen, people living with HIV/AIDS (PLWHA) are observed by CTH to be a homogeneous group in need of long-term care. Both the fishermen and PLWHA are forced to sacrifice their future security for immediate need: the fishermen try to catch what few scallops are left, and high-risk PLWHA miss their doctors’ appointments and are non-adherent to antiretroviral medications.

Secondly, the problematization of New York City politicians is analogous to that of Callon’s scientific community. The politicians support public health; but they know little about case management, and must be convinced that their constituents will be satisfied. The scientific colleagues support the pursuit of knowledge; but they know little about scallops in the bay, and must be convinced that their previous work will not be overturned. The credentials of Callon’s
scientific community are more similar to New York City’s doctors than its politicians, but their role in Callon’s narrative is chiefly political. The transactions described by Callon, in which alliances and citations feed the production of new knowledge, are a central point of Callon and Bruno Latour’s Science and Technology Studies (STS).

Thirdly, New York City’s case management providers – consisting of hospitals and community-based organizations (CBOs) – are analogous to Callon’s scallops. Both populations are in disarray: the scallops’ numbers are dwindling; the case managers’ numbers are gorged, and they are disconnected from medical providers. Like Callon’s scallops, New York’s hospitals and CBOs are policy receivers. Callon’s scallops accept or reject the anchor system and the shelter that comes with it. New York’s hospitals and CBOs accept or reject the PACT program and the funding that comes with it.

This leads into the fourth correlation: the PACT model, like the Japanese anchors, becomes the intellectual property of the translators. CTH and the three researchers absorb the original model and adapt it, creating a specialized version to convey to their targets. However, in the New York narrative, the model is a terrain of political contest: the PACT staff and CTH disagree on the core elements that must be included in a PACT innovation package. The result reflects the two parties’ imbalanced resources: CTH’s opinions are paramount in shaping the model that is sent to 28 replication sites.

Finally, the goals of CTH itself are analogous to those of the three researchers. The researchers seek to advance science and rescue the livelihood of the bay; CTH seeks to advance community health and rescue the chaos of HIV case management. Both embrace their role as translators: they are the go-betweens for diverse groups, and are leading an alliance towards a cutting-edge, cross-sector solution.
Up to this point, the section has introduced the actors in the PACT replication and drawn correspondences to the actors of St. Brieuc’s Bay. In the following subsections, CTH’s definition of key actors and their goals will be presented in depth.
Figure 1: Actors in St. Brieuc’s Bay and New York City (Callon, 1986:20)
Office of Care, Treatment, and Housing

In order for Callon’s researchers or New York City’s CTH to develop an alliance, their own identity and mission must be clearly projected. This subsection examines the circumstances that led CTH to tackle case management reform, and the institutional characteristics that impacted its decisions.

The Office of Care, Treatment, and Housing (CTH) resides in the Bureau of HIV/AIDS in the New York City Department of Mental Health and Hygiene (DOHMH). In previous years, this office had been a hands-off grants administrator: HIV case management programs would make a proposal and receive funding. Grantees interacted only with Public Health Solutions, a master contractor company. In 2006, the office was due to rebid their federal funding for case management, and they prepared a comprehensive assessment. They uncovered a mess: overlapping programs in countless hospitals and community-based organizations (CBOs), which talked neither to each other nor to their patients’ doctors. Like the crisis in the scallop population of Brieuc’s Bay, CTH found a chaotic and unsustainable system. Unimpressed by the hospitals’ helter-skelter applications for the renewed case management funding, CTH was ready to deny them.

Health Commissioner Tom Frieden stepped in: rejecting these struggling public hospitals’ requests was not an option. He told Dr. Daniel Weglein, then director of CTH, “if they don’t know how to write a grant proposal or design a program, do it for them” (DW). CTH was redefined as a policy design team. In this new grant cycle, they would lead the design and implementation process. Like Callon’s researchers, CTH undertook a rescue project through the translation of an innovation. Callon’s researchers would rescue scallops and fishermen through the Japanese anchors; CTH would rescue case management programs and PLWHA through a
homogenized model. The CBOs then dominating case management were scattered throughout the city and were state-funded through Medicaid. They received no funding from the city, and could not be held accountable by CTH or by their clients’ medical providers. The model sought by CTH would embed these programs into the medical establishment, trading grants for program reform and thus drawing state-funded operations into the city’s purview.

CTH self-identifies several characteristics that guide its actions. First of all, New York City’s DOHMH as a whole embraces a scientific approach (AD). In the experience of Assistant Commissioner Dr. Monica Sweeney, “the cultures of health departments are very different,” and New York’s is “one of high professionalism and science” (MS)\(^{14}\). A program can prove its worth only through data, and in decision-making, “you go by the data that you have, not by the assurance of everybody who yells loudest” (DW)\(^{15}\).

Secondly, CTH recently shifted its institutional practice. Directorship passed from Dr. Weglein to Dr. Fabienne Laraque, previously of the Bureau of Tuberculosis Control. Says Weglein, “HIV is different from the vast majority of health department interventions, certainly tuberculosis. And Tuberculosis, the health department does everything; they run their program. And here, we contract everything out” (DW). Under Dr. Laraque’s leadership, CTH’s decisions would shift in favor of internal programming. Most notably, PACT staff members would be phased out of the troubleshooting process and replaced by an in-house technical assistance unit.

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\(^{14}\) New York’s DOHMH is known to pay close attention to conferences and publications in search of evidence-based innovations (AD). Says Assistant Commissioner Sweeney, “people often borrow heavily from successes elsewhere.” To Sweeney, the result is “one of the premier health departments in the United States, maybe the world” (MS). Commissioner of Health Tom Frieden is a prominent researcher of tuberculosis control, and has published over 200 scientific articles.

\(^{15}\) Science and Technology Studies (Callon, 1986; Latour, 1987) asserts that the language of science is inherently powerful and carries assumed expertise. The translators at the center of each story – the three researchers, and Dr. Weglein in CTH – invoke the power of evidence basis and the creation of scientific certainty.
The opportunity window through which CTH entered policy design is distinct from that of St. Brieuc’s Bay, where the disappearance of scallops had led to an open call for proposed solutions. In New York City, it was CTH that first problematized the case management situation. By refusing to renew the grants of haphazard programs, CTH created a rupture and was tasked with solving it. They searched for an evidence-based solution, and once they found it, they requested that an unprecedented $25 million – roughly a quarter of the city’s federally furnished Ryan White HIV budget – be channeled into case management.

Kingdon (1984) defines a policy window to be a narrow stretch of time in which to balance rapid implementation with diminishing political opportunity. After procuring $25 million for that fiscal year, CTH had one year’s green light to roll out their program. The gravity is captured by Dr. Daniel Weglein, then director of the CTH:

> When we thought that we would take PACT or take something like PACT and scale it up to 25 million dollars, we really had no idea what we were getting into. But we did know that we had 25 million dollars, and it was an opportunity that wasn’t going to come along too often. So we’d rather get it started and get it wrong, or get it partially wrong, than wait to make it perfect. So as long as we can keep our eyes on where the glaring holes are, and keep going in there to try to fix them, then we can feel good that we’re getting somewhere. (DW)

The situation was delicate: case managers were being told to trade in open-ended grants for a rigid stipulations adapted from Boston and Haiti. Says Weglein, “when you’re just making a pitch – if you want our money, you can take it on these conditions – that’s one thing, but when you have a competitive solicitation, everything gets politicized. Everyone’s going to charge you with not being a good steward of public money.” CTH was anxious not to appear overly wedded to the PACT model: “As we were preparing, we had to play this sort of balancing act. On the one hand, we had a lot of faith in the PACT model, but on the other hand, we didn’t want to be really
explicit about saying that. So we were using much more vague language about evidence-based interventions, and at some point we talked a lot about Philadelphia, and Chicago, other jurisdictions that had used evidence basis.” This act of camouflage affected even project manager Beau Mitts, who arrived after the pilot programs: “I know it was not just the PACT model - they also looked at the way that medical case management was done in Chicago” (BM). Says Weglein of these other sources:

We didn’t have any data outside of the PACT program, so that’s what we believed in. but it wasn’t easy. We could not have said, “we want to set up PACT sites 100 through 150” - in other words, “we just want some rubber-stamp PACT sites in New York.” Because that just would not have flown. We had to massage it a little bit (DW).

If CTH did have the power to make a rubber stamp of the PACT innovation, what would it look like? The next section explores CTH’s understanding of PACT and the innovations it could bring to New York City.

**PACT**

In the preceding subsection, we saw the CTH step into a program design role. When tasked with finding an alternative case management scheme, CTH turned to their standard practice: an “exhaustive review of the literature” in search of evidence-based success (DW). The model selected through this process was PACT. Like Callon’s anchor system developed in Japan, PACT was a promising model developed in Boston and Haiti. Here, we examine CTH’s perception and definition of the program they chose to replicate. In the first of two great departures from Callon’s framework, it is argued here that the PACT model was pivotal to the initiation and course of the translation process. Familiarity played a key role in CTH’s selection of the PACT model as a device to bring a new order to case management.
Before a discussion of familiarity, other attractive characteristics of the PACT model can be observed. To CTH, the PACT model could bring order to chaos. It emphasized the investment of case managers into the medical infrastructure, instead of floating in the city on state Medicaid dollars. It regimented the process of health education. While any case manager would claim to discuss health education topics, “PACT literally has a workbook…a rigorous way to ensure that all the bases are covered in a consistent way, and that they have measurable outcomes” (DW). The PACT model imbues case management with evidence-basis. PACT had published in prominent journals, and it stood out in the literature as a potential best practice.\textsuperscript{16}

Crucially, the PACT model was familiar to CTH and resonated with past successes. Two elements of the PACT model were familiar to CTH: the health navigation model of case management, and directly observed therapy. CTH highlighted these two elements as they found a model that they could trust and sell. As Latour writes, “the first time we encounter some event, we do not know it; we start knowing something when it is at least the second time we encounter it, that is, when it is familiar to us” (219). To know the model which they would select as best practice, CTH looked for what it had seen once before\textsuperscript{17}. The first highlighted element was health navigation\textsuperscript{18}. To PACT’s client services director, navigation is “a really catch title these days” and only captures one component of their model, which also includes counseling on stigma and treatment adherence. Nevertheless, CTH renamed their community health workers as

\textsuperscript{16} Bruno Latour (1987) describes the process through which ideas are placed into a hierarchy. Our body of knowledge becomes a series of “black boxes”: conjectures are empowered by citation and the recruitment of allies to become fact. PACT was backed by the scientific article, Latour’s key device in the transition from conjecture to knowledge.

\textsuperscript{17} The health policy community has long been known for its familiarity with dominant ideas: “huge, foundation-funded conferences bring civil servants, nonprofit entrepreneurs and academics together” (Kingdon 1984: 123-4)

\textsuperscript{18} Health navigation means lifting logistical barriers between their clients and regular care. It encompasses such services as transportation and accompaniment at appointments.
“Health Navigators.” Says Weglein, who spearheaded the model selection, “You read PACT literature, at least what was published as of 2006– they weren’t saying navigation, but they were doing it” (DW). CTH read a popular, familiar concept into the model they would choose as best practice.

The second familiar element was directly observed therapy (DOT)\textsuperscript{19}. As with health navigation, the PACT staff members “weren’t making a big deal about their directly observed therapy, except to say lots of people try it,” but it quickly took the spotlight in New York (DW). Says Weglein, “You say directly observed therapy in New York City, and everyone thinks about the TB epidemic in the 90s that was rapidly controlled once we implemented a very robust directly observed therapy program.” Commissioner of Health Tom Frieden was receptive to repeating this success, and both he and Dr. Laraque, director of CTH and former director of surveillance at the Bureau of Tuberculosis Control, embraced the DOT model. CTH selected a best practice that would resonate with the department’s history and needs.

The resonance of PACT’s model at CTH was enhanced by personal connections with CTH staff. Former director Daniel Weglein and two of the four project officers are from Boston, PACT’s home. In the replication process, city rivalries would flare as New York medical directors and community organizations protested a Boston transplant and in one case argued with Weglein, who speaks with a Boston accent, about the Red Sox and the Yankees (DW). Current director Fabian Laraque is Haitian, and Jessica Aguilera-Steinert of PACT conjectures that the earthquake relief work of Partners In Health increased Dr. Laraque’s receptiveness to their Boston program.

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\textsuperscript{19} DOT, a technique famously affiliated with Partners In Health in Haiti, is the process by which a health worker brings a patient medications every day and watches the patient take them. It is costly, but highly effective in combating drug resistance among highly vulnerable patient populations.
Finally, CTH perceived PACT as small-scale. Through their collaboration, CTH was helping PACT to grow. Says Weglein, “they were not at all set up to have a technical assistance shop when we first found them. And we helped them become that, just by virtue of needing their guidance” (DW). Speaking generally of small innovative NGOs, Assistant Commissioner Monica Sweeney observed that they “get married to the project. They get entrenched in it. So that 5 years from now, there might come along a more effective approach. But because this is what they’ve gotten their funding on, what they’ve learned how to do best…they want to keep doing it.” (MS). Sweeney’s statement suggests that the health department’s large, evidence-focused team lacks the sentimentality that binds NGOs to their creations. The flexibility, if present, is large-scale and does not appear within one implementation: CTH’s project officers would critique the government’s rigidity, and admire the flexibility with which PACT adjusts its design.

**PACT’s View of Government**

As CTH defined PACT, PACT too weighed the DOH’s strengths and weaknesses. PACT found the government unwilling to change – a tendency observed by many CTH officials. They were cautious; for example, “they felt like safety was a much bigger factor than we do here,” even though “we’re working in similar types of neighborhoods” (JAS). PACT itself had struggled between wanting to be completely open-source, and wanting to protect their materials and unique niche. “Our philosophy comes from the grassroots, whatever-it-takes type of attitude. And the department of health is the department of health, you know? It’s a huge institution, a city- and state- and federally-funded institution, that does wonderful things, but it can’t function in the same way that Partners In Health or PACT does” (JAS).

**Community-Based Organizations**
This chapter began by drawing correspondences between five New York actors and analogs in Callon’s narrative. Next, it began to present greater empirical detail on CTH’s perception of these five New York actors and their goals. Thus far, two actors have been examined: CTH itself, which corresponds with Callon’s three researchers; and the PACT model, which is analogous to the Japanese anchor system. We now turn to a third actor: community-based organizations (CBOs), which together with city hospitals, correspond to the scallops that anchor to an imported model. Like scallops to the people of St. Brieuc’s Bay, CBOs appear to CTH to be a population in disarray. The scallop population is dwindling, and the case management field is overlapping and inefficient. To the outside world, both are opaque and non-functioning. It becomes the role of the translator – Callon’s researchers, and New York’s CTH – to implicate itself in the population and impose an order upon it.

The community-based organizations (CBOs) are defined by CTH officials to be chaotic and outdated. They were created with Medicaid funding twenty years ago, when the epidemic was migrating from men who have sex with men to poor, predominantly minority communities. The disease was untreatable; therefore, these CBOs were designed to provide community support independent of the medical establishment. As treatment became feasible, CBOs and medical providers were haphazardly linked. CBOs served patients from mismatched hospitals and did not communicate with hospital-based case management programs (DW).

New York City’s hundreds of CBOs related to HIV care constitute a powerful lobby: given their original purpose, they carry a mandate to defend minority community health. Fearing irrelevance, the CBOs invoked their racial mandate as they petitioned their representatives: in the words of Weglein, “we’re the grassroots people, we look after the people, we have community in
mind, and we’re going to lose money. And so that’s a bad thing for minority people everywhere…the city plan is racist’” (DW).

Overall, CBOs are constructed by CTH as a chaotic, powerful force that is resistant to change. Because they operate outside of the medical establishment, their activities cannot be held accountable. The correspondence to Callon’s scallops is the opaqueness of their operations; the scallops’ growth patterns were a mystery and their larvae had never been seen. Their illegible population could not be held to fishable levels. The reconstruction of medical case management in New York City was designed to bring a system to order; the PACT model, like Japanese anchors in St. Brieuc’s Bay, became a platform to do so.

**Hospitals**

Like the CBOs, the hospitals are in a position to accept or deny CTH’s reformed program and the funding that accompanies it. To CTH, they pose a greater challenge for reform because as institutions they have “serious infrastructure limitations. And that infrastructure requires them to jump through their hoops” (JAS). The systems change was resisted by medical directors, who defended the approach to case management that they had practiced for 25 years. Assistant Commissioner Monica Sweeney responded, “Well, we wouldn’t be telling you how to do it if you were doing it effectively.” Everybody was “doing what they think is best, and it wasn’t working” (MS).

Doctors, too, resisted the imposition of a foreign model. As a former clinician, Danny Weglein empathizes with doctors and their argument: “I know the difference between anecdote and systematic review of data… And pardon me if I’m a busy practitioner, that I didn’t have time to run data tables and write reports, but I know that what I do works.’ And so we can sympathize
with that, but at the end of the day, a public health agency is sort of bound by the norms of practice:” a commitment to evidence basis (DW).

**Ryan White Funding**

CTH’s power in the face of this resistance lies in its control of Ryan White dollars. Ryan White funding was created by the 2006 Ryan White HIV/AIDS Treatment Modernization Act, and is a Federal grant system that serves as the “payer of last resort:” the funder of HIV/AIDS services excluded by every other form of coverage (Medicaid, Medicare, private insurance, etc.)

Given New York State’s ample supply of Medicaid funding for HIV/AIDS, almost all New Yorkers have access to traditional medical services. Ryan White becomes a safety-net for those that traditional services have failed. This is PACT’s target population: HIV-positive individuals with social barriers that overwhelm and invalidate their access to traditional medical regimens.

Of the $2 billion dollars spent annually on HIV in the New York City area, Ryan White grants account for $110 million dollars.

Ryan White mandates that each city’s funds are allocated by an HIV Planning Council, composed primarily of community providers and consumers. Of the council’s 45 mayoral appointees, 15 are non-aligned consumers (unaffiliated people living with HIV/AIDS). The remaining 30 are mostly representatives from CBOs, with some from hospitals and government agencies. CBOs dominate the HIV Planning Council. Weglein calls it “heavily self-interested,” as only organizations dependent on funding seek seats or show up for meetings. Given the ample Medicaid resources available in New York and the extensive reporting requirements of Ryan White grants, rich hospitals and research institutions have little interest and are absent on the list of 28 replication sites (DW, NR).
The HIV Planning Council is responsible for dividing this grant between service categories. For the PACT replication, CTH requested that an unprecedented $24 million dollars - roughly a quarter of the annual Ryan White budget - be allocated to the case management service category. The HIV Planning Council is dominated by CBO interests whose buy-in would be needed.

The Ryan White Act’s Payer of Last Resort clause would make for a difficult dance between city and state. No Medicaid-eligible service can be budgeted to Ryan White, and thus, CTH sought to leverage and reshape Medicaid-funded programs that accepted supplemental Ryan White funding.

**People Living with HIV/AIDS**

The fourth actor apparent to CTH is the community of people living with HIV/AIDS (PLWHA). PLWHA are voiceless in this story, and yet “whenever you talk about HIV, everybody’s going to be the champion of the patient” (DW). In Callon’s story, the three researchers stepped in to champion the fishermen whose livelihood was at risk; their voice was reduced to a few delegates and their acquiescence was assumed.

The Bureau of HIV/AIDS refers to PLWHA as “consumers” to imply decision-making power, but ironically, they “actually don’t like being called consumers. But nobody has ever explained to me what they’d prefer to be called instead” (NR). PLWHA are described in terms of medical indicators, such as CD4 count and safety of sexual practices. They are surveyed by the DOHMH, but “patient satisfaction surveys give us the same sort of outcomes. People in programs tend to like the programs” (DW). Dr. Weglein believes that CTH lacks the infrastructure to connect to patients because they are so new to policy design. Home visits are referred to as “work in the field,” and were almost eliminated from the New York model due to

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20 In addition to medical case management, service categories include care coordination, the AIDS Drug Assistance Program, housing services, and mental health services for people living with HIV/AIDS.
safety concerns (BM, JAS). Most PLWHA are part of racial minorities. CBOs were licensed as patient advocates as HIV/AIDS became a minority epidemic, and according to Weglein they carry a political mandate for “communities of poor minority folk” (DW).

Both CTH and PACT adamantly blame the patients’ social barriers, not personal efficacy, for their treatment failure; however, this line is hazy. To Project Officer Beau Mitts, the programs can “hopefully help people gain some self-sufficiency” and make it to a point where they can “take their own health care in their own hands and kind of run with it” (BM). To the larger DOHMH, however, the new case management model resounds with patient empowerment. To Assistant Commissioner Monica Sweeney, specific implementation details are irrelevant “as long as we stay in the framework of making sure that the barriers are overcome, that we impart the education, that we make patients a partner, that it’s patient-centric” (MS). Thus, CTH is included in Weglein’s observation that all players in HIV care aspire to be the champion of their patients.

15 of the 45 HIV Planning Council members are “unaligned consumers,” or PLWHA that are not affiliated with a CBO or hospital. Despite constituting a third of the council, they are generally considered “professional patients”: the same few individuals almost always serve as patient representatives. Unelected, they are given little weight on the council. “There’s nothing remotely random about it… We have upwards of 70,000 people living with HIV and AIDS in this city,” and apart from a few doctors in the Bureau who had clinical practice, “nobody else could name more than ten patients” (DW).

Socioeconomic and cultural disparities also obscure the voice of PLWHA. Says Planning Council staffer Nina Rothschild,

Some of the consumers provide a more real role than others… they don’t tend to be primarily a highly educated group; they are very, as I say, vibrant, active
participants in the process; they come and they sit there, and they raise their hand for a vote, but whether they are really fully understanding all of what’s going on, I don’t know. Because the spreadsheets, the budget stuff, is pretty complicated. It’s pretty technical, it’s pretty dry….The typical consumer tends to be, as I say, from various disenfranchised groups and so on (NR).21

PLWHA representatives on the council attend a Leadership Training Institute, to be familiarized with the spreadsheets and other technical tools used in the council’s priority-setting process. A second consumers’ committee, the People With AIDS Advisory Group, exists to assist the council; however, Rothschild considers this group dysfunctional, filled with people who come for the free meal and metro card:

They sit around, they hold endless elections for steering committee members, because everyone wants, you know, a title. And they want to be able to set the agenda…. [the DOH] try to arrange presentations for them, but its often a lot of people sitting around screaming and yelling…You know, they want – they want attention. And they feel the health department doesn’t listen to their voice (NR).

Given that the presence of this advisory group is not mandated in the Ryan White grant process, there are plans to collapse it. The group has become an “unnecessary appendage that is not really serving any useful function at this point” (NR).

Like other players in HIV care, PACT aspires to champion PLWHA and claims a patient connection not achieved by the DOHMH. Invoking the NGO birthright of operating close to the ground (MS; Fisher 1997; Brinkerhoff 2002), they take on the role of a patient whisperer. PACT’s CHWs have a “unique ability to connect and help people with chronic diseases reengage with their health care, improve the quality of their lives, and recognize and address some of their barriers. Which are not just health-related – they’re emotional, and social, and spiritual” (JAS).

Of the replication, PACT’s Jessica Aguilera-Steinert continues, “I want the people in NYC to

21 Rothschild continues, describing an individual on the council: “Some of them – they tend to be lovely people. Um – one is, she’s a sweetheart, she’s a mother of, gosh, I think four….she might have shot drugs at some point in the past, I don’t know…She’s got a really bad stutter, but nevertheless she comes, and she speaks, and she takes a leadership role” (NR)
benefit from that…even if it’s watered down a bit, that would be wonderful.” By replicating the PACT program, CTH can hope to bring multi-dimensional relief to New York’s most vulnerable patients.

**Politicians**

The final actors that this chapter will introduce are the city politicians and DOHMH officials who signed off on the project. A correspondence is drawn between this group and Callon’s scientific community. In Callon’s narrative, a set of scientists learned about the St. Brieuc’s Bay project through conferences and publications, discussed it internally, and mutually decided to approve. In New York, a set of politicians were asked for their signature, heard the same presentations on the PACT model, and across the hierarchy they collectively lent their approval.

In the words of Weglein, however, “HIV can upset political systems.” City politicians are at risk of putting their name on a project protested by CBOs, a prominent voice of minority communities. From CTH’s perspective, these politicians desire, personally, to be safe from accusations of racism that would harm their chance of reelection; and publicly, to expand access to care for the New York HIV/AIDS community. In Callon’s narrative, the scientists desire, personally, that their previous work be acknowledged; and publicly, to expand scientific understanding.

As policy designers, CTH had to negotiate with politicians at multiple levels of government. The new RFP was developed during an election cycle; Michael Bloomberg was attempting to run for a third term, so they had an especially “nervous mayor” (DW). The buy-in of the Commissioner of Health was essential; after granting approval, Commissioner Tom Frieden voiced a predilection for a particular health indicator and it was immediately grafted into
PACT’s model. After Commissioner Frieden left to assume the leadership of the Centers for Disease Control, CTH had to win the support of his replacement, Tom Farley.

The bureaucracy of the DOHMH was a constant constriction on implementation: says Project Officer Kevin Dugan, “if you realize you make a mistake, you can’t just correct it… you can’t just say, ‘okay, we’ll move some money around….We’ll just fix it.’ And then even if you can, it’s a lot of money. Because we’ve got to provide this for 28 agencies. We have to go through everyone in New York City - we have to get like, 8 million signatures to sign off” (KD).

This section introduced five key stakeholders in the translation of PACT to New York City. It compared each to its analog in Callon’s actor network theory framework: CTH to the three researchers; the PACT model to the Japanese anchors; CBOs and hospitals to the scallops; PLWHA to the fishermen; and finally, politicians to the scientific community.

Through this exercise, the chapter uncovered a serious disjuncture between the PACT and St. Brieuc’s Bay narratives. Callon’s theory pays little attention to the innovation, a foreign anchoring system as static as a cardboard cutout. By contrast, characteristics of PACT and its resonance with CTH’s past successes were the impetus behind this cross-sector undertaking. While the innovators in Callon’s narrative are silent, their anchor system easily becoming the intellectual property of the translators, PACT itself is a key actor and the essential components of its model are contested by CTH, replication sites, and its Boston-based creators.

The following section will bring the PACT replication story into the next stage: interessement. In this stage, the roles established in problematization will be solidified and drawn into an alliance in support of the grand relocation and translation of PACT.

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22 This transaction will be discussed in greater depth in Chapter 4, Enrolment.
CHAPTER 3: INTERESSEMENT

“You’ve got to get the case managers to understand: even though we’re not going to continue with business as usual, you’re not going to lose your shirts. And we’re not saying that you’ve been wasting your time for the past 20 years. We’re trying to nudge this in a new direction and form some good collaborations where everybody wins. And we’re going to all do better in achieving patient goals.”

– Dr. Daniel Weglein, NYC Director of Public Health Practice for HIV Care

Callon’s second stage of translation, *interessement*, stabilizes the identity of the actors and locks them into roles. Employing such mechanisms as force, seduction, or solicitation, a group imposes tests on the limits of other actors’ commitment. Whether these tests are passed or rejected adjusts and reshapes the identities defined in problematization. Additionally, the translating entities build devices between the relevant actors and rival projects, weakening or dismantling their links to others. This relationship between the translator, an actor, and a rival influence is Callon’s “triangle of *interessement*.” By way of these tests and barriers, all identities are modified and consolidated.

*Interessement in St. Brieuc’s Bay*

In St. Brieuc’s Bay, the scallops are interested through the experimental apparatus: a device that protects the vulnerable larvae from predators, and provides an anchor for them. The larvae are thus extracted from their context and shielded from currents, predators, and fishermen, in exchange for anchoring. The hypothesis from *problematization* is materialized. To interest the fishermen, the three researchers need only influence their few representatives; by drawing graphs on a chalkboard and discussing “spectacular” results in Japan, they persuade the fishermen to ally with their project. Thirdly, the three researchers interest their scientific colleagues through conferences and publications. The researchers claim that an exhaustive literature review has
produced no knowledge of scallops; this species is endangered, and research is needed to save them. Connections are broken between these three actors and those that would define them in competitive ways: the scallops are physically dissociated from predators and currents that would draw them down different pathways.

In the next five sections, I will elaborate on *interessement* in the PACT story: the processes through which stakeholders are approached by CTH and drawn into an alliance. I will seek to correspondences between the PACT story and Callon’s devices of *interessement*, such as force, seduction, and solicitation. I will end the chapter by considering points of great theoretical disjuncture between the PACT story and the translation framework.

**PACT**

PACT responded enthusiastically to CTH’s approach. Director Heidi Behforouz hesitated only briefly before consenting to the New York City replication. Though concerned about the faithful use of PACT’s model, this was an unprecedented opportunity for systems change. This concern, a question of rigidity versus flexibility in replication, is an issue that Callon’s framework does not address and constitutes the second major divergence of the two narratives. This issue will be discussed in greater depth in Chapter 4: Enrolment, which discusses the negotiations that reconstruct the PACT model.

PACT’s contract with the DOHMH committed them to extensive technical assistance at the pilot sites, and effectively sold the city their curriculum. The pilot process was crucial to PACT’s *interessement*. Employing Callon’s *interessement* devices of solicitation and empowerment, CTH asked PACT to lead training and implementation at three city hospitals. PACT’s vision was privileged at the expense of individual replication sites’ authority. According to Weglein, the pilot sites “had a lot more hand-holding, and every time they would say ‘we can’t use the
curriculum,’ they’d have a lot of people shouting them down and saying, ‘yes you can, and you will.’ And it got through” (DW).

PACT took advantage of their authority during the pilot to push through elements of their model that CTH was ready to drop, most notably home visits. Despite the safety concerns of participating agencies, home visits would be retained at all 28 replication sites, and CTH would ensure that agencies were not shirking this element. “If the patient’s preference is to come in (rather than be visited in their home), then that’s acceptable. But we’re talking about patients who have trouble keeping appointments, so we don’t expect too many people to say ‘I’d rather come in’…we know the frequencies with which we expect to see services delivered, so we’ll monitor the actual against the expected” (DW).

After the pilots, however, CTH developed a rigid protocol that would distance both PACT and individual agencies from the decision-making process. However, by leaving the PACT education curriculum and workbook would be almost unchanged, CTH could continue to claim faithfulness to PACT. “We just said, ‘the PACT curriculum’s not broken. Let’s not try and fix this.’ I think it’s pretty close, if not identical, to the original” (DW). CTH’s training process, and the ensuing implementation at 28 replication sites, would be a different story.

**Community-Based Organizations**

CTH made a great error in their first *interessement*: they attempted to exclude the community-based organizations. Says Weglein, “we toyed with the idea of actually taking all the money away from the community organizations, and saying, ‘You know what we want? We want hospitals to be more community, so we want to build a community unit within each hospital’” (DW). In the first request for proposals released by CTH, community-based organizations could not apply; only hospitals and health centers could receive funding to create
an integrated case management system. Commissioner Frieden “was all in favor,” chiefly concerned with the flow of funding to hospitals (DW).

The reaction was swift. Community-based organizations protested the RFP through two powerful channels: the HIV Planning Council and political representatives. Through these channels, CBOs employed one of Callon’s devices – force – to inverted ends, not to *interesse* others, but to cancel the project from which they were excluded and to be *intressé* into an alternative. The first channel of influence was the HIV Planning Council. Dominated by CBOs, the council questioned whether New York could be served by a Boston transplant. To project officer Kevin Dugan, a Boston native, this complaint was hollow: “they found one little thing to grab onto to say, ‘Ah, it’s not going to work here, because of this. People in Boston are different than they are in New York.’ They are, but they’re really not. They’re very similar” (KD).

The council also protested the allocation of an unprecedented $26 million to the case management service category, which would likely favor hospitals and outcompete CBO case managers. Money would have to be drawn away from services for which “there is often a very strong, vocal contingent -- housing, we know, is a major issue for PWAs” (NR). Housing Works, a large and well-established CBO, was one of the most powerful voices protesting the first RFP.

The second channel through which CBOs protested the first RFP was through their city representatives. “They would go to the politicians and say, ‘the city health department wants to shutter my community organization. And my community of poor minority folk are going to be without my services” (DW). As a result of this advocacy, CTH fully withdrew the RFP, and rereleased it a number of months later with a new stipulation: CBOs could apply, as long as they had signed a memorandum of understanding with a hospital or health center that would be their
medical home. CBOs proved that they could not be circumvented, and were *intér essés* into the replication process through their invitation into alliances with hospitals.

Danny Weglein had to persuade CBOs to accept the second RFP: “you’ve got to get the case managers to understand that even though we’re not going to continue with business as usual, you’re not going to lose your shirts. And we’re not saying that you’ve been wasting your time for the past 20 years. We’re trying to nudge this in a new direction, and we’re going to form some good collaborations where everybody wins, and we’re going to all do better in achieving patient goals” (DW). To New York City’s uniquely segmented network of HIV care-providers, in which hospitals and CBOs were distinct, “the idea of collaboration was inherently threatening to all of them” (DW).

In Callon’s “triangle of intér essement,” the translating entity breaks ties between key actors and rival affiliates that do not fit into the translation network. In Callon’s narrative, the three researchers break ties between the scallops and two rival suitors: predators and a strong current. In New York, the CBOs’ most troublesome ties are with their peers: the replication sites communicate with one another, undercutting CTH as an obligatory passage point. As a consequence, says project officer Stephanie Boarden, “We have to send the same message to all of our agencies. Because…they talk. And so it’s very clear when there are inconsistent messages being sent” (SB). Adds Jessica Auerbach, “they all know each other. So they know anything we say to any of them…there’s both our own reasons that we don’t want that, and then the programs themselves feel like there’s double messages” (JA). By ensuring equal treatment of all the agencies, CTH limits the CBOs’ need to discuss inconsistencies through their own private channels.

*Hospitals*
The previous section examined the *interessement* of CBOs by way of their financial imperative, and only after they were excluded from the first RFP. This section examines the *interessement* of public hospitals by way of their financial imperative, and only after their programs were almost excluded from CTH’s grant budget, prompting Commissioner Frieden to intervene. New York’s public hospitals require grant money to function, and as Commissioner Tom Frieden asserted, denying Ryan White funding to chaotic public hospital case management programs was not an option. Rich, research-based hospitals are not players in this story.

In the past, CTH had contacted hospitals only through their master contractor, Public Health Solutions. For the *interessement* of PACT replication sites, CTH eliminated the middle man and formed a direct alliance with each health center. According to project officer Kevin Dugan, programs in previous grant cycles could “steer themselves in a way that their individual leadership wants to go, so their own culture could be maintained. You didn’t really know where the money came from, usually; it’s just, you have the money to deliver services. Now it’s pretty clear that the money comes from somewhere, and that somewhere wants you to do things their way” (KD). Like French fishermen wary of a Japanese solution, the medical directors of hospitals were wary of having twenty years of history in case management invalidated by a Boston transplant program. Says Danny Weglein,

There I was, talking about Boston with a Boston accent in New York, and that’s about the worst thing you can do. And we literally had a very well-respected medical director who was a staunch Yankees fan, just arguing with me about the Yankees and the Red Sox. And this became such a city issue: “our city’s better than your city, don’t tell us how to do things. Everyone’s always talking about Harvard, Harvard, Harvard, but we have good institutions in this city too.” And there was this tremendous push-back that had to do with, you know, “please respect what we’ve developed here” (DW).
Some hospitals that received the RFP had hoped to skate by with little change; according to Acharya (2004), due to the “social and political cost to changing existing institutions,” an idea recipient’s chief intention is often to strengthen, rather than replace, existing institutions. Some grantees hoped to receive the RFP funding without truly paying this cost, and the extent to which they change is continually renegotiated.

**Politicians**

Up to this point, the chapter has examined the devices of *intérêtement* through which CTH engaged three groups: PACT, CBOs, and hospitals. Next, I turn to the mechanisms through which New York City politicians’ interests became aligned with the case management reform.

“There was a lot of time spent in the offices of the important people to get them on board,” says Danny Weglein. “We probably spent more time talking in-house to our concerned directors than we did talking to the service partners. The politicians were much more nervous, so we had to do a lot of hand-holding” (DW)\(^{23}\). To engage the politicians, CTH invoked three main devices.

After the failure of the first RFP, it became clear that the communications between CBOs and city politicians was devastating to CTH as an obligatory passage point. Thus, CTH’s first move was to undercut this channel. Through two of Callon’s devices – persuasion, and seduction with the promise of cost savings – CTH invalidated the complaints that CBOs were bringing to their representatives. Says Weglein, “any community organization that wants to go to their council-member and say, ‘I stand to lose five hundred thousand dollars because of X Y and Z,’ just isn’t being honest” (DW). CBOs had been given the option of partnering with a medical provider,

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\(^{23}\)This contrasts with Rogers’ orthodox Diffusion of Innovations explanation, presented in Chapter 1 under *Alternative Explanations*. In Rogers’ framework, the rate of adoption is proportional to the energy that the change-agent spends to persuade potential adopters. In this scenario, replication sites are drawn by financial imperative to adopt the model, and persuasive energy is spent on city politicians. This is representative of orthodox diffusion theory’s limited vocabulary for describing the politics of translation.
though as the implementation would show, these MOUs would place CBOs at the mercy of their disinterested hospital counterparts.

Secondly, employing Callon’s device of seduction, CTH promoted the benefits of the PACT model itself: the current case management system was chaos, and poor and minority communities would have better care and fewer costly emergency room visits.

Thirdly, CTH employed Callon’s device of solicitation: they created a mathematical algorithm to distribute grants without any suspicion of favoritism, alleviating the politicians’ fear of being blamed for injustice. One of the health commissioner’s own staff helped to design the algorithm, tapping the device of familiarity. Here, as with the selection of an innovation, the importance of familiarity is overlooked by Callon’s analysis. Through the office of the commissioner’s own algorithm, CTH promises to “put the money where the patients are” and invoke efficiencies of scale, appealing to the scientific culture of the New York City DOHMH (DW).

CTH’s counterparts at the state level were also key stakeholders; the new case management sought to reform Medicaid-funded turf. Through negotiation and Callon’s device of solicitation, state officials “have been able to hear and understand that leveraging Medicaid means growing the entire pie, not taking their slice and making it ours. So that’s the most recent development, but we don’t yet have a happy marriage where we’re all moving forward” (DW).

**Project Officers**

After the pilot projects, CTH developed an in-house technical assistance unit composed of two program managers and four project officers responsible for seven sites each. The project officers are pulled in two directions: they desire to “champion the cause of those who are confiding in us,” even as they are responsible for halting deviations from the model (KD). To
project officer Kevin Dugan, “having to wear the two hats is the trickiest part of the dance.” They are problem-solvers who raise their agencies’ issues at project officer meetings, but they are not allowed vote on issues raised by their own sites. “It’s almost like parenting a little bit…you want to be able to do well. You know, make them happy, and be able to give them nice things. Like a program that works for them. But you can’t always. And sometimes you kind of have to come down hard on them, and say, ‘you’re doing things wrong. You need to get your act together’” (KD).

**People Living With HIV/AIDS**

The PLWHA did not have to be intéressé: they were targeted and championed by these projects, and token delegates on the HIV Planning Council witnessed CTH’s decisions. Like Callon’s fishermen, their representatives are signed on as witnesses and unity behind the delegates must be assumed. Unlike Callon’s fishermen, PLWHA’s delegates are not elected; the Council does not credit them as a substantive voice of the HIV/AIDS community. Thus, without even the device of persuasion through which Callon’s fishermen are intéressé, CTH implicates PLWHA council appointees as mere witnesses to the process that surrounds them.

This chapter advanced the New York City narrative through Callon’s second stage: intéressement. In this stage, the actors whose roles had been defined in problematization were engaged in an alliance behind case management reform. This was accomplished through devices including persuasion, solicitation, and seduction. In the attraction of politicians to the project, as with the attraction of CTH to the PACT model in the problematization stage, familiarity was an important factor in the course of the translation. This factor is overlooked in Callon’s framework, constituting a major point of divergence between the two narratives.
The next chapter will explore the next stage of translation in New York City: enrolment. In this stage, the roles set out in intérressement are substantiated and, through a series of transactions and contests, renegotiated.
CHAPTER 4: ENROLMENT

“This became such a city issue: “our city’s better than your city, don’t tell us how to do things. Everyone’s always talking about Harvard, Harvard, Harvard, but we have good institutions in this city too.” And there was this tremendous push-back that had to do with, ‘please respect what we’ve developed here.’”

– Dr. Daniel Weglein, NYC Director of Public Health Practice for HIV Care

Callon’s stage of enrolment is a process of negotiation: it “transforms a question into a series of statements which are more certain” (Callon, 10). Enrolment is a set of strategies by which a powerful entity redefines and renegotiates the interrelated roles of the network of actors. It is the natural conclusion of successful intéressement – the solidification of allied intent. In the PACT story, enrolment resulted in a number of changes to the PACT model. Power imbalances reshaped the model to fit the interest of some, against the interest of others.

Enrolment in St. Brieuc’s Bay

The centerpiece of Callon’s own enrolment story is the scallops themselves: “a veritable battle” is fought to negotiate their anchorage. It is determined that the scallops anchor more frequently in inner parts of the bay; that they are “extremely sensitive to all manipulations,” and react by relinquishing their anchor; and that they prefer certain types of net material over others. The researchers make all these concessions. Through a series of transactions, “a modus Vivendi is progressively arranged” (Callon, 1986: 11). To enroll the scientific colleagues, another transaction is made: the three researchers implicitly agree to recognize all previous work, and “it is at this price that the number of anchorages claimed by the researchers will be judged as sufficient.” Transactions with Callon’s final group, the fishermen, are non-existent: “they watch
like amused spectators and wait for the final verdict” (Callon, 1986: 12). The fishermen’s representatives lack the power to make demands. Through the process of *interessement*, their voice has already been wholly passed on to the three researchers.

In the next sections, I will examine the process of *enrolment* as it relates to actors in New York City. A series of negotiations with PACT, politicians, and state Medicaid funding streams impact the shape of the model.

Also in this chapter, we encounter the second great departure between the PACT story and Callon’s framework: Callon’s theory does not address the central replication issue of rigidity. While Callon’s *enrolment* does involve contestation of the translators’ original vision, it does not provide a vocabulary to describe the conflicting motives that drive each actor to pursue either rigidity or flexibility at the 28 implementation sites. PACT desires faithfulness to their original innovation, to safeguard the outcomes of a model that bears their name. CTH seeks rigidity to their protocol, a re-invention of the PACT model, at each of the 28 sites, for reasons of consistency and ease of evaluation. Finally, hospitals and CBOs fight for CTH’s rigid standards to be relaxed, in order for reform to be flexible and their previous case management processes to stand firm.

In the next sections, the chapter turns to a detailed examination of *enrolment* in New York City.

**The Office of Care, Treatment, and Housing**

Before turning to the transactions between CTH and other actors, this section examines the internal transactions of CTH: the process by which, in service of its own institutional needs, CTH transforms PACT’s innovation and exports a distinctly repackaged model to 28 New York sites. Here, 4 major points in the repackaging process are highlighted. The section will end by
discussing CTH’s motivations for rigidity, the second of two crucial issues that cannot be addressed within Callon’s narrative.\footnote{These two issues are familiarity, which influenced the selection of PACT (Chapter 2); and rigidity, which had contested impact on the implementation process (Chapter 4).}

First, the DOHMH culture of science and standardization had great impact on the model. The hospitals and CBOs that had been interested by the RFP were faced with a rigid CTH package. Unlike PACT’s services, which were continually reinvented at the implementation stage, each New York program was built with a protocol and a timeline of deliverables. Any exceptions made by the DOH were instantly criticized due to the communication between the 28 agencies.

Second, in order to stabilize CTH’s role as an information conduit, they replaced PACT’s troubleshooting with an in-house technical assistance unit staffed by four project officers. Difficulties reported by the replication sites only became “problems,” rather than the inherent friction of adoption, only when they were defined as such by CTH troubleshooting team. Says Weglein, “One of the things we learned from working with PACT as we were rolling out our pilots is that we’ve got to have a lot of eyes on the ground…They have a whole slew of responsibilities to make sure that what we envision gets carried out” (DW).

As the obligatory passage point, CTH held the reins of assessment and evaluation. Project sites created swathes of paperwork, which would be reviewed at CTH’s discretion. “Success” was mystified even to CTH Project Officers. Said one officer, “if we were out there every day for a week at each site, we might be able to get our finger on the pulse a little better.” As a “program that’s focused on maintenance,” few patients are expected to graduate to full independence, “so I think the variables that we’re going to look at may not necessarily lead one to believe success …success is a tough word with this structure” (KD).
Third, New York programs had a larger target population: “the DOH in New York needs to provide services to all people with HIV, not just the people who are falling through the cracks. So their criteria are slightly different, their eligibility for entrance into this program” (JAS).

This section now turns to a discussion of CTH’s complex relationship with rigidity. High-level officials readily advocated the export of a homogeneous model. By contrast, the four project officers – who interacted directly with replication sites – were torn in two directions, compelled to enforce rigidity but sympathetic to their clients’ demands. Their competing points of view are discussed in the next two paragraphs.

Assistant Commissioner Monica Sweeney and project manager Beau Mitts and are not chief contacts with any of the agencies, and thus advocated rigidity without having to wear the “two hats” – good cop, bad cop – described by project officer Kevin Dugan. To Sweeney, hospitals and CBOs “want to make it more fluid. But if you make it too fluid, then you go back to the way things were being done before. Everybody doing what they think is best, and it wasn’t working” (MS). Mitts advocates standardization to ensure that patients “are getting the same quality of care at agency X as they would at agency Y” (BM).

The project officers, by contrast, unequivocally call for greater flexibility for the agencies that they “parent.” Says one officer, “the majority of the issues are coming from us, not from PACT. …It’s the way we’re handling the implementation.” As long as CTH “stays true to what’s at the heart of it,” the program should be adapted to “fit the community that it’s serving.”

25 Adds another officer, “when you see something that’s not working, you want to change it so it does work” (SB). The project officers found their timelines to be rigid: “We’ve kind of rushed some of our deadlines sometimes, which has caused us to have to go back and change things.” In

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25 Simmons (2007) supports this belief: user organizations that are flexible and willing to learn are more likely to succeed than those that are rigidly bound by rules and emphasize standardization.
hindsight, “if you don’t have the time to do it right the first time, when are you going to have time to do it?” (KD) This contrasts sharply with Dr. Weglein’s big-picture view: “we had 25 million dollars, and it was an opportunity that wasn’t going to come along too often. So we’d rather get it started and get it wrong, or get it partially wrong, than wait to make it perfect” (DW).

Only one project officer was at CTH during the pilots, and Weglein observes that her view of the model is more favorable than the others’. “The new project officer with new programs starts to integrate this idea that the curriculum is the problem. The patients say it, the staff say it, now our project officer thinks we should change our curriculum. So it’s interesting for all of them sitting around the table to hear that. Everybody gets a siloed view” (DW). Weglein implies that rather than the curriculum being the problem, resistance at each replication sites is threatening the integrity of the CTH protocol.

Even within one actor-group, there are two distinctly competing views on rigidity: to high-level officials focused on the big picture, in particular Dr. Weglein who led the model’s selection and redesign, rigidity is desirable and the friction of adoption should be overcome. To the implementation-level project officers, who are loyal to the hospitals and CBOs in their charge, their difficulties are not friction, but a poor fit that must be eased through local transformation.

**PACT**

PACT gave up great power in the enrolment stage. After enjoying great authority at the pilot sites during intéressement, their curriculum was turned over to a private company: PACT was asked to train the trainers. Jessica Aguilera-Steinert considers this their “first mistake.” There is no consensus on why PACT was not hired for the full training. Jessica Aguilera-Steinert believes they lacked the capacity; director Heidi Behforouz believes they were turned down because
higher-ups were financially unwilling to equip PACT for this amount of technical assistance; Danny Weglein says it’s a mystery and that PACT did not apply, perhaps because Dr. Behforouz was on leave; Project Officer Jessica Auerbach’s impression was that they just “couldn’t work it out” (JA). In Callon’s story, there is no place for the Japanese model to have a mind of its own; it must be the intellectual property of the translators, or authority is scattered and alliances are unglued. PACT is an actor, but they are necessarily reconceived by CTH as a two-dimensional model with “spectacular” credibility, but gcooperative mutability.

The training program took the curriculum out of PACT’s hands. Power over the curriculum was generally dissipated, and those tasked with hanging onto it were the project officers at CTH, not PACT. Three weeks of PACT’s training were compressed into just 2 days of a 10-day training, which the training company performed 16 times. “We have no idea what they’re doing with the curriculum. They were never trained on it per se, formally, and they all have it” (JAS). The DOHMH considered stripping several chapters of the curriculum; there was an intellectual property rights discussion with PACT’s lawyer, and the possibility was dropped. Weglein called this a “‘what the hell did you do to our curriculum’ kind of moment.” the full workbook was maintained, symbolizing to the DOH that the PACT curriculum was being replicated faithfully. But as PACT argued, and as the DOH would discover, the heart of the model was lost when corners were cut on supervision and training. Says Weglein:

You can’t train and walk away. We were hearing from the service providers that they just didn’t feel competent. And we knew that. They didn’t feel competent with the curriculum, or with the home visits, or how to get someone on DOT, and our POs didn’t have the competency to support it all (DW).

The PACT model is particularly demanding, requiring health workers to complete an education workbook on issues of stigma and adherence. Says Weglein, “if somebody comes to
you out of the blue and says, ‘I have a workbook, we’re going to do work in a workbook,’ you’re going to think they’re crazy. There’s a way to talk to a patient – yes, this is uncomfortable, and it seems weird, and it’s not something you’ve done, but you and I have agreed that this is the best thing we can do today to ensure that the goals we want to achieve are going to be met. And it’s that means of talking to a patient, that wasn’t adequately trained” (DW).

The project officers, too, were ready for greater involvement from PACT. “There hasn’t been as much as what everybody would like. It seems like, moving into the second year, like they will be a lot more involved” (JA). Project officer Stephanie Boarden defined the heart of PACT to be “the amount of time that they invest up front in their staff” to ensure that “every single one of them really understands the mission of program…it’s probably easier to do that when you’re one program,” without “trying to deal with different policies, different communities, different personalities. Scaling up is always difficult, because implementation is opened up to so many more external factors” (SB).

In the enrolment stage, the PACT model was purchased and trimmed. Key efficacy was lost, and discomfort at the disjointed model would grow in both Boston and New York. This dissonance would be resolved in Callon’s fifth and final stage, discussed in the next chapter: dissidence and controversy.

**Politicians**

In the previous stage of interessement, city politicians were persuaded that CBOs would not be shuttered and the chaos of case management would be imbued with accountability and evidence basis. To advance this engagement through enrolment, CTH incorporated politicians’ personal vision more intimately into the project.
First, “at a meeting with Commissioner Frieden about the PACT model, he kept talking about Malawi,” says Weglein. The commissioner had read an article about the use of body weight as a health indicator in a Malawi study, and had cited it in one of his own papers (Frieden, 2005, citing Libamba, 2005). This indicator was swept into the model: “we were going to give the commissioner that nod, that we would monitor patient body weight as an indicator of progress. But everything else was going to come from PACT” (DW).

In a second personal connection, Commissioner Frieden’s own staff helped to develop a mathematical algorithm for distributing grant money. Amidst the flurry of petitions that the city plan was anti-grassroots and anti-minority, the program would be scientifically ironclad and thus deflect future complaints of unfairness.

**Hospitals and CBOS**

This section examines the transactions through which hospitals and CBOs, despite CTH’s efforts at rigidity, affected their own adjustments upon the PACT model. Replication did not follow CTH’s script: the hospitals brought bargaining chips to the table that precluded homogenization, and CBOs lacked the power to achieve the hospital-CBO collaboration set out in their contracts. A correspondence can be drawn to the transactions between Callon’s researchers and St. Brieuc’s scallops: the scallops demonstrated their needs regarding net type and anchor placement and the scientists conceded, shifting the design towards a suitable compromise. In New York City, the process of negotiation is actively underway: struggling programs are grasping for solutions and bartering exceptions from a reticent CTH. This section will first examine the *enrolment* of hospitals; second, the *enrolment* of CBOs; and finally, the duress endured by both, as observed by their project officers.
The enrolment of hospitals and health centers reflected that each was bound by its own administrative hoops. Depending on the institution, elements such as home visits were either welcomed or violently protested. In the difficult financial climate, many hospitals were unable to hire new staff. The largest hospitals received grants to serve 200 patients, and these “weren’t able to scale up in time” (DW). Those with unions often had to reassign existing staff members. Says project officer Kevin Dugan, “At that point, that person might just be working a job. And I don’t think this is a job that you can ‘just work’” (KD).

By contrast, CBOs found themselves at the mercy of their medical providers. Their CTH contract required that they schedule check-ins with doctors, but the hospitals with which they had signed MOUs were not receiving Ryan White funds, and had no financial incentive to schedule them in. “There’s a power dynamic,” says project officer Stephanie Boarden. “Hospitals generally have a lot more money and a lot more power.” To meet funding milestones, CBOs need doctors’ signatures: “we have 14 or 16 different forms for them to fill out at different times during the program” (KD). To the benefit of CBOs, however, some case managers who lost their jobs were able to find work elsewhere in the program. Almost 300 staff were needed for the 28 sites, and given the relative hiring of CBOs, “they were exceedingly efficient in terms of moving staff whose grants terminated – staff just knew where to go to find the new jobs in the programs that had to scale up” (DW).

By all accounts, replication sites found the process overwhelming and stressful. Says project officer Kevin Dugan, “I think it was very intimidating…We hand them a stack of papers that’s two inches thick, and say, ‘read this, memorize it, and then you’re going to have to do all this paperwork as well.’ And it’s not easy, by any chance. I mean, we haven’t made this a simple program. It really can’t be” (KD). The level of CTH involvement in their grantees’ affairs was
unprecedented. “Contractors get really nervous because of the protocol, and we certainly understand – this is a first year, a huge system change, and a huge system” (BM). Adds another project officer, “I do think they genuinely want to do what we’re asking them to do, but I don’t think they totally get what that is, or how to do it. Because it’s so complicated, and so new, and on such a large scale. They are the guinea pigs, basically…And we don’t have it totally together for them” (JA).

As the program goes on, these agencies are beginning to gain more ownership of their projects. In the transactions and tests of enrolment, the relationship between actors is mutually reconstituted. According to Dugan, agencies are finding some “wiggle room” and taking ownership of the big picture: “we can mold this; we can make this our program, not just DOH’s program” (KD). Some hospitals are reclaiming their administrative agency, going “above and beyond to create their own forms that would help ease their internal work flow” (KD).

The DOHMH had never been too concerned with the internal structures of hospitals and CBOs, but through this contentious process, a new awareness developed. “We’ve learned a little bit more about the structure of the organizations…we’ve delved so much into their internal processes. We haven’t integrated ourselves so finely into people’s day-to-day with other grants – this is a first” (KD). In the formation of a new relationship between CTH and their grantees, “there’s been a lot of bidirectional communication,” and CTH is “allowing feedback from the grantees to help shape the program moving forward.” Adds Dugan, “we don’t take everything they say, but we listen to everything say” (KD).

**Funding**

The New York replication has been profoundly impacted by the negotiation of two financial issues: funding streams, and the shifting reimbursement system. *Enrolment* examines the
evolution of the innovation as hypothetical commitments become contending forces. New York’s financial incentives are the greatest force guiding the reality of implementation.

First of all, the course of implementation was determined by funding streams. A subset of PACT services – accompaniment, treatment adherence, and navigation – is reimbursable by Medicaid. Given that Ryan White is a “payer of last resort,” it cannot be charged for these services. Two PACT components – directly observed therapy and educational health promotion – are the “safety net” services for which Ryan White is responsible. Case management reform offered CTH an opportunity to leverage New York State’s ample Medicaid funding. Agencies that accepted a Ryan White grant were asked to adapt their entire case management program to the Ryan White model, while still charging Medicaid for the majority of services.

This strategy steps on the turf of CTH’s state-level counterparts by reshaping what state Medicaid funding is being used for. Like city politicians, the state’s AIDS Institute worried that the reform would harm their CBO dependents. Through the interessement device of persuasion, “they have been able to hear and understand that leveraging Medicaid means growing the entire pie, not taking their slice and making it ours…but we don’t yet have a happy marriage where we’re all moving forward” (DW). Asked about the state’s reaction to the replication, Weglein laughed:

How do they feel about the program change on your tape recorder, huh? That’s wonderful. Let’s see…it’s been a very delicate dance. It’s not just the financial investment, but the emotional investment, the professional investment. This is their baby for twenty years, and here we are saying, ‘hey! We’ve got something new and better.’ So yeah, it’s been – that’s a lot of work. And I mean, that’s part of the reason why we still don’t have a good approach on how to split [the two sets of services] (DW).

In practice, CTH cannot control what agencies do with their Medicaid funding. The 28 agencies are dividing the funding streams in one of two ways, one of which CTH prefers and will
require in next year’s contract. In CTH’s preferred method, each agency has two sets of staff serving the same patients: one to provide Medicaid services, and one to provide Ryan White services. PACT’s health worker role is split into two: a care coordinator and navigator. Weglein hopes that ultimately “programs will acknowledge on their own that they like the idea of the accompanier and a health promoter being separate people. And we’ll certainly push the PACT-ness of it: that accompaniment and health promotion go hand in hand, and it doesn’t make sense to split them apart. It’s not going to be easy– that’s going to be a tough nut to crack” (DW).

In CTH’s less preferred method, agencies run two separate case management programs for two different sets of patients. Because Medicaid is fee-per-service and Ryan White gives a staggered lump sum, it is in the agency’s interest to see as many patients as possible through their Medicaid program, and receive the same Ryan White grant for seeing relatively few patients. Given that 90% of target patients qualify for Medicaid, an agency chooses a few patients “based on their hair color or something” to sidetrack into the Ryan White program. Says Weglein:

If you’re not taking Medicaid revenue, then your patients are more expensive. That means we have to settle for a lower target, and we don’t like that. We like higher targets. And particularly when the higher targets come at Medicaid’s expense. We love that. Especially in this state - Medicaid is virtually a bottomless pit. And it’s not in reality, but HIV is still relatively small-scale compared to the universe, so as far as we’re concerned it’s bottomless. So we do want to maximize it (DW).

The second financial force shaping the replication process is CTH’s chosen reimbursement structure. In this first year, CTH employed a “deliverables-based reimbursement system:” the 28 sites received payment when they achieved percentage milestones of their target number of patients. However, the contract indicated a switch to a fee-for-service structure in the second

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26 The Medicaid-funded case management model is called COBRA, and co-exists with distinct Ryan White programs.
year, once CTH had time to design one. Fee-for-service would allow CTH to be “more performance-based in our reimbursement, to ensure that we’re getting what we pay for” (BM).27

Thus, financial considerations drove CTH to combine persuasion (staggered funding) with coercion (contractual obligations) to maximize the number of patients served by Ryan White, sending as much of the bill as possible to state Medicaid while taking the reins of the city’s case management. In the enrolment stage, the hypothetical alliance between CTH and replication sites was negotiated into a mutually acceptable reality, and CTH’s financial incentives had a profound influence on the course of implementation.

This chapter advanced the New York City story through Callon’s third stage: enrolment. The next chapter will follow the PACT replication through the fourth stage, mobilization, and end by discussing the inevitable backlash in Callon’s fifth stage: dissidence and controversy.

27 A true fee-for-service model would be unfeasible, because there are so many moving parts: various tracks of treatment intensity, various approaches to home visits. The coming year’s fee-for-service system contains three tiers: first, reimbursement per patient in each service track; secondly, direct reimbursement for all DOT activities; and finally, reimbursement based on milestones in which patients are down-graded from high-intensity to low-intensity care (BM).
CHAPTER 5: MOBILIZATION

“To speak for others is to first silence those in whose name we speak.”
- Michel Callon (1986: 14)

Mobilization is a crucial stage for the power dynamics of translation: it is the process of reducing enrolled groups to individual spokespeople. It is the displacement of identity, a process that underlies all of translation. As the name suggests, this stage renders a group mobile – or accessible – through a series of equivalencies and reductions. In the end, the translating entity incorporates the voice of these representatives and thus of entire populations. Each new representative must “meet a double requirement: it renders each new displacement easier and it establishes equivalences which result in the designation of the three researchers as spokesmen” (Callon, 1986: 14). Through this mobilization, the enrolment becomes active support.

Mobilization in St. Brieuc’s Bay

Callon’s model of mobilization shows fascinating symmetry between the scallops and the fishermen. The scallops are represented by their larvae: by deciding to anchor or not, each casts a “ballot” and is converted into a statistic. This becomes a set of tables and curves on sheets of paper, carried by the researchers and presented at Brest. Similarly, the fishermen cast their ballots to select a representative. This official spokesman’s views are recorded by the researchers, and like the scallop statistics, are voiced by the researchers at Brest. Thus, each party is displaced through a series of equivalencies and thus rendered both mobile. Their final form is interpretable by the researchers alone, who are thus empowered to communicate on both populations’ behalf.
Mobilization affects all the central actors in our story, and is discussed in the ensuing sections. Correspondences between the mobilization processes in New York City and St. Brieuc’s Bay are illustrated in Figure 2.

Figure 2: Mobilization in St. Brieuc’s Bay and New York City (Callon, 1986: 22)
“We have no idea what they’re doing with the curriculum. They were never trained on it, formally, and they all have it.”

- Jessica Aguilera-Steinert, PACT Director of Client Services

PACT was directly involved in the pilot process, but once they met limits of funding and capacity, their model was mobilized as their paper curriculum and workbook. They entered as dynamic actors, but their role became the provision of a legitimated, two-dimensional model to be translated at the discretion of CTH, Callon’s obligatory passage point. The use of the PACT workbook allowed CTH to claim faithful replication, even as training, staffing, and supervision differences reinvented the model. When PACT trained professional trainers, their authority was symbolically transferred.

**PLWHA**

In the second instance of mobilization, PLWHA were reduced to a few “professional patients.” These few voices were then discounted for two reasons. First, in the dysfunctional Consumer Advisory Group, they were dismissed as rowdy and attention-seeking. Second, in the HIV Planning Council itself, the patients were known to lack a true electoral mandate from the HIV/AIDS population and were thus powerless. Patient satisfaction was mobilized by DOH surveys, which are consistently positive: “people in programs tend to like the programs” (DW). They were trained at an institute before participating in the HIV Planning Council; like Callon’s fishermen, they were “informed (i.e., formed)” (Callon, 1986: 16).

**CBOs and Hospitals**
In the third instance of mobilization, CTH sought to make CBOs and hospital programs legible via the rigid implementation of protocol. An array of disordered case management programs were disciplined through the mechanism of a Ryan White grant, and though this grant paid only a portion of services, participating sites were expected to adapt their whole process to CTH’s vision. Local institutions were displaced. A correspondence can be drawn to St. Brieuc’s Bay, where a disordered and declining scallop population was displaced from its existing behaviors, brought under the discipline of an anchor program, and illuminated by scientific observation.

The programs’ performance was mobilized as paperwork, to be gathered and eventually reviewed by CTH staff itself. These papers alone have the power to indicate a problem in the curriculum; the complaints of CBOs and hospitals can be dismissed resistance to change. The power for assessment was in the hands of CTH alone. A correspondence can be drawn to St. Brieuc’s Bay, where similarly, the researchers assessed the project based on a statistic they gathered. Like the replication sites, Callon’s individual scallops had no authority for assessment: once they had anchored, they were a simple “yes” vote.

The four project officers became the spokespeople for their seven replication sites, mobilizing the voices of these agencies for access at CTH team meetings. As confidantes and aides to these sites, the project officers wished they could minimize their displacement by allowing for local adjustment. To one officer, the hardest part of the job is telling agencies, “we’re not on your side, actually. We’re actually going to continue to tell you no” (KD). If CTH staff were to find an adjustment that would benefit all 28 sites, “you can’t just say, ‘we’ll just

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28 The percentage of *Pectus Maximus* scallops attaching to the anchors
29 As the spokesperson representing their assigned agencies, project officers must abstain from the vote on whether or not to turn an agency’s complaint into a universal allowance. They have allowed “a small handful, if even that many,” exceptions, fearing backlash if they act inconsistently.
move some money around, and just fix it’…It’s a lot of money. We have to go through everyone in New York City” (KD).

The system enforces the distribution of power: assessment is the purview of CTH, and for changes to be implemented, a CTH team member must be personally invested enough to push them through the DOHMH bureaucracy. Like Callon’s anchoring scallops, these replication sites cast their vote when they became a unit of compliance. Their ensuing difficulties can be construed, particularly by upper-level CTH officials, as wrinkles to be pressed in the fractious process of adaptation.
DISSIDENCE AND CONTROVERSY

“There was a ‘what the Hell did you do to our curriculum’ kind of moment.”

– Dr. Daniel Weglein, NYC Director of Public Health Practice for HIV Care

This last section of Chapter 5 turns to Callon’s almost inevitable final stage, controversy. The representativity of the spokesmen is questioned, rejected, and renegotiated. “Consensus and the alliances which it implies can be contested at any moment. Translation becomes treason” (Callon, 1986: 15). In this process, identities are recrafted along with beliefs, and the actors’ true interests are called into question.

**Controversy in St. Brieuc’s Bay**

The story of the three researchers was followed by catastrophe. A few years after their successful enrolment as an anchoring species, the scallops rejected the researchers’ findings: the repeat experiment found all the anchors empty. The scallops become dissidents, and “the larvae which complied are betrayed by those they were thought to represent” (Callon, 1986: 16). The fishermen, no longer able to resist the temptation of fishing the growing scallop population, similarly break the vows of their representatives. “Brutally, and without a word, they disavowed their spokesmen and long term plans.” In light of these failures, even scientific colleagues lose faith in the project. “What do the fishermen really want? How does Pectin maximus behave?” (Callon, 1986: 16).

In Callon’s framework, controversy is closed when the spokespeople are once again deemed to be beyond question. To arrive at this point, the three researchers engage in desperate renegotiations. They reenact *interessement* of the scallops, seeking an alternative anchoring
apparatus that will once again draw their cooperation. To interest the fishermen who have thrown off their compliant delegates, the researches “undertake a vast campaign to educate and inform (i.e. form) the fishermen to choose other intermediaries and other representatives” (Callon, 1986: 16).

**PACT’s Return**

The locus of controversy in New York is PACT. After enjoying leadership of the pilot programs during *interessement*, PACT was swiftly disempowered, first, when a private company was hired to do an abbreviated training; and second, when CTH created their own in-house technical assistance unit.

To PACT’s director Heidi Behforouz, the shortfall was that front-line staff were unprepared for challenging and intimate counseling. While DOHMH had not yet compiled results, the PACT team was certain that the results would not merit the PACT label.

This story is paced by annual contracts. As the 2011-2012 contract cycle approached, PACT took action to throw off their mobilization into a purchased curriculum. They would not be displaced into their paper workbook without the expertise needed for its rightful implementation. Director Heidi Behforouz and program manager Jessica Aguilera-Steinert drove to New York and met with Dr. Fabienne Laraque. Much of the CTH staff was new, including three of the four project officers, which created “a good opening for us to be convincing, and say ‘you guys really need to know what this program is about to be able to provide oversight and TA to the actual programs, clinics and hospitals’” (JAS). In rejection of their displacement into a two-dimensional model akin to the Japanese anchoring technique, PACT climbed out of the page and drove to New York.
They were successful. Behforouz and Aguillera-Steinert negotiated a huge package of services for the 2011-2012 contract: re-trainings, workshops, and ongoing, in-depth technical assistance. Aguillera-Steinert identifies three factors that allowed them to achieve this. First was the charisma of director Heidi Behforouz, “not unlike Paul (Farmer)” (JAS). Through the *interessement* device of persuasion, CTH was convinced to shift their path back towards PACT. Secondly, PACT’s credibility had grown: since the process began, they were “getting much more press” and had gathered more data. Finally, Aguilera-Steinert suggests a personal connection between CTH’s new director, Dr. Fabienne Laraque, and Partners In Health. “I’d love to know this, I really would, and I think I really should explore it – it could have been partially due to the earthquake. The director of HIV services is Haitian. She went to Haiti, and she lost family members. She has connected with PIH in the past, has a personal link to PIH. That may be relevant. I don’t know” (JAS). Thus, familiarity presents itself as a profound influence on the outcome, as well as the initiation, of translation.

After their experience in New York, PACT is defining a minimum package of services that future replication sites must commit to. They are thus following a key recommendation of nonprofit-government partnership literature, which suggests that the elements essential to a model’s social good must be identified, packaged and thus preserved (Simmons, 2007: 15). Says Aguilera-Steinert:

“We’re not giving this away now. We’re not giving just the patient curriculum, or just 3 days of training for a group that wants to know about us or does something similar. What we’re doing is creating an institute, and a niche – what this model is, and what are the required components of it, so that it then can be clinically successful or have similar outcomes. Now, that’s not to say that there won’t be differences in every site that we go to. Absolutely. And we’ll learn a lot from that. But those are the largest lessons learned for us” (JAS).
PACT’s next act was to reclaim the power of assessment, which had been monopolized by translators both in New York and in St. Brieuc’s Bay. To better understand their perceived failures, PACT interviewed CHWs, clinicians, and patients in New York City as well as in Boston. As requests for replication abound, PACT hopes to “create a more comprehensive assessment tool, so that the necessary infrastructure is in place for an organization: the buy-in, the culture.” It will be crucial that PACT “put more energy there in the beginning …one of the huge lessons learned is that whenever we go into a relationship, especially one as big as the DOH, that we have to do an extremely thorough and sophisticated assessment of the organization’s readiness” (JAS).

Going forward in New York, the 2011-2012 contract is reshaping the trajectory of PACT-DOHMH relations. Says Weglein:

The past eleven or twelve months have been all about gradually going back toward PACT. It’s this indirect path, where we found the PACT program, we tried to replicate it, met some resistance, kind of backed off, and now we’re gradually getting back there to where it’s fairly faithful (DW).

To Weglein, the new contract is filling a gap that they could have anticipated. Given the complexity of implementation, the TB Bureau veteran Dr. Laraque’s decision to create an in-house technical assistance bureau distanced the replication sites from expertise that they needed. Says Weglein:

You can’t train and walk away. We were hearing from the service providers that they just didn’t feel competent. And we knew that. They didn’t feel competent with the curriculum, or with the home visits, or how to get someone on DOT, and our POs didn’t have the competency to support it all. So, what would we have done two years ago under our pilots? We would have gone to PACT. So we should just go back to doing that. So yeah, it was a very smart move, and it was sort of inevitable. Again, Jessica and Heidi, they pitched it a year ago, and I
don’t know why we turned them down, but we did. So it was just a matter of time until we figured out ourselves that we needed it (DW)

Jessica Aguilera-Steinert believes that in the best-case scenario, the Bureau of HIV Services will continue this “enthusiastic wave of integrity to this model” and the next RFP will be “85% or 90% consistent” with PACT’s vision. For the DOHMH, “the next thing is figuring out where we can save money, because PACT costs us upwards of $7000 per patient per year, and that’s not cheap. But I think everybody here has been pretty happy with the evidence of PACT. And everybody’s pretty confident that we’re going to see the outcomes that we’re hoping for” (DW).

**CBOs and Hospitals**

Just as PACT succeeded in recreating their contract, CBOs had much earlier cleaved the process of *interessement* by rejecting the first RFP from which they were excluded. Since then, New York’s 28 agencies have continued a form of passive resistance and renegotiation. Case management administrators petition their project officers for assistance and are usually turned down, but these project officers are becoming their spokespeople and there is a growing will in CTH for greater adaptability and agency empowerment. Agencies are saying, “we can mold this; we can make this our program, not just DOH’s program’…People are more calm now than they were last year at this time,” says project officer Kevin Dugan. As actors, these replication sites are investing themselves in the network and carving out their space within it. “We’re seeing a little more ownership being taken over the program…things are getting easier with each passing day” (KD).

Ever apparent is the mutual respect between PACT and New York’s Bureau of HIV Services. Great faith in PACT’s model inspired Danny Weglein and the staff of CTH to undertake this translation. “There are a lot of challenges to taking ownership of something that’s already out there, re-crafting it, and then promulgating it and getting buy-in from everybody that you now
want to do it. It’s not an easy way to go,” says Weglein. But in all honesty, “Heidi and PACT have done all the heavy lifting; we just cut the $25 million check.”

This chapter was the last episode of the PACT replication story, which continues to unfold in New York. The next chapter will conclude the thesis in three sections: first, the illumination of PACT through Callon’s stages of translation; second, two key points that are lost in Callon’s framework; and finally, avenues for future research.
CHAPTER 6: CONCLUSIONS

“The past eleven or twelve months have been all about gradually going back toward PACT...it was just a matter of time until we figured out ourselves that we needed it.”

– Dr. Daniel Weglein, NYC Director of Public Health Practice for HIV Care

This chapter will conclude the thesis in three sections: first, the key elements of added value from a translation analysis; second, two themes from the PACT story that Callon’s narrative overlooks; and finally, avenues for future research.

Translation and PACT

In this first concluding section, I will highlight three junctures in the PACT story that a translation framework has illuminated. These are, first, that evaluation is reserved for the powerful; second, that the PACT model was displaced into a two-dimensional, easily manipulated symbol of grassroots legitimacy; and finally, that Callon’s devices of *interessement* were applied to each stakeholder group in accordance with their decision-making authority.

First, the corresponding narratives of St. Brieuc’s Bay and New York City illuminate the extent to which evaluation is a power-laden act. In Callon’s narrative, the three researchers possessed the right to assess the anchors’ effectiveness. Anchoring scallops were units of compliance, and unattached scallops signaled not that the hypothesis was false, but that renegotiation of the material or location of the nets was needed. The three researchers ultimately came to speak for all spokespeople, guiding a project that dovetailed with shared interests. In New York City, CTH implicitly monopolized the power of assessment: they designed and collected evaluation forms and held them until they felt the time was right. Difficulties at the
level of implementation were not interpreted as faults in the model, but rather, the inevitable friction of adoption among institutions that have enjoyed 20 years of open-ended funding.

Secondly, a translation analysis highlights that the PACT model was disconnected from its innovators, repackaged in two-dimensional form, and thus mobilized to preserve CTH’s role as the obligatory passage point. Despite the divorce of CTH’s protocol package from PACT’s original model, the protocol retained PACT’s name and its stamp of nonprofit, best-practice legitimacy. This assumed legitimacy threatens to block the programs’ outcomes from critical assessment, and calls for further research to unpack the transformation experienced by nonprofit models in the public sector.

Thirdly, translation analysis illuminated the presence or absence of Callon’s central device of *interessement*, persuasion. Rather than actors at the top distributing their persuasive energy among adopters at the bottom, as per Rogers’ framework, energy is invested into stakeholder groups in accordance with their powers of purse and politics. CTH expends the most energy convincing DOHMH officials, and the least energy convincing the poorest of the public hospitals and CBOs among the 28 true adopters.

This section has presented three lights that translation theory shines upon the PACT events. The next section will propose two areas that translation theory leaves in darkness.

*Departures from the Translation Framework*

Two themes were identified for which translation theory has little vocabulary. These themes are familiarity and rigidity.

Familiarity guides the arc of the PACT narrative chronicled in this thesis. Chapter 2 uncovered the role of familiarity in CTH’s selection of the PACT model and its commitment of resources for replication. PACT’s use of directly observed therapy, the silver bullet with which
Commissioner Tom Frieden curbed New York City’s tuberculosis epidemic, won the approval of Commissioner Frieden and CTH director Fabienne Laraque, a veteran of the Bureau of TB Control. Next, in the development of New York’s PACT protocols, Commissioner Frieden’s familiarity with the use of body weight as a health indicator – encountered in a Malawian study that he personally cited (Libamba, 2005; Frieden, 2005) – led to its inclusion in the New York implementation. Finally, familiarity spurred the resolution of this installment of the story: Dr. Laraque’s familiarity with Partners In Health, whose work in Haiti she admired, may have increased her receptiveness to re-contracting PACT for the 2011-2012 cycle.

Callon’s framework offers no vocabulary to discuss the influence of familiarity. This gap is incumbent in the larger analytical decision to pay little attention to traits of the innovation being implemented. In St. Brieuc’s Bay, the Japanese innovation is hazy and unexamined, and focus is channeled into the negotiation of alliances swirling around it. This thesis presents a case in which characteristics of the model itself illuminate the course of the translation. These insights depend on a knowledge of CTH’s history, which is another window that Callon chooses to close. By Callon’s principle of free association, actor network theory analyzes the forces at hand without interrogating their environment or historical context. In the case of PACT, Callon’s purposeful blindness to CTH’s history and its resonance with the PACT model comprises an analytical loss.

Everett Rogers’ orthodox diffusion theory, an alternative explanation introduced in Chapter 1, is mindful of the characteristics of an innovation that enhance or detract from its adoption. I argue that just as Rogers may have enveloped translation theory concepts in his 1995 edition30, Callon should incorporate Rogers’ attention to the characteristics of an innovation.

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30 Rogers’ discussion of “re-invention” in his 1995 edition, which did not appear in previous editions dating back to 1962, may be Rogers’ response to translation literature which was released in the late 1980s.
The second New York theme that Callon does not speak to is rigidity. Chapter 4 encountered the complex incentives that drive each actor to pursue rigid or flexible replication. At CTH, high-level officials advocate rigidity for its consistency, fairness to replication sites, and ease of evaluation. Ground-level project officers, however, experience the daily barrage of maladjustment and share the hospital and CBO administrators’ view that the model must be locally transformed. The replication sites enjoyed complete flexibility for twenty years of previous case management grants, and advocate the loose adherence that would allow them to maintain inertia along their previous course. To their staff and to the project officers torn by competing loyalties, each sites’ difficulties are not easily endured as generic friction of adoption.

PACT pursued rigidity in defense of their original innovation, rather than to CTH’s reinvented protocol. When first approached by the City of New York, PACT hesitated due to concerns of faithfulness to the model. To client services director Jessica Aguilera-Steinert, their loss of control over training was their “first big mistake” and brought an untenable deterioration of their model. After reclaiming the authority to lead trainings in 2011, PACT conducted research to better understand the course of events. Turning their lens inward, they are now developing a rigid package of services that future replication sites must commit to. Everett Rogers referred to this action as “reinvention-proofing” (1995).

Despite advocating rigidity, both CTH and PACT are conscious of the dangers of ill fit. As with any transplant, there is a risk of rejection. CTH was granted a policy window when it secured $26 million for case management reform, but the renewal of this allocation depends on their program’s success. CTH must navigate a tenuous course: though invested in each replication site’s success, it must honor institutional practice and consistency by enforcing the
same protocol at each site. CTH’s power of disbursement allows it to keep its balance on this tightrope.

This section presented two points of disjuncture between the PACT events and Callon’s analysis. In the next and final section, I will suggest avenues for future study.

**Future Research**

Callon’s principle of agnosticism demands impartiality towards the actors engaged in controversy and the consideration of their arguments without judgment. However, the omission of motivation from the PACT story undercuts the researcher’s ability to recognize mission drift and to map the program’s commitment to social good. Further research is needed to critically examine the ways in which a model shifts during replication, and to challenge the assumed legitimacy of its best-practice roots. This task requires that outcomes are judged and situated on various axes, such as mission integrity, patient services, and cost efficacy.

There is a need for research that further interrogates the forces that act upon a model undergoing replication. By incorporating evaluation of outcomes, this future research will protect target populations from the potential dangers of scaled-up models that are lost to translation.

**Policy Recommendations**

At the end of the first year of implementation, CTH succumbed to an undeniable need to re-engage PACT in the training and troubleshooting process. I end this thesis with dual recommendations: one directed to public agencies seeking to replicate nonprofit best practices, and one directed towards nonprofits pursuing a scale-up in the public sector.
Despite contrary pressures of cost and speed, I recommend that government agencies resist the pressure to purchase authority from the model’s innovators. While PACT lacked the capacity to run training programs in 28 replication sites, they could easily have led the design of the training curriculum and supervised its quality. Students of social entrepreneurship have identified the role of inspirational leaders in an innovation’s success, and the difficulty in maintaining it during the scale-up process. In the coming calendar year, CTH will re-infuse its training and support with the personality and ideology that made PACT’s success possible in Boston. Other public agencies can learn from their experience by ensuring this involvement from day one.

Secondly, nonprofits can learn from the PACT events that once their curriculum is sold, all strictly defined agency over implementation is lost. To negotiate this reality, nonprofits must intimately understand the essential elements of their social good. By defining a rigid implementation package for those seeking to replicate the model, the innovators can pre-empt the loss of direction that was initially faced by the New York replication sites.

In New York, two institutions – a sweeping public agency and a celebrated not-for-profit – sought to champion their cities’ most vulnerable HIV patients while bringing a new order to the health care system. The power imbalance between these groups privileged the vision of one, and facilitated the model’s passage into 28 hospitals and health centers.

CTH highlighted familiar elements as it repackaged the innovation into a rigid set of protocols. Ultimately PACT disavowed its compression into CTH’s protocol, climbing out of the page and driving to New York to negotiate a re-entry into the city’s lagging replication. In the coming calendar year, PACT will re-infuse the New York replication with its own experience and philosophy.
In Callon’s analysis, translation becomes power relations theory: a mechanism to understand how core actors define the interests of others and draw them into alliances. Translators displace groups into spokespeople and then speak on these representatives’ behalf, becoming the gatekeepers of information and the guardians of translation.

In the French bay that inspired Callon, a group of scallop researchers gained the power to speak for the scientific community, the fishermen, and the scallops themselves. In New York City, an office director selected and pursued an innovative model that would resonate with the DOH’s cultural history and methodical future. Politicians sign off from a distance, once they were blocked from CBO lobbies. The replication sites latched on to the model to receive funding, just as Callon’s scallops anchored to the nets to escape the ravages of current and attack. As acceptors, they have no power of assessment, and thus their defiance of the model is interpreted as resistance to change. Finally, like Callon’s fishermen, disadvantaged HIV-positive New Yorkers are channeled into representatives who bear token witness to an intricate process of translation.
APPENDICES AND FIGURES

Appendix: Interview Transcripts

New York City Department of Health and Mental Hygiene, Bureau of HIV/AIDS Prevention and Control, Office of Care, Treatment, and Housing:

- DW – Dr. Danny Weglein, Director of Public Health Practice for HIV Care at the Bureau of HIV Services; former Director of the Office of Care, Treatment, and Housing, 11/19/10....104
- MS – Dr. Monica Sweeney, Assistant Commissioner, Bureau of HIV/AIDS Prevention and Control, 12/6/10..........................................................132
- NR – Nina Rothschild, Community Planner, HIV Planning Council Support Unit, 12/6/10..137
- BM – Beau Mitts, project Manager, Health Care Services Unit, 12/6/10.........................149
- JA – Jessica Auerbach, Project officer, Health Care Services Unit, 12/6/10...............160
- SB – Stephanie Boarden, Project officer, Health Care Services Unit, 12/6/10................160
- KD – Kevin Dugan, Project officer, Health Care Services Unit, 12/6/10..............172

Prevention and Access to Care and Treatment (PACT), Boston, MA

- HB – Heidi Behforouz, Director and Founder, 11/8/10........................................183
- JAS – Jessica Aguilera-Steinert, Director of Client Services, 10/26/2010..........184

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Figures

- Figure 1: Actors in St. Brieuc’s Bay and New York City.............................46
- Figure 2: Mobilization the Callon and PACT narratives............................86
CD: So, what I was very originally interested in was the limits on NGO care, specifically in terms of HIV care, and how there are a lot of great models out there but there are so many challenges, and there’s a lot of fragmented care. So I started to look into the process by which NGOs are kind of laboratories for larger replication by governments. And of course, that leads straight to this story – your replication of PACT, I think, is really spectacular and very unique in terms of the scale of what’s being attempted. So I would love to learn more about how that process happens, and what are some of the challenges, and what are the ways in which the PACT model has been changed and translated – and kind of who has translated that model, in terms of making that transition feasible. What are the changes that have to happen, and who has to be on board. And I’ve prepared some questions – I spoke to Dr. Behforouz and to Jessica, and they both had really wonderful things to say about working with you.

DW: And did you talk to them also about Miami?

CD: I’ve been kind of focusing on this story.

DW: Just on this partnership. Ok.

CD: But yeah, I know they have lots of things going on.

DW: Yeah, they keep getting people who are interested. Now the state of Massachusetts – but the state, right, just contracted with them? The state didn’t take their model and say, “thank you for having done all the heavy lifting, we will now go and build this again.” I think the state just signed a contract with them, saying, “You’re doing great work, here’s more money, do more of it.” Which is – that’s really nice when a public health entity has that sort of resources, that they can scale up in that way. That’s really nice, because I hope I can get across, there are a lot of challenges to doing the other way. To kind of taking ownership of something that’s already out there, recrafting it, and then sort of promulgating it and getting buy-in from everybody that you now want to do it. It’s not an easy way to go.

So, it’s really interesting - it’s a fascinating topic. I mean, just personally, the idea wouldn’t have occurred to me until probably a couple years ago. I think most people doing this sort of work in the city see the NGOs as their own world, and don’t really value them in the sense that there are a lot of lessons to be learned there. And we’ll go through why that’s the case. But I think you’re absolutely right, the NGOS are laboratories. They try so many subtle permutations on a theme, that invariably, someone’s going to do something really well. And it’s in the government’s interest to identify those star performers, and promote those methods on a wider scale. So I think you’ve hit on something really interesting. And I know when we talked on the phone about how you’d come across PACT in something written on social entrepreneurship?

DW: So, I have a good friend who writes a lot on social entrepreneurship. And, you know, in talking with him, I’ve thought a lot about how we do the same thing. So essentially he looks for social entrepreneurs to write about them, we look for social entrepreneurs to get good ideas, and sort of do something with them. So I think you’re right on target, it’s going to be an interesting paper. So again, thanks for taking the time to do it.

CD: No, it’s such a – I’m really overwhelmed that you’ve been so generous with your time.

DW: Don’t mention it. So, I’ll give you the nuts and bolts story of how it happened, and then I’m sure your questions will come in, and we’ll cover it all. So a word of background – you probably know a lot of this already, but you’re sitting in the HIV Treatment, Care, and Housing program for the City of New York, within the HIV Bureau. The HIV bureau has three divisions: Epidemiology and Surveillance, HIV Prevention which is mostly primary prevention, and then Care, Treatment, and Housing. Care, treatment, and housing is brand new – under three years old, I think – and it is a public health practice evaluation and research unit, that was constructed around a couple of grants administration units. So, four or five years ago there were two separate entities: HOPWA, which administered a HUD grant (HOPWA being Housing Opportunities for People With AIDS) and the Ryan White Care Act program. And they were very very small – they had these grants administrators and some support personnel, but there weren’t any epidemiologists, there weren’t any public health planners, there weren’t any policy writers. And it was just really the nuts and bolts – whatever the Feds said, you had to do. People to write the grant – actually, we didn’t even write the grant, we outsourced that to consultants. So, it was people making sure that the terms of the Federal grants were being met. So, that the reports were getting out there, that the planning processes ran. It was pretty much all done by consultants.

So one of the assistant commissioners a couple years ago said, this isn’t the right way to do it, let’s build a new program. So we administer the HOPWA grant and the Ryan White grant; if you consider all the money, it’s over 200 million dollars. And there are big chunks that go flying off in different directions before you know it. But it’s a lot of money. So as part of that challenge of administering these grants, we started looking at HIV case management, actually even going back to before the Care, Treatment, and Housing program existed. And that’s because one of the requirements of the Ryan White care act is sort of quality control, quality management, contract management – you can’t just let your contracts, right, and just leave them be; you have to make sure you’re doing the right thing; so periodically you have to rebid your contracts. So several years ago, we made the decision, we were going to rebid our case management portfolio. Case management being one chunk, and then whatever it was, 15, 20 million dollars. So we started at that point a planning process on, what would it look like when we redid case management. And that was probably about five years ago. And there were a couple of us who – together, independently, a bunch of people got charged to learn about case management, and let’s put it down on paper and understand what it does, what the need gaps look like, and let’s start to construct a plan. I had a little bit of background before that – I had a fair amount of background, I was a medical provider in the community, since the mid-90s, I trained in the early 90s and have been working with communities from 1994. And I worked for about 10 years as a clinician and medical administrator, and I was working with case managers all along. So I had a pretty good
sense what the lay of the land was, which is why I was one of the people who got this
assignment. So that sort of bubbled along for several years, right, this sort of intellectual exercise
of trying to understand case management. And the basic gist of it was, case management is utter
chaos. That’s what we all came up with, right? So, why is it utter chaos? Because the state has
money, the city has money, the feds have money, it’s not all working together, you’ve got a
housing administration services agency and they’ve got case managers, you’ve got this kind of
case manager, and no one was talking to anybody. And they all had protocols of, you know, you
fill out this form and countersign here, and that’s how we document that we’re talking to each
other, but it wasn’t really happening. So, all these fragmented, duplicated systems. That’s the
upshot, right? So, lesson learned, we have to do something streamlined and get better
collaboration. So, that’s one strain of activity that’s going on.

Somewhere in there – I’ll say 2006, 2007 – we had some sort of again, grand rebid process,
that had to do with treatment adherence contracts. And we can talk a little bit later, it’s not at all
intuitive or shouldn’t be intuitive why you would split apart something called case management
from treatment adherence, it’s kind of an artifact of how things are organized in New York, but
we did. We had some providers who were calling themselves case managers, and others who
were working on sticking to treatment. And they were separate. We had a rebid contract with
those treatment adherence contracts, and many of our public hospitals lost out in the rebid; and
so they had these legacy staff that they had no money for. And long story short, when there’s a
problem in the public hospital system, it becomes a problem for the health department because
we work very closely together. And one day the commissioner, who was at the time Tom
Frieden, came to us and said, you’ve got to do something for these public hospitals – they need
treatment adherence programs, they need money. And after looking at this situation, we went
back and said, we’re not going to give them any money because they don’t know how to write a
grant proposal, and they don’t know how to design a program, and we’re not going to waste our
money, which is why we had the open bid process, and that’s the sad truth. And his response
was, if they don’t know how to write a grant proposal or design a program, do it for them. I’ll
make that the condition of the reward, we’re agreeing at the uppermost level that this is how
we’ll get the award out. And you guys start becoming program designers.

So we did. So we designed a program. And in the work, in designing the program, that’s how
we came across PACT. So this is how health departments work – when you want to set up a
program, you go looking for the best practices. And so we combed through the available
literature, and – essentially deduced – I mean, there’s not a whole lot of publication on PACT,
but we were able to see that within PACT there were some proven methods. Such as the
navigation model for case managers. PACT uses the navigation model. You read PACT
literature, at least what was published as of 2006– they weren’t saying navigation, but they were
doing it. And they weren’t making a big deal about their directly observed therapy, except to say
lots of people try it, it doesn’t always work. But you say directly observed therapy in New York
City, and everyone thinks about the TB epidemic in the 90s that was rapidly controlled once we
implemented a very robust directly observed therapy program. So we saw in the PACT model a
lot of things that we thought were going to resonate within this department, as programs that
would. So if we were going to put our money into something that we thought there would be a
lot of support for, we thought PACT was a great place to start.
And over the course of years, we rolled it out to a couple of sites. Essentially, for whatever reason, money would become available, somebody would be looking for funding, but every time that we had the opportunity, we would say “we’ve been working on this model, if you want to do it, maybe we’ll work with you.” So as we were getting farther along in terms of planning, for rebidding the case management portfolio, we were signing up sites to essentially do the PACT model for treatment adherence. So we were gaining some real-world experience in translating the PACT model. And from the first moment that we did it, we were in touch with Heidi and with Jessica and the whole crew. And so the very first site that we set up and running was PACT trained, even before they started work. And so we figured out pretty quickly that if you want to learn from an NGO that’s out there and has been doing it, there’s only so much you can learn from reading, and only so much you can support by writing good support materials, just go out there and get the experts in there. And so we sort of dragged them along – they were not at all set up to be a TA, and have a technical assistance shop, when we first found them. And we helped them become that, just by virtue of needing their guidance. And so in addition to having them do the training, we eventually realized that any time we’d go out to one of our sites we would encounter all sorts of problems that made us pull our hair out, and the program staffers would say “well we can’t do this because of that, and we can’t do this because of that,” and we wouldn’t know what to tell them. So we’d end up getting on the phone with Boston, and so we started a system of weekly phone calls, so that we could compile all the problems our providers had encountered, and for sure PACT had encountered them before and had some solutions. So we went about troubleshooting that way. And as we sat down to write our solicitation, our RFP, it just started to look more and more like PACT. And that was a little bit of tricky process, because I guess, let me back up a little bit. So we sort of waited passively while we had this PACT model; if you came and inquired, we’d give you the PACT model. But every now and then, we’d look for a big opportunity to sell it in a big way. So for example, at one point, we tried to sell it to a whole bunch of providers, essentially saying, “we’re going to have this rebid – we’re going to have this competitive re-solicitation. And you don’t want to have to compete, because if you re-compete, you could lose. So we’re going to give you a guarantee: if you sign on the dotted line today that you’re going to adopt the PACT model, then you don’t have to re-compete, you’re in for the next five years. And when we did that, we got a lot of anger, we got a lot of resistance. And what was really interesting was that, you know, we talked a lot about PACT, and often when I talk, people hear hints of my Boston accent. And there I was, talking about Boston with a Boston accent in New York, and that’s about the worst thing you can do. And we literally had a very well-respected medical director who was a staunch Yankees fan, just arguing with me about the Yankees and the red sox. And this became such a city issue: our city’s better than your city, don’t tell us how to do things. Everyone’s always talking about Harvard, Harvard, Harvard, but we have good institutions in this city too. And there was this tremendous push-back that had to do with, you know, please respect what we’ve developed here.

CD: And who was that push-back from?

DW: From the providers. Form the service providers – the hospitals. So we were talking primarily to grants managers and medical directors – those were our stakeholders. And what they
wanted to say is, we’ve been doing this work for ten years, twenty years, whatever it was in an individual’s case, and we know how to do this. Don’t come tell us that Dr. Behforouz and her staff have developed something that’s better than what we’ve developed. So we then had this resistance to work against in terms of a solicitation. When you’re just making a pitch – if you want our money, you can take it on these conditions – that’s one thing, but when you have a competitive solicitation, then everything gets politicized, and everyone’s going to charge you with not being a good steward of public money. And so you have to be a lot more careful as you go into a public solicitation. And so as we were preparing, we had to play this sort of balancing act, where on the one hand, we had a lot of faith in the PACT model, but on the other hand, we didn’t want to be really explicit about saying that. So we were using much more vague language, about evidence-based interventions, and at some point we talked a lot about Philadelphia, and Chicago, other jurisdictions that had used evidence basis. But we didn’t have anything in terms of published outcomes, or even unpublished outcomes – we didn’t have any data outside of the PACT program. So that’s what we believed in, but it wasn’t easy – we could not have said, “we want to set up PACT sites 100 through 150.” In other words, we just want some rubber-stamp PACT sites in New York – because that just would not have flown. We had to massage it a little bit. That was – was it only 2009? It was, it feels like so long ago. But it was a very long process. Our RFP went out either December 2008 or January 2009, around there, and that process didn’t wrap up – or, the awards themselves didn’t wrap up, until September 2009. And the programs didn’t start up until December 2009. So it was a very lengthy process, it remained a very contentious process, and again the contention was all about this idea of us having a model and not wavering for that model, where everything that we had done before had been the reverse, where we would say, “we’ve got money to spend on case management, you tell us how you’re going to do case management and we’ll weigh in as to whether we think that’s good or not, and we’ll reward it whether we think that’s good.” But so, it was a tough process, and once the awards were made, everything quieted down very quickly, and everyone sort of got to work. And the past eleven or twelve months have been all about gradually going back toward PACT, to the point where we’re on the phone yesterday with Jessica to get them back on their weekly schedule of conference calls. And in order to train the hundreds of staff that were hired – at the end of the day it was a 25 million dollar portfolio, serving about 4000 patients, over 200 staff, close to 300 – and so, in order to get everybody trained, we went out – we had another solicitation for the training, and we selected someone from here in the city. They did a very good job with what they did, but they also left out what’s difficult to translate if you haven’t been exposed to the PACT model for months and years. And so we’re now looking at ways that we can introduce some components of the PACT training that didn’t get across. So all that’s to say, it’s this indirect path, where we found the PACT program, we tried to replicate it, met some resistance, kind of backed off, and now we’re gradually getting back there to where it’s fairly faithful. And it’s become the general mode of operation for all these programs – that when we encounter a problem, we’re going to go to PACT and see how they solved it in the past, because we’re not going to try to reinvent anything.

Alright, so how’s that for answering your question? Have we migrated there?
CD: It’s incredibly fascinating! I wonder if you could talk more about the components that were missing –

DW: In training?

CD: Right, and also, how did that training contractor end up being hired as opposed to – like, was it ever on the table to have PACT conduct the training?

DW: It was. It was. And that’s a great mystery – it’ll be one of those whodunit movies some day. I don’t know. I honestly don’t know. What I know – so it was a competitive process, and certainly PACT knew that the competitive process was there and could have applied, and didn’t apply. And I have some sense that they didn’t feel qualified, but it never…and it also had to do with Heidi, I don’t know if Heidi was out – she had a baby – so I don’t know if it was who was there, I don’t know. It was a difficult – when we started working with PACT, it was me talking to Heidi on the phone. By the time we were at RFP, it was five people here talking to five people there. And so there was a lot that didn’t – there was a lot of indirect conversation, I don’t quite know what happens. I think in retrospect, everyone acknowledges that we could have done that better.

So, one of the great strengths of PACT, or what we see as a great strength, or what we consider innovative here in the city, is the degree to which health education and health promotion are structured in the PACT model. So, go to any case management program, and every case manager will say that they talk about things like pill-taking – they work on pill-taking, or they work on safe-sex behaviors. But they don’t have a rigorous way to ensure that all the bases are covered in a consistent way, and that they have measurable outcomes – that a health promoter knows, based on precise exercises, that the patient gets the message or doesn’t get the message. So, PACT literally has a workbook, right, and it’s exercises that you do in the workbook that let you know that we need to do more here, or we’ve finished this module, we can move on to the next one. So the topic areas – things like harm reduction and safer sex, those were covered in the training, but how do you take this workbook and use this workbook in covering those topic areas? That wasn’t covered at all. And you can imagine that if you’re in a health care environment, you’re seeing a doctor, you’re seeing a nurse, you’ve been assigned a health promoter, if somebody comes to you out of the blue and says, “I have a workbook, we’re going to do work in a workbook,” you’re going to think they’re crazy. And so the only way that that health promoter can be successful is if they’re trained on how do they foist this workbook on you. And so what we find otherwise is that the health promoter – who knows what they’re doing, but they’re coming back to us saying, “my patients don’t want to see this workbook, they think I’m crazy.” And of course they do. Because you haven’t been trained on – how do you broach the subject, how do you say, “we’re going to work on adherence to a medical regimen by working through these exercises, and this is how we do it.” There are all these reinforcement messages about – “this is about your health, we’re doing this because we all agree that you want to be healthy and able to care for your three-year-old child.” There’s a way to talk to a patient that – yes, this is uncomfortable, and it seems weird, and it’s not something you’ve done, but you and I have agreed that this is the best thing we can do today to ensure that the goals we want to
achieve are going to be met. And it’s that means of talking to a patient, that wasn’t adequately trained. And I mean honestly, if you’re a well-trained health promoter, you get that in a month. All you have to do is do it day-in day-out for a couple of weeks, and you’ll understand, oh, this is how it’s done. And if you don’t have that – I mean, you can just imagine the wealth of experience that PACT has in every scenario where a patient is resistance to what seems intrusive or uncomfortable. They’re just a wealth of information when it comes to helping health promoters work through those difficulties.

**CD:** Do you think the PACT model for supervision – the next level up, the middle management – was that replicated in the New York City hospitals? Or was there a different structure for the supervision, or management, or support, for the community health workers?

**DW:** I honestly don’t know enough about management supervision at PACT. Heidi and I and Jessica, we’ve talked quite a bit about – just generally, we here have not spent enough thinking about management supervision. So I think we can pretty much conclude that PACT has thought it through, and has some ideas that have to be implemented. But we made a strategic decision last year, which was a money decision, that we’re going to prioritize our dollars to training the frontline staff – knowing full well that we have at terrible management challenge, and our managers are going to struggle probably 50% of the time. But that’s been back-burnered, and kind of work that we have to get to. I think – and we say this over and over again, when we thought that we would take PACT or take something like PACT and scale it up to 25 million dollars, we really had no idea what we were getting into. But we did know that we had 25 million dollars, and it was an opportunity that wasn’t going to come along too often. So we’d rather get it started and get it wrong, or get it partially wrong, than wait to make it perfect. So as long as we can keep our eyes on where the glaring holes are, and keep going in there to try to fix them, then we can feel good that we’re getting somewhere.

**CD:** So, who else had to be on board to make this happen? You talked about the medical directors as being a real…

**DW:** Yeah. So medical directors were huge, and I can go into some of the others. Medical directors were a real departure from our usual way of doing business, and that’s because in New York State, and probably even more so in the city, the access to care for people with HIV is excellent. Meaning that the Medicaid and the ADAP programs are so well-funded, that even private doctors, it’s financially not only viable, but it’s financially worthwhile for private providers to take indigent patients. So Ryan White is intended as this safety net kind of program, and it’s almost as though NYC didn’t need that safety net, right? From the standpoint of traditional medicine. We’ll talk about in PACT, that traditional medicine doesn’t do very well, it’s got some holes in it, right? But if you wanted to provide traditional health care, the third party payers, Medicaid Medicare and ADAP, were going to get it done. And so you’ve got 120 plus million dollars of Ryan White money, and the doctors could pretty much turn their backs on it because there’s what’s called the Payers of Last Resort provision, and the doctors couldn’t touch any of the money. And so over 15,20, no it’s more than 25 years, of the Ryan White
program, it built its own infrastructure of grants managers and health educators – folks who always worked alongside the medical infrastructure but operated very independently.

So to give you an example: you’d have all these treatment adherence programs, but the treatment adherence programs would go and recruit their own patients. They wouldn’t be asking the doctors necessarily, “which of your patients are not doing well on treatment and need my services?” They would go out and recruit their own patients. And there was the financial reason that the doctors didn’t need the money, but there was also because, again, there wasn’t a whole lot of evidence basis behind what constituted a service like treatment adherence. And so a doctor could observe his patient going into a treatment adherence program, but he didn’t know what was going on there. He didn’t necessarily perceive a pattern that his patients who go in there are doing better than the patients who don’t go in there. So there’s no value-add, and you’ve got these people with the grant money, and they’ve got to do their grant thing and they’re doing it, and the doctors keep doing what they’re doing, and the doctors at the same time are moaning that the patients aren’t taking their pills and it’s not working.

So we were clear that we wanted to sell to the doctors that the goal of case management, and when we say case management, treatment adherence is a core part of case management, so we were just going to roll that all together –

CD: And so the treatment adherence programs were operating out of hospitals, but two different funding structures, and they just weren’t really talking?

DW: Right. They talked to the doctors, but not in the same way that the physical therapist talks to the physiatrist. The physical therapist carries out the treatment plan of the physiatrist, and goes back and says, “this is what we’ve accomplished, this is what we haven’t yet accomplished.” And that’s not at all the case in terms of our various case management programs. So we wanted the doctors to understand that when we were going to rebid this money, it was so that when doctors came up with treatment plans, there would be a body there to make sure the treatment plan was carried out. And it was all about treatment plans, and medical treatment plans, and a medical home, that’s where – HIV is a medical condition, right, and so how we were going to expect case management programs to work closely with the medical providers.

So what that meant – right – and the flip side of that – so you have to get the medical providers on board, and the flip side of that is that you’ve got to get the case managers to understand that even though we’re not going to continue with business as usual, you’re not going to lose your shirts. And we’re not saying that you’ve been wasting your time for the past 20 years. We’re trying to nudge this in a new direction, and we’re going to form some good collaborations where everybody wins, and we’re going to all do better in achieving patient goals.

New York probably more than other cities, probably because it’s so large, had very very segmented HIV service providers. I mean, the hospitals and the large medical providers were very very distinct from the community organizations that were providing these social services and most of the case management services. And so the idea of collaboration was inherently threatening to all of them. We didn’t go there all at once, we didn’t decide right away that we were going to try to make these collaborations work; at some point we toyed with the idea of actually asking all the money away from the community organizations, and saying, “you know
what we want? We want hospitals to be more community, so we want to build a community unit within each hospital.” To the extent that commissioner Frieden was all in favor of that. So we weren’t that far away from dramatically restructuring aids services in the city. And I don’t have a good reason why we didn’t go that way. We just thought it would be the path of less resistance.

**CD:** And the community organizations – were they the case management programs?

**DW:** So, like I said a little bit earlier, there was case management money of some sort pretty much everywhere. But yeah, the community organizations have the lion’s share of it.

**CD:** And they’re not NGOs?

**DW:** They are. They are. We call our NGOs here CBOs, community-based organizations, but they are NGOs.

**CD:** But just directly funded from Ryan White money?

**DW:** They are. Some of them have Medicaid money; all cities have some of them, New York just has zillions of them. I mean, imagine just hundreds upon hundreds of grassroots organizations. And that’s what they are – they’re all small, community grassroots organizations. But there are just so many of them, and some of them have grown so large, that they’re a tremendous force. And social service and case management money has always been concentrated there. So we made a conscious decision at some point that we were going to keep that intact, but in order to keep that intact, we were going to have to get them to partner with the medical organizations. So that was a lot of negotiation.

The other big stakeholders were internal – I mean, all the way up to the mayor. Only because - well, HIV of course can upset political systems. And it was just our luck that when we were putting the RFP out was an election cycle, and not only that, but Mayor Bloomberg had decided that he could run for a third term. So we had a nervous mayor, and like I said, it did become a contentious process. So we spent a lot of time – and not only that, but of course Commissioner Frieden left in the middle to go head the CDC, and so in the middle of the process we had a new commissioner. So everything we had told the old commissioner, we had to then go back and tell the new commissioner. So there was a lot of time spent in the offices of the important people to get them on board. So, I would definitely advise the next group to do this to think about the election cycle, and make sure your commissioner sticks around. But yeah, that was – I mean, we probably spent more time talking in-house to our concerned directors than we did talking to the service partners.

And are you familiar with Housing Works? So, Housing Works is one of the largest community-based organizations. I guess their claim to fame is as advocates for housing. So, they have a very very strong political presence. They sued Mayor Giuliani in the state court, I think, I don’t remember – and I think they sued successfully – but they have a strong credence in DC as well. So, they were exceedingly vocal in objecting to our plans. But I think at the end of the day, we reacted a lot more to the fear of housing works than to housing works. So we ended up
talking to our people about housing works a lot more than – we pretty much convinced them. They knew they weren’t going to win the argument. But the politicians were much more nervous, so we had to do a lot of hand-holding.

**CD:** What were the concerns, and what were the arguments that saved the day?

**DW:** Whose concerns?

**CD:** I guess both – Housing Works, and the internal politicians.

**DW:** So – it’s very interesting. Okay, so let’s see. The idea that case managers would work closely with doctors is a big departure here in the city. Or even in the state. The reason it’s a big departure is because about twenty years ago, or a little bit less, when there were no good treatment options, and when the epidemic was at its peak and migrating from men who have sex with men to minority communities – when it was becoming apparent that this was a minority epidemic – the state created Medicaid-funded case management programs. And because there was no treatment – so, essentially you’re talking about a social condition – the state created community-based case management, called a community follow-up program. So essentially they created, they licensed these community organizations to provide case management services, without any connection to health care services. So in the community follow-up program, essentially you’re supposed to make sure that people do as well in the community as possible. Over time they’ve gradually become more medically-oriented, right, but they’ve never aligned with medical institutions. There are some that are in medical institutions, a minority of the programs are within medical institutions, but a vast majority are in community-based organizations. They have no necessary affiliation with the medical entity. So you can imagine – you have a program that’s serving 500 people, they come from 20 different medical providers. So you as a case management provider are kind of spread out all over the place in terms of your relationship with medical providers. And so the typical experience for a medical provider – I’ll give you my own personal experience, I won’t speak for the entire medical community, though we’re starting to hear more and more – is that you can’t hold these community follow-up workers accountable, because you’re never sure who works for whom, and who their bosses are, and there’s turnover, and you’re not exactly sure what their job is, your agency doesn’t have a close relationship with their agency.

**CD:** And for the most part they’re not doing home care, it’s just speaking with –

**DW:** Well they do some home care, but it’s not home-based health promotion. They’re doing home assessments, and making sure that there isn’t domestic violence in the home, but they’re certainly not going in there with a workbook saying we’re going to work on a module about – right?

**CD:** And not directly observed therapy?
**DW:** Right, and certainly not doing directly observed therapy. But the big difference is that there’s no intimate connection with health care facilities. So I think the fear was something like this: that if you’re a patient, and I say to you, “you know what, I’m a doctor, I’ve got a case manager, I want my case manager to work with you and they’ll do X Y and Z,” then you’ll say, “well, I have a community follow-up provider and they do X Y and Z.” And I’ll say, “well, yeah, but here’s the problem: I didn’t even know you had that community follow-up provider, so how can we work together if I don’t even know you’ve got this provider? On the other hand, I know my case manager, he’s right over here, and if the three of us are working together, you’re going to be healthier.” And so what you’re going to do is say, “well, I’ll fire my community follow-up provider. I don’t need him. Right? Because I have the same services right here, we’ll work as a team; you’re right, this hasn’t been a productive…” and so all the patients would go and fire their community follow-up providers. I think that was the fear. And we’ve heard that – that the community programs would cease to exist. And if they had that fear, that they would become irrelevant and therefore cease to exist, if that was their fear, then they would go to the politicians and say, “the city health department wants to shutter my community organization. And my community of poor minority folk are going to be without my services, because we had to shut down because we lost all our money.” And that was everybody’s fear.

**CD:** And they were getting reimbursed per patient, pretty much, by Medicaid?

**DW:** That’s right. And so what we were saying is, “forget about the Medicaid program.” This was difficult. We were saying, forget about the Medicaid, because we’ve got this Ryan White that’s better.

**CD:** And that’s not per-service?

**DW:** No, it’s still per service. But there was also this fear, you’re right, that the money would preferentially go to other entities. So not only would it take the Medicaid money away from the community organizations, but our Ryan White money would not flow equitably to those community organizations. So we weren’t going to make up dollar for dollar to the community organizations. Right? Our money would preferentially go to the hospitals.

**CD:** So, where were they worried that the money would be concentrated? In some hospitals.

**DW:** In the hospitals and not in the community organizations. So it’s the community organizations saying, “we’re the grassroots people, we look after the people, we have community in mind, and we’re going to lose money. And so that’s a bad thing for minority people everywhere.” And so “the city plan is racist, it’s not good for the city,” whatever adjectives and descriptors you want to use. So that was the fear. So what we had to do to get over the hump is demonstrate that in fact, we’re not trying – I mean, the Feds don’t let us -- supplant state Medicaid dollars with federal dollars. We’d lose our grant if we did that. And so in fact what we want to do with the grant is strengthen those Medicaid programs. And essentially, what they
need in order to get strengthened, is they’ve got to align themselves with medical providers according to the same model.

So essentially what we did – it’s almost more clever than we thought of, it just worked out better than we could have imagined – we set a model. Right? We created a model. And everything forces everything else – by that I mean, our model is that, our PACT-type programs work in concert with medical providers. What that forces – we can’t spend any dollars doing that until we’re optimally using our Medicaid dollars. And so that forces the Medicaid dollars into the same sort of alignment. So where they used to be these sort of free-agent community providers, they now have to work more closely with medical providers. And so then we’re spending our Medicaid dollars more efficiently.

CD: OK. And so there’s a navigator and a care coordinator –

DW: They’ve always had that same sort of structure. What we try and do – so, it’s a little bit complicated, let me try to explain it. So let’s imagine that you’re one of the unique hospitals – it happens to be the same public hospitals that we were bailing out five years ago – so if you’re a public hospital, chances are pretty good that you have a community follow-up program in your hospital. And that’s because they’re public hospitals, they’re situated in the poorer neighborhoods, and so that was an intentional decision on the part of the state program that there’d be not just these community organizations, also these public hospitals. So you’ve got both resources. OK? Now you have a patient who’s not doing well and needs case management services. So you want the patient – you want the sign the patient up for case management services, the patient agrees; good. Let’s go. What the Feds require under something called the Payer of Last Resort rule is that if there’s a particular service that Medicaid will pay you for under case management, you must bill Medicaid and you must not bill Ryan White for that service. You can’t even charge it, it’s not a line-item budget – you can’t charge it to Ryan White. You get your money from Medicaid, you only get your money once, and so give Ryan White that money back. Or better yet, don’t even budget it to Ryan White.

So a good example of that service is accompaniment. So, one part of case management is that in order to provide support, in order to provide some better understanding of treatment planning, advocacy in the doctor’s office, the case manager, navigator, whatever you want to call them, will accompany the patient from somewhere out in the community into the medical facility, into the doctor’s office, we’ll have a three-way conversation, reflect the treatment plan, clear up any questions, etc. The community follow-up program, Medicaid will pay for that. And so will we. Payer of last resort, though, they have to pay first. So we have budgeted our program in such a way that we expect you, because you have those Medicaid resources, we expect you to bill Medicaid and it’s not on our budget. you can’t charge us - you can charge us for it, you won’t get it; and you can’t budget it - you’d better not hire staff expecting you’ll get it, you’re not gonna get it. And so what we’ve said, essentially, is we expect your Medicaid-funded staff to do the same sort of work that the Ryan White staff are. We don’t care what the Medicaid regs are, we don’t know what Medicaid expects; but we’re not going to pay you for something Medicaid will pay you for, and because it’s the same program that is serving the patient regarding of funding stream, we expect the same standard of care, so you’re obligated to meet them at home, bring
them in, do up the same work. But we’re just not going to pay for it. So essentially, without using a penny, we’re getting the same quality of care – we’re getting the same PACT model, but leveraging Medicaid dollars. So that’s how it works. Don’t ask me if it works well – we won’t go there yet.

**CD:** Right. So if the hospital responds to the RFP and commits to doing this program, then they’re committing to get some Ryan White money, but also continue to get the Medicaid money, but hold all their Medicaid services to the Ryan White services?

**DW:** Ah, so that’s a very – right, so this is why I say don’t ask me if it works well. So you are a hospital, and you say that’s how you’re going to do it, so your Medicaid dollars should flow to the same patients who are getting both sets of services. And the program will say, or you’ll say, “but wait, wait, I’ve got some other patients, and they get their medical care over there somewhere.” So we go back to you and say, “well, that’s a bad idea. Get rid of those patients. Give them back to “over there.” This is our wonderful innovation: that medical case management should work with medical care. If you get your medical care here, you should get your medical case management here. If you get your medical case management here, you should get your medical care here. If you get one here and one there, figure out which one you like better, and get it all there. But don’t keep the services apart. And so, that’s our challenge today: for the next twelve months, this is what we’re working on: getting programs to understand that, “remember when we promised you you weren’t going to lose money? You won’t, because for every patient that you give up, you should be getting a new patient. For every patient that you don’t have whole care of, and they’re going to get their whole care over there, you’re going to get one in exchange. Yeah, there’ll be some losers on the margin over there, some winners on the margin, but nobody - when it all shakes out, it’ll be pretty fair. You just have to have faith that it won’t – in the same way that you’ve always been committed, you have to offer a good package of services, you’ve got to still do that. But just because you’ve signed up someone for the dental hygienist, doesn’t mean you can do that – if you have the dentist, you can do both services, but don’t have dental hygiene here and dentist over there. That model doesn’t make any sense. Don’t think that you locked in the patient for partial services, start thinking about how to serve the patient as a whole.

So that’s – so, building on the idea of – we can see the PACT model replicated, pay for it, we can also use the leverage of public funds to get more good service than we’re actually paying for.

**CD:** So, how are the community-based organizations retained in the structure? Did their staff continue to serve as the care coordinators?

**DW:** For the most part, yes. It was a competitive process in one sense: I mean, it wasn’t a fair competition – it wasn’t a skills competition, I should say. So the competition was all about where are the patients, right. So if you came and said, “I have 3000 patients,” we’d say, “well, that’s a lot of patients, you get an award.” And if you came and said “I have sixty patients,” we’d say “we’d love to fund you, but we don’t have a bottomless resource, you’re not a priority.” So some of the money did move around; for example, if you said you had 3000 patients, there’s no
way going in that you had enough staff to serve them all. No one got funded for their full 3000; the largest programs serve about 200. But nobody had staff to serve 200, not when you have to consider weekly health promotion and daily DOT. So all the big programs had to staff up. But apparently, and some of the project officers were just telling me today, they were exceedingly efficient in terms of moving staff whose grants terminated – staff just, like, knew where to go to find the new jobs in the programs that had to scale up. So we have a lot of case managers who lost a job in one place, and gained a job somewhere else. So we’re still looking at – our biggest problem staff-wise now is those large programs weren’t able to scale up in time. That’s a challenge, particularly in hospitals, particularly when there’s a difficult financial climate and hiring freezes. That’s been tough.

CD: OK. So, where does the Ryan White money go and where does the Medicaid money go? Is Ryan White funding one set of services –

DW: So as of today, there’s not a single case manager that we’re aware of who’s on both budgets. Though that would be the ideal. So if you would imagine that a health promoter, when they do an accompaniment, which is a Medicaid-reimbursable service, is billing Medicaid, and when they go into somebody’s home and do an hour of health promotion, which is not Medicaid-reimbursable, then that’s counted towards their Ryan White award. But nobody’s doing that for a number of reasons. And that’s part of our work to be done.

So as of today, how does it usually work? There are two variants – one that we like, and one that we don’t like. The one that we don’t like – I’ll start there – is where you have two siloed programs. So, an agency says, when I encounter you, I’m going to decide, I don’t know, based on your hair color or something, you’re going to go into Medicaid or not. I mean, assuming that you’re Medicaid-eligible. The reason we don’t like that obviously is that the Medicaid-eligibles, then, don’t get the advantages of the Ryan White program. They get – I mean, what they try and assure us, then, is, “don’t worry, we’re going to run our Medicaid program exactly like we run our Ryan White program.” But we have no way of monitoring that, we have no authority to look at their data. And since the payer of last resort principles don’t apply to everybody that’s Medicaid-eligible, by definition, no patient that’s Medicaid-eligible could go into the Ryan White program. They’d all have to go into the Medicaid program. So we don’t like that, and we’re putting an end to it effectively in the next contract.

CD: So then the Ryan White would be reserved for people with too high of an income, or something –

DW: Right. So, there are two classes, or three classes – I think it’s too – I think one is just an income class, and another is immigration status.

CD: And the hospital would get the same lump of Ryan White funding regardless of how many patients are funneled into that –
**DW:** Well, yes and no. Yes. The answer is yes. But the reason they get the same amount is, the variable we use is just how many patients you serve. So, we don’t want to hold onto our money – we want to budget our money once and then live with it. So if each patient is cheaper, we’ll say ok, do more patients, and if each one’s more expensive, we’ll say, you can do fewer. So the bottom line is – so obviously if you’re not taking Medicaid revenue, then your patients are more expensive, that means we have to settle for a lower target and we don’t like that. Right? We like higher targets. And particularly when the higher targets come at Medicaid’s expense. We love that. Especially in this state. Medicaid is virtually a bottomless pit. And it’s not in reality, but – HIV is still relatively small-scale compared to the universe, so as far as we’re concerned it’s bottomless, so we do want to maximize it.

So the good approach, and the one that we’re going to force as of next year, is where no individual front-line staff is being paid with both streams, right, but there’s joint management of both streams. So for example, **you’ll just have one person being the accompanier, and you’ll have one person** – now, hopefully when we force that, or even as we start to look at it, programs will acknowledge on their own that they like the idea of the accompanier and a health promoter being separate people. And we’ll certainly push the PACT-ness of it, right, that accompaniment and health promotion go hand in hand, and it doesn’t make sense to split them apart. It’s not going to be easy to – that’s going to be a tough nut to crack. We’re not even sure how it’s going to work out. I mean, the Medicaid program is administered by the state, and so we don’t have oversight of that program. So we have to do a lot of inter-agency negotiation to make that work, and that’s not easy. So yeah, that should be way up there in that list of stakeholders that we were talking about.

**CD:** The state Medicaid?

**DW:** Yeah, the other government agencies. So in our case, it’s the state department of health. They have what’s called the AIDS institute; so they’re our analog on the state side, and we’ve done a lot of talking with them.

**CD:** And how do they feel about the program change?

**DW:** How do they feel about the program change on your tape recorder, huh? It’s wonderful. (Laughs) Let’s see. It’s – I guess, it’s a challenge. Certainly, we do a lot of negotiation with the AIDS institute for every HIV and AIDS program that we operate. And because they’re so close to – they are the administrators on the community follow-up program, it’s been a very delicate dance.

**CD:** It’s kind of – slightly altering what their money is being used for?

**DW:** Yeah. Absolutely. And it’s not so much the altering, it’s that – they have a lot of – it’s not just the financial investment, but the emotional investment, the professional investment. This is their baby for twenty years, and here we are saying, “hey! We’ve got something new and better.” So yeah, it’s been – that’s a lot of work. And I mean, that’s part of the reason why we
still don’t have a good approach on how to split them, but the good news is that, you know, again, their concerns – and this is my impression, it’s not written anywhere – but their concerns, like the agencies, like a lot of our own politicians, were that the unintended effect of what we’re doing here would somehow harm the community follow-up programs or even take them apart. And they have been able to hear and understand that leveraging Medicaid means growing the entire pie, not taking their slice and making it ours. So that’s the most recent development, but we don’t yet have a happy marriage where we’re all moving forward.

**CD:** Got it. So just to make sure that I understand the basics – so the community organizations have these case managers, and they’re not going away, they’re going to stay and work more closely with one specific hospital. And ideally, each patient would be paired with one case manager whose –

**DW:** Let me give you a little more background, and then we’ll see if you understand.

**CD:** I’m already off track!

**DW:** Well, yes, but there’s an important part that I haven’t told you. And that is this. So if you’re a public hospital with a community follow-up program, when we had our solicitation, you could come to us and say, whatever, “I have my 3000 patients, could I have some money please?” and we’d say, “yes, you can.” In virtually all other circumstances – so, you’re a big private hospital and you came to us and said, “I have 3000 patients, can I have some of the money,” we’d say “Well, you could, and you’re going to have to build up this case management entity within your hospital, but it would be really great if you went out to the community organization down the street from you and formed a partnership, and applied together. And we’ll tell you what, if you apply together, that will make you even more competitive. We’ll give you a preferential advantage in the competitive process. And then you’ll have the patients, and you’ll have some skeleton staff at your site that will do some support stuff, but most of the work out in the community – of going to the homes, doing the DOT, doing the community health promotion, doing the navigation – all that will be done by this community organization. And so in structuring our RFP that way, we got a pretty good response. And I’m sorry I don’t know the numbers, but I can let you know. We got a pretty good response in terms of the proportion of applications that consisted of these novel partnerships. Right? And in two flavors. One flavor was hospitals who said, ok we’re applying, but here’s the name of our community organization who’s going to sub-contract. And other applications from community organizations who said, we’re going to apply, and we’re eligible to apply because we’ve signed on as our partner this medical provider. Or these medical providers – some of them could come with a whole slew, you’d have this whole big network of medical providers and they would again have, you know, culled patients from all over the place.

So, in our RFP itself, we allowed for the creation of these networks. So that’s one way that we’ve created relationships between a case manager sitting in a community organization, and a medical provider. And we’ve gone beyond that with one of the criteria for that relationship, is that they don’t literally sit in a community organization, they have to have a chair to sit in a
medical organization too. In other words, a doctor’s got to know what their face looks like. They’ve got to go there, they’ve got to be able to look at charts, they have to act as though – and in the best-functioning networks, that’s how it works – you wouldn’t know that the person walking around with a hospital ID tag is not an employee of the hospital. They’re like any other sub-contractor who spends their day working in the hospital. And so, we do have some examples where that’s worked.

So now what we’re saying is that – is that, so that’s the gold standard, that you applied under the RFP in this way. But now, if you’re a hospital or community organization and you’re interested in a partnership, and you didn’t apply under the RFP in this way, it’s not too late to enter into a memorandum of understanding. Business associates – you can forge a partnership and start setting up these relationships, because that’s the way that you can then blend Ryan White and Medicaid money.

And again, if you think about it – so we estimate, if you have 3000 patients, and our largest programs do, if you have 3000 patients we estimate that 25% need case management. That’s 750 people. Today, with Ryan White dollars, we can’t afford to give anyone more than funding for 200 people. Big gap between 200 and 750. So if you can leverage Medicaid dollars to fill that gap, you’re better off. So that’s the message that we’re trying to put out there, is that if you – we don’t even have to say this to medical providers. They know, that if they rely on community follow-up staff that don’t have a committed affiliation, staff doesn’t do their job, right, they don’t do exactly what they were told, they can’t do anything with them. They have no manager’s name that they can go to, they can’t give it to their medical director and have an agency-director-level conversation. They’re powerless to make it work. But if they have a committed partner – in the same way, you’re working in the hospital, your food service is a contracted service, not owned by the hospital. But if your kitchen sends up a regular diet to a patient who’s got to be on a low-sodium diet, you as the doctor can do something about it. You got to the food supervisor, right. And we expect the same level of relationship between the medical providers and case managers.

**CD:** OK, got it. So, the Medicaid will continue to fund a lot of things like accompaniment to eligible patients, but Ryan White, even for Medicaid-eligible patients, will be funding some extra services like education?

**DW:** Right. Non-Medicaid eligible services.

**CD:** And then there are some people, probably very few, that just don’t qualify for Medicaid but need...

**DW:** Exactly. Probably about – under 20% of the population. Probably closer to 10 or 15%.

**CD:** And that’s fully Ryan White?

**DW:** Those are 100% on Ryan White. Okay?

**CD:** Yeah! I think that totally makes sense, thank you. How did the HIV community –
**DW:** The patient community? Or consumer community?

**CD:** Yeah – was the consumer community involved in the decision-making? Or it was really more the community organizations, hospitals, politicians…

**DW:** That’s a really good question. And I don’t know…I don’t know how to explain it, except, I think it’s probably a legacy of the fact that the Ryan White program was just a grants administration office until two years ago. We’re not well-connected to the provider community. So… I mean, the Ryan White care act requires that… the Ryan White HIV Treatment and Modernization Act regulations require that the grant be administered in part – well, there’s the grantee, but a lot of the planning and decision-making resides in this “HIV Planning Council” independent of government. There’s government representation, but the big decision-maker with Ryan White dollars is the HIV planning council. It’s terribly terribly complicated, because it has to have representation from the community – which usually means the provider community. It includes some of the consumer community, but it’s like 80% provider community, and 5% consumer community.

**CD:** And providers are community organizations and hospitals?

**DW:** Both. But of course they’re heavily self-interested. So you can imagine that if you’re a poor community hospital, dependent on grant funding, you’re going to be heavily self-interested and you’re going to be a member of the committee; on the other hand, if you’re a wealthy tertiary care facility that doesn’t want to touch Ryan White dollars because of all the reporting requirements, you may have a very robust HIV program but you’re not going to be at all interested in the HIV planning council because it doesn’t impact anything that you do.

So it’s a very very self-interested body; there are conflicts of interest all over the place. Very, very difficult process. And it’s a bigger problem in New York than in many other places, particularly because of the divide between community providers and hospital providers, and particularly the tertiary hospital providers and the researchers. So you’re not getting representation from the top research institutions at the planning council.

I’m sorry, I forgot the question.

**CD:** We were talking about patient involvement–

**DW:** Right, so patient involvement. So the planning council is our best avenue of access to the consumer community, and it’s not very good. You have a small core of sort of “professional patients” who – you see them on this community one year, and the other committee the next year, and it’s the same ones over and over again. We have upwards of 70,000 people living with HIV and AIDS in this city, and there’s nobody –well, there’s me and one other doctor who have had clinical practice, but nobody else could name more than ten patients in the city. So I mean, it’s something that we have to do – that we have to do. We did a little work with our treatment adherence, those sort of pilot projects, we did something with patient satisfaction – and they
were very well received – but most of our patient satisfaction surveys give us the same sort of outcomes. People in programs tend to like the programs. It’s not surprising. But it will be – I think there’s certainly work to be done there, particularly because the relationship – the implications for the community follow-up program have been such a topic of discussion, and so much of it – whenever you talk about HIV, everybody’s going to be the champion of the patient. “so what you’re doing is going to ruin things for the patients” – so we will, in the next year or so, want to hear from the patients with regard to, how did this impact your relationship with the community follow-up program, and did it work out for the best for you, and what changed for the better and what changed for the worse?

CD: And those few professional patients – how are they selected or compensated? Do they mostly kind of step up?

DW: So, gosh, I don’t know. I mean, they’re not – there’s nothing remotely random about it. They’re very – they tend to be the sort of people who like to have their ideas heard. And so, they’ll go from being on an organization community advisory board, and – they’re everywhere. They’re the same people. I mean, they’re professional patients. But – we’ve actually been spending a lot of time thinking about, just in general, how we capture the thoughts of the consumer community. Years ago, we used to have a survey but it was terribly flawed and so we scrapped it, and when we scrapped it we were heavily criticized because it was a consumer survey. But it was essentially a consumer survey of these professional consumers. And so we scrapped it on the grounds that it wasn’t representative, and in the meantime, we replaced it with some consumer focus groups. Which again, they don’t reach very deep to find people, but they’re a little bit better. Obviously again, then, the sample is very limited. So we’re looking at one or two years to have a very robust, several hundred-consumer survey with regard to satisfaction and adequacy of services.

CD: And so, those small number of professional patients, they don’t have a very big – they haven’t shaped the program very significantly up to this point?

DW: No, no.

CD: Because they’re not speaking from a big place…

DW: No, no. I mean, it’s been a big challenge here. We do have a – for lack of a better word, scientific, longitudinal cohort, that’s run out of Columbia. It’s about a 5 or 600 patient cohort.

CD: Is that the CHAIN?

DW: That’s the CHAIN study.

CD: Yeah, I saw that in the comprehensive strategic plan.
DW: Uh-huh. So, the CHAIN study – it gives us a view of, well, it’s more a cross-sectional study, just the way that it’s operated. But whatever. It gives us, at least, a good cross-sectional view of the population. In terms of what are you getting, is it working, what do you need, it’s not very good – and in fact, we do better with some of our qualitative focus group stuff, because it’s sort of a very rich area to get at some of these ideas of what’s working, what’s not working, and particularly when it comes to treatment planning and execution of treatment planning.

I should tell you, we have another body of research that doesn’t get at the patient perspective, but we’ve been looking at sort of the doctor-case manager dyad relationship. So, we have quantitatively assessed, you know, what are the factors that promote good collaboration. And that was really interesting – I mean, we did sort of our baseline study to get a sense of both the quality of the collaboration at baseline, as well as what the predictors of collaboration are. But that’s something that we’re going to follow over time to get a sense of – you know, when you create these partnerships, or when you create just a PACT model that necessitates accompaniments and directly observed therapy, are you building better collaborative practices just by doing that.

CD: Cool. So those evaluation set-ups are going on the 28 hospitals and health centers that –

DW: So, follow-up for that is not yet going on. The baseline was conducted by one of our staff for her dissertation thesis, but yeah, we’re I think in the process of developing the plans for repeated, serial measures to look at the progress over time.

CD: Great. Do you mind if we step back for a second –

DW: (Laughs) Go ahead, go ahead!

CD: Yeah, I’m probably taking –

DW: It’s – let’s see, I’m on Jerusalem time – but no, my body’s adjusted, just my watch is still on Jerusalem time – we’re at 4:10. So I’m good for another half-hour.

CD: Ok, great – wow, so generous of you! So in terms of persuading – internally – the politicians, what kinds of arguments were successful when they were scared by the Housing –

DW: Sure, sure. So, our…I guess our biggest – well so, let’s see. Number one was just clarifying the issue of, you know, were we going to take the money out of the pockets of the community organizations and put it somewhere else. Right? So, at that point we hadn’t even stumbled upon the idea of using Ryan White as an indirect lever for Medicaid, but just the idea that a community organization could apply in partnership with a medical organization – whether as a sub-contract or as the lead – right, so let’s clear that up, so any community organization that wants to go to their council-member and say, “I stand to lose, you know, five hundred thousand dollars because of X Y and Z,” just isn’t being honest. Because they don’t have to lose. What they have to do, if they don’t have any patients of their own, is they have to get into a
partnership. We’re not going to give money to organizations that don’t have patients, right? But as long as they have patients of their own, or patients in a partnership, they don’t stand to lose any money. So that was just a clarification.

The other argument was that – or I guess, another two arguments. So the second is that we’re going to put the money where the patients are. Again, we’d love to fund every fifty-patient shop, but we can’t. and there are efficiencies of scale. And so therefore a program with 2000 patients is more efficient than a hundred programs that each have 20. So that’s what we’re going to do – we’re going to go to the big ones first. It didn’t hurt that we came up with a very very clever algorithm for the allocation. And – actually, we shouldn’t take credit for it, we actually got tremendous input from one of the commissioner’s men. And so – we had a pretty good method, and he made it even better. Essentially what we did is, so we said, if bigness is good, if our primary – if we had one dollar, we’d put it in the center with the most need, right? So we’re going to go there, we’re going to make our first award. Well, actually, our first decision was, we’re going to cap awards at a certain value so we don’t get stuck making only 3 or 4 or 5 awards. We’re not going to go to a giant provider and fund it 100%, and then consume all the resources. So we’re going to cap – we’re not going to give anybody more than X, so that we can expect that we’ll be in the ballpark of 20 to 30 awards. And then what we did is, we said we’ll go to the biggest place first, and – I’m trying to remember – was it the biggest institution? Or – no, this is what we did. We said, we’re going to go to the geographic region. There’s a map up there hung up on the wall. So, the dark lines were called united hospital fund neighborhoods. So, we’ll go to the ones that are the darkest grey – the darkest one, we’ll go there, that’s going to be our priority. And then we’ll go to the largest applicant within the biggest area, and we’ll give them an award. And then we’ll subtract from that area the value of that institution. In other words, so we’ve covered 1000 people there, so we can subtract that 1000 from the total in that area. Now reshuffle the deck, and see who comes out on top next. Right? And we kept doing that, so that every award was made to the most deserving, or the most needy region, having considered all the awards that came before. And so no one could accuse us of favoritism, because it was a strictly mathematical formula, right, that always made sure that the highest need was being met first.

And then, last – so, we made sure that the organizations could get it, we made sure that we were being rational about where we put our dollars, and – then, I guess, we just did all sorts of checks afterwards to make sure that in fact everything worked out – that the geographic distribution was pretty good, and that the mix of hospitals and community organizations was pretty good, and it all balanced out in the end.

CD: Were you selling that the PACT model itself has cost-saving and stuff like that, or were you more selling that Ryan White likes this program – like, how much did they need to believe in the model itself, and how much did they trust Ryan White?

DW: So, we absolutely sold the model. No question about that. And there’s – there was tremendous respect already – I mean, certainly – I guess it was a different sell depending on our audience, right. So with our internal stakeholders, there was already a healthy respect for evidence basis; and a good understanding that New York City, and New York City-funded programs, had not generated much in terms of data. So go back to our friend the medical director
from New York, the staunch Yankee fan, right, she could talk all she wants about, she’s been
doing this longer than Dr. Behforouz and knows what she’s doing, but she hasn’t published
anything with regard to the outcomes. And there’s nothing we can do with that. She doesn’t even
have data tables that she’s sitting on that she could show us. She’s got some subjective notion,
but no commissioner of health is going to rely on a medical director’s subjective notion that the
program is good when you have published data that shows you something that does work. So we
definitely had the backing internally there, and –

**CD:** Just because PACT has published in some really serious journals.

**DW:** Yeah, exactly. Exactly. And that got a sort of grudging respect from the community.
And I mean, I certainly understand that – from my background as a provider – as a provider, you
know, what you think, or what you know, is – I know the difference between anecdote and
systematic review of data. I know I haven’t written it up. But I know that my program was
working because I saw a consistent trend of my patients improving. And pardon me if I’m a busy
practitioner, that I didn’t have time to run data tables and write reports, but I know that what I do
works. And so we can sympathize with that, but at the end of the day, a public health agency is
sort of bound by the norms of practice. Which is, you go by the data that you have, not by the
assurance of everybody who yells loudest that their program is good. Because it becomes a very
slippery slope. Some providers are going to have a better idea than others, and if you don’t have
data – or actually, for my medical school graduation, our speaker, a professor of surgery, gave us
dollar bills that said “in God we trust,” and on the back he had stamped, “all others have to bring
data.” So, I mean, that’s what’s drilled into you. And that sold here. And it did ultimately sell
with the community as well.

**CD:** And so, just a quick point – did you first find out about PACT by reading these
journals? Or was it at a big conference?

**DW:** No, we got it from reading. I mean, that’s our standard operating procedure when we
don’t know anything, is just start searching the literature very aggressively. And you normally
get 2 or 3 people doing it at the same time, doing literature searches side by side, and culling for
anything that you can find. And we’re pretty good at that. And so we were pretty confident that,
when – at one point, I remember at the meeting with commissioner Frieden and talking about the
PACT model, and he kept talking about Malawi. And Malawi had a very nice program. And
ultimately, we decided that the evidence from Malawi suggested that you could monitor patient
body weight as an indicator, and so we were going to give the commissioner that nod, that we
would monitor patient body weight as an indicator of progress, but everything else was going to
come from PACT. So we were pretty confident that – you know, when you talk to commissioner
Frieden that way, and say “we’ll give you one indicator,” you’re pretty sure that you’ve found
the best thing that you could find. And he went for it. He’s a pretty smart guy. So – yeah, we
couldn’t have been happier than what we found. I think – the next next thing is figuring out
where we can save money, because PACT costs us upwards of $7000 per patient per year, and
that’s not cheap. But I think everybody here has been pretty happy with – just with the evidence
of PACT and, you know, everybody’s pretty confident that we’re going to see the outcomes that we’re hoping for.

**CD:** So, you talked about how these really big hospitals in really high-need areas are getting the grants, but they don’t get a large enough grant to cover all their patients. So, kind of a larger question on rigidity vs. adaptability in this model – how much do you know, or how much do you control, whether the funding is going to a smaller number of patients and replicating the model exactly, or whether they’re kind of spreading it out to a larger patient body and going kind of half-way?

**DW:** Yup. So, we modeled everything mathematically. Right? So, for example, so, the first thing that we came up with prior to year one was that it would cost us $6000 per patient per year. And it’s since become more expensive, though, because we moved the model.

**CD:** And, that’s doing everything that PACT suggested?

**DW:** That’s everything that PACT suggests. So, $6000 is an average – our model is a little bit different than PACT. We have services for some people that are not an anti-retrovirals, for example. We have some lower-intensity interventions. We have – PACT will step you down to a monthly health promotion before you graduate, we’ll step you down all the way to quarterly health promotion. So we’ll let you string along for a few more quarters, getting barely any services. So we have these low-intensity low-cost services. But if you took a weighted average, it would come out to $6000 dollars per patient per year. And that’s forecasting – you know, weekly means weekly, but there are inefficiencies built in, etcetera. So weekly is 3 point something times per month, and so on. And so, we expect, and I say we expect because we’re not doing it yet – we have an obsolete data system that we’re phasing out, and we’re bringing in a new one that’s now three months late, but data systems are always late. So we expect to monitor services, and services per service track, so that we’ll know when patients are not getting adequate services for what’s anticipated. So for example, you’re enrolled, you get weekly health promotions, we expect to see health promotions every week, and not less.

**CD:** And that’s in the hospital, not in the home?

**DW:** No, that’s in the home. Health promotion’s in the home.

**CD:** Oh, so you are doing the home visits?

**DW:** Oh yeah. Everything’s home-based. Yeah. I mean, we have an allowance that, if the patient preferences to come in, then that’s acceptable. But again, we’re talking about patients who have trouble keeping appointments, so we don’t expect too many people to say “I’d rather come in” and then be good at coming in. so we expect to see it in a minority of circumstances. But so, we know the frequencies with which we expect to see services delivered. We’ll monitor the actual against the expecteds; I’m waiting to hear from Jessica, I just gave her a data request,
we want to know pretty precisely, from the time you enroll into the weekly health promotion, what’s the average duration of staying in that weekly health promotion? Not what’s the model six months, we know the model’s six months, but in real life, how does it pan out – what does the average patient look like? So that when we see a program where the average patient is standing there two months two long, you can go and look, are they reviewing their cases frequently enough? Are they getting their CD4s and viral loads done? Looking at their adherence and thinking about stepping them down? So – we expect to be able to monitor pretty closely in terms of adherence to the model.

So, one of the things we learned from working with PACT as we were rolling out our pilots is that we’ve got to have a lot of eyes on the ground. So we created a technical assistance unit. We now have four project officers supporting the care coordination initiative – each one has seven program sites. And they do, sort of, the whole wrap-around from data collection to data review, and all sorts of technical assistance, working on quality management. They have a whole slew of responsibilities to make sure that what we envision gets carried out.

**CD:** OK. So, making sure that the hospital is spending the full $6000 per patient per year on a smaller number of patients?

**DW:** Yeah. I mean, there seems to be intentional redundancy, we’ve always had what we call our “master contractor” - because they do in fact let the contracts - but they’re also our fiscal monitor. Fiscal monitoring agent. And so they have all sorts of monitoring indices that look at payment. What our project officers are going to do is look a lot more in detail. So they’ll for example, they will be attending case review rounds and see how the decisions are made so that they’ll have some sort of real time knowledge of, are they looking correctly at their indices, like the adherence measurements and the biologic indicators to see when it’s time to move a patient from one track to another. Are the health promoters actually going out to the houses on that schedule. I mean, some of their responsibility is actually hanging out in the health center, and then tagging along with health promoters and seeing how they do their job, that they do their job. They have a lot of work, but at least it’s something in terms of us having a reliable sense that the programs are doing what’s expected. But no doubt, monitoring, and this whole notion of fidelity to the model, is a challenging one. And we’re wrapping up right now – well actually, not wrapping up, we’re wrapping up phase 1 of a 3-phase intelligence-gathering on sort of the implementation phase. So we know that implementation and ramp-up is a real challenge – everything’s new, and no one likes anything new, and they try to do things the old way –

**CD:** And it’s both the hospitals and the community organizations that have an old way.

**DW:** Yeah. So we’re wrapping up chart reviews – we’re doing about a thousand chart reviews, just to look at that – we’ve given them a whole bunch of mandatory forms that they have to complete for each patient, which are kind of standard operating procedure kind of forms, but just in a standardized format. And so we’re wrapping up the chart review; I think early next month we’ll be doing some focus groups that fill in the gaps, and conducting a survey of some of the staff. So we’ll get a sense of some of the key elements. So for example, home visiting is a
key element because, I mean obviously, it’s central to the model; and at the same time, it’s a radical departure from the way programs have done business before. And so we know from our pilots, what we’ll get is, “oh, you know, we’re not really doing those home visits because our patients don’t like them. Our patients all want to come in here.” And we know that to some extent that’s true, that’s a patient phenomenon; but to a larger extent, that’s a staff phenomenon, right. That they’re not comfortable, and as soon as they get the slightest hint of resistance from the patient, they can say, “okay, whatever, I don’t have to do it.” And so we want to get at that – like, how many staff, and where are the staff, that have really figured out how it is that they can convince their patients that they can do it. And one of the things we saw, we were just talking this afternoon – we have a weekly care coordination team meeting, so the project officers, the project manager who’s their supervisor, the director of Ryan White, and me, and Dr. Laraque if we can get her – and so today, we were talking about subjective reviews of what we’d seen from the charts that we had looked at, and what we realized is that on the health promotion curriculum, there was a pretty stark difference between some of the providers who had started as pilot sites, and therefore had a year or two-year lead time, compared to some of the newer programs, where the newer programs were giving us the excuse that we’d heard for years from some of the others, which was, “the patient doesn’t want to see that workbook, they think we’re crazy.” And yet if you go into an experienced site, they know how to do it, and so their curriculum logs look great. They’re doing a session a week, no problem. So it was very interesting to be able to demonstrate – and what you get, it’s really fascinating – what you get is that a project officer, and as it turns out, of course, we like anybody else hire our staff in phases. So we have one project officer who’s been here two years plus, one who’s been here a year and a half, and the other two are new. The one who’s been here the longest had all the pilot programs, and she kept them. And so her view of the programs is radically different from a new project officer working with new programs. The new project officer with new programs starts to integrate this idea that the curriculum is the problem, right. The patients say it, the staff say it, now our project officer thinks we should change our curriculum. Whereas the other project officer has a very different view. So it’s interesting for all of them sitting around the table to hear that. That everybody gets a siloed view, and that’s why we do this in a systematic way and get the data from all the various sites, and then you can see that an experienced provider behaves very very differently from a brand-new provider.

**CD:** Do you think that any of that is related to the training? Just that those few pilots sites got a lot more intensive –

**DW:** Oh, absolutely. Absolutely. The pilot sites got the more intensive training, they got to hear from PACT directly. And not only that, their training was followed up by any number of not only troubleshooting, but regular technical assistance interventions. So, the pilot sites had weekly technical assistance calls. They had a much higher technical assistance to program ratio than we’ve got right now. They had a lot more hand-holding, and every time they would say “we can’t use the curriculum,” they’d have a lot of people shouting them down and saying, “yes you can, and you will.” And it got through. So, yeah. It’s both the time and the intensity that they got, that allowed that to translate.
CD: Right. Would you say that all the essential elements of the PACT model are in the New York curriculum? Or, what was changed, and who decided what elements –

DW: You know, I honestly don’t know. The last – I know it was an issue. What, did Jessica tell you about that?

CD: Oh, I was just wondering –

DW: Oh, you just – no, there was an issue at one point. A “what the hell did you do to our curriculum” kind of moment.

CD: Early on, you mean?

DW: In the planning process. OK, so, the pilot projects all had actual PACT-branded materials, with a little note that said “the department of health thanks PACT for giving us this.” And then somewhere in the planning for the whole care coordination initiative, at some point somebody decided to strip out several chapters. And that was at the time when there were a lot of different hands involved, and we were getting into discussions with a lawyer there, who – intellectual property things. And I think the end result was, we just said, “the PACT curriculum’s not broken. Let’s not try and fix this.” I think it’s pretty close, if not identical, to the original. Yeah. I don’t think, at the end of the day, we had any reason to substantially change it. And we certainly didn’t have the resources to go through it with a fine-toothed comb and really find those items that we’d want to change and change them. There were some that were obvious that don’t even really count – like for example, there was a resource-guide component. So it’s a Boston resource guide, take it out and put in whatever you have for here. But I think it’s pretty faithful now.

CD: Ok. Including the supervision of community health workers, and kind of, going on up –

DW: Yeah. So, supervision, that’s something that we’re going to cover in our focus groups. We know it was a challenge in our pilot sites, but we did in fact budget for it. This is the clinical supervision. So, we did budget for it, and we expect it to be happening. Because it’s not patient-related, we don’t have any actual documentation of what happens and when. So we’re going to try to learn from our focus groups what’s going on.

CD: And, there’s a new contract with PACT.

DW: Right.

CD: What inspired – because that’s a lot more money on training, right?
DW: Right. So why, then, the new contract? So going back to what I was saying earlier, I think it’s filling a gap that we could have anticipated. There’s only so much that staff here can retain when they go through a PACT training. And honestly, I don’t think our role as a technical assistance provider is to assume the expertise. I think it’s always good to match up the experts with those who need to learn from the experts. And I think that was the realization. And I think the director, the care treatment and housing director, Dr. Laraque, came from tuberculosis. And HIV is different from the vast majority of health department interventions, certainly tuberculosis. And tuberculosis, the health department does everything; they run their program. And here, we contract everything out. And so when you run your program, you acquire the expertise, whether quickly by training or whether gradually by doing. And I think that’s the model that we started out with – that it doesn’t matter, you go out and hire some project officers, and you train them until they know it very well. But that’s not really reasonable when they’re not doing it, and imagine a project officer overseeing 7 programs, that’s over 1000 patients, that’s a lot of responsibility, you’re not going to become expert in much of anything that way. And so the model has to shift to where the project officer knows what the resources are, knows how to draw on those resources.

And I think what we heard – and again, I wasn’t really here for much of it, I was on leave last year and so I caught it after the fact – but my sense is that you can’t train and walk away. We were hearing from the service providers that they just didn’t feel competent. And we knew that. They didn’t feel competent with the curriculum, or with the home visits, or how to get someone on DOT, and our POs didn’t have the competency to support it all. So, what would we have done two years ago under our pilots? We would have gone to PACT. So we should just go back to doing that. So yeah, it was a very smart move, and it was sort of inevitable. Again, Jessica and Heidi, they pitched it a year ago, and I don’t know why we turned them down, but we did. So it was just a matter of time until we figured out ourselves that we needed it.

Heidi and Jessica did all the heavy lifting; we just cut the $25 million dollar check.

CD: So you went back to them and –

DW: I honestly don’t know who connected the dots at this point. I do know that at some point, for whatever reason, Jessica was moving to New York. And she was offering to install herself in here one day a week, and we were gung-ho about it, and I don’t know where it went. It cooled off, and it didn’t happen. So yeah, I don’t know whoever said, “you know what, Jessica made that offer, we should go back to them and see what they’re willing to do at this point.” So yeah, it’s good, it’ll be a much-needed back-up in terms of us getting some good ideas for how to help the programs out.

CD: Yeah. Great! Well, I don’t want to take up more of your time –

DW: Yeah, I should probably get going. Did you cover all the key areas?

CD: Absolutely. Would you mind if I email you one or two questions if something comes up?
DW: Yeah, please do. You have my email, right? OK. So let me take you around and quickly show you who’s who.
Interview with Dr. Monica Sweeney, 12/6/2010

**Monica Sweeney:** It’s all about the evidence basis. A bunch of organizations – whether its private, or public-private partnerships, like Columbia University, who has the skills to do epidemiology or help people write surveys – there are lots of skills that small NGOs don’t have. And they don’t know how to do the work, but they have the right instincts, because they’re closer to the ground. And the people in academia and in government have the skills, but they’re not close enough to the ground sometimes to know what’s really effective. So I think there’s a place for both.

The only problem is when people in NGOs start a project, it’s effective, and works with department of health, or however they get the pilot tested, and know it’s effective. But then they get married to the project. They get entrenched in it. So that 5 years from now, there might come along a more effective approach. But because this is what they’ve gotten their funding on, what they’ve learned how to do best; even if it’s no longer effective they want to keep doing it. And that’s the major problem that I see with small organizations and so forth. Not that government doesn’t have the same problem sometimes.

**CD:** So is that something that you’re looking to change with the New York replication of the model? Develop a more fluid and flexible version?

**MS:** They have tested the model really robustly. So we’re being as faithful to the model as possible. Translation out in the community – they want to make it more fluid. But if you make it too fluid, then you go back to the way things were being done before. Everybody doing what they think is best, and it wasn’t working. So that’s also the tension. So the department of health wants to do it based on the evidence from this model, and the people in the community are saying, “we’ve been doing this work for 25 years and we don’t need you to tell us how to do things.” Well, we wouldn’t be telling you how to do it if you were doing it effectively. So getting entrenched isn’t just small organizations; large organizations can do that too. So we want to stay faithful to the model, to operationalize it exactly the way it’s supposed to be, and then evaluate it on a large scale. And that’s what we’re hoping to do. I hope you’ve discussed with Fabienne, or Danny, or somebody who’s much closer to it. Because as the assistant commissioner running the entire Bureau – that’s why we have the care treatment and housing unit, the prevention unit, the epi and field services unit, and you know. So that everybody can be more engaged with their area of expertise. But from what I’ve gathered, this is what we’re trying to do. Be faithful to the model, and us evaluate it, this large thing that we scaled up, and then see if it worked.

**CD:** Wow. So is this collaboration something that you’ve been looking for in the past? Or something that has come up in the past? Kind of, replicating a model from an NGO?

**MS:** We look at the literature when we have an issue; we do literature searches and see what’s out there, and see how well we think it’s scalable. Because New York City – it has the largest epidemic in the United States. And then to see how well it will replicate in a large setting. Because some things that work very well in a small setting – when you try to scale them up, they don’t necessarily work. Have you heard of the Debbies?

**CD:** No I haven’t.

**MS:** Well, that’s one example. It’s a CDC program where they take models for behavioral interventions and train people on them, and then you take them back to your community and try to do them. And sometimes when you come to a setting like this, when the model was developed on a different
cultural group, or in a different language, or on a smaller scale, and try to scale them up, they just don’t work.

So we look for programs that we evaluate and that we think can be scaled up to New York City scale.

**CD:** So when you first heard this proposal, what was your reaction?

**MS:** When Fabienne first heard it, when she first read about it, she brought it to me, and said, “I think this is doable here.” And I said, “ok!” She’s a first-rate public health professional, so I know by the time she brings it to me she’s gone through it thoroughly. And then I just read it and go through it and ask any questions, and she gives me the details, and then we go from there.

**CD:** Wow. So were you involved in the process of bringing other people on board? I’d imagine that lots and lots of layers would have to sign off on this.

**MS:** No.

**CD:** That was more, um, the Office of Care –

**MS:** After they decided that it was what they’d have to do, then I just had to sign off on it. And then we had to do an RFP. Put it out there and see who would want to do it. So a lot of people said they wanted to do it, but then after they got the funding they said, “well can we change it to do this? And can we change it to do that?” and that’s when we have to say, “we want to be faithful to a model.”

**CD:** Ok. Do you have concerns about the way that it’s being implemented now? Or, things that you’d like to see differently in the future?

**MS:** We don’t have any outcomes yet. So what we’ll do after we get the first bit of data and they’re analyzed, then we’ll see. And we’ll look at the programs and see how faithfully they stuck to it. We also have project officers who look at them and give them technical assistance, so that they’re working with them; we’re not just going to wait to the end to say “oh it didn’t work, because you did x y and z.” so we do have project officers that are working with them.

**CD:** And how involved has PACT been? And would you like to see them more involved?

**MS:** You’d have to ask that to the program people.

**CD:** Ok. I have, I was just wondering if you had a different perspective on it.

**MS:** I don’t know.

**CD:** Ok. Any other reactions to the program, or things that you’re looking for from it in the future?

**MS:** You know, the thing that’s very interesting is that people in low-income countries do better with adherence than people in the United States when it comes to their antiretrovirals.

**CD:** I didn’t know that.
**MS:** So we need to look at – when we’re evaluating this program, and we can finally see what the outcome is – if we can’t get our numbers up to the adherence that people have in low-income countries. Then we’ll need to look very carefully at why it is that people in countries with many many many barriers to getting and staying on antiretrovirals have a higher adherence rate than people who have relatively few barriers in this country. Relatively speaking. And so that will be one thing that I’d like us to look at going forward.

**CD:** Where would you like to see the balance between, as you said, having enough rigidity that whatever’s great about the pact model is maintained and is replicated, versus adapting it to the much larger New York setting and to different communities?

**MS:** I would like to see the principles adhered to in all communities. Because the principles are sound. Whatever barriers people have to staying connected to care, we should make a program around that to make sure that we meet those and address those needs. Because other than that, they’re not going to stay in care. So whatever we have to do in the Hispanic, or the Haitian Creole, or the Russian, or Chinese – whatever we have to do, as long as we stay in the framework of making sure that the barriers are overcome, that we impart the education, that we make patients a partner, that it’s patient-centric – you know, we can do it in a group if people want groups; or if people want to do it while they serve dinner, and you take people one-by-one into a room to give them the education that they need; or you take it to their place of worship; those are details that I don’t personally care about. As long as the principles are adhered to, that it’s focused, that it’s patient-centric, and that we look for these outcomes, that we do assessments and we meet the needs and the – not only the medical needs, but the support services.

**CD:** Ok. And is it difficult to navigate the Ryan White versus Medicaid funding streams? Or that’s kind of the nitty-gritty involved with the project officers?

**MS:** Well, that’s the nitty-gritty…and personally, it’s all tax dollars, I don’t really care. We do have to obey Ryan White being the dollar of last resort. But…as a tax-payer, I’m much more concerned about people getting the services they need than where the funding stream is coming from. But we do have to abide by Ryan White rules. And many of the people who get Ryan White aren’t eligible for Medicaid, so I don’t see that that’s a major problem. We’ll see as we evaluate it.

**CD:** Do you think that there’s a cultural difference between NGOs and the department of health that requires models to be translated in some way?

**MS:** When you’ve seen one NGO, you’ve seen one NGO. I don’t want to make any broad strokes about the cultures of NGOs, because every single one of them is so different.

**CD:** What about the cultures of health departments?

**MS:** Even the cultures of health departments. That was gonna be my next statement. Even the cultures of health departments are very different. I just happen to be very fortunate to work for one of the premier health departments in the United States, maybe the world, if I might say that. And the culture that has been established by Dr. Farley and his predecessor who hired me, Dr. Frieden, is one of high professionalism and – you know, science. Both in terms of research, and publishing, and applied. So the culture of health departments are different too. And so – you’ve seen one, you’ve seen one. I don’t know – I haven’t worked for another health department, so I don’t know. But I’ve worked enough
professionally to know that this one is very special. And I’m happy to be a part of it, and it’s fairly recent. And even within health departments, from – you know, what people do in one division as opposed to another – may differ significantly. And this is a health department of over 6000 people. So there are certainly going to be differences.

**CD:** Yeah, definitely. So could you see this kind of process happening in another major city at this point? Or New York is kind of on the cutting edge –

**MS:** Oh, absolutely I could see it happening in other cities! We have meetings all the time at the CDC where we get to talk to our colleagues all over the place. And people often borrow heavily from successes elsewhere. And that’s what – we share them. We share them through publishing, and we share them through going to conferences and presenting posters and presentations. So – yeah. I could see it happening someplace else.

**CD:** And as a final question, would you have any cautionary notes, or warnings, or suggestions, for another major city that would seek to undertake something like this?

**MS:** The program people could tell you that better than I could. I don’t have any. But they’re closer to the process, so they would be the people to ask that to. I don’t have any. I just know that it took a long time in preparation, and a long time in terms of training, and having the curriculums written by people whose expertise is writing curriculums, and training by people whose expertise is training, and – so it’s not something that you can read about and jump into. And that would be my only caution. Is to be prepared for the process to take a while, and make sure you give it the time needed, or it’s doomed to fail before you even start it.

**CD:** It reminds me of – at this tiny NGO in Mali, it would be like, “who knows how to write a survey?” and I would Google writing a survey and write a survey. And, “who knows how to analyze data?” and Google analyzing data. And it’s just not the same breed of thing as the work that you do here.

**MS:** Mmmm… NO.

**CD:** No. (Laughs) not at all.

**MS:** No, we have a whole department that does surveys, and writes them, and tests them, and pilots them. And you know.

**CD:** Yeah, absolutely. Well thank you so incredibly much for making the time for me. It’s such an honor for me to be in the same room as you.

**MS:** Oh my!

**CD:** Oh my goodness, it’s like my – you know, my hero –

**MS:** It’s very nice to meet you, and to know the work that you’re doing, and to know that the next generation of public health professionals is out there already, working and getting ready. We still have a lot of challenges.
CD: Yeah. And New York is only getting bigger.

MS: New York is only getting bigger, and all of the epidemics are only getting bigger, so there’ll be plenty of work for you to do. And it is the most cost-effective work that can be done. Almost everything else addresses problems after they’ve happened. But we keep trying to get ahead of the curve.

CD: You mean the health department? Or government?

MS: The health department.

CD: Wow, what a job. I’m sure you sleep very well at night, but not for very many hours.

MS: Oh, I do! I do! It’s a pleasure meeting you.

CD: it’s such a pleasure meeting you!

MS: Good luck if you keeping working with Arthur Ashe, and wherever you find….I worked only once internationally, for a long time in South America in Bogota, Colombia. And it has continually contributed to my knowledge base, and things that I can bring to bear that I’ve learned there. Because –

CD: Yeah, I’ll take that to heart. Thank you so much! Have a wonderful night.
Interview with Nina Rothschild, 12/6/2010

Nina Rothschild: So I got the DrPH from Columbia, and then I came to the health department, and I’ve been here ever since. First I was in maternity service, and then I moved into HIV and AIDS.

So in terms of the implementation of the PACT program, one thing – because I really haven’t been directly involved with that. I gather you’ve talked with Danny, and did you speak with Fabienne as well?

Colette DeJong: No, I haven’t spoken with Fabienne.

NR: Okay, but she’s very very very busy.

CD: Yeah, it seems like it.

NR: If you have a chance to meet with her that would be great, but I don’t know if that fits into her schedule.

CD: It seems like everyone in this office has a lot of things on their plate.

NR: Yeah. One thing that came to mind as you were talking – it was very interesting to hear your experience of a bunch of kids volunteering for NGOs, and maybe not sure – this sounds great, that sounds great, but what do we know will have an impact – are you familiar with a book called The Wisdom of Whores?

CD: No!

NR: It is fantastic. I highly recommend it. It is by Elizabeth Pisani – as I say it’s called the wisdom of whores, it’s a marvelous title. Elizabeth Pisani is an epidemiologist and a journalist. And she – it focuses all on international aid, it’s not at all domestic issues. But she spent a lot of time in Africa and a lot of time in Indonesia working with HIV. And it was a while ago that I read it, but I remember she does sometimes question whether NGOs are the most effective ways to work and whether sometimes government – and you know, they usually come with all this bureaucracy, and layers and layers and layers and layers – but she does at some point question whether that is a more efficient way to do mass education, dispensation of condoms, and so on and so forth. That isn’t the focus of her book, but I think she does deal with that question. And she has this incredibly charismatic writing style – it’s like she’s chatting with you, but it’s so vibrant, and interesting, and funny – it radiates this tremendous sort of intelligence and enthusiasm, it’s not like reading a dry technical article by an epidemiologist, it reads like a novel. It really is good. So if you have time go to Borders.com.

CD: I wonder if Brown has that.

NR: Oh, they might have that in their library! Do libraries still exist? Do people actually go to libraries any more, or just sit in their dorm rooms?

CD: I have a big stack! I haven’t used them as much as I’ve used my laptop, but Brown has this really great system where if they don’t have it, they’ll find someone who does –

NR: Oh, they’ll order it from another university. Oh, that’s good. I just remember when I was in graduate school at Columbia, the actual physical space of the library was the most incredibly underutilized – like, nobody went there. This was the health sciences campus library – it would be like a morgue.

CD: How ironic!

NR: So now that it’s all electronic communication, I was wondering if students just sit in their dorm rooms.

CD: I would say that social studiers go to the library. And the books are pretty much untouched, but –

NR: I see. So they drink coffee, chat, study – gotcha.

CD: People that really work hard stay in their rooms, but I’ve always needed the opportunity to walk around with a cup of coffee and bother people that are trying to study.

NR: One needs a break occasionally. I agree.

So in terms of the implementation of the PACT program. As I say, I have not been involved in it directly at all. I’ve just heard presentations by Fabienne, and when she had Dr. Heidi Behforouz come
down from Boston and talk to the Planning Council about it…so I’ve just been on the receiving end of presentations, I haven’t been at all involved in implementation.

What I can tell you about the Planning Council response is basically as follows. But I wonder if I should precede it by – how familiar are you with the Planning Council – are you familiar with the fact that we have these service categories? I don’t want to repeat stuff, but I don’t want to leave you saying, “What?”

CD: I know very little about it. I just know that it’s mandated by the Ryan White funding to represent providers and consumers, but I really know very little about it.

NR: What you know then is on the right track – I’ll just tell you a little more as I provide some background and comments.

The Ryan White Planning Council is a group of roughly 45 mayoral appointees – they’re appointed by Mayor Bloomberg. And having a Ryan White Planning Council is a federal mandate – is part of our grant from HRSA, the Health Resources and Services Administration, which as you probably know is an arm of HHS. So, HRSA says that we have to have this Planning Council, and mayor Bloomberg as I say appoints the members; there are roughly 45.

And some of them are government appointees. So for example my boss Jan – we just poked our heads into his office – he is the governmental co-chair. And he is also a staff member here at the New York City health department. Someone from the NYC health and hospitals corporation, which handles the NYC hospitals – like Bellevue, is the most famous – she also has a seat on the Planning Council. There is someone from the department of corrections who has a seat on the Planning Council; the medical director from the department of homeless services has a seat on the Planning Council; so there are various governmental appointees. Someone from the health department’s division of mental hygiene has a seat on the Planning Council. So there are a bunch of governmental appointees. And the other appointees are members of the HIV/AIDS community. So, those are mostly either service providers are consumers – in other words, people living with HIV and AIDS. The service providers tend to be from various social service agencies; the best known is GMHC, Gay Men’s Health Crisis, but they come from a whole panoply of social service agencies in the city. In the past we’ve also had some physicians on the Planning Council, but currently I believe the only two MDs on the council are Fabienne Laraque and the medical director of the department of homeless services. There have been more in the past.

The planning council meets once per month, every month except August they’re in recess, and usually September while we’re waiting to hear from the Mayor about new appointments, we don’t usually meet in September either.

And then the Planning Council also has various committees. There’s a policy committee, and integration of care committee, and needs assessment committee, a committee called priority setting and resource allocation that’s kind of the key committee, a finance committee, an executive committee, a consumer’s committee…a lot of committees.

And just to expound a bit more on the role of the consumers, I don’t know if you’re familiar with the sort of lingo term that we refer to people living with HIV and AIDS, is “consumers.” I think the idea is that they’re not just patients, that they’re capable of participating in decision-making about their course of care. We don’t define them just by their illness. I’ve kind of heard anecdotally they actually don’t like being called consumers, but nobody has ever explained to me what they’d prefer to be called instead. So we call them consumers.

And technically by federal law, one third of the Planning Council members have to be non-aligned consumers. That is, a consumer that is not an employee of one of these social service agencies. Also, the full membership of the planning council is intended to be representative of the epidemic in the city. So we try to have people from every borough, we try to have a mix of racial and ethnic groups. We tend to get overloaded in the white heterosexual women category, because there are a lot of white heterosexual
women who are in the provider community and so on. But we try – we have them from Staten Island, we have from queens, we have from every borough, Brooklyn’s not a problem. And this I say – it’s supposed to be representative of the demographics of the epidemic in the city.

**CD:** The consumers specifically are mostly –

**NR:** Basically the entire committee. The entire Planning Council, actually. And the consumers – and I guess I should probably explain to you a little bit about how Ryan White funding works. Because there are multiple funding streams in New York City for HIV, so I should probably explain a little bit because I don’t know how much you know about the Planning Council funding.

Ok. So the federal government, I think, spends about 2 billion dollar on HIV in the New York area. The HRSA funding for Ryan White services is just one among many streams. The CDC gives money for HIV prevention; SAMSA, the substance abuse and mental health services administration, gives money of course for substance abuse and mental health services and so on; Medicaid, of course, is a huge payer of services; Medicare; the VA; private insurance; and so on. So, what is unique about Ryan White funding?

Ryan White funding from HRSA is – we are the payer of last resort. We are the payer for people who don’t have any of those other forms of coverage that I mentioned. They may have Medicare but it may not cover a specific type of service, so they may get one thing paid for by Medicare, and something else paid for by Ryan White; they may get one thing paid for by Medicaid, and something else paid for by Ryan White; they may be the working poor who have a job that does not come with health insurance, but because they are working, they make too much money to qualify for Medicaid. But every other payer has to be excluded, and then the Ryan White funding kicks in.

So our most recent grant was about $110 million dollars. And that gets allocated to what are called service categories, which is a term that I hate, because it’s just – off the cuff, it doesn’t mean anything. Like, what the hell is a service category? And it’s very dry, and bureaucratic. But this is just the language of Ryan White funding.

So when we say service categories, we mean most importantly ADAP, the aids drug assistance program. So that’s the medications, that’s what really keeps them alive. Other service categories are legal services; mental health services; harm reduction services; testing services; mental health services; housing services; food and nutrition services; basically all these services are kind of collectively referred to as treatment and care. So, it’s medical treatment and all these other forms of treatment and care for people living with HIV.

So, what exactly is the Planning Council’s role with regard to all this huge - $110 million is, I guess, compared with $2 billion isn’t that much, but it is substantial. So what is the Planning Council’s role?

Well, The Planning Council – most importantly, the priority-setting and resource allocation committee- that’s kind of where the core work takes place, and then it is validated by the executive committee and the full Planning Council. And – but those in that process, starting with – we’d call it PSRA, priority-setting and resource allocation, and moving up through the executive committee to the full Planning Council – what they do is they set priorities and they allocate resources. So they have a whole complicated tool – if you want, I can send it to you electronically – that they use to say, “we think we want X amount of funding to go to mental health services. And we want Y amount of funding to go to medication. And we want Z amount of funding to go to legal services.” But it is an evidence-based tool. So it’s not simply who on the Planning Council screams the loudest, and says, “I know that PWAs need more mental health services.” Or, “I know that PWAs need more food and nutrition services.” Or, “I know that PWAs the money has to go to mental health services.” Because that just becomes a question of who sounds really effective, who speaks the loudest, who has a really convincing delivery – that’s not a really reliable way on which to make a decision about millions and millions and millions of dollars in funding.

So, there is, as I say, a tool – I would be happy to send it to you, if you want to send me an email to remind me if you decide on your notes that it would be useful. So they use this evidence-based tool to set
priorities and to allocate resources. And one of these service categories – and it is a huge one – is case management. We refer to it both as case management and care coordination. So you probably heard – I don’t know which set of terms Danny was using, but you’ll hear it variously referred to as case management, care coordination.

CD: That’s distinct from treatment adherence?

NR: It includes treatment adherence. And that is where the New York City replication of the PACT program comes in.

So, case management – treatment adherence is a major major component of it, because as you know, it’s very easy to become resistant to the medication, and you cannot go on drug holidays, and you and I know for a given prescription of antibiotics we take the full thing, but – you know, people from the backgrounds we’re dealing with, when you get to the payer of last resort, you know, these aren’t people who necessarily know or understand – or sometimes its denial, frustration, anger, whatever, you know, “I don’t want to be tethered to my medications.” So treatment adherence – working on treatment adherence is major. That’s really key.

So the case management or care coordination service category currently has about $24 million dollars allocated to it out of our entire pool of funding. So that’s roughly a quarter of our funding. And the only thing I can really tell you in terms of the Planning Council’s reaction to and involvement with this is that there has been a lot of – what would be a diplomatic term to use – there was questioning on the part of the Planning Council about whether putting that much money, basically one quarter of our funding, into care coordination, into the New York city replication of the pact model, was really a wise decision. Because people didn’t really know, would it work here? I believe it started in Haiti with Paul Farmer…

CD: I think…my understanding is that they used their experience in Haiti to inform the Boston project.

NR: Yeah. That’s what I seem to remember hearing. And I think one major question they had was, would this translate to New York City? I mean, Boston is a much much smaller town. New York is huge. We have more than 100,000 people living with HIV. Of course not all those are Ryan White funded individuals. And I think the concern – people had a lot of worries about whether it would really translate on the ground, you know. So let’s say you have a social worker case manager going to the home of somebody living with HIV, knocking on their door, take your medication, who knows if they’re going to be let in…these people lead complicated, chaotic lives, they’ve known drugs, and alcohol, and commercial sex work…I don’t need to tell you, the AIDS afflicted population is often a rather fragile group. So I think the question was, would this really be able to translate on the ground into effective provision of services, effective coordination of care, would people really – despite the best intentions of, say, a 22-year-old case manager who really wants this to work, but – would they really be able to make that work, and does it make sense to put such a large portion of our funding into that when – you know, the economy’s in terrible shape, people are hungry; there’s often a very strong, vocal contingent that comes to Planning Council meetings to advocate for additional services – food and nutrition services, housing we know is a major issue for PWAs – if they don’t have housing they’re not going to be taking their medications, housing in New York city is probably more expensive than anywhere else in the country except san Francisco and - I don’t know what real estate prices are like in Boston, but you know, housing is a very important service for PWAs in New York city. And the council had a lot of concerns about whether the pact model could really be effectively replicated here.

The Planning Council has not yet seen any data on care coordination. I believe they have requested it. I do not staff the priority-setting and resource allocation committee, that is staffed by another colleague of mine, David. And I don’t know if they have recently asked for a presentation on the implementation of case management – I don’t believe that they have seen one. So I think that will probably be a big issue when they do the next round of priority-setting and resource allocation, and that process – the priority-
setting and resource-allocation process – really gears up intensively as we go into the spring of the summer. It’s usually heavy-duty in June and July; most other parts of the world are in recess, but that’s when that committee – and then at the end of July, first the executive committee and then the entire Planning Council has to vote on the proposed budget. So I’m sure that the PSRA committee will have long since received presentations on the case management care coordination, what effect they’ve been seeing, whether it’s working, so on and so forth. But to date, I have not seen any data, and I don’t believe the Planning Council has either, on whether or not the pact model is effectively working here.

I think it’s a great idea; you know, sometimes putting a great idea to work on the ground can be pretty complicated. And I think that when you come in and try to shake up a system, people resist. And they’re not in this case necessarily resisting because it’s the pact program, they’re resisting – if there was a resistance -- in any such situation. People get dead comfortable with what they’re doing. They’re used to what they’re doing, and to get change is often very very very challenging, because people simply don’t respond well to change. Meaning they get kind of entrenched. So I think there was just a lot of concern about – you know, we had been doing case management in the past, not in nearly as complex and detailed a model as the pact model, but you know, there had been – and you know, did it really makes sense to now sweep so much of our portfolio into case management.

CD: It had been a much smaller chunk of the budget?
NR: It was smaller. I don’t recall exactly what it was. But I mean certainly case management is, and has been a part of HIV management, and probably in other bureaus of the health department – you know, I’m sure they have it in TB as well, I haven’t worked in the TB bureau, but actually that’s what Dr. Laraque came from TB to this bureau – but I think, you know, as I said there’s often resistance and so on. You know, do we really know, what’s the evidence, that it will work. So I think the Planning Council will want to see some pretty strong data when the allocation process comes up again this spring and summer going forward.

We do – I guess as Danny probably told you, we – I assume he spoke about the technical assistance providers who work with the CBOs and the hospitals that are funded to do case management? Did he –

CD: A little. He said that in the pilot programs it was pretty much PACT directly, and after the pilots, it became – you know, no longer PACT.

NR: OK. I was only mentioning it because we have a whole bunch of technical assistance providers here. They’re all lovely young MPHs, and if you were interested in talking to one of them, I would be more than happy to arrange that. But I don’t know if that really – because they would be able to tell you a bit more about what it’s like trying to negotiate with the hospitals that are funded to do case management, or the CBOs that contract with hospitals to do case management, and if you wanted to – because I wouldn’t be able to address that at all. But if you decide you’re interested in that, I could connect you with someone.

CD: I’m meeting with one of the project officers – Jessica Auerbach –
NR: Oh yes, Jessica Auerbach! Yes, she’s a great resource. So she’ll be great. Yeah. She’s over in that general area where I am, that’ll be perfect.

CD: Different sides of the story, right.
NR: Different sites and so on. She could address that much better than I could in terms of actual on-the-ground translation, and mediating between the health department’s expectations, and the funded organizations’ expectations, and so on.

And I’m sorry, I hope I’m not throwing too much information at you, but I may not have made it exactly clear – I mentioned that all this money, this funding, goes to these different service categories. I may not have made it clear – I think I didn’t at all, actually – how that then gets translated into services on the ground. So at the risk of possibly telling you something you’ve heard about before, I’ll just tell you a little bit about that.
So as I said, roughly $24 million dollars was allocated to case management. Ok. So that means that $24 million dollars were available, but how does that actually translate into services on the ground? Well, what happens is that the health department issues what’s called a RFP – request for proposals – and all these organizations apply for funding. And the ones that turn in the best grant applications get the funding.

**CD:** And is the planning council involved in –

**NR:** So the Planning Council is actually not involved in selecting specific organizations. The planning council deals with service categories, but it does not make the decisions, “yes we’re going to fund GMHC, no we’re not going to fund GMHC, yes we’re going to fund Harlem hospital, no we’re not going to fund Harlem hospital.” That’s out of the Planning Council’s purview; they do not vote on anything related to an individual contract with an individual agency.

**CD:** Because a lot of them are actually represented –

**NR:** Right, there would be a conflict of interest. For example, Sean Cahill is – happens to be, he’s the managing director of public policy at GMHC. He has a seat on the council; GMHC applied for a care coordination contract; it would have been a conflict of interest for him to make a decision about whether or not their application was sufficiently good to be awarded money. So the planning council does not deal with any contracting issues. They just deal with categories: legal, mental health, case management, etc. The actual decision about which organizations will and won’t receive funding – there are always a whole bunch of people who review grant applications. I’m almost always one of them, because for some warped reason I happen to enjoy it. I enjoy reading grant applications. I don’t know why call me disturbed. So often, staff from the bureau of HIV will read grant applications; sometimes they try to have some consumer readers, consumers that are sort of active – not planning council consumers, but consumers that are kind of known to the health department. But all applications are read by at least, I believe, 2 people. So it’s not just, like, Nina Rothschild reads this application and decides this looks good, or this doesn’t look good. The process is pretty tightly controlled; if the two readers have very dissimilar scores, then there’ll be a meeting, and so on. So it’s done really pretty scientifically, it’s not just “oh, this sounds good,” or “oh, this doesn’t sound good.” But so that’s how the money gets translated onto the ground. So as I say, a whole slew of organizations applied for the $24 million dollars in funding. Some got it, some didn’t get it.

There was a lot of hostility initially – I wouldn’t say hostility necessarily, but some resistance, I think, within the Planning Council – to the whole idea of care coordination. Because as Fabienne was envisioning it, it was much more hospital-based and much more medically-oriented than it had been in the past. And there was a concern that this RFP was structured in such a way that basically only hospitals and possibly community health centers would be able to respond to it, because they wanted co-location of services. And when I say “they,” I mean the health department. So the health department wanted the case management services, basically, to be applied at the same place you were going for your medical care, and to see your doctor for your check-up, and the same place you were going to get your mental health services. They didn’t want to have consumers going to GMHC for their health care, and to Harlem hospital for something else over there, and a third agency – they felt, coordination. Literally. Care coordination. But there was a fair amount of resistance within the Planning Council community, because they recognized kind of collectively – they felt - those members of the Planning Council who represented community based organizations – whether it’s the Brooklyn aids task force, or GMHC, or whatever – they perceived correctly that the application was structured in a way to kind of favor hospitals and favor community health centers, and they were concerned about it being out of their turf. They were concerned that they would not be able to submit an effective application that would convince the health department to turn over the money to them.
So in response to the fair amount of protest from the Planning Council community, there were some revisions made to the RFP so that, for example, a free-standing community-based organization could link up with a hospital and propose a case management slash care coordination program.

CD: Ok. So would you say that the main voice of those CBOs is through the Planning Council, as opposed to individual CBOs-

NR: Yes. I mean many CBOs are represented on the Planning Council; and also, every Planning Council meeting includes a period for public comment. So literally any member of the public can show up. So you may be from – one CBO that happens to come to mind that is not on the Planning Council is African Services Committee. I don’t think anyone from African services committee actually came, but just as an example, someone from that CBO can come and speak during a public comment period, and say, “I believe that you’re structuring the grant application in such a way that it’s going to make it impossible for my agency to apply, even though we have had a good track record in the past of providing case management and services,” and so on. Because all Planning Council meetings are open to the public. You want to come down from brown university to the next one, you’re more than welcome. We’re having an executive committee meeting on Thursday, I don’t think you want to take Amtrak or bus back down on Thursday, but…(Laughs)

CD: I wonder if you could tell me more about the groups that are represented on the Planning Council, and why certain people would be on the council. Like, what they’re looking for, and how they’re appointed.

NR: Yeah. That’s a good question. So as I say, the government members basically have a standing – they don’t’ change, unless they happen to leave the governmental agency that they represent. But you know, as I say, the medical director for the department of homeless services has been on the council for as long as I’ve been staffing it, which has been like, 4 years. So those are kind of stable, continuing positions.

The planning council members, who – aside from the governmental representatives, who gets to be on the Planning Council? Basically, anyone can fill out an application. And you are asked on the application of course to disclose your affiliation, what you do, submit a biographical statement, and so on and so forth. You are asked – but it is completely voluntary – you are asked to disclose whether or not you are HIV-infected. That’s of course in part towards fulfilling the 33% consumer representation. But some people may choose not to disclose, and we have no way of knowing. They may just want to keep that private.

CD: And could someone be representing a hospital or representing a CBO, but meeting the HIV-positive requirement?

NR: Yeah. You could, for example – we have a very, happens to be a very charismatic, young to me but old to you, community co-chair. He was just elected at the last planning council meeting. His name is Matt LeSire. The Planning Council, by the way, I should preface this by saying, has two co-chairs. There’s a governmental co-chair – that’s my boss, Jan Park, who openly has been living with HIV for thirty years, almost. He was one of the first one hundred men diagnosed in New York City. He’s the governmental co-chair.

The community co-chair was just elected at our last meeting in November; he’s named Matt LeSire. He happens to be a PWA who’s also – obviously open about it, that’s why I mentioned it – but neither position has to be held by a PWA. It’s just kind of coincidental that Jan happens to be a long-term non-progressor, and Matt is – I think – I don’t know when he was infected but – it just happens that – in other words, you don’t have to be infected to have a leadership position on the council, that’s just coincidence.

So, matt actually works for two different community-based organizations. He works for one in New York City called Village Care of New York, and another one that is based in Washington called NAPWA, National Association of Persons with AIDS. And I believe his title at village care is director of public
policy. So he happens, as I say, also to be a consumer; but he is an aligned consumer. Most of the consumers are what we call non-aligned; they are not associated with a particular organization. He happens to be associated with an organization that does get funding from us.

**CD:** So the 33% quota, that’s all un-aligned?

**NR:** Exactly. Those are all un-aligned. And basically, as I say, anybody can apply. So – yeah, you could apply! I’m serious. And we typically have representatives from a whole number of social services agencies – like god’s love we deliver, and we don’t currently have anyone from project hospitality but we have in the past, and – a whole slew.

**CD:** And hospitals as well?

**NR:** The New York City health and hospitals corporation has a permanent seat on the Planning Council – as I say, that’s the organization that oversees all the public hospitals, the most famous of which is Bellevue. That person happens not to attend very regularly. She’s a good person, but I guess she’s just too busy, she’s overcommitted. She doesn’t show up that regularly. But basically, anybody can apply – and you submit your biographical statement, you fill out this form indicating whether or not, if you choose to disclose, you are PWA, and what racial and ethnic group you belong to, and so on and so forth. And then a committee of the Planning Council called Rules and Membership evaluates all the applications. And then they select more promising candidates, who then come for interviews. So they are interviewed I believe first by the rules and membership committee members; they go through then an interview generally with our bureau’s assistant commissioner, Dr. Monica Sweeney; then the nominations go to the commissioner for the department of health and mental hygiene, Dr. Tom Farley; and then they are forwarded to the mayor’s office. I think the department of investigation probably does a background check on them, just to make sure we’re not appointing anyone who is, you know, cheating on their income taxes for the last ten years or something like that.

**CD:** So is there no real voice of hospitals and medical providers on the committee? It’s just the one HHC person?

**NR:** So lemme think, that’s a good question. Terri Hamilton is the HHC representative, but her attendance is sporadic. Do we currently have anyone else from a hospital? You know, if you want to accompany me back to my desk, I can look through the list of Planning Council members. Yes, I think Nina Pinon is a Planning Council member, and she works at Montefurie Medical Center. She is a nurse practitioner. Montefurie is a major academic medical center in the Bronx. They’re a big one.

**CD:** So they’re a research –

**NR:** Yeah, they are a research – I don’t think she does research, I think she’s purely a clinical provider. But she has a seat on the Planning Council, and she’s also a co-chair on one of the committees. In the past, we had the director of infectious diseases, who was a physician at Bronx Lebanon hospital center. And he was a very very active, very engaged Planning Council member. So he fulfilled - you can serve for a maximum of two two-year consecutive terms and then you cycle off; he was fantastic. I don’t know how he did it, but he was like chair of the finance committee, he never missed any meetings of anything – he was superb. So he was a representative of a hospital, and as I say, happened to be an infectious diseases specialist.

Do we currently have – there is – so, Minnie Pinon is from Montefurie – I don’t think we have anyone currently from Bronx Lebanon, that the physician I just mentioned was in the past. But when I go back to my desk we can go through the list of Planning Council members.

**CD:** So is it pretty much dominated by these community providers?

**NR:** It is. Yes. There are a lot of community-based organization representatives. Oh wait, there is – Nancy Katali, she is also co-chair of a committee, and I think she’s at North Central Bronx hospital. She’s a social worker by training. So there are hospital staff members on it, but it is primarily – and – no, what am I saying? As I’m talking, other people are coming to mind. There is a very nice fellow, his name is
Damien Bird, and he works at Downstate Medical Center, which is in Brooklyn. And they have a big, big AIDS program there.

**CD**: So are these for the most part big hospitals that need the money? Not very wealthy hospitals?

**NR**: You know, the questions you’re getting at basically – I think the what you’re getting at is the question of the conflict of interest thing? Or –

**CD**: Yeah – not – not in terms of like, conflict of interest on individual obligations. Just like, whose voices are most heard, or –

**NR**: Are most dominant and key. And fundamentally, is it part of a “I need the money so let me join the Planning Council so my organization –“ not I need the money, but “my organization needs the money so let me join the Planning Council so I can make sure that the interests of my institution would be adequately represented.”

**CD**: Yeah, I mean – I know so little about it. Would you say that that’s a good description?

**NR**: You know, that’s – it’s a good question that you ask. And some people would say that the Planning Council overall, the way that the entire thing is structured, is potentially conflict-of-interest-ridden for exactly that reason. Because an organization –let’s say its Downstate Medical Center, serves a very very very poor population in Brooklyn. It’s a large HIV population, and they have this very nice young fellow who is on the Planning Council and happens to co-chair one of the committees. So one could say, “well yes, the Planning Council does not vote on individual contractual issues, they vote on service categories,” but yes, he could potentially, you know, when they vote on a budget, vote for a budget that happens to mean that his organization would be – you know, let’s say his organization provides case management services, so if he votes on a budget that allocates $24 million dollars to case management, then his organization would be in a very nice position to apply for it. And maybe he would be less interested in voting for a budget that allocates less money to services which his institution can provide, and more money to services which his institution does not provide.

So some would say that yes, the Planning Council is inherently a conflict-ridden process. Because, you know, people volunteer to join, there is no compensation…but yes, one could say that, you know, you might well be motivated to join because you see potential benefits for your organization down the line.

The thing is that there is no real other way to do this kind of work. If we made sure to absolutely exclude any organization that receives Ryan White funding from participating in the Planning Council process, there would be like – nobody we could appoint to the Planning Council. Because we have contracts with like, I think somewhere around 200 or – 100 and something? 200? - over 200 contracts at least, I’m not sure how many organizations, because some organizations have more than one contract. But if we wanted to exclude anyone from an agency –whether it’s a hospital, CBO, whatever – if we wanted to exclude anyone who has a contract with us from participating in the planning council, as I say, there’d be no way – there’d be nobody left to serve on the Planning Council. And we might get someone, but who knows how interested, knowledgeable, committed to HIV they would be.

**CD**: Who are the non-aligned consumers? Do they participate a lot in the –

**NR**: Where do they come from and so on. There are actually – we fund something called the Leadership Training Institute. And that has, up till now, its primary role has been preparing consumers to serve on the Planning Council. Because some of the Planning Council’s work is fairly technical. And the consumers that we serve – because they are typically people whose services are funded by Ryan White, these are not the gay white men who are highly educated and employed. They tend to be poor members of minority groups, that’s for educational, and also selling it.

So, how do they get to be knowledgeable enough to serve on the Planning Council? Well, many of them take this series of courses called “the Leadership Training Institute,” which is offered through an
organization called Chiccatelli, which is located up on – I don’t know how well you know New York, it’s located up on 35th street and 8th avenue. Lovely, very nice place.

CD: So they’re paid by this office?
NR: Yeah. I think they’re paid both by us and by the state, by New York State. Their role is going to expanded – we’re actually going to require all council members to go through some trainings, not just consumers. But traditionally up till now, the leadership training institute, or LTI’s role has been preparing consumers to participate in the Planning Council, because you know, they’re not familiar with things like spreadsheets. You know? And the priority-setting process – as I mentioned I can send you this tool – but you look at it, it is not intuitive. I mean, it took me a while to figure out what this whole thing – the service categories, the – and you know, we do the strategizing in advance, what if we get a 2% cut to our award, what if we get a 2% increase to award, how are we going to allocate that among all the different service categories…it’s pretty complex. As I say, even if you have a college degree, it’s not very intuitive. So the leadership training institute does a very good job preparing consumers. It’s run by a guy who is himself a PWA, and he’s a really good guy.

CD: Do you know how patients are recruited to the leadership training?
NR: You know, I don’t really know how they outreach to the community. I think it’s partly word of mouth –

CD: Because it’s only fifteen people that you need to –
NR: Yeah. And the Planning Council calendar is – well, you know our website, NY HIV.org. So the Planning Council is posted on that, and the leadership training institute trainings are included in the calendar. But you would somehow have to heard of the existence of the Planning Council before you would presumably go to the website, and… so it might be a service provider at a hospital or an agency who might say, “oh, you know, I think you might want to;” might just be word of mouth, you know, you know someone in your support group, and she’s on the Planning Council, and say, “huh, that sounds interesting.”

Some of the consumers provide a more real role than others. Some are very vigorous and active and engaged; there are some who, you know, they don’t tend to be primarily a highly educated group; they are very, as I say, vibrant, active participants in the process; come and they sit there, and they raise their hand for a vote, but whether they are really fully understanding all of what’s going on, I don’t know, because the spreadsheets, the budget stuff, is pretty complicated. It’s pretty technical, it’s pretty dry. So just to provide a footnote, when I mentioned before that Matt Leseure who is community-co-chair is openly a consumer, he is among the sort of elite. I mean he is highly educated, he is employed, he has insurance. So he is one of the aligned consumers. He is not typical – the typical consumer tends to be, as I say, from various disenfranchised groups and so on. Some of them – they tend to be lovely people. Um – one is, she’s a sweetheart, she’s a mother of, gosh, I think four – I didn’t actually know what her route of infection as, whether it was heterosexual transmission, she might have shot drugs at some point in the past, I don’t know – but she’s got four kids, she’s done very well with them, her twin daughters are in college. She’s got a really bad stutter, but nevertheless she comes, and she speaks, and she takes a leadership role.

We do have two specific groups that work with consumers, or that provide a voice for consumers, although we’re possibly going to collapse them into one. There is a consumer’s committee, and there is a PWA Advisory Group.

CD: Which is outside of the council?
NR: Which is outside. But can provide sort of advice to the council.

The consumer’s committee is a very – a pretty functional group. One of my colleagues, he’s out of the office today but his name is Darryl, he staffs the consumers’ committee. And all of the consumers who are on the Planning Council are de facto members of that committee. The PWA advisory group is
open to any consumer in New York City who would like to show up for a meeting. And it’s pretty dysfunctional. They sit around, (laughs) I’m sorry that my colleague who staffs that is – he’s in Puerto Rico because of family illness, his brother’s – but he could tell you some stories. They sit around, they hold endless elections, you know, for steering committee members, because everyone wants, you know, a title. And they want to be able to set the agenda. So the advisory group is a pretty dysfunctional group. They try to arrange presentations for them, but it’s often a lot of people sitting around screaming and yelling about, you know, they want – they want attention. And they feel the health department doesn’t listen to their voice. And so on and so forth. It’s a pretty dysfunctional group.

So there’s talk about, I think – I think what we would like to do is basically collapse the consumer’s committee and the advisory group into one group, because –

CD: And still have it be open door?

NR: Still have it be open…I don’t know exactly how they would work all the details out. But the feeling is that some of the people come to the advisory group- in the past it was always held on weekends – so I think the feeling is that the reason a lot of people came, you know, is because they came for the meal and the metro card. That’s the only form of acknowledgement, or compensation – we cannot pay stipends. They used to want stipends, we cannot pay stipends. All we can do is provide a meal and a metro card. So, meals are provided at all Planning Council meetings, at all committee meetings, and metro cards are provided but only to consumers. But we think that a lot of the advisory council members would just show up on Saturday for the meal and the metro card, and they just – they wanted to have a place to go, and they weren’t really providing any effective input into the Planning Council process. So if a lot of those people were to decide to join the consumers’ committee, I don’t know – maybe they would just try to get rid of the AG altogether without expanding the consumers’ committee – I don’t know exactly what the thinking is on that topic. But I think the feeling is, the AG is just too dysfunctional at this point to be continued. And apparently, other eligible metropolitan areas, other jurisdictions do not have two separate bodies for consumers.

CD: They just have the –

NR: They just have one, they just have the consumers’ committee. So the feeling is this has become sort of an unnecessary appendage that is not really serving any useful function at this point.

CD: OK, thank you. That’s fascinating. I just realized I lost track of time, I’m supposed to see someone at one, but – so just to make sure, so would you say that the Planning Council for the most part is represented by these community organizations, as kind of the more dominant group –

NR: Yes.

CD: And then the government positions on the Planning Council, do they – kind of have specific things that they want to see out of the Planning Council, or it’s more like they’re in a facilitating role?

NR: Um…they tend to be relatively quiet at meetings. But some of them do show up very regularly – the medical director of homeless services, as I said, she always comes or she sends her deputy –

CD: And you mentioned that the Planning Council was concerned about – to bring money to housing, that that’s such a big issue. Was she a big representative of that need?

NR: That is a need that tends to be voiced very strongly primarily by consumers, actually. They tend to be very, very vigorous on that. But the governmental members – some of them are very good and come very very very regularly. Some, like as I say, like the woman from the health and hospitals corporation, very sporadic. The department of corrections – sometimes she sends a representative, the woman who is herself the appointee never comes. It does tend to be the community-based organization members and the consumers who are most actively engaged in the process.

And we do also actually –we have in the past gotten rid of people who really have not shown up on a sustained basis. There were a whole bunch of doctors that were discharged – we discharged the doctors not last year, but the previous year, because their attendance was lousy. And they were occupying a seat
that could be taken by somebody who would actually come to meetings. And you know, we understand that they have other things to do, and coming down is an imposition. But you know, it made no sense.

So, I’ll let you go. I’ll send you the priority-setting tool – I can email that to you so you’ll have that. And I can also send you a list of members of the Planning Council, but I would just request that you hold onto it. I don’t know who you might – but, just to keep it private. But just so you can see – their organizational affiliations are all listed, so you’d be able to see which is community-based organization, which are hospitals, and so on and so forth. The consumers generally have no affiliations, so you can often tell.

CD: Ok. But it’s not an open –
NR: you know, we did use to provide all the information openly, but we had a kind of crazy consumer –w ho would show up periodically, and he like, tracked me down where I live – and I wasn’t home thank god, but my kids – he’s got issues. And he would like, call Planning Council members, and talk to them, and try to give them presents – it was all very strange. So I’d be happy to send you a list of members of the Planning Council, but I would just ask – not that at Brown University in Rhode Island you’re going to – but, I would just say, keep the information. So I’ll be happy to send you those two things, and feel free to call or email if anything else comes up, and so – I guess I’ll let you be on your way!

CD: Great! Yeah, I’m just meeting with Stephanie over in the –
NR: Oh, Stephanie! She’s great, too. She’s lovely. So I’ll walk you over to her desk.
CD: I can’t thank you enough!
Colette DeJong: so, thanks again. My name is Colette DeJong, and I’m a student at Brown, and I’m writing my thesis about this work – about the process of taking PACT to New York and reinventing it at this amazingly larger scale. Kind of what motivated my finding this topic was – at Brown, there are kind of all these 20-year-old kids – we love to start NGOs, or do unpaid internships in Tanzania, or we’re running a small school – just kind of, ridiculous things that just left me feeling very confused about what NGOs can do to address these kinds of issues. And really made me interested in kind of how can this type of work move into the government – which already does so much of it, but specifically, NGO models when they’re translated to a government scale, to a government language, just seem like they can be - just have such a greater impact, and probably be also translated and changed in a lot of ways. And so I’m writing kind of – not so much very specifically about the details of the PACT model, as how you found the process of translating it; who’s been involved, and kind of how you found the journey. So yeah, I’d love to hear your experience of the model, and of kind of, just how difficult it’s been to change it to the New York setting.

Beau Mitts: Well just I guess, a little bit about my interaction or history with care coordination. Is, I’m fairly new to the department; well, I guess I can’t say that any more, I’ve been here a year. So I literally started maybe a week or two before the care coordination contract started, on December 1st. they started December 1st of 09. So that’s when care coordination began, as far as contracts were concerned; obviously the planning, and the RFP, and all of that, working with the community to get these contracts in place, happened prior to that. So I wasn’t here for any of the, I guess, protocol development, and kind of looking at other models, and putting it all together. I know it was not just the PACT model; they also looked at the way that medical case management was done in Chicago. So there were elements of care coordination that came from the Chicago model. But the large, like, health promotion pieces, and the navigation pieces, really came from PACT in Boston. Or, from Haiti as well.

So I think our main role here, like my staff that you’ve talked to today and myself, is to provide technical assistance to – right now we have 28 agencies that we fund, it’s about – nearly $26 million dollars that is going into this intervention here in New York City. So it’s the largest portfolio of any Ryan White service category here in New York City. So it’s a lot of effort that’s going into trying to ensure that programs are able to implement it appropriately; we’re in the middle of a process of evaluation right now to see how it’s being implemented on the ground, what are areas that we really need to focus on for technical assistance, and just what things might need to be tweaked or changed a little bit. So, I don’t know – did any of the other staff kind of tell you about that process, and what’s happening with that right now? The evaluation?

CD: Yeah, they mentioned the chart review - so yeah, I’m curious where you find the balance between rigidity, in terms of replicating the model to the letter as much as possible, versus adapting it in either kind of – broadly to New York, or to each of the 28 different sites.

BM: So – yeah. I mean, I know it’s something that we were very interested in, and I think as a health department you really want to try to standardize a program whenever you implement it. So the protocol was created; PACT didn’t at the time, to my knowledge, didn’t have necessarily a kind of a protocol for how their program – I mean, they obviously had the materials already developed, because that’s what we’re using, the health promotion materials. But as far as like, the protocol, I don’t believe they had…they didn’t have, and I think working with them, we’ve been working closely with them and they
actually have been providing us technical assistance and will continue to do so moving forward. But they themselves have created an operations manual after looking at what we developed, to kind of protocolize the intervention.

But I think that it’s good to have that standardization, especially if you want to have any kind of quality control across 28 different agencies. You really want to have a program where if someone’s at one agency and changes mid-stream, and goes to another agency, they can get – we can be relatively sure that they’re getting the same quality of care at agency X as they would at agency Y. so that being said, I think that contractors get really nervous because of the protocol, and we certainly understand – this is a first year, a huge system change, and a huge system. But we’re willing to kind of work with, and learn from, the contractors what’s working, what’s not working. That’s really what we’re trying to do with this process evaluation. So I think that we are going to learn a couple of things; we’re going to learn things that might work better if we really are able to get out there, provide some technical assistance, and make sure everybody knows what resources are available and how things should be working. But I also think we’re going to learn about things that might not be working the best way, and might need a change. So I think – and we’re definitely open to that, but I feel like contractors sometimes get caught up in – especially when they’re working with the health department – like, the black and white of a contract or of a protocol, and there’s really a lot of gray area in there that – that’s where we need to be working and providing the technical assistance and making sure that everybody is comfortable with how they’re implementing the program.

CD: Are there any big areas that you think have been changed from how it is in Boston, to make it relevant to New York? Or, in this first iteration, it’s pretty similar?

BM: no, I think there are a lot of differences. And I probably am not the best person to speak to all the differences, because I’m less familiar with PACT. But I think one big difference is, PACT – we have like an extra layer of staff in our model. So the PACT model, from what I understand, has the community health worker, the health promoter; which is kind of equivalent to our patient navigator. And then they have a program director. And they don’t have – we have a middle step, which is called the care coordinator. That middle level step, which supervises the navigators, is really responsible for – kind of the case management aspects of care coordination.

CD: So they work with the patient directly as well?

BM: So, they also do. They’re responsible for doing the initial and take-in assessment, and developing a care plan. And then the navigators kind of take it and run with it. Do all the fieldwork, the home visits, the navigation, the health promotion in the field. But ultimately it’s the care coordinator that’s responsible for ensuring that that client meets their goals, and reaches their goals, and develops new goals, and moves forward through the process.

CD: And is that related to the Medicaid vs. Ryan White funding?

BM: No, that’s a totally different issue. (Laughs)

CD: So it wasn’t split in order to have the care coordinator under Medicaid and the navigator under Ryan White?
**BM:** No, not at all. The care coordination model is solely a Ryan White model. Medicaid has another model of medical case management, and it’s called Cobra case management. So – I mean, they’re really two separate programs. Cobra and Care Coordination. And at some of our agencies – and this is one of the areas we’re still really working through all of the details and specifics on how to make it work well, especially at agencies that have both funding streams. Because there are a few of our agencies that also have cobra programs, and so, figuring out how they best work together. Because truly when you interpret, the Ryan White should be the payer of last resort. So if there’s another funding source out there that could provide the services, you should be using that other funding source. So Medicaid is the Cobra medical case management program; so if someone is eligible for Medicaid, they should be receiving their medical case management from Cobra if the agency has both programs. But there are aspects, also, of care coordination that Cobra does not cover. So, the health promotion and the directly observed therapy are pieces that Cobra does not do. So then you have the potential to have someone who’s dually enrolled in both cobra and care coordination, and receiving – like, their accompaniment, their treatment adherence, navigations stuff, from Cobra, but then care coordination is providing those – health promotion and those directly observed therapy components of our model. And that’s very – it sounds like, very clear cut, but it’s not clear cut at all. And we’re still working – cobra is – Medicaid is all done through the AIDS Institute, which is the state health department. So we are working closely with the AIDS Institute to try to develop a joint technical guidance, or like a TA guidance, for both of our contractors on how to work together. So we’ve been working on that for a while, and we’re still working on that.

**CD:** Are you trying to change a little bit how the Cobra program operates to make it mirror the PACT program more? Or that’s really kind of a separate thing?

**BM:** I mean, that’s not – really what we’re trying to do at all. I think that we may see, like, also depending on the kind of evidence that comes out of care coordination, if we see the impact that it has on outcomes with individual clients, and – you may be able to see kind of a shift in how cobra and care coordination work together, and how they provide their services. But we are so brand new at this, that’s going to be a while down the road. Where we can really compare and look at the two programs, and see how they’re – what their efficacy is.

**CD:** OK. So would it be hospitals or CBOs that are getting the Medicaid Cobra funding and the Ryan White funding?

**BM:** It could be either. And there are cobra programs at both, and there are card coordination programs at both. I can give you the list of contractors if you want, and it breaks out which ones are hospital and which ones are community-based. And it’s not quite 50-50, but it’s close.

**CD:** OK. So when I was talking with Dr. Weglein, he mentioned that in the new contract, you were hoping to adjust the requirements of funding structure. In terms of, he mentioned that at this point, it wasn’t very standardized –kind of, whether people were going into the Ryan White program or into the Medicaid program. Am I understanding that right?

**BM:** What we’re looking to do – we are shifting our reimbursement structure. So for year one, we had an entirely deliverables-based reimbursement. Which means that it still wasn’t cost-based, which is kind of the old way of contracting, you just reimburse that contractor for what their costs are.

**CD:** After the fact.
BM: Exactly. So – we did a deliverables-based contract for year one, which means, like, you met a certain deliverable, and we would pay you a certain amount of money. So we had – I mean, I think there were 20 to 30 deliverables that contractors have to meet, which ranged from submitting a quality management plan, to attending required trainings, to a certain enrollment deliverable – once you met 25% of your desired, or required, enrollment, you’d get so much money; 50%, you’d get so much money; 75%, you’d get so much money. So that was the model for year one. And we’re in the process of – we always knew we were going to move to a more – not necessarily fee-for-service, but close to that – model. So our structure we’re looking at now, it’s called a per-member-per-month. So we’re looking to reimburse contractors based on how many clients they have enrolled in a given month, and then also, what intensity level of a program they’re enrolled into. So, there’s five different tracks that a client can be enrolled into; and that’s A, B, C1, C2, and D. D is DOT, it’s the most intense, so it’ll be reimbursed at the highest rate; A is for individuals who are not on antiretroviral therapy, and it’s a quarterly kind of a track. So it’s the lowest-intensity track. So depending on – looking at number of clients and which tracks they’re enrolled, they’ll get kind of a baseline reimbursement rate each month. And then – so the three-tier system. So that’s kind of the first tier of reimbursement. The second tier is going to be DOT; so any DOT activity is going to be reimbursed on a strictly straight fee-for-service basis. So if you do a DOT visit, you’ll get this much money. Basically. And then the third piece is based on milestones, and moving – so, it’s to encourage programs to appropriately assess and move their clients through the program. This is not meant to be – it was not designed to be, kind of, a long term case management program. It’s meant to hopefully help people gain some self-sufficiency, learn how to navigate the system themselves, and make it to a point where then they take it and, they take their own health care in their own hands and kind of run with it. So that’s how it’s designed, and we obviously know that not everybody’s ever going to be to a point of self-sufficiency, but we anticipate that a lot of people will be able to do that. And looking at the length of time that that’s going to take, that’s another thing that we don’t really know right now. We can look at the PACT program and kind of know, roughly maybe a year or so, year and a half, most people can move through the program; but there are going to be people that kind of hang out with us for several years, you know.

CD: Yeah. And so, what’s motivating the shift from staggered lump sum to much more fee-for-service? Is it to kind of set up incentive systems for the providers?

BM: It’s really to be more performance-based in our reimbursement, to ensure that we’re getting what we pay for, basically. To ensure that providers are actually, kind of, serving as many clients in the most appropriate way as possible and tying reimbursement to that way that we feel the model should be implemented. It kind of ensures that that happens.

CD: OK. And did you decide to do that after seeing what was happening in the early implementation? Or it’s just that –

BM: No no no, not at all. And in fact – from the very beginning, even in the RFP, the plan was to deliverables-based the first year and then move to performance basis for payment in year two. It’s just, we weren’t really sure what the performance reimbursement was going to look like. And so it’s taken us a while to really develop that, and to learn from contractors what might work and what might not work. Should we do a straight fee for service; but there’s so many moving parts to this; like, to try to pay for each service that’s provided is also too many payment points. So…but we always knew from the beginning we wanted the first year to be deliverables-based, because we knew it would take at least a year
for programs to really get staffed up, and ramped up, and learn the protocol, get trained, and really be able
to kind of fully function at full capacity. And we’re seeing now, even, it’s taking a little bit longer.
Because I think we’re not going to have that many programs that reach 100% of enrollment by the first
year, like we had anticipated.

CD: OK, got it. And when both programs are going on in the same agency, how is it decided if
someone is going to Medicaid or to the Ryan White case management?

BM: That is really – right now it’s an agency decision. So I don’t know exactly. I think each agency
may be treating those programs differently. I know that some of our agencies – where it works the best,
like, when the same program director is over both programs. So like, for example, at one of our hospitals,
the program director for care coordination is also the program director for the cobra program. So that
works wonderfully, because you have the same person in charge and can make sure that clients are
assigned appropriately to the right programs, and if there’s dual enrollment then it’s really clear, and
everyone participates in the case conferences that they should…but there are other programs that we have
that, like, the cobra programs and the care coordination programs are really siloed, and not necessarily
even talking to each other. So that’s kind of one of the things we’re hoping to work with agencies on, as
we move to this new fee structure. The per-member-per-month. Because it’s really going to encourage
agencies to leverage their cobra resources that they have, if they have a cobra program on site. So if we
help to be there and help them kind of work through those issues if they’re having problems dually
enrolling people, that there’s science to kind of help work through that. Because they really are required
to, considering the Ryan White payer of last resort. If you have those cobra resources, and you have
someone who’s eligible for them, they really should be receiving those.

CD: OK, got it. So, that’s interesting. When I first hear fee-per-service, it makes me think –
encourages more service. Whereas lump sum, if you have fewer patients – if you always send people to
the Medicaid program, you have less costs for the same grant money. But you’re saying that that’s kind of
the goal of using Ryan White for – or, I guess, is the goal to like, have more and more patients on –like,
partially funded by Ryan White?

BM: Well, it’s to be able to leverage your resources to confer more clients. So if you have another
resource, for example, cobra, that can fund these services that are provided by care coordination, than
yeah, you should make sure that they’re getting those services from cobra. The navigation,
accompaniment, treatment adherence. All those kind of – and just your general entitlement kind of case
management stuff. So if you have both of those programs on site, and you can leverage that cobra
resource, and then if the person needs DOT, or needs the health promotion, then care coordination can
provide those couple of services. And so then the care coordination program can serve more clients,
because those other pieces – they’re able to serve another person.

CD: OK, that makes sense. And with the per-service, they’re motivated to draw as many people as
need that extra service.

BM: Right. So, that’s kind of our expectation. If you have clients that are dually enrolled, we expect
you to serve more people. So for example, our highest contract award was to serve 200 clients. So we
have several agencies that are funded at the highest award to serve 200 clients. Yet, in negotiations in the
beginning, if we looked at and we saw that you had a cobra resource, and that you would be dually
enrolling clients, then your total clients that you should be serving – that number would increase. So it
could have been increased to 230 or 250 based on the amount of cobra resources that you had. So we expect you to serve more clients over here with the same amount of money, because you're leveraging some of your services over here with the Medicaid-funded service.

**CD:** OK. And would you say that most agencies have both funding streams?

**BM:** No, I think it's a - it's not a majority at all. It's definitely the minority of agencies that have both services.

**CD:** OK. Because a lot of agencies that already have those services wouldn't necessarily apply –

**BM:** They may not apply. I guess that's probably the main reason.

**CD:** OK. And so looking between the different models of agencies that you have so that there're - my understanding is that there're CBOs who apply on their own, but with an MOU with a hospital, and are trying to work with that; and that hospitals that apply on their own; and then more kind of partnership applications. Is it working out better for one of those models?

**BM:** I - I mean, I feel like - just operationally, wholly contained programs have a lot less barriers.

**CD:** That's the hospital that applied –

**BM:** So, it could be a hospital; it could also be - we have community health centers that applied – and you know, they have a clinic, they are the medical provider, they… it's a one-stop shop. So the one-stop shops, whether it be hospital-based or community-based, have a lot fewer barriers to implementation than if you were a community-based program partnering with a medical provider that you don’t really have - essentially, you don’t have control over, or say-so about. And yes, they have an MOU in between the two of them, and we have programs that go both ways; we have some that are hospital providers sub-contracting with community-based organizations, and we have community-based organizations that have MOUs with medical providers…

**CD:** Right. And so, the medical providers would pay its sub-contracted case managers, but not vice versa? Like, case managers who have an MOU with a medical provider don’t –

**BM:** right. There’s no, like – for a medical partner, there’s not any kind of financial incentive necessarily. It’s just a service that’s been offered to your clients. So we’re offering this medical case management program; we’ll go out and find your people, bring them back into you, make sure they come to their appointments, make sure they have all the health education promotion that they need. So it’s really kind of this service that you’re selling to the medical provider. And the one piece that could sort of be a financial, I guess, incentive, would be if – depending on how large and how many clients you’re estimated to provide into the case management program, we may station a medical center liaison over here with you; or give you some money to hire a medical center liaison that’s, like, one of your staff, that then serves as a liaison between you and then the case management program. So that would be the only kind of financial, I guess, funding going from the community-based medical case manager program to a medical provider. Some people have set it up like that, some have not; but the other kind of aspect we have is, like, for example, a hospital that applied for the program and said they were going to subcontract with a community-based organization to provide some of the medical case management services. So we
have two of those I can think of off the top of my head – two hospitals that have contracted with the same community-based organization. So essentially, at those two hospitals, they have two care coordination teams – that are like, a care coordinator and like, 4-5 navigators that are the hospital staff, and one care coordination team which is the care coordinator and 4-5 navigators that are the community-based organization staff. But essentially they operate all under the umbrella of the hospital. So they have the same – well, in the ideal situation, they would have the same level of access, and really just get treated like a hospital employee. But yet, they’re really employed by this community-based organization that is working with the hospital.

**CD:** OK. And you said that there is just a purely hospital team as well, so it’s like they sub-contracted half the work;

**BM:** some of them, yeah. Some of them did it like that, some of them I’ve seen it – there’s like, a whole bunch of different models. As far as staffing models go.

**CD:** Why would they not do, like, all of one or all the other? Why would they want to do half and half as opposed to – you know, make completely their own program, or contract it all out –

**BM:** I think that the answer to that question is going to be different for each agency. But for a lot of the large hospitals, I know they have such a problem hiring staff. And I mean, we still are not fully staffed at a lot of our hospital-based programs, just because the administration and hiring freezes and all that kind of stuff – right now, especially, with the economy – big institutions don’t like to hire a whole bunch of new staff. So that’s part of it. You know. It’s easier for a community-based organization to move quicker and hire quicker. But – yeah. So, each individual agency is going to have a reason for why they set it out the way they did, and I don’t know all the reasons. But another way that I’ve seen it is, like, all the care coordinators, for example, are hospital employees, but then the patient navigators are community based organization employees, that report to these care coordinators that are at the hospital. So that’s another model that I’ve seen.

**CD:** OK. And how has it been working with the hospital administrators and supervisors over there? Do you think – I mean, I’m sure there are a range, but are people buying into the total model change? Or is there a lot of kind of, trying to keep what they have but make it match the deliverables?

**BM:** I would say there’s more buy-in to the change than the other. I think that we definitely have one or two where, you know, they have in their mind, have -- their program has worked for the last ten years, and they’re trying to make our model fit into the way they do business and they way they have always done business. And so that’s a struggle. That’s where we have to provide a lot of TA to make sure that they’re going in the right direction. But I would say for the most part, people are really excited and bought in – I mean, it’s a system-wide change, you’re part of this huge effort across the entire city. And I think once – especially administrators, kind of really realize how large the effort is, that they’re really part of this big movement, that they get on board.

**CD:** and so, would you say that the uniquely Ryan White, very new chunks are the DOT, the workbook, and the home visits?

**BM:** yeah. I think those are all really – DOT definitely, especially DOT for HIV, is really kind of – I don’t know a lot of other – in fact, I don’t know any other jurisdictions, like jurisdiction-wide, that they
have taken on DOT to try to provide to people living with HIV. Health promotion is definitely – it’s not new, but the way that it’s packaged for this, and the amount of health promotion and really having some structure to it, is I think, new for us. The treatment adherence, and the extent of the treatment adherence, and really helping people ensure that they take their medications through home visits, through accompaniment, through – you know, pillbox count, and the DOT is another part of that, I think it’s new.

But there’s another piece that we haven’t really talked about at all, which is the return-to-care piece – which I think involves a lot of field work. And the whole field aspect of this program is new for – at least for all of our hospital-based programs. Community-based organizations have probably been doing some field work, but not necessarily tied to case management. So I think that that – well, I take that back. I mean, case management involves field work. But they’re really kind of going out trying to find people, and get them to come back into care, and doing weekly home visits – it’s pretty intense. And a bit new for a lot of people.

**CD:** Yes. Has one group been slightly easier to work with, between the CBOs and the hospitals? Or is there like, a big institutional difference in negotiating with one versus the other?

**BM:** I haven’t seen a huge difference between the two, personally.

**CD:** Right. And so, the CBOs that apply pretty much on their own and have an MOU, do they have seats in the hospital?

**BM:** Most of them have suite space. The hospitals, or the medical providers, set up space for them to have office hours. And that’s working better in some places than others, but that really was a requirement of the RFP. The RFP, we kind of laid out what an MOU should look like, and what kind of arrangement should be made, and so that was set forth from the beginning.

**CD:** OK. And do you feel like you have the resources that you need to provide this TA and kind of, address the challenges that come up? Or do you wish that – also, are you happy with the level of involvement of PACT? Or do you wish you had more, or less –

**BM:** I think that moving forward in 2011, we’re going to have more, which I think is great. We’ve seen areas where we needed some more support from PACT; PACT really wasn’t so involved. They were involved in the beginning, before the contracts started, and then kind of we didn’t really have much involvement with them. Just kind of ad hoc as we needed something ehre or there. But again, for next year, we’ve seen that we really need more, mainly around the health promotion. All the curriculum, the health promotion materials, making sure that people really are trained appropriately, understand how they should be having these conversations about health promotion with the client – I just – I feel like people are not as prepared as they should be, or could be, and maybe just kind of sitting there reading through the book with the client. And that’s not how that should be happening. So I think for PACT in particular, I think we’re on the right direction to have some more involvement and more support from them.

**CD:** OK. And do you like the model overall? Do you think it’s something that’s going to have all the seams ironed out?

**BM:** I think – I do like the model. I think that it’s going to be a little while before we have everything ironed out. I would say a good 2 or 3 years before we really have – and know, have the data to support, have the changes and tweaks made that we know we need to make, and then are really in a place where
we are just kind of at a steady state moving forward. It’s going to take a little time. It’s still very…brand new. (Laughs)

CD: Yeah. Are people treating this as a long-term undertaking? Or it’s more like a, “let’s try this out for two years and see?”

BM: I think people are pretty committed to having this be a long-term…I think that in everybody’s mind, anyway, it’s, this is kind of the direction we’re moving. And less, it’s a horrible flop and the data shows nothing works. I think some form or fashion of this model will continue on for a long time.

CD: Great. And kind of finally, what’s the hardest part of your job? I’m sure there are many.

BM: Trying to make sure everybody gets all the information that they need in a timely manner. Because there are so many players. We’re such a large jurisdiction; we have to deal with Public Health Solutions for all of our – they’re our master contractor. So the health department has a master contractor, which is Public Health Solutions. So they’re the ones that actually let our RFPs and let our contracts. So if one of our agencies has a contract, it’s with Public Health Solutions, it’s not with the city of New York. So essentially, they manage all the fiscal aspects of our contracts. And we’re brand new too. Like, this whole kind of technical assistance even, unit, is brand new. It’s been two years at the most. And Fabienne has been really trying to build up the technical assistance, and the presence of the health department with our contractors. That’s kind of a new thing. Like historically, Public Health Solutions has been everything to our contractors. Like, we have a contract with Public Health Solutions, and they were the contract programmatic aspect of everything. And so – we’re really kind of trying – and contractors really didn’t even understand that funding was department of health funding, because we just weren’t that involved. So it’s a change. And just making sure - that whole change is a difficult process to manage. But Public Health Solutions is one of our contractors; we also have a contract with the AIDS Institute, which is the state department, to do a lot of our quality management with our contractors. So for our contractors, sometimes it’s confusing for them too, because they get communications from the state health department, form the city health department, from Public Health Solutions. And they have contact people. So there’s a project officer who’s assigned to a bunch of the agencies here from the health department; Public Health Solutions have a contract manager assigned to each agency; and then the AIDS institute has a point person assigned for each service category as well. So it’s just – always making sure that everybody knows all the pieces of information that they need to know. That’s probably the most challenging part.

CD: Yeah. Wow. That sounds really challenging. Are there any specific suggestions, or cautions, that you’d have for another city that’s trying to do this?... Or just, “good luck?”

BM: I don’t know…Yeah, good luck. Let’s talk about specifics whenever they want to do that, then we can talk about specifics. But certainly I know that we were definitely willing to talk to other people, and kind of help people work through their own hurdles that they identified, which may or may not be the same as ours. One of our big hurdles, which I was not here for, was gathering the buy-in from the community. And I think that – like I said, I wasn’t here, I think that it was a rocky start. And so, that’s definitely something that’s critical for anybody thinking about doing this. Being sure that you educate the community appropriately, and make sure you gather that buy-in before you really try to make a big step. That goes with any systems change. So, working with our planning council – did they explain to you – I mean, do you know about Ryan White and how – the whole planning council?
CD: Yeah, I spoke with Nina a little bit earlier.

BM: Oh, ok!

CD: And so – Dr. Weglein was – he kind of started this process, and then was replaced by Dr. Laraque at some point?

BM: No, I think they worked on it together. Like, I think Danny, Dr. Weglein, and Dr. Laraque were here together, and I think they really worked together to develop the model. And then Danny, or Dr. Weglein, he was here, and then he went away for a little while. I know for about a year he was gone on sabbatical. And so, now he’s back and that – that was challenging, I think. Not for me necessarily, because I wasn’t here, but I think for people – everybody involved, just kind of translating – because, when you have that lack of continuity with a big systems change, it’s challenging.

CD: Yeah. Were you working with an interim person for a while after Danny left?

BM: No, there was not an interim person for that particular position.

CD: OK. It was just not present then?

BM: Right. But I mean, he was one of the architects of the New York formation, along with Dr. Laraque.

CD: OK. And they all continue to be involved?

BM: Yeah.

CD: Do you think everyone’s pretty much on the same page? Or you have very different –

BM: Oh, no. you can ask – not that people have different opinions, it’s not necessarily opinion-based. Sometimes it can be. But it’s more just about being consistent with our messages. And that’s a challenge to do.

CD: To like, different sites, you mean?

BM: Yeah, to different sites…to everybody, in just kind of – in all different ways. And that’s something that we definitely work on improving all the time.

CD: Well, thank you so much! Is there anything else that we haven’t covered, that maybe you wanted to add?

BM: No, I guess I would just say on that last point, is that one of the things that we did start recently – a couple of months ago – is just to have a team meeting once a week with, like, everybody involved. So my team, me, my supervisor, and Dr. Laraque all meet once a week to kind of – touching base on the care coordination, and how things are working, what’s working, what’s not working, what kind of questions are agencies having so we can be consistent with our messaging.
CD: Well, thank you so incredibly much! This is so helpful, and so interesting.
Interview with Stephanie Boarden and Jessica Auerbach, 12/6/2010

Colette DeJong: So just to introduce myself, my name is Colette DeJong and I’m a senior at Brown, and I’m writing my honor’s thesis about this story, about your work: just the process of replicating something really small and unusual like PACT at such a massive scale. And kind of what motivated me as I was first developing the thesis, was that at brown and in my major specifically, which is Development Studies, there are tons of 20-year-old white kids from Illinois like me, who are either starting NGOs, or doing unpaid internships in Tanzania, and doing all this development work that is kind of made up. And I’ve done some of it. And it just made me very confused about what the role of these NGOs is, and that brought me to look at the practice of how NGO practices get replicated in the government. Because that just seems like a very powerful way for them to have a real, professional and responsible contribution. And I think that your work is so unparalleled in terms of a tiny NGO, a very interesting and unique model, being taken to such a vast scale. And I’d love to hear – and also, I’m not writing specifically about the model so much as about how you’ve had to translate it, and who has been involved in bringing it, and how the hospitals have reacted – kind of more the process of translation than the model itself. So yeah, that’s kind of my topic. I was hoping we could start by you just telling me a little bit more about what has been involved in starting these new programs.

Stephanie Boarden: You were here before me!

Jessica Auerbach: I’m not sure if you’re going to talk to the other project officers, or just us, but one thing I wanted you to know is that the two of us tend to work more with community-based organizations that are the leads for this contract, or small hospitals, and the other two project officers work more with large hospitals or the public hospitals. You work with one of them –

SB: I have a few – I have one public hospital, and one private hospital, which are pretty big.

CD: And were either of you involved with the pilot programs?

SB: No, that project officer is Jenna. So if you get a chance to talk to her, she would be a good perspective to have. She worked with the TAP and at MIT, and the care and the treatment adherence program, that were pilots too. My understanding is that they contained components of this larger care coordination model, so there’s some experience there with, kind of like, what treatment adherence would be like in a New York hospital setting. And the challenges there. But then, this is the –

JA: This is like combining what used to be five separate service categories into one. And the pilots were like one service category implementing one piece of it. Or two, I guess – TAP is kind of health education and treatment adherence.
CD: OK, got it. So in terms of your sites, are you usually working with a CBO and a hospital that have applied in partnership? Or you’re working specifically with a CBO?

SB: So the lead agents for the CBOs – I guess when we say CBO and hospital, that defines who the lead agency is. So, the CBOs that are lead agencies typically don’t provide health care services. So they have to partner with an external health care provider. Some of those providers are private providers, and sometimes they are able to partner with hospitals or community health clinics. Community hospitals. So in many ways, the lead agency was supposed to define how the program operates at that specific agency, and how processes are put into place, and that can vary depending on whether or not your lead is a hospital or your lead is a community based organization, because I guess as you can imagine, one of the things we’ve seen is that – it’s easier to get things done and to have a streamlined process when your program, when the care coordination program, is co-located with the health care services. With the service provider. So I think some of the CBOs really find it challenging to – have found it challenging just to kind of get the program going, and build trust, and – and just figure out what their processes are for communication, because oftentimes they’re not physically located with their providers.

JA: Yeah. And a few other factors, I think, that influence the relationship – one, if there’s a history between the two agencies, or however many agencies – if they have a history of working together. If they already know each other and have already developed certain systems for communication or meeting or whatever. And I think it’s harder when they’re new to each other.

Another factor is the configuration related to money. I think when the CBO has all the money, and the hospital has none of the money, it’s a challenge because the CBO is totally reliant upon the hospital in order to do their work, and the hospital doesn’t necessarily have the same level of incentive or ownership to make it work the way that it would, or the way that it does work when they do have a different kind of an investment in it. So I think that’s one of the challenges that’s happening right now.

CD: So it’s been more successful when the hospital and CBO are both pretty involved in the money, and in receiving the money?

SB: Well, technically – I guess technically, who they have on file, or who their memorandum of understanding is with, is who they apply with. So there were conversations had, and they have an MOU, so those needed to be in place in order for contracts to be assigned and funds to be reimbursed. But even then, I think there is this time period where – I mean, that’s just kind of on paper, “this is our arrangement.” But then, once you’ve actually started implementing, there’s still I think this process this time or where the CBO has to build trust with the providers that they’ve partnered with. And I think Jessica brought up a really good point, which is the history. If there’s a history of the two working together, it makes it a lot easier, because they already have a relationship, they know each other. But if there isn’t a history, then there’s, I think, a power dynamic. Hospitals generally have a lot more money, and a lot more power, and CBOs don’t. and I think that’s a dynamic that hospitals aren’t used to – I don’t think they’re used to having to look to a CBO to lead the process, tell them how it’s going to be. If the CBOs lead, they’re the
ones hiring the staff, they’re paying the staff, they’re providing the supervision. But like Jessica said, because they don’t have providers, since this program is built on a medical home, and it’s about communicating with providers and ensuring that the program is supporting the medical care, you’re very much reliant on the hospital, because that’s where the providers are. The hospital controls the provider schedule, the hospital is who you have to go to to get buy-in from the providers, and so it makes – I think it makes it tricky.

CD: yeah. And, so, do the CBOs need – what do they need from the providers in order to be considered successful? Do they have, like, quotas of meeting with the providers?

JA: I think access to the medical information is one thing. Like, access to the patients’ medical records, and ability to easily move through the medical space. Another factor is getting appropriate referrals in the way that the referrals are supposed to be done, according to the protocol. And then the third thing is conducting regular case conferences, which are like, quarterly meetings where all of the people working with the patient are present, and have a discussion with each other. I would say those are the three main things.

CD: Ok. And what do you think of the PACT model?

SB: I – I mean, I really like it. I think it’s great. And it is in a number of ways different than the model that we’ve employed here, because like you said, this is an adaptation of PACT, which is an adaptation of PIH’s model in Haiti. So it’s gone through several – I wouldn’t say iterations, but adaptations, based on setting and context.

And I like PACT. I think the one thing I really do like about PACT – well, there are a few things – is just the amount of time that they invest up front in their staff, and in their health promoters. The attention they pay to kind of training them, and – and really ensuring that every single one of them – this is as an outsider, and my understanding – that every single one of them really understands the mission of program, really understands their role in the program. And so that is kind of consistently reinforced. And I think by giving them adequate training, they prepare their staff to go into the field, and kind of do their job and be focused and do it well. And I think that that is – that it’s probably easier to do that when you’re one program. Whereas this is 28 programs, serving 28 different communities –

JA: With different models – I mean, in terms of staff, in terms of agency models.

SB: Right. So you’re trying to deal with different policies, different communities, different personalities – and you know, it just complicates things. Scaling up is always difficult, because the model is one thing, but then implementation is now kind of opened up to so many more external factors that you have to really try and deal with and navigate.

JA: And I think PACT, being one agency, or one – you know, on a small scale, and being sort of all internal, seems like they did a really good job of being receptive to what was happening, and what works and what doesn’t work, and sort of adapt according to that. And I
think part of the challenge here is that a lot of what the agencies are implementing is totally external. And they don’t have – they don’t get to impact the way it looks, they don’t – it’s much more about following the rules than how it looks, I think, that PACT approaches it, because it’s their own program. And this is like the government giving them a very prescriptive model and telling them exactly how they have to do it. So I think it has a very different feeling.

SB: And to that, I think – PACT didn’t start off with a protocol. Whereas we have a very detailed – some areas are very detailed, other areas are a little more open. But we have a protocol that, you know, kind of spells out steps for follow-up and we have a number of forms that need to be filled out to capture pieces of information, because we are the government, and this program is funded through federal monies, and we do have an obligation to report back on outcomes so that we can continue to receive funding and fund these programs. So I think – I guess to try and tie it with the development piece that you were speaking of earlier, I think that is what in essence – to me, I think it is one of the major things that changes when a model goes from something that’s initiated by a CBO, and becomes institutionalized. Because as a government institution, we kind of have to play by different rules. So I think it in ways has taken away some of the flexibility of – well, I don’t know. That may be a function of our leadership, and I mean, I think we could be fluid if we wanted to. But I think – the department of health, and you know, I think there is a culture of, kind of, evidence-based models. Which I think is good, but I feel like we have less flexibility than PACT does. To just take feedback in real time and make a change. Because to do that across 28 programs, would – it’s difficult. And we always say this: we get feedback from multiple people, and we always hear this; you know, ok, so we got feedback from 3 out of 28, what worked for one program doesn’t necessarily work for the other programs. So just that process of feedback, and incorporating it into the model, and revising it, is more complex because we have more voices.

JA: And it’s like, um - if you let one person make an exception, they all know about it.

SB: Because they’re communicating.

JA: They all know each other. So they know anything we say to any of them. So we have to be really aware of that, and it in some ways, I think that’s great, because I think they should be in communication with each other. And in some ways, I think there should be more allowance for flexibility between the programs. But there’s both our own reasons that we don’t want that, and then the programs themselves, feel like there’s double messages or inconsistencies or that kind of thing.

Oh, and the other thing I wanted to say – kind of going back to what you were asking about earlier, is I think, everybody’s like, at least initially, the majority of people being introduced to care coordination and PACT are like, “well, New York is different. We don’t care if it works somewhere else, we don’t care about Boston, we don’t care about it working in Haiti, this is New York City and nowhere else is like New York City.” And like, that’s the first attitude, I think, that people bring to it.
CD: Regardless of whether they’re in the hospitals or the CBOs?

SB: Yes. It’s all about like, “this is New York City, and you have to prove that it works here.” And that proof – like, you’re not going to convince me that it’ll work here just because it worked in some other, you know, urban city or populated – you know, with similar populations.”

JA: And I think it’s true – I think there’s a lot of truth to that, New York is really different than anywhere else. You know? Not that I think it couldn’t work, but I think that there are really big differences. Like transportation, or like the size of the population, or like, all kinds of things.

CD: So how does that attitude influence, kind of, the work that gets done?

SB: I think it adds to people’s desire to personalize the program. Because they come with this attitude that this is New York, you’re kind of imposing this model, it’s based on a model that worked somewhere else…and so I think that they obviously, I think, try it out, but I think that people are always looking – and I think it’s natural – to always you know, when you see something that’s not working, you want to change it so it does work.

JA: Right. I also think people are skeptical. And stressed out.

CD: On the phone with you 24-7…

JA: Yeah. And I mean, there’s a lot of things about it that they don’t think works or is gonna work. And they are the guinea pigs, basically. This is the first year. And we don’t have it totally together for them.

SB: Mm-hmm.

JA: And I think it’s really stressful for them. Especially because, like we were saying before, there are so many requirements of them. I do think they genuinely want to do what we’re asking them to do, but I don’t think they totally get what that is. Or how to do that. Because it’s so complicated, and so new. And on such a large scale.

SB: And I think we could do a better job of being transparent. Just in our rationale for certain decisions that are made, and changes that are made – yeah, I think that would help. That would go a long way too, because instead of – yeah. I think people could then react to, kind of, the logic behind the decision, as opposed to the decision itself. Because I think it’s – it’s easier once you understand why someone did something that they did, to kind of work with that. With the help – you know. They have a lot of knowledge, and if they understood where we were, where our heads were, they could probably help us figure out the right – well, not the right way, but you know, their way. Their perspective.
**JA:** But wait – what are you doing with this? And are you going to quote us? Just so we know.

**CD:** Um – it’s totally up to you. It’s just a senior thesis, so probably the readership will be minimal…

**SB:** You never know though! But is it going to be confidential, or anonymous –

**JA:** Because if it’s shared, I mean even if it’s shared with the department, people will figure it out. So you might just say “project officers” instead of our names.

**CD:** OK. Absolutely. Yeah. And also, I’m sure that if I ended up sharing it with the department, it might be a different –

**JA:** Different version?

**CD:** Mine is, like, a sociology thesis, and I don’t think that the department would be interested in a lot of it…

**SB:** You never know.

**CD:** But yeah, I’ll make sure your names are not in this.

**SB:** Thank you. So I was just – originally you asked, kind of, what were hospitals’ reaction. And I wasn’t here, but I think it seems to be pretty well known that originally this was released and it was only for hospitals, and there was an – you know, understandably, CBOs were not the CBO community, the CBO community were not happy about that. So I guess the RFP was like, taken back, and then re-released, and was opened up to CBOs.

**JA:** But not necessarily adapted enough to make it actually work –

**SB:** Exactly. Work for CBOs. So they re-released it, but their implementation – it’s very apparent to me that some of the processes actually have to be adapted for CBOs. Because certain – I mean – it makes sense when you’re co-located, all of this stuff. It’s fairly easy, there’s not a lot of red tape. But when you’re not, and there’s two different institutions, things like sharing information for clients becomes very difficult. Because you have to get a HIPA form signed.

**JA:** Or telling someone that’s not – like a doctor, that’s not at your agency, who’s your superior in a certain kind of hierarchy, but that you have no authority over, telling them they have to meet with you on a regular basis –

**SB:** Do something –
**JA:** Like, that’s an impossible dynamic.

**CD:** Right. So there’s an MOU between the organizations, but they’re not in the same location, so they’re trying to meet these requirements for talking, but the hospital isn’t really –

**SB:** And many times, I think the folks who were involved in putting together the MOU and even applying for the grant are not the same people who are running the program. And so there’s some disconnect between, kind of, what is written in the scope of services and what the expectations are for certain things, and what the program director is like, “this is not feasible.” But had they been involved in the process, it may have looked at it different because you’ve got administrators in some instances kind of applying and writing these things, and then you’ve got actual folks who are closer to implementation, they’re the ones asked to carry it out.

**JA:** And they can have totally different perspectives. On what they want, how to get it done, whether it’s feasible – all of those things.

**CD:** So where have you found the balance – you mentioned that there have been adaptations, like it’s not the PACT model exactly. So where have those adaptations been, and how have you decided where to find the balance between what stays really rigid about the model, and what can be changed?

**JA:** Well, the adaptations are like, our overall model, the PACT model is like a part of it. So it’s less like each agency has an adaptation, but more like what we’ve done – like, we’ve included case management. That’s the main difference.

**SB:** And DOT.

**JA:** The case management, and then all of those forms in the database.

**SB:** Having a protocol.

**JA:** Yeah, the protocol. The really prescriptive part. I think we also have maybe adapted the tracks and the timeline a little bit, because I think PACT has the induction period and the intensity of levels a little bit differently than we do.

**CD:** And the DOT, you have more of that than PACT does?

**SB:** They allow 5-7 days. Like, you can have true DOT where you’re observed 7 days a week. And I guess there’s room for it, but to be honest, no one’s doing it more than five days a week. It’s, you know, Monday through Friday.

**CD:** Here in New York.
SB: Yeah. And we’re seeing you take only one of your doses. They could, but they’re not. Because, I mean, a lot of people just aren’t creating the shifts like – coverage like that.

JA: I think it’s also an issue because DOT is such a small percentage, and every agency has DOT. I think that – for agencies that – if there was like, one DOT person who worked on the weekends for like, a borough, I think it would be more feasible. But the amount of DOT that each agency has is not enough to have a full staff, I think, for the weekend. Unless it was like one DOT person for more agencies, or something.

SB: Yeah. And they’re not really, like, even straddling shifts. So maybe someone works Sunday through Thursday. They’re not doing that. And I mean, that’s fine. But it’s just one of the differences between our model and theirs. But I think a lot of – what Jessica said, a lot of the more prescriptive pieces of the protocol – the forms, the required data reporting – those are pieces that aren’t in PACT. They have like one form, but it’s like, you know, to help you keep track of what you did that day with the client.

JA: It’s in the workbook.

SB: Yeah. So they have a form, but it’s minimal.

CD: How involved has PACT been? And do you wish they had been more involved, or less involved?

JA: Well, they were really involved with the pilot. So you should talk to Jenna about that, because I think she worked with them a lot. She worked with Jessica a lot. For the last year, or something like that, it seems that their contract has been in flux. So there hasn’t been as much involvement, I think, as what everybody would like. But it seems like that just got resolved. So it seems like, moving into the second year, like they will be a lot more involved. And they will be – well, we just had last week the first direct training with Jessica from PACT and the patient navigators, here, so we had like 3 different trainings that she did last week. And it seems like moving forward, she’s going to be doing a lot more training. And my impression of the reason that wasn’t the case last year was just, like, they couldn’t work it out. (Laughs) basically.

SB: Yeah. I think it would have been great had they been more involved. Just because – from my interactions with Jessica, she has a ton to offer. And I think her perspective is really welcomed and valued. And she is to this program what we are to our agencies, you know. She’s providing technical assistance to us as a program. And so I think having – hearing about her experiences is really helpful. Hearing about what they did, and what they were able to do to build, kind of, capacity.

CD: So, how are you evaluating success of these programs? Or is that a piece that hasn’t really been started yet, the evaluation?
SB: Interesting question. (Laughs) so I guess ultimately, we’re collecting outcomes information. All of those forms that we have and collect, are full of information about not only CD4 and viral load and like, biological markers, but also substance use, behavior and hospitalizations,

JA: Sexual behavior, adherence, all kinds of things. And we’re developing a new database that is called e-share, that is not ready. So it was supposed to be ready a long time ago, but it is still in the works. So that’s going to be the main way that they report the data to us. And then we’ll use all – it’s like, a lot of data that we’ll use for outcomes. And right now we’re using AIRS, which is the state aids reporting system. And it does not have the majority of the detail and data that we want on our forms. It’s very – it’s like, much more basic. So for this year, we don’t have that level of detail. But we –

SB: We have it in paper form.

JA: We did just complete the first part of a process evaluation, which you probably have heard a little bit about.

CD: I think a little bit.

JA: So we just almost completed chart reviews – going through all of the forms at each of our agencies. But we’re not using that to evaluate the outcomes, we’re doing that more for like, the implementation of the program across time. And there’s gonna be – this week I guess – focus groups, and then census surveys, to all the staff.

SB: So we’re trying to evaluate the implementation phase, and also at some point, outcomes. And I guess it’s also one of the pluses – is that the evaluation is automatically built in. the outcome evaluation piece. Because we have reporting requirements, and – I mean, I don’t know. I like to think that as a government entity, you have obligation to your community to show them results and be accountable for the money that you’re spending. I think the planning council probably helps out keeping us in check. Because – I mean, you spoke with Nina, but they essentially have the power to kind of dictate where money is allocated. Where Ryan white dollars are spent. And from what I hear, it was a big sell to get them to allocate, you know, over $20 million dollars to this medical case management, care coordination program.

CD: So in the absence of PACT being really involved this past year, is it pretty much the 4 project officers and Daniel Weglein that – I mean, are you getting support from anyone? Or you guys are, ilke -

SB: We have a program manager above us who is dedicated to our – like, care coordination. And he oversees the four of us. I guess –

JA: There are a lot of people involved though.
SB: Yeah, like NDRI –

JA: Yeah, NDRI does training. Research and evaluation, like were not the only ones, but they took the lead with developing the forms and the database. The director of health care services, the unit we’re under…

SB: She is the one who developed –

JA: No no –

SB: Oh.

JA: (Laughs) I was like, “she?”

SB: He – now it’s a he – was Segai not here?

JA: Segai was only here for like 3 months. She was not a part of the development at all.

SB: Ok.

CD: And do you tend to be pretty much of one mind, like especially in terms of the project officers? Or is – do people do kind of different things with their – or feel differently about the model?

SB: Well, I would say people probably have different feelings about the model. But that is very different from, kind of, your job and your responsibility to your agency. I think the bottom line is that we all have to try really hard and be conscious about standardizing our messages. We have to send the same message to all of our agencies. Because – I mean, not because they talk, but they talk. And so it’s very clear when there are inconsistent messages being sent. And we don’t want to confuse them, and – there is one model.

CD: I should let you go – can I ask one really quick last question?

SB: You have four minutes, yeah!

CD: (Laughs) wow! You guys are really giving me every second. What warnings would you have for other cities that are thinking about taking an NGO model and replicating it in hospitals and health centers, like this? Or concerns for this model?

SB: I mean – in general, I’m a fan of a participatory process. I think that speaking to your community stakeholders – folks who are actively doing similar work, working with the populations that you want to reach – is really important.
JA: My thoughts about it overall, are that the majority of the issues are coming from us, not from PACT. You know. It’s not like the PACT model – it’s the way we’re handling the implementation.

SB: It’s the way we’ve adapted it.

CD: The DOH or the CBOs?

SB: The DOH.

JA: So that’s – that’s like, not –

SB: It’s not them.

JA: I think that there’s other ways that it could be implemented, that could be approached differently than we are. So I wouldn’t say personally that it’s, like, PACT.

CD: Ok. So kind of, rewriting the model more?

JA: But I think – well, I guess what I think is like, that it’s important if you’re adapting it to be flexible.

SB: Yeah.

JA: And to adapt it based on your population, your community, your agency’s structure. And to like –

SB: Make room for change.

JA: Exactly.

SB: Because I think that’s probably why PACT is where it is now – is because they were open to change. And we, I think, need to be more open to change. Based on this feedback that we’re getting from our agencies.

CD: Would you worry about it losing the core, like, umph of whatever it is that makes PACT good?

JA: I don’t feel like – I mean, I guess it depends on how you’re doing it, but if you’re staying true to the basic principles then I think you can – I mean, if you’re staying true to what’s at the heart of it, then I think there are ways to adapt it, and keep that same goal, and keep the like, same – you know. But I think it has to fit the community that it’s serving.
**SB:** The goals are the same. I think the way you would change those goals –

[JA leaves for a meeting]

**SB:** I think it’s - just like she said, I think it’s almost the goals stay the same. I think it’s being mindful of how you adapt. And how you get there can be slightly different, but if the end goal is met, it shouldn’t matter.

**CD:** And so, would you say that the principle of PACT that you’re trying to convey is the – like, you mentioned how you really admire how they make sure that the health promoters are on board?

**SB:** Yeah. And I think that…we need to do a bit more training of our patient navigators and our care navigators. So in this coming year, we’re going to be doing more of that. So you know, I think we’re learning. And we’re using that. It’s something that maybe we should have done earlier. I mean, you definitely should have trained people comprehensively early on. But to recognize that that is a thing that you didn’t do, and be willing to take a step back and say, “ok, now we recognize where we maybe made a mistake, and we’re going to correct that moving forward, and address that moving forward,” I think there are some things to be said for that. And so as far as training is concerned, we’re doing that. And it’s become apparent that, you know – this is something that we feel really strongly about, and you have to prepare people adequately. So if you really feel strongly about the health education and the treatment adherence, and the accompaniment as a department, I think it’s a part of our role to prepare people to do that. Our role in a big way in supporting them is through training. I think that, going back to what you said, what are the key tenets and do we feel that adapting it would in any way take away from those – I don’t think so. Because I think that the issues people have are less with the goals, and more with the processes that we have outlined for reaching those goals. So I think just a little bit of wiggle room to get to those goals.

**CD:** Yeah, make sense. Great!
Interview with Kevin Dugan, Project Officer, 12/6/2010

Colette DeJong: So I’m a senior at brown, and writing a thesis about your work here in terms of replicating the PACT project. And kind of what inspired it is — in my major at brown, and in my experience, there’s just a lot of 20-year-old white kids going all over the world, kind of doing development work — my major is development studies — but really knowing nothing about what we’re doing, and just having the money to kind of make things happen. And so I was really interested about kind of what these types of projects can look like on a much larger, much more professional, and kind of responsible, scale. And so I’m looking at the use of NGO models at a government scale, and of course, that leads straight to the work that you’re doing here. I think it’s really unparalleled. And I’m writing not so much about the specific PACT model, as the process of translation. And kind of, how it has to be changed in order to meet New York requirements. And kind of, how people feel about the model, how people are reacting to it, and whether you think it’s a good thing — whether you think it’s helpful.

KD: Whether I think what’s a good thing? The reactions?

CD: The reactions, the model, and kind of where you found the balance between flexibility, in terms of everyone weighing in on how to change it, and rigidity, with the idea that there’s some sort of best practice that can’t be changed or the good of it will be lost. So I was hoping to just here — kind of what your experience has been.

KD: My thoughts on all those things. (Laughs) sure.

CD: Yeah. Your experience with your project sites, and your feelings about the model.

KD: So, where to start. That’s a lot. Um… I think that there’s certainly been — like, the DOH has certainly undertaken a lot by trying to expand, you know, like you said, a small NGO model that’s really a partnership between two organizations, that is sub-directed, and trying to expand it to another city which — I mean, I’m from Boston. Boston and New York are very similar. They’re very different, but they’re very similar. That’s part of the feedback we’ve gotten — I’ll touch on that in a second. But trying to be, kind of, the central holder of information to 28 different agencies that — the only power connection there is the grantor grantee relationship. So we can tell them what to do, but we can’t necessarily tell them how to do every piece of it, because they have their own institutional protocols that they have to follow. So, trying to make our model fit into what already exists at their agencies, I think, has been — you know, there’s been a learning curve. As to be expected with the implementation of any project, really, never mind the scale of it. But I think we’ve found that some places where we wanted to be flexible we have to be a little more rigid, and some places where wanted to be really rigid we found out that, you know what, it’s just not feasible to remain so forceful on certain issues. Just because — just legitimately it may not work. Because of, you know, we go to site A and say “you have to do this process our way,” they say, “well we’d love to, but we’re not allowed to do that here. We have to do things differently in our hospital. We have different protocols, so we can’t do it that way.” And just trying to balance all that out. So, take that times 28. Because there are a lot of similarities, but a lot of people have slightly different processes, certain people have to be on certain — different people’s signatures are needed at different institutions, so sometimes it’s really easy to push things through, sometimes it’s very difficult…things that we think would be very easy are not. Like hiring, for example. We give you money, you should be able to hire people. Right? Well some people – some institutions don’t operate as fluidly as we would hope.
can’t deliver services until they have the people, but they can’t have the people until we give them—something. A document. Or, you know, provide them with X amount of dollars over what the staff salary would be, so that way you have that coverage between… so it’s not – there’s been a lot of institutional learning for the DOH, and then just kind of of the – I think we’ve learned a little bit more about the structure of the organizations that we’re working with. More through this process than we have with past, or other, grants, current or past. Because we’ve had delved so much into their internal processes. We haven’t integrated ourselves so finely into people’s day-to-day with other grants. This is kind of like a first. This is our first grant that has a protocol, where people have to follow certain guidelines that we put out.

I’m not sure how familiar you are with how grants operate, but it’s basically, “we want you to do, you know, this, and if you do that, we’ll give you this amount of money.” And then how you figure out how to do it is kind of up to you; you kind of drive the ship. It’s like, “this is your deal, but we’re going to provide you with the money as long as you do X, Y, and Z, then everyone’s happy.” But we’re not structured that way with this grant. It’s much more, “well, you have to do X, but you have to do a b c and d in this order, on these forms that we’ve created, in order to get paid for that process.” So it’s much more regimented. Usually it’s a little more open-ended; agencies can be much more independent. And really steer themselves in a way that their individual leadership wants to go. So their own culture can be maintained. You don’t really know where the money came from, usually, it’s just, you have the money to deliver services. Now it’s pretty clear that the money comes from somewhere, and that somewhere wants you to do things their way. So there’s been definitely a lot of pushback. Not as much as you might think about some areas of the program; way more than we would have anticipated with other areas of the program. And it’s been, I think – one strength of our program is that there’s been a lot of bidirectional communication. Which is not, from what I’ve been told, because I’ve only been at DOH for about a year and a half, it’s not the typical way of operating. And allowing feedback from the grantees to help shape the program moving forward. We don’t take everything they say, but we listen to everything say.

**CD:** Ok. So the DOH kind of stepped into this project design role, but also opened itself up to a lot more feedback from the grantees?

**KD:** Yeah. Well – we always accept feedback. But in terms of allowing feedback to shape the program. And not – from what I’ve been told by my agencies, that’s not a process they’re used to. Not that it doesn’t happen, but that’s just the feedback I’ve been receiving, which is kind of what my role is as a project officer. To act as the liaison between funded agencies and the department, and try to make it a nice happy little family where we all get along and agree on the same ideal way of doing this. Doubtful we’ll ever get there, in terms of being a happy little family.

**CD:** So, how much would you say the model is being changed between the different sites, and what are the things that really were changed, would you say?

**KD:** If I were to say how much I think it’s being changed, that would really just be conjecture. It wouldn’t really be based on anything. So I’m just going to avoid that.

**CD:** Because you’re not entirely sure what’s happening at these seven sites, or you’re not entirely sure what’s happening in Boston?

**KD:** I think a little bit of both, is fair to say. And I think the only way to know that is either to observe it or be a part of it – the day to day. And as much as I have a feeling what my agencies are doing and a feeling what PACT does, I don’t think it would be fair to either or any involved party to say how
much I think it’s being changed. Just because I don’t really know. But I think each agency is adapting the program where it’s applicable to adapt, to fit the culture of their own environment. And I think some of them are definitely playing to the strengths of their employees, the ones that they’ve hired to do this work. For example, you know, the structure of the staff. The staffing structure at each agency varies a little bit. Sometimes it’s pairing experience with the inexperienced; sometimes pairing people by language; you know, by common language, having a Spanish-speaking team, having a French Creole-speaking team, things like that. And I think people are starting to — I think people are getting a little bit more comfortable. I think it was very intimidating to find out, like, “oh hey, we got 1.2 million dollars,” or “we did this,” or “we did that,” and then find out, “OK, we have to do all these things.” And it’s just like, you know, we hand them a stack of papers that’s two inches thick, and say, “read this, memorize it, and then you’re going to have to do all this paperwork as well.” Which, again – different from what people are used to, and it’s not easy, by any chance. I mean, we haven’t made this a simple program. It really can’t be, based on the model, based on the research and evidence we have that were fed into the design and development of this. I think it caused a lot of anxiety, and a lot of – different kinds of emotions were coming out. Backlash; some people were recoiling, didn’t want to deal with it, just kind of hoped it would go away, or would go unnoticed that they weren’t interested in doing paperwork; but I think now, that people are kind of – they’ve staffed a little bit, they’ve received some payments for various deliverables, and I think now they’re kind of – across the board, I feel like people are more calm now than they were last year at this time when things were just starting. So getting more comfortable, and seeing a bigger picture, and saying “OK, you know what, we have to do these required things, but there’s also some wiggle room. And we can mold this; we can make this our program, not just DOH’s program.” So, we’re seeing a little more ownership being taken over the program, as opposed to blindly following orders. Not that everyone was. But – I think you can sense – even seeing when you’re going to the agencies doing chart reviews, seeing – you know, we have 14 or 16 different forms for them to fill out at different times during the program, which is a lot, and everyone’s complained about how much paperwork there is, but some agencies still went above and beyond to create their own forms that would help ease their internal work flow. So we’re definitely seeing some of that. So things are getting easier with each passing day.

**CD:** And would you say that every organization that’s participating, all of the 28, they have to be fully bought-in to the new model? Or is it possible for some of them – are some of them trying to make what they had fit the new –

**KD:** Yeah, I think we’re seeing both. And that can be – for a number of reasons. Some people really buy into it, they think it’s a great model, and they’re 100% on board.

**CD:** Hospitals and CBOs?

**KD:** Hospitals and CBOs. And I’m not sure if it is a clean break one way or the other. I think it’s a good mix of people who are kind of like the early adapters – whether it’s through past experience with similar pilot programs that we’ve had in the past, or they just look at the model and say, “you know what, this makes sense, I get it, I’m totally into it.” Some people don’t like change; some people are very hesitant to adopt something new. Some of that is because people are very – we’ve heard a lot of feedback about how, you know, “Boston is different, you can’t take a program from Boston and relate it to New York because New York is so different. Our population is so different.” Which, you know – yeah, like, if you look at how many people are here, the kinds of people that are here – the demographic breakdown is certainly different than it is in Boston. But in the same way, the demographic breakdown in Boston is much different than it is here. So it’s not – if you’re looking strictly at numbers, like, yes, things are not
the same. And I think that’s pretty evident to anyone. But that doesn’t mean they’re not translatable, and that you can’t – just because it works there, shouldn’t automatically disqualify it from working here. And I think there are definitely lessons to be learned and parallels that can be drawn. The different sites-

**CD:** Yeah. And the home visits, and the workbook, that’s all being –

**KD:** Yeah. Because, we don’t – you know, on the larger scale of things, we don’t break down patient behavior by geographic region. And if we were, I feel like Boston and New York would probably fall into the same grouping. They’re these two US large cities.

**CD:** Right. Just Red Sox and Yankees.

**KD:** Red Sox and Yankees. You know? One or the other. So we don’t do that in other demographics, or any other statistical analyses that we’re doing, so I don’t know why – it’s like “oh yeah, we should just pare it down and find this one little thing to grab onto to say, like, ‘Ah, it’s not going to work here, because of this. It’s like, people in Boston are different than they are in New York.'” They are, but they’re really not. They’re very similar. I think people across the country would tell you that. So, that’s my little Boston bias there.

So, I think there’s been a lot of feedback. There’s been a lot of kickback. But I think we’re starting to see more people buy into it. And there are going to be some people that don’t buy into it. And that doesn’t necessarily mean program directors – it could be frontline staff, it could be medical directors, it could be administrators. It could be a lot of things. But I think that’s typical.

**CD:** And is there a big range of successfulness of these programs?

**KD:** I think it’s a little too early to say. The only data that we’re really looking at right now is enrollment numbers. In terms of what we’ve seen on a consistent basis. We’re starting to get into other pieces of information, but – so, if that’s what we’re going to categorize success as, then yes, there is variance. In terms of patient outcomes, or adherence, or –

**CD:** Just the smoothness of the process –

**KD:** Yeah, I think it’s still a little too early for us to know. Given the level of involvement that we currently have with these agencies. I mean if we’re out there every day for a week at each site, alright, we might be able to get our finger on the pulse a little better, we might be able to make some qualitative assessments and really start to draw some early conclusions about success. But I think especially – any program that’s focused on maintenance, I think it’s really tough to categorize success. Because you’re really only going to know when you’re not successful. At least, this early on. Because we’re expecting people to be in this program a year, 18 months, 2 years. But we’re not expecting that many people to be able to enter - fully progress through the entire program, and then be able to be classified as self-sufficient or independent. I mean, we’re not expecting a high success rate in that sense. So I think the variables that we’re going to look at may not necessarily lead one to believe success, but I think they align with the design of the program and the goals of the program. But just, I think success is a tough word with this structure.

**CD:** Yeah, for sure. Um, how’s your relationship with PACT been?
**KD:** My personal relationship, or our DOH relationship? Like, organizationally or personally?

**CD:** Whichever you’d like to speak to. The first thing I’d be really interested – just how it’s affected your work.

**KD:** I think that our relationship with PACT is a really strong one. I think they’re very willing to help this model to flourish. And they seem very invested in it. You know, there’s the business side of things – you know, contracts, and just kind of – you know, timing, and training, and like, all that stuff, so that has kind of led us to where we are now. But in my view, it seems that they’re very willing and interested in helping provide technical assistance, helping provide trainings – you know, Jessica from PACT was down here just last week to do three trainings for us.

**CD:** For the officers? Or –

**KD:** For the frontline staff. So the patient navigators, and a couple care coordinators, as well as DOT field specialists. They’re – I mean, they’re really helpful. They’re always willing to answer any questions that we have; I haven’t heard of any sort of disagreements, unless it’s you know, again, like dollars and cents, and that’s just kind of business. But when it comes to programmatic stuff, they’re all ears, and they’re very passionate about things. So it’s easy to work with – they’re an easy group to work with in terms of like, day-to-day stuff.

**CD:** and so after the pilots, but before Jessica started being more involved with the trainings, were you satisfied with the amount of training that was happening for the administrators and for the front-line staff? Like, did they all seem to be on the same page and on your page?

**KD:** no. (Laughs) and it’s tough. Because there’s a lot that goes into it, and not being able to make the hires ourselves – like, we’re the ones who know what the program is supposed to look like, what kind of people are needed, but it’s impossible to enforce hiring regulations at all of these agencies. So this is one of the agencies where I think – we’re seeing a bump in the road. About – whereas PACT was able to self-select, they can find – you know, they hire who they see fit to see the program that they designed. So DOH has designed this program, but we don’t do any of the hiring. So sometimes people just take whoever’s around; especially, you know, “in this economy,” they take whoever’s around; if there are unions – if your staff members are union, you may not be able to hire for that position, you may have to take someone from somewhere else that was given to you by HR. And at that point, that person might just be working a job. And I don’t think this is a job that you can “just work.” Like, I don’t think you can just kind of skirt by it. Because there’s a lot to it, you’re very busy. So I don’t think you can just kind of, like, aide your time until retirement. And I actually had a person at one of my agencies who was working like that, and has now decided to retire. Was put into the program because of her union title, so they weren’t allowed to hire someone else, the program was forced to take her on. It was not a good fit. She was not interested in the model, didn’t feel like doing the work. From her own mouth. And has now retired. So, there’s been a lot of issues, I think – or just like, unique issues with hiring.

And so when it comes to training them, you know, you can’t make that assessment – like, “alright, you’ve never done this work before, but you seem like a bright kid, we’re going to give you a shot,” or “you’re a seasoned vet, we’re very confident that you’re going to be into this.” There are too many – it’s not exactly a straightforward process, since a lot of people that were doing the hiring – the program directors, the administrators – were still kind of trying to wrap their heads around the program in general. So when they were hiring, they needed to hire people so they could get paid – so they could deliver
services, so they could get paid – it felt, like, a little frantic. Especially in the beginning. So – sometimes people made the right choice, sometimes they hired someone who they thought was going to be great and then they finally learned a little bit more about the program, and it’s been kind of rocky. You know, just for example – documentation is a really huge component of this program. Someone can be as passionate as they want, but if they’re not documenting anything, they’re not helping you. They’re doing a disservice to this program. Because it’s driven – not driven, it utilizes -- lots of documentation. Forms, progress notes, communicating with other providers through your notes – not just necessarily having it written down for review, but also being able to share information that can tell you stuff by itself.

I feel like we’ve definitely provided some training – I think the training could have been better, I think it could have been – there could have been more of it, more frequent, more intensive. You know, I think there’s a lot of things that we – you know, hindsight’s 20/20; could have gone back and done things a little better. There’s also the reality of – we’re the government. We only have X amount of dollars, we can’t just freely spend, there’s a huge process that goes through getting budgets approved. So it’s not as smooth sailing as you want. And if you realize you make a mistake, you can’t just correct it. Like, you can’t just say, “oh okay, well, we’ll just move some money around. And we’ll just do that. We’ll just fix it.” And then even if we can, it’s a lot of money. Because we’ve got to provide this for 28 agencies. So –

**CD:** Right. Because you have to go through the Planning Council? Or you have to go through the bureau?

**KD:** We have to go through like – everyone in New York City. We have to get like, 8 million signatures to sign off. And you know, it just has to be properly vetted in this process that’s in place. So you know, it can be frustrating at times for that. But I think moving forward, we’re recognizing where we’ve had gaps in training, in meeting training needs. So we’re looking to fill that in for the coming year. And it’s been good that we’ve had the technical assistance piece – you know, having the project officers be available. I think in the future, a more structured and more planned-out way of training – but it’s also tough to know, because you don’t know what people’s needs are until they kind of get into it. We have some assumptions, but we can’t be sure. It’s not worth allocating resources towards it if your assumption is wrong. So –

**CD:** And what about clinical supervision? Does that vary a lot between the 28 sites?

**KD:** My feeling is yes. There’s definitely variants. Just because of - whether the agencies choose to do individual versus group sessions; if they choose to do both; if it’s a supervisor – if it’s their programmatic supervisor who’s also conducting clinical supervision, versus someone outside of the program operating in kind, or who’s involved in the program only for this small piece…

**CD:** And what would group clinical supervision look like?

**KD:** It would be a group.

**CD:** A group of health promoters?

**KD:** Yeah. And you just talk about it. Talk about – it’s the same.

**CD:** Talk about what you’re doing?
KD: Yeah. Group session. It also depends on the background of the person or the people providing the training. There are psychologists, there are psychiatrists – I think there’s a psychiatrist at one spot, they were hoping they would have psychiatrists do something in kind – social workers, other licensed therapists. So there’s a lot of variance in the backgrounds of those people, so that will affect how it’s – how the sessions will be delivered. And also just, you know, the capability of the person providing the supervision. As well as their style, their role in the agency. So you know, there’s definitely – I don’t think there’s one consistent way or method of developing clinical supervision. But I don’t know if the variance is that great, but I don’t think any two places are really doing it – I don’t think if you were to sit in on a session at two different sites, I don’t think you would have the same experience. Or be able to say, “oh, well, you did this the same, and this was similar.” Other than, “you had a conversation, you talked about issues.”

CD: Yeah. So what warnings would you have for other cities or agencies -

KD: Warnings?

CD: Or – yeah, cautions, suggestions, for people that are considering this kind of replication.

KD: I think it’s…well, I guess it would depend on the type of agency that’s developing this model. You know, if it were to go over to another city, or…I think just clear communication. I think that is one struggle that we’ve had. We have, you know, a million and one groups involved in our situation here, which adds to it, but I think just really striving to ensure clear communication. And I think it needs to be bidirectional as well. I think, you know, you need to be able to take that feedback, and say – because, developing the program is all theory. “I think this will work, I have reasons to think this’ll work.” But you’re not actually going to know until it hits the ground and starts running. And at that point, I think you need to take that feedback and really funnel it back into the ongoing implementation and structuring of the program. But – so I think just keeping clear communication. Allowing communication to be open.

And be OK with pushing back your own deadlines. You know? We all understand that in order to successfully implement whatever whatever whatever, you need to have projected timeline, you need to have milestones, you need to start doing things in an organized fashion and some semblance of an order so that your program is properly implemented. That’s just the reality, that’s how you do it. But I think we’ve kind of rushed some of our deadlines sometimes, which has caused us to have to go back and change things a little bit. Which, you know. Hindsight, again. Everything’s easier that way. But just, if you don’t have the time to do it right the first time, when are you going to have time to do it? So just really – just kind of like, keeping that in mind. Because we’ve tried to stay busy, we try to do a lot of things, and sometimes we jump the gun a little bit. Not necessarily on huge huge important pieces, but just, every now and again. We find ourselves readdressing, when perhaps if we’d taken an extra week, or an extra month or something, maybe we could have avoided replicating the process.

CD: Yeah. Makes sense. Are your seven sites CBOs as the primary contractor? Or…

KD: I have all hospitals. I have five health and hospital corporations – so, the city public hospitals –

CD: So, big.

KD: Mm-hmm. And then I have – one is attached to an academic university. Or actually, I guess a lot of them are. But one is a private hospital - -well, it’s a clinic – attached to a hospital, attached to a
university. SUNY downstate, which is in Brooklyn. And then just a private medical center. So – that’s my row. I actually don’t have any of the CBOs.

**CD:** OK. And so, did those hospitals make a memorandum of understanding with CBOs? Or they started their own –

**KD:** Let’s see. Three of them are networked with other HHC facilities. So another hospital, like – HHC Elmhurst, which is in Queens – it’s a large hospital – it’s partnered with HHC Queens Hospital Center. They’re two – like, one-stop-shop kind of deals that are networked together. So I have three of those arrangements; I have one HHC that’s free-standing; one HHC is partnered with two CBOs, mainly for return to care – so, locating clients that had been lost to follow-up, who have had a medical appointment – we have a definition – no medical appointments in the past 9 months, but at least one in the past two years. So just like, really inconsistent with attending medical appointments, which is one of the main practices we try to enhance. You know, try to, I guess, correct that practice. Improve their – remove barriers, so they can more consistently attend medical appointments. Because yada yada yada, research says. And I think…that’s it. Nobody else is partnered with anyone. So most of them are really just free-standing medical facilities, but they might have a team staffed at another free-standing medical facility. So only the one really partners with any CBO.

**CD:** Yeah. And in light of Stephanie and Jessica’s work, are you glad that you’re working with hospitals rather than CBOs? Or –

**KD:** I wouldn’t say in light of. Because I think there are definitely some negatives that I deal with that they don’t have to deal with, and there are some positives that they get to experience that I don’t necessarily. I personally just like working with hospitals – you know, most of my experience prior to this position has been working in, you know, large medical centers. So I kind of just understand the dynamics and the culture there, so I’m comfortable with that. So that’s kind of how I happened upon the agencies that I’m with. It sounds like it’s easier.

**CD:** Working with CBOs?

**KD:** No, it sounds like it’s easier working with hospitals. Based on, you know, some of the challenges that some of the CBOs have to experience and endure. But I think – I think our experiences are really very similar. Just when you just drive down to – we communicate with our agencies, we help them to understand the program and protocol; if they have issues implementing pieces of the program, we troubleshoot with them. Their problems seem to be larger than many of mine; but, we essentially are doing the same things. They just – their issues tend to be more involved. And I think that’s just the nature of delivering this model in a CBO. Because if you don’t have medical providers on staff, and you need to do that partnership, I think that really just complicates things.

**CD:** OK. And so to help them solve their issues, its - you and the other project officers are just kind of a – like, you’re the last line? Like, are there resources that you direct them to, or resources that you invoke?

**KD:** Yeah. I mean, it depends on what the issue is. If it’s something that is like a simple fix, like “we’re having trouble scheduling or assigning caseloads to our navigators, we’re finding that they can’t possibly do more than this amount even though they’re supposed to do this amount plus 5;” they’re
supposed to do 20, and they’re only able to figure out 15; if we find another agency has developed
something that really helped them, we’ll share the information. We bounce ideas off each other; and if it’s
something a little more involved, we’ll kick it up to Beau, or up to Graham or Fabienne. You know, up
our ladder here.

**CD:** And Danny? Or is he not as involved?

**KD:** Danny has not been around consistently. He kind of took like a little sabbatical leave thing; and
now he’s kind of like, here sometimes, not here sometimes. But he is another resource that we can utilize.
Really anyone on our time – you know, if it’s like a data situation, we’ll go to our research and evaluation
unit; we have our HOPWA unit here, which essentially – it’s like a housing resource, to just get through it
quickly; so if our agencies have question about housing – housing resources, housing law, you know,
we’ll go over to John Rohassi’s team and say, “John, can you help me with this.” So we’re definitely –
we’re the go-to for their questions, but the questions don’t have to stop at us. And it’s up to us to help find
a resource. If we don’t have anything there, then we’ll Google search. Or you know, something more
involved. So the questions come to us, but they’re not limited to our individual expertise. We can
definitely work with others. Or even other people on our team who are not involved in care coordination.
You know, the project officer who works on harm reduction; she might know something about testing
laws that we don’t know. So if that question comes up, we can get the information that way.

**CD:** Yeah. Well, I don’t want to take up more of your time, but this is so so helpful for me, thank you
so much for making the time. I feel like it’s been longer than half an hour by quite a lot already. So – can
I ask one last question?

**KD:** Go ahead!

**CD:** So what’s the hardest part of your job?

**KD:** As it relates to care coordination? Or do you really want to delve into my whole portfolio here?

**CD:** Well, anything to do with the PACT – but I would be interested to hear anything.

**KD:** Yeah, I won’t bore you with that. It’s mainly care coordination. I was joking with you. The most
difficult part, I think, is – so, as project officers, we become kind of the advocates for our agencies. Right?
We want – I want to make this work for them. Like, it’s important to me that we maintain the design of
the program. I think it also has to be a workable program, and I think it has to – we have to kind of meet
somewhere in the middle with where the agencies are coming from. Obviously they want it this way, or at
one end of the spectrum, and we want it our way. So, however far away that is. So I’m not saying we have
to meet at 50%, but I think there needs to be a little bit of a give and take. And I think through the nature
of our position, you become kind of attached. Like, you feel like you’re rallying for them, and you’re like,
“ah don’t worry guys. Like, there’s a problem for you, I’m going to help you fix it.” Because our job is
essentially to solve problems. Some problems aren’t going to be solved. So I think sometimes not being
able to be the bearer of good news – but also having to – I don’t know if this is really an appropriate
analogy, but I’m going to do it anyway – I almost feel like it’s like parenting a little bit. Like, you want to
champion for your kids, and you want to champion for your kids, and you want to be able to do well –
you know, make them happy, and like, be able to give them nice things. (Laughs) like a program that
works for them. But you can’t always. And sometimes you kind of have to come down hard on them, and
say, “you’re doing things wrong. You need to get your act together.” Which we have to do much more pleasantly. But there is sometimes that reality of, “we’re your buddy, we’re your buddy, we’re your buddy,” (hits the table). Just like, drawing that line sometimes. Because the rest of it is just kind of – business. We make a change, we don’t make a change, it’s good, it’s - Like, you just kind of roll with the punches. You know, we speak up, we speak our mind, and then it’s just office dynamics. It’s just – we bring it to a vote, “oh no, you don’t get a vote, because you’re the chief of this program,” ok, I guess that’s that. Alright. I did my piece by bringing it forward.

CD: OK. So like, if your project sites wanted something, you might bring it up, but then everyone else –

KD: Right. So say for like, the HHCs, the city hospitals, if they’re all telling me the same thing, I say, “ok, I’m going to take this information and bring it forward and say, ‘hey, listen, this is an issue, we need to address it, yada yada yada, here’s why.’” Being told, “No.” Its like, (sighs).

CD: And that’s by the other project officers? Beau, Graham -

KD: Yeah. By whoever - Like, whether it gets voted against, or if you know, someone higher than you just shoots it down, says, “we’re not going to address that, we’re not going to do that.” Or, “you know what, that’s an issue, and you need to handle it. You need to make sure that you stop doing whatever they’re doing. Because it’s – they’re not doing things the right way.” So then just kind of, you know, having to deal with that. And then other than that, there’s just kind of, you know, the typical struggles of implementing a program. I don’t think it’s anything too exceptional that you couldn’t read elsewhere. (Laughs) Yeah, but I think just not being able to always be on their side. Like, kind of having to wear the two hats. Because it’s like, sometimes we’re on your side, we’re at the agency, and other times, we’re the DOH, we’re kind of not on your side actually, we’re actually going to continue to tell you no. So, the two hats kind of – I think it’s the trickiest part of the dance.

CD: Yeah. And if the care coordination meeting were to vote yes, then does that mean that you’d make a change for those very specific sites? Or that means that then anyone who wants to can invoke that change?

KD: It would be more of a universal change, in this fantastic hypothetical that we’re working on. It would be more universal. I don’t think we’ve done very many agency-specific – allowed many agency-specific modifications to things. We’ve made a very small handful, if even that many. Which is another component of it. But I think just being able to like, champion the cause of those who are confiding in us, and having the relationship with them that we have. I think that’s where that is.

CD: Yeah. And have the four project officers been here since the beginning pretty much, since the pilots?

KD: No. Jenna was here for the pilots; Jessica and I came before care coordination started; and Stephanie came like a month or two into it starting. So – and Beau came right before it started. So as he was getting his feet wet, it’s happening.

CD: So, after the pilots?
**KD:** Yeah, after the pilots.

**CD:** Ok, got it. Do you think that you have a different perspective on the project than Jenna, just coming from – they’re coming out of the pilots, and other people not? Or really, you’re all on the same page at this point?

**KD:** I think essentially we’re all on the same page, allowing for difference of opinion on certain issues. But I think generally speaking, I would say that the four of us are pretty much in the same area on how we feel about things, protocol, or programmatic, or otherwise. No, I think we all have things that we feel more strongly about than others, and I think we all kind of balance each other out.

**CD:** And Jessica and Danny were saying they’re from Boston as well. Are Stephanie and Jenna from Boston also? Or –

**KD:** No, Stephanie’s from California. Jenna’s from Michigan.

**CD:** Ok, cool. Have you been to providence?

**KD:** I have been to providence. And I know you have to pay for parking at the mall! I’ve also been to Brown.

**CD:** (laughs) OK, neat!

**KD:** so, I know a little bit about Rhodey.

**CD:** did you know it’s the second largest indoor carpeted mall in New England?

**KD:** I did!

**CD:** Really! Well, thank you incredibly much for making the time for me – this has been so, so interesting!
Interview with Dr. Heidi Behforouz, 11/8/2010  
(Notes from unrecorded personal communication)

Middle managers – didn’t have the same commitment to clinical supervision; in-depth, finding out what the barriers to care are. It’s not just having the CHWs: they must be trained and supported to know how to respond in various situations, when they come to know their patient better and learn that they have issues with depression, etc. The managers for the 26 health centers should have been brought to PACT, to learn here; but there wasn’t the funding for it (due to Anthony).

If PACT HAD been asked to be more involved in the training, rather than going through that private company (because Anthony cut the funding), they would have had to face some real capacity issues: it’s only Jessica doing TA and training, so they would have had to find other solutions.

Anthony – stopped money from being allotted to training

No home visits, because the NYC commission thinks that people wouldn’t WANT home visits – which she disagrees with, they figured that people in Boston were pretty much the same as people in New York…

Policy entrepreneur = Danny Weglan. He read about the PACT model, and had Heidi come to New York and present. It was pretty straight-forward for him (didn’t have to persuade too many people) because he was in charge of evaluation for the existing coordinated care program. He convinced the commissioner to allot 800,000 of discretionary funds to running the pilot program at Lincoln hospital. After that, they got Ryan White funding to bring the model to 26 more hospitals and health centers.

Initially, the HIV activism community in New York was not consulted. As a result, the program was hybridized.

To some extent, it must be adapted to each health center; however, it’s so hard to have good managers. Managers mostly aren’t good.

When she was approached by Danny Weglan to replicate the model, it was a straight-forward YES. The CHWs at PACT were really excited about it, too.

She thinks the DOHMH ultimately are good people and have the same goal: helping the outcomes of people with HIV/AIDS.

They’re now realizing that they have to commit the money to that middle level: the clinical supervision and management.
Interview with Jessica Aguilera-Steinert, 10/26/2010

Colette DeJong: I’m a senior at Brown University, and I’m writing a thesis about the intersection between NGOs and governments, and I’m really fascinated by the PACT situation in which such a successful, really unique model is being picked up, especially in New York City.

I was hoping you could start by telling me the story of PACT going to New York.

Jessica Aguilera-Steinert: So, this story began about three and a half years ago, officially. But prior to that – so, Heidi Behforouz, who is my boss, executive director, she had been invited down by the New York City Department of Health AIDS Bureau – HIV Bureau – many years ago, to talk about quality improvement, by the subgroup of quality improvement. We presented – it must have been five years ago now. And the guy in charge of that, who was an HIV physician, asked us to consider a partnership about four years ago, in which we would be mentoring his staff and then funded projects through the Ryan White program, which is federal HIV funding. We first did a pilot with one hospital in the Bronx, Lincoln, and we helped the DOHMH HIV services create the program – everything from data collection to program design to training to supervision models and all of that. And we had done this before, but not in such a comprehensive way; we had provided trainings, or consultations on program design, or evaluation support, but not a huge package. The goal was to try this pilot with one hospital, and see if the clinical outcomes for the folks with HIV matched the clinical outcomes of folks with HIV here in Boston.

There are some different pieces of the program design. Here in Boston, we serve as a community-based organization; we have our own community health workers who work with up to 16 hospitals and health centers around the city. We don’t belong to the health centers and hospitals themselves, so we’re not a formal member of their team, but we work as a member of their team. Whereas in New York, they hired the CHWS, and all of the infrastructure was internal.

CD: Through the City of New York?

JAS: Yeah, through the City of New York. There are various different city health structures in NYC that made things really complicated. There’s the DOH, and then there’s another organization, and I’m not going to explain it well, so I won’t – it’s Health and Hospitals, I believe it’s called? So there’s a whole bunch of bureaucratic stuff that had to be worked through.

So we started this pilot; we trained about 8-10 people, mostly CHWs, less so the supervisors, or the people above them, the program administrators. First mistake. Our help was that we were going to be able to inculcate everyone on the team who had anything to do with it, but for lots of different reasons, not the least of which was time …big training – it’s a little different now, but we did it in a two-week chunk, which is a long time.

CD: And so the 8 CHWs were recruited not from the City of New York staff already?

JAS: Some were hospital staff already, but most were hired from outside the hospital.

CD: Were they selected by the PACT team?

JAS: No, by them. We had nothing to do with the hiring. So…I mean, we gave them our job descriptions and our interviewing questions and everything like that, but we weren’t that involved in the HR aspects.
So the program ran, we provided TA (technical assistance) for the next year. I did a lot of consultation by phone with CHWs, and their program manager, with their clinical supervisor, social worker…after a year we started with two other hospitals, one in Manhattan, one a clinic in the Bronx, and piloted them for a year; and Lincoln kept going. And about half-way through that second year, the director of the HIV services, Danny Weglan, wrote a request for proposals with our model as a new model for the same old money, the Ryan White money. So it was imposing a new model on a group of services and staff in 25 hospitals and health centers that were used to an old model, much more a case management model.

CD: And so he’s at the DOH?

JAS: Yeah. So the DOH is the one who creates a proposal for this Ryan White funding, and then each clinic and health center and other types of agencies apply, submit a proposal, for that. Within weeks of releasing the proposal, the HIV community was up in arms because this new model was so radically different, and they felt…the process of proposing a new model was not inclusive at all – it didn’t incorporate people with AIDS, people working with AIDS, in other words the community, effectively. And in New York City there’s a long history of advocacy for people with HIV and AIDS, within the infected community as well; and they were having nothing of it.

So the DOH HIV Services retracted the RFP, and sent out a new one within a couple of months that was more like a hybrid of the old version of services – called Care Coordination – and the new version, the PACT model.

So we’re talking about 25 million dollars; 28 hospitals health centers and community based organizations have been funded; the funded started January 1st, 2010. Our trainings in 2009 were for the pilot sites only – so the first 3 pilot sites – and technical assistance. About half-way through 2009, DOH asked us if we could provide a comprehensive training for all of the new programs that would be funded, that would be weeks and weeks and hundreds and hundreds of trainees. And I’m the only staff person in training and technical assistance, formally; there are bits and pieces of other people who certainly help out, but it was just not something that we could handle. So reluctantly, we had to decline that offer, and they contracted a for-profit training company. At that point – well, still – we didn’t have the money for start-up; if we had had a couple hundred thousand dollars to hire people, and train staff, and be ready to do that kind of a training, we would have. But we don’t have that kind of funding. So the model that we use for reimbursement for training and TA now is just a reimbursement model, where we contract – an amount of money - for trainings and TA and materials, and then we invoice with the recipients and get paid for it after the fact. So..this is a significant theme in our growth and sustainability challenges. Until we get seed money – and we’re constantly writing grants, but we’re talking about a pretty big chunk of money – we won’t be able to build our capacity to serve the need, and the need is growing growing growing, and I’ll tell you about that.

So instead of providing the training on our curriculum, how to be a CHW – which is the core CHW training, the medical pieces; the intro to PACT; all of that – a total of three weeks, if you really do it every day – DOH hired this training company, and I trained them. But they created a training of ten days, and they were going to be doing it group after group after group, site after site after site, something like 16 times. But in their training plan – their syllabus – they only incorporated two days of PACT, formally, officially our stuff, our materials, our content – and this is a three week training that we do, and that’s only the initial training, it’s not the continuing TA. So it didn’t by any means address the depth of the support that we give to organizations starting out with this model.

So then they had no more money, DOH, and we took a step back and about six months ago, tried to think through…we were starting another huge project that I’ll tell you about hear in Massachusetts, and
started thinking through what kind of future relationship that we wanted to have with the Department of Health and Human Services in New York, and other sites that were replicating or adapting our model, because we’ve been involved in lots in different ways over the years.

So Heidi and I went back to the new director of HIV services, and we had talked to her several times before, and said, “so where are you guys at, what are you going to do?” (this was about three months ago.) “What are your future training needs? This is what can we provide. How’s the program going? What’s start-up like? Where are the gaps?” And they lost a lot of staff – the DOH - the project officers and the management of the project officers – so basically, except for one project officer, everyone was new. And so that was a good opening for us to be convincing, and say, “you guys really need to know what this program is about to be able to provide oversight and TA to the actual programs, clinics and hospitals.”

CD: So the program itself had the same staff, but everyone above them in the DOH had been changed over in that 2009-2010 period? Wow.

JAS: Right. But the programs themselves were just funded January 1st of last year, so this whole thing was kind of happening simultaneously. I mean it’s only October now, so – this was happening over the summer. So they agreed; we set up our first contract, we’re working on the second contract now – to train up all the project officers, who are the people who oversee the actual funded programs in New York, there’s 28 programs. And they’ve agreed - we’ve contracted with them, or they’ve contracted with us – to do a curriculum training, our educational curriculum, to direct service providers – CHWs (they call them navigators) and their supervisors, who are called care coordinators – or a trainer/trainer model, where we train the managers and then they train their staff. A clinical supervision training – so each program has required a certain number of hours of a mental health provider who provides supervision to the CHWs; a directly observed therapy (DOT) training to managers and staff; and a big package of technical assistance. So we’re working on that contract now for 2011.

CD: And these are not things that they’ve already purchased from PACT, because PACT had just helped train this private company in the past?

JAS: And we had done a 3-day, “what is PACT” intro to PACT for the old DOHMH staff. And we had trained the three pilot programs, including CHWs – the whole package (I can show you what that package looks like.)

So we’ve started that work. The TA is happening, I’m in very close contact with the director and the assistant director of the folks who do project management and TA for DOHMH HIV Services. And I’ve trained – I’ve done an introductory management training to the prevention folks; the head of prevention in HIV Services; it’s split up to treatment care and housing, and prevention. So we’ve done a management training for them as well, and they’re thinking about how they want to incorporate our patient education curriculum. So that’s spreading, which is good, into potentially other parts of the DOH.

CD: So this is all within the blanket of HIV services?

JAS: Right. But prevention is split from the access to care and direct service stuff.

So I would say that this is about 25% of my time - for this one site, or contract. And then we have contracts or relationships with lots of other organizations outside of Massachusetts, as well.
**CD:** Wow, that’s fascinating. Can you tell me a little more about what the program ended up looking like? You said that 2 days were for PACT, and then 8 days were for other things…how the program ended up being translated.

**JAS:** Yeah. I wasn’t there at the trainings, but the training company – we’ve developed a good relationship with this training company, but we’re kind of in competition; we do very similar things. The whole idea of – you know, we’re very much a non-profit – of a for-profit taking our model and training on our model, and our materials, felt really weird for us. We had really struggled between wanting to be completely open-source, to thinking about our budgetary constraints, as well as thinking about the integrity of the model; and over time, have decided, or we’re getting to a place of, feeling like this is our expertise, materials we’ve developed over a long period of time (over 10 years), and this niche is unique. So we’ve been wanting to…we sort of changed our training and TA model from doing whatever piece the client wanted, to doing the whole training – the whole packet, the whole product, from start-up and assessment of readiness in an organization, to all the CHW training, all the management training, the curriculum training, giving them our materials, etc.

So that’s really my job – to develop this package. And I’ve only been doing this…formerly, I’ve been overseeing the HIV programs for six and a half years. Only in the last six months have we been able to get enough money and hire enough people, managers in the other programs, that I’ve been able to come over here full time.

So, what did that look like? I can actually show you the outline. It’s basic HIV 101 – adherence, relationship-building with patients, professional boundaries…a lot of policy stuff…confidentiality, disclosure…so some of the topics are very much the same, but presented in a different way. Just really presented in a different way. And, initially only presented to the managers of the sites, not to the CHWs themselves – and they have rethought that, and are now providing that for the CHWs. Unfortunately they haven’t adapted them to CHW content; they’re very lecture-based, I think. So yeah – it’s not that those topics weren’t good, it’s just that it’s not our model. (Laughs) It’s a lot of relevant stuff, it’s just different.

**CD:** So this is their outline?

**JAS:** Yeah.

**CD:** OK. So are there some key features of the PACT project that you weren’t seeing at that initial meeting, when you and Heidi saw what this hybrid program was looking like?

**JAS:** Yes. I think the significant difference between the old DOHMH model and the ever-growing and shifting new model – which ultimately will be changed, ideally, after 3 years when the next RP is sent out – they had to compromise on this model, due to the advocacy politics and all of that – but I’ve seen over the last three months a significant shift towards – just closer to the fidelity of the PACT model. So what are the differences?

Well, first of all it’s different staff people. The present New York model has a navigator and a care coordinator. We have typically one person, that we call a CHW or a health promoter. So the responsibilities are split there; the navigator does navigation, really, more than anything else. Navigator is a really catch title these days for the role of the person who helps ensure that patients have access to their health care. So arranging transportation, reminding of appointments, sometimes accompanying them in appointments, connecting to social services, solidifying insurance if there are issues there, helping with insuring medication access…so we’re all of that, but our CHWs also do a lot of support and education around what is adherence, why is it important to take your meds, what happens if you don’t take your
antiretrovirals, let’s talk in great depth about disclosure and about stigma…the patient curriculum that we’ve developed, and I’ll show it to you, is really designed to help uncover the barriers to non-adherence to medications and medical appointments. There isn’t the assumption in the DOHMH model that – they’re not looking only at this subgroup of people who have adherence problems. So we’re looking at a smaller group of people, more like 10-15% of the broader HIV community, who – basically the system has failed. They have access to health care, access to medications, insurance, to Medicaid, or free care; but for lots of different internal and external reasons, systems reasons, they remain non-adherent. So what that means is that certain groups of people are dying sooner and getting sicker from HIV, and those people, not surprisingly, are people who are poor, people of color, people who are isolated, disconnected from their communities and their families, who have untreated mental health issues, who are often active substance users, who have trauma histories…

CD: Who qualify for the 2 highly vulnerable qualities, right?

JAS: Yeah. So that’s the group that PACT seeks out. And of course the DOH in New York needs to provide services to all people with HIV, right? Not just the people who are falling through the cracks. So their criteria are slightly different, their eligibility for entrance into this program. The roles as I said are really different between the navigator and the care coordinator. The care coordinator is more of a case management person; and the navigator role sometimes works in people’s homes. Ideally they should – they’re supposed to work in people’s homes – but in the pilot, there was some reluctance around that due to the logistics, and the distance – just how big NYC is, as well as safety issues. The pilot programs felt like safety was a much bigger factor than we do here; I mean, safety is certainly part of…we don’t feel that way. We feel that safety is similar – there are safety issues here, there are safety issues there, we’re working in similar types of neighborhoods. But they…also, this is a new model, working in people’s homes, for the Ryan White-funded programs, and so they’re not used to it.

CD: So, do you think these are due to, kind of, differences of institutional approach – kind of different attitudes between PACT and the DOHMH?

JAS: I think this a cultural – yes. Absolutely. Both of those things, plus – I would name it more a cultural or philosophical difference. We’re a community-based organization that’s part of Partners In Health. Our philosophy comes from the grassroots, whatever-it-takes type of attitude. And the department of health is the department of health, you know? It’s a huge institution, a city- and state- and federally-funded institution, that does wonderful things, but it can’t function in the same way that partners In Health or PACT does. That’s not to say that there aren’t a whole lot of people who are mission-consistent with the PACT philosophy, or PIH philosophy, but – you know about Partners In Health?

CD: Yeah. Paul Farmer was at Brown pretty recently, a couple weeks ago.

JAS: So you know what I’m referring to in terms of that philosophy. So…that point is an extremely relevant one in our interests in adapting this model to other institutions. Now generally, the DOH in New York is the only DOH that we’ve had a contact with. Not Massachusetts DOH, and no other state. Now we’ve talked with people in other DOHs, but we don’t have a contract with them. So…typically we’re partnering with individual health centers and hospitals.

CD: Private hospitals for the most part?
JAS: Well, private and public doesn’t really make a whole lot of sense anymore because the population is the same. It’s still the Medicaid group of people. So in Boston, there’s an extremely limited number of Public hospitals now – extremely limited. I mean, Boston Medical Center is not considered a private hospital any more, and neither is Cambridge Health Alliance. Cambridge Hospital used to be.

So that point of the cultural differences, I think, is the primary factor in a site’s - or I should put it the other way – our ability to adapt or replicate this model in other sites.

So, here in Massachusetts – are you interested in that as well? Or it’s just the New York?

CD: You know, it seems like it’s such a complicated issue, I would love to focus on that, since we have kind of limited time.

JAS: OK!

CD: So – how would you describe…could you tell me a little more about that cultural difference? Sort of, how you observe the culture in the DOHMH?

JAS: Sure. So…I think there are institutional differences – there are individual hospital differences – and then there are DOH differences. All of these hospitals that received these funds through the DOH have their own unique personalities and cultures. Some of them are very HIV-focused and have…are located in communities where there’s large – or, in the 80s in the 90s, there was aggressive advocacy through largely gay men. Others are in poor communities, or people of color, or mostly immigrants, that don’t have a lot of advocacy but are, you know, free clinics, and not part of huge institutions. But all of those institutions have serious infrastructure limitations. And that infrastructure requires them to jump through their hoops. So whenever you introduce a new model – I mean think about it, this case management and navigation model has existed in New York for 20 years, essentially. 15 years. So to bring in a new model, and probably in the wrong way, that it was originally brought in, or presented to the sites – is a really tough thing to do. So I think – my feeling is that they’re looking at this as, these first three years, as a pilot, even though we spent two and a half years on a real pilot in only 3 sites; this is 28 sites. Because you can’t change a huge HIV service model overnight. So I think we’re in it with them for the long haul.

Interestingly, over the last year when the DOH staff turned over, and I’ve only known these guys for 3 or 4 months now (altho though I’ve known the director for a while), it seems like we’re more on the same page. And yet these guys work in a huge behemoth infrastructure themselves, the DOH. So I can make recommendations to them about what I think their programs need in order to adapt this model better to their institution, but, you know, they can go to their bosses and say “this is what PACT says is the best thing to do,” and there are budgetary considerations, there are politics, there are lots of things, that we will never know the details about.

The head of HIV Services – her buy-in is absolutely essential. She has not played an extremely active role in any of this, whereas the previous director brought it, so it’s a little unclear to us what her vision is around PACT and this model. So – that is to say, answering your question, it’s a little unclear what we’re dealing with. And that’s true whenever you consult with another organization – whether it be a government or a small community clinic. You’re outsiders – and as much as people in the institution may love what you’re doing, not everyone does. And getting people on the same page is an incredibly challenging thing to do. And any consulting group will tell you that.

And we’re not experts in consulting. Yet. We have learned so much through that relationship, our relationship with Camden Square Health Center and Diabetes Project, and our newest, which is with a
managed care organization in Massachusetts for people with Medicaid with multiple chronic diseases. We’ve expanded from HIV to diabetes, now, and general chronic diseases.

So one of the huge lessons learned is that whenever we go into a relationship, especially one as big as the DOH, that we have to do an extremely thorough and sophisticated assessment of the organization’s readiness. And we’re still developing those tools. It’s everything from the culture of the organization, to the financial status and their ability to support this model, to their commitment to the fidelity of the model or the consistency of all the components of the model; their commitment to monitoring and evaluation of the outcomes; all of the supervision that we require; the development for the CHWs, the training obviously that we would provide, and ongoing TA…so I think it’s a real skill that we’re developing to create a tool that can, instead of doing it along the way, [a tool] to see if an organization is ready to accept this model.

**CD:** Ok. So in terms of the hybrid that ended up being developed in New York, what concerns do you have for the services that were being provided that were technically kind of under the stamp of PACT, but that as you said, had been shifted in many ways?

**JAS:** So the biggest one is that – either that they’re not using the educational curriculum, or that they’re using it in a different way than it was intended. So that’s this. *(Picks up a book)* So this whole big thing is the educational piece of what the navigator, or CHW, does with the patient. I’m happy to have you take a look of that.

So that’s one: we have no idea what they’re doing with the curriculum. They were never trained on it per se, like formally, and they all have it. So that’s one piece.

Another is the supervision model. We’re not exactly sure what each site is getting: whether they’re getting as much time, and the quality, of supervision and internal training. I haven’t trained any of the clinical supervisors, so that group in particular is a big question mark. They really watered down the requirement for clinical supervision; and some programs are getting as little as an hour and half to two hours a month, as a group, for CHWs, of a mental health- or social worker-type of supervision. Others have a whole half-person for that, depending on the size of the organization and their commitment.

**CD:** So that would be supervision of the CHWs’ activities?

**JAS:** Yeah. That’s one of the supervisors – it’s a two-supervisor model. One is a programmatic supervisor, and one is a mental health supervisor.

So what happens when you respond to an RFP – you write your proposal in the way that you want to run the program. Now, there are 300 guidelines, but there is flexibility through those as well. And then you negotiate a contract with the DOH, the funder. So if you decide you’re going to put .3 of an FTE, of a person, as the clinical supervisor, and use -- even though it’s recommended that all the staff get X hours of clinical supervision a month, and use the .3 for something else (but related) – those details are negotiated between the site (the hospital or health center) and the DOH, after they’ve been rewarded the money. So that contract looks different at every site. So, that in itself shifts the model.

In the next funding period, maybe one of the lessons learned will be to shore up what the requirements are more, in specific areas – that would be one that I would recommend requiring more specifically.

**CD:** So, maybe requiring one person to be fully devoted to clinical supervision of the CHWs?
**JAS:** Yeah, I mean – you can’t say that, you’d probably have to say it in terms of the amount of hours of supervision you’d want each individual to get, because if it’s a program of 4 staff versus a program of 15 staff, they’d need different support – different number of hours.

**CD:** Would that be following the CHWs as they even do home visits? Or is it more like –

**JAS:** So, it’s typically clinic-based. Ideally, if they can get as much time of a programmatic or of a clinical supervisor or both, that person should supervise in the field. Our supervisors (we have a clinical supervisor and a programmatic supervisor) – I mean, we are differently funded, so – and we’re sort of like the ideal. And it’s to be expected that the ideal has much more than … it’s going to get watered down to the other funded sites. So, our two supervisors go out at least quarterly with each CHW to observe them doing their work: to coach them, to observe them, to give them feedback, but also to get to know the patients because they’re supervising around each patient, so it’s helpful for them to get to know them.

**CD:** Ok. And without enough supervision, do you just worry about the quality of the care that’s being provided?

**JAS:** So that’s one piece, definitely. Supervision of CHWs is really really really crucial. One of it has to do with the quality. Another has to do with productivity in general, because this is…you know, it’s a very autonomous role. And it’s all out there. It doesn’t take place here – patients rarely come here. *(To the PACT office in Boston.)* So CHWs are out there on their own: making their own schedules, visiting their people – I mean we monitor it in terms of their data, and what they report in progress notes and all that, but that’s not the same. Any home-based program managers would tell you, supervising people who do work outside of your site brings a whole bunch of challenges.

So it’s productivity, it’s quality…it’s ensuring that all of the activities are being accomplished, or the problems are being assessed as well as they could, and the response – the intervention – is being provided in the best way that it could. Yeah. So that fits into quality.

**CD:** Ok. So what would be the worst-case scenario for what the New York City replication ended up looking like? If it kind of stayed on this track? Or, maybe any implications or consequences?

**JAS:** So…recently, in the last three or four months, we’ve re-contracted with them, so I’m hopeful that we will get…in 2011, you know, we have a lot of stuff planned. In 2012, which is the third year of the contract, my feeling is that we will continue to be actively involved.

So the best case scenario…my personal feeling is that the best-case scenario is that the present management of HIV services continues on this enthusiastic wave of integrity to this model, and by the next RFP, writes something that is 85% or 90% consistent with this model.

But having said that – ultimately, that’s because I want them to have similar outcomes to our patients. Right? Because I want that for their patients. But I also want it because that confirms that this isn’t just one program’s success. Right? We’ve got a hundred patients – you know, or, through the years we’ve had three four patients, and it hasn’t worked for all of them, but overall, we’ve had really great clinical success. And some cost-savings, and some other really positive outcomes. And I want the people in NYC to benefit from that. So even if it’s watered down a bit, that would be wonderful. I don’t expect…I don’t know how many staff is involved here, but I’m thinking thousands? Maybe a thousand if I break it down – 28 sites, 4-15 staff per site – this is just the city – because ultimately, what we’re trying to do is reform the health care system. To decrease cost, to use clinicians who are so expensive less, and for this whole institution of medicine to recognize the incredible skill and benefits of CHWs. And their unique ability to
connect and help people with chronic diseases reengage with their health care, improve the quality of their lives, and recognize and address some of their barriers. Which are not just health-related – they’re emotional, and social, and spiritual, and all sorts of barriers.

**CD:** How exciting that there’s this new, more open and receptive person –

**JAS:** Yeah! We’ll see, because these people aren’t at the top of the heap. We’ll have to see some benefits to convince the powers at the top. One of the other things that we’re doing simultaneously, that I hope will help, is a lot of advocacy work in Massachusetts to get CHW’s certified. To create a CHW certification program and process – and that doesn’t exist in New York either, there’s only a handle of states that have certification of CHWs. That’s a whole paper in itself. But we have been able to be at the table, and pretty much leading the data – the evidence – that the CHW can be the answer to engaging a certain group of people with chronic diseases, so that they’re not dying as quickly and are healthier longer. And in Massachusetts the legislature just voted on creating a certification board for CHWs, so over the next year, until January 2010, this committee – it’s the Mass Association of CHWs, the DOH, and Massachusetts Public Health Association – and us, and a bunch of other community-based organizations – are developing what this certification process will look like. And that’s very consistent with what PACT is working on simultaneously. So in addition to helping develop these other programs and sites, I’m working on developing our own core competencies for CHWs. I mean we have an informal core competency set of skills in mind, that we train all of our staff in, and other sites, but we need to develop evaluation tools for our staff’s competency in these various different areas. And this would work really well in tandem with this certification board development.

**CD:** Yeah, that sounds really interesting. And may make it easier to have a minimum package that people have to buy into. One thing you mentioned before – I was wondering if you could talk more about who was crucial in the decision to replicate the PACT model. You mentioned that the HIV community was initially resistant, or resistant to a complete change?

**JAS:** So – specifically to New York? Or just in general?

**CD:** I think first of all specifically to New York, but I would be interested to hear…

**JAS:** So – I think it’s really different if you are attempting to change a model of service throughout a huge institution that affects funding for 28 hospitals and health centers and community-based organizations, or, you know, any number other than one or two, with so much money. And really, the bread and butter of these workers’ existence in the HIV field. I mean, this is their full funding for HIV Services - at least the community-based organizations, and many of the roles at the hospitals and health centers. So, excluding the actual clinical care, but everything else.

So the first lesson is – if you’re in NYC, where advocacy for people with AIDS started, include the community in any significant funding changes, model changes…so that would be number one.

You know, they did to a certain extent. They brought it to the planning council, which is this kind of non— it’s a mixture of people with AIDS, service providers, physicians, and state government, city government, people who make decisions about the allocation of funding and the design of RFPs (request for proposals). So they did bring it to them. But I think they brought it late. And I don’t think that group is entirely representative of the whole HIV community. So, that would be lesson number one.

You know, the fact that we’re from out of state probably doesn’t help. I think being part of Partners In Health, for some people, really helps, and other people, it’s a reason for people to say – for programs to
say – well, that’s Paul Farmer, they have amazing funding, he’s a lone ranger - you know, he’s out there on his own, making the world a better place, but that’s not what real life is like in a New York hospital. Now that’s not exactly the accurate representation of Paul, or of Partners In Health, but it’s true. Partners In Health has good funding, especially over the last year after the earthquake, and he’s an extremely charismatic guy. Most people who work in HIV have read the book, Mountains Beyond Mountains. And either you love him, or you distance yourself from him. Either you’re inspired by him, or you feel that that’s’ an extremely unrealistic approach for an average human being like you or me. It’s impossible for one person to change the world, but somehow Paul has made it look like he can.

**CD:** And a lot of people behind him.

**JAS:** And a lot of people believe him. Absolutely.

**CD:** Or, a lot of people in Partners In Health, more so than just him alone.

**JAS:** Absolutely – of course, of course. So that has been both a Pro and a Con for the buy-in of this model.

**CD:** And do you think that’s to people with HIV in New York, or the New York City government –

**JAS:** It’s more to government providers. Service providers. And more clinicians, than your average, maybe, health worker. A lot of folks – more academicians, more higher-level professionals – have heard of Partners In Health.

**CD:** Ok. So within that coalition that you mentioned, there were people with HIV, NYC government officials, and –

**JAS:** Service-providers.

**CD:** And it was more so the service providers and the government officials that –

**JAS:** I don’t know what happened in that coalition. I have no idea how actually they responded initially to the proposal, the request for proposals, or actually who spoke up first. My sense was it was more the grassroots advocacy crowd, and less the clinicians. Because clinicians…many HIV clinicians really buy into this model because the clinical outcomes have been so successful; many do not, because it’s a “paraprofessional,” quote unquote, model, and CHWs are doing much of the work of clinicians who have been through many more years of education and training, and get paid, you know, 3, 4, 5 times as much. And we’ve found, at least here at our HIV program in Boston, the CHWs have often had better success - connecting with the patient and helping the patient improve their outcomes. So that’s another group who may feel reluctant.

But, in New York, the CHW role was already there; there was a navigator role. And it’s been that way for years – there have always been case managers. Now, CHW is kind of a generic term for a non-degree health professional. But, I think that their model – the role of a navigator, or a CHW prior to the introduction of the PACT model, is much more limited than our vision of what a CHW can be. So that’s another culture shift.
CD: OK. So in the care coordination program the navigators were doing fewer home visits, and also just less…

JAS: I don’t even think they were doing home visits. They were doing the navigation piece; they were not doing as much education and as much relationship-building, and not involved in some of the more mental health and medical support and education.

CD: OK. So, you mentioned that New York grassroots advocates seemed to be the people that spoke up most against this transition. Do you think that –

JAS: So, I don’t know who spoke – who said what. I’m using that as sort of a more general sense that I got.

CD: It’s unclear what’s not to like about the PACT –

JAS: You know, it’s not so much what’s not to like as, change is hard. And if you’re not included – I f you’ve been working in this field for 15 years, if you’re a case manager and you’ve been doing this, if you’re someone who has HIV, or you’re in recovery, and you’ve been doing outreach for fifteen years in your community – what would it feel like from the funding source – the people who are perceived as in the ivory tower – to come down and say, “your role is not going to be funded anymore; you’re going to have to change yourself if you want to keep working here.” And you’re going to have to do this thing that another group says works, but you’ve never even heard about it before.” So I think it’s more how it got done, and the fact that change is hard.

CD: Who do you think was involved in the initial – or, did PACT initially intend to be replicated in the public sector in this way?

JAS: No. Our intention was to, ideally, to have Massachusetts recognize community health workers as the professionals that they are, and to fund their services – reimburse their services. We started replicating in locations that pursued us. The University of Miami, New York, the department of health in Baltimore, but not anywhere near the same size.

CD: New Mexico…

JAS: Yeah, Navajo Nation in New Mexico, but that was through a PIH doctor, an outside program coming into support that. And, this managed care program in Massachusetts serving people with Medicaid. That’s more like what we were hoping to become, except that that’s not really the PACT model in that it’s a…well, working with an insurance company is a whole new experience for us, even though the insurance is Medicaid. It’s network health, and it’s one of the four Medicaid managed care organizations in the state. And they matched us with another organization that offers this wrap-around service for people with chronic diseases who are high utilizers, and cost a lot to the insurance company – high utilizers meaning they have longer hospitalizations, more hospitalizations, and more ER visits, for things that are preventable – for things that could be treated in an outpatient primary care environment. So that organization, called Commonwealth Care Alliance, is a nurse practitioner and behavioral health model; it did not include CHWs until we started working with them. So it’s not just the add-on of the CHW, it’s the add-on of free providers. So again, it’s different, and it’s much more expensive because of that. Our model really is to add CHWs to the actual sites, the health centers and hospitals. One of the
reasons that we’re doing it this way is because managed care physicians have money. Health centers and hospitals these days have less and less and less, and this is not sustainable by writing a grant here and there. It would have to be taken up by the state, or Medicaid. You know, we went to Medicaid originally, and they said, “We love it! But we have no money.”

CD: And this is talking about in Massachusetts, making the CHWs reimbursable by HMOs?

JAS: Right.

CD: So, what do you think initially motivated New York – I mean, there are so many places that have sought you out, but – what do you think motivated them to come to PACT?

JAS: So, it was the outcomes. The clinical outcomes. And the cost savings. Mostly the clinical stuff. This is the group of patients that drive the HIV clinicians crazy, because they do their own thing, they don’t engage with the medical team, they cost the institution the most money, and I think they make providers feel powerless. Regardless of how hard the provider tries, he or she can’t really reach them. And I mean, literally, and spiritually. The accompagnateur model is very different than the medical model, even though we dovetail each other. The accompagnateur model is really about walking hand-in-hand with someone, at their own speed, with their own readiness, to help themselves – to save themselves, to survive, and figure out what tools they’re willing to grasp. And the accompagnateur can help them connect to those tools. Which is different than the medical model, right? To want to live.

So, I would say those are the primary things. Now, just like any transformation, there was an individual who was already a PIH-er, a PIH type of person, Danny Weglan, who pursued Heidi, explored the PACT model for years, and had her presenting to the senior HIV quality care group through the Department of Health – clinicians from various sites that they fund – and got to know her, got to know us, looked at our data, and then as we developed our capacity to train and develop other programs, engaged us to help them. It was a very loose grassroots activity. Today, we look really different. We had no contract, for example. It was all sort of agreement with the DOH. We built a contract eventually, but we didn’t have the capacity to do that – we didn’t know anything about contracting. We knew that we should, eventually. But we learned a lot about our business structure. Now we have a director of operations who oversees all of our contracting and our finances. We didn’t have the capacity to have a position like that. Most of our funding comes through PIH and grants, and slowly but surely we are using up the local foundation opportunities. And a couple of our bigger, private foundation donors have – one in particular – have sort of come around a couple times for us, but we’re kind of at a crucial moment right now where if we want to develop this institute that is pretty small, and our capacity is pretty small at this point, we have to find significant money for infrastructure development.

CD: Definitely. So what entered into your decision at this end of things when you were approached by New York? Who was involved – who were the people that had to sign on?

JAS: Good question. You know…we work for Brigham and Women’s; we were under the division of Global Health Equity, so we’ve always had an administrative boss there. So they certainly were advising us in that decision; the executive dean of PIH had to weigh in as well. But I would say 70% of it was us. I don’t know. If you ask Heidi…I think Heidi developed her desire to impact the health care system, developed over time, the desire to impact it in a significant way – statewide or nation-wide – developed over the last twelve years, since she founded the program. I don’t necessarily…I don’t know. It’s a really interesting question, whether she had that idea when she was in her internship at Brigham and Women’s,
she’s a physician. I suspect not. Because it wasn’t until we saw the incredible results that we got the idea that, ooh, this would really work for other programs.

So we just really needed to get them on board behind us. They weren’t doing a whole lot for us, especially the Brigham. It’s really more an administrative – we get paid from them, HR comes through them, it’s not…although, we are now gradually moving away from Global Health Equity and into Primary Care at Brigham. And the reason is that Global Health Equity – which has gone through three names in the past seven years – was created only seven years ago, for the physicians of PIH to have an academic and administrative home. Because they all worked at the Brigham as well, and they needed an institution to do their research through. So the medical school and the Brigham became one of the employers of the various different people who work at PIH. When you ask people, particularly the clinicians, they work for the medical school, or for Brigham, or for PIH, or for the Brigham through Global Health Equity. It’s really confusing – the three pillars. PACT, as the only US-based PIH project, was kind of like a black sheep; we didn’t really have a home. We used to work for PIH, we used to get our paycheck from PIH. But when the Division of Global Health Equity, which was called the Division of Social Medicine and Health Inequalities seven years ago when it was created, was developed, PACT went under there. Which doesn’t really make sense, because it’s not a direct service department. So over the last two years or so, we’ve been gradually increasing our visibility at the Brigham, and now we’re being moved under Primary Care, where the community health centers and other community programs are located. Ultimately, our hope is to get funded through the Brigham. We literally get no money from them. We get in-kind support, which is important. But now that we are this replication institute and we’re sitting at important tables around health care reform, and we make the Brigham look good, because this is a high-impact community service for people who are born of color in the community that the Brigham serves, they’re touting us in all their sort of fancy – both legislative, and funder, meetings, we are hoping that they’ll put their money where their mouth is and give us some start-up money for this replication, for this whole sort of – it’s got a couple of different arms. It’s adaptation, it’s advocacy, continuing our existing HIV services.

**CD:** So at this point, it’s just you who has been doing all the technical assistance and…

**JAS:** Well, I do the training and technical assistance, but the start-up stuff – all of our program design stuff with this managed care organization – has happened between Heidi and the project manager of that project, specifically, and our director of operations. And I’ve attended the relevant planning sessions to training and technical assistance; for actual program design, I’m much more on the programmatic end, and they’re more on the administrative end. But Heidi does both.

**CD:** Kind of a clarification question on the new direction that the NYC project is going in, as of a few months ago – what do you think changed? Is it just the one person – is it just the personal leanings of this director of HIV services? Or, you mentioned there was a big shift…

**JAS:** Actually, the previous director was the one who was much more enthusiastic about it. I don’t know. It’s still too early. I really am as aggressive about marketing our services, so to speak, because we were really at the place of saying, “Well, they’re just not motivated – they don’t see, they can’t, they don’t, they’re not able, whatever – to recognize that they need more support to have it be more consistent with our model.” So we kind of put a full court press, and decided to make another attempt at rebuilding the relationship. It’s not that it failed, just that they said, “Oh we have no money, get back to us in a while. Oh we have no money, we have no money,” and finally we went there and, somehow, we convinced them that it was really important. We also decided that we needed to dedicate a significant amount of time to –
so, once we were there saying “this is what we can provide for you,” we needed to be able to provide it for them. And part of the reason we couldn’t do that previously is because we didn’t have the staffing to do that. I tried to hire a program manager in HIV services for a year and a half; the other senior management role, the clinical supervisor, I tried to hire for two and a half years. Long story. So I was the only one doing the direct services oversight, so we just didn’t have bodies to do that. And it really didn’t make sense to hire someone who didn’t know the program, who didn’t know the services, couldn’t really do the training, so we waited until we hired those folks, and my time was freed up, so we actually had bits of Heidi, me, to dedicate to training and technical assistance. And that’s when – the timing was right then, because we had now greater capacity, even though we didn’t have capacity like we hoped we would do, could, and said, “this is what we can do for you. This is why we think you need this.” And they said yes. Not immediately.

CD: What do you think swayed them? Do you think that the hybrid program, the current status, wasn’t having the clinical or the cost-effectiveness…

JAS: No, they didn’t even know yet. They didn’t have that data yet. They don’t have the data. They have the data from the pilots, but they didn’t have the data from the more hybrid version. I don’t know. I don’t know. I do know that the folks that I’m dealing with are very enthusiastic. So it’s the one step under the director of HIV services -- are very enthusiastic. We’ve built a really good relationship. They’re new. So I don’t know. I mean it had to come from up above, right? They couldn’t make it happen after being there only for a couple of months. One of them, I think, in particular – the one who I think could really carry this – has only been there for like 2 months. So it must have come from the director. I don’t know…oh, you know -- I’d love to know this, I really would, and now that you’re asking about it I think I really should explore it – it could have been partially due to the earthquake. The director of HIV services is Haitian, she went to Haiti, and she lost family members. She has connected with PIH in the past, has a personal link to PIH. That may be relevant. I don’t know. I don’t know. I really don’t know. I mean in the meantime, we have honed our data. We’re out there as best practices in various different AIDS research groups. We’re getting much more press, PIH is getting much more press, and we have more data to show our success. So I think probably all of those things play a part.

The other is Heidi. She’s a very charismatic and convincing person; she’s really good at, not unlike Paul, bringing people on to this idea.

CD: That’s so interesting. Do you hope that, in future replications if it should happen again, do you hope to have a more rigid package that – for example in New York, that each of the 28 centers would have to sign on to? Like, less adaptation at each site?

JAS: Versus replication? That’s a great question. We are writing up right now kind of a qualitative analysis of the lessons learned from our diabetes project across the street, which technically failed. In some ways. I mean in that they probably aren’t going to be able to maintain the project; they didn’t fail the individuals who received the service, or the CHWs who learned so much. But the goal of that was to test the feasibility of this model at that health center. And just like in any different site, it has a different personality and different dynamics that made it less successful, even though they’re right across the street, even though we’ve known them for many years. So this qualitative analysis we’re doing is interviewing all of the people involved: from patients to CHWs to clinicians over there, to program managers over there, to program managers over here, to me, to Heidi, to CHWs over here with HIV – and where we’re leaning is just you just said. To create a more comprehensive assessment tool, so that the necessary infrastructure is in place for an organization, the buy-in, the culture, and that we put more energy there in
the beginning and not necessarily…and also present the whole package. Not present, you know – we’re not giving this away now. We’re not giving just the patient curriculum, or just 3 days of training for a group that wants to know about us or does something similar. What we’re doing is creating an institute, and our niche, of what this model is, and what are the required components of it, so that it then can be clinically successful or have similar outcomes. Now, that’s not to say that there won’t be differences in every site that we go to. Absolutely. And we’ll learn a lot from that. But those are the largest lessons learned for us.

And it’s really - part of it is a switch from being direct service providers. I mean, I’m a social worker. I’ve been doing direct services, as a manager, up until 6 months ago; and Heidi’s a clinician. And we’ve been doing program design stuff, but it’s moving from this direct service way of thinking to a consultancy – a training type of institute, a group that has other institutions prepare and then successfully carry out this program plan.

CD: What do you think are the chances that this full package, with more detailed specifications for what are the important ingredients of the PACT model, what are the chances that Boston would involve that in their own DOH?

JAS: Good question!

CD: or even other cities. Do you think that would still be – would people still seek you out?

JAS: So – this project through this managed care organization will be a six-site…in six out of the seven zones of Massachusetts by the end of 3 years. So, in two more years, theoretically. So that’s with a large number of people with Medicaid; I don’t know what the ultimate patient number is supposed to be, somewhere close to 20,000 patients, with lots of different diseases.

CD: And that’s accrediting CHWs, but not specifically the PACT model?

JAS: It’s the PACT model Plus. Plus NPs and behavioral health people. But that may shift. That may shift. We might do a little more of this personnel role, and a little bit less of this, because we’re still in pilot stages. And those are collaborations with – for example, the first site is with Cambridge Health Alliance, which is all of the Cambridge and some of the health centers and hospitals. The next is in MGH, starting in January, with a couple of their community health centers. So they’re all with the major health institutions in the state. That has got to get us greater visibility with the DOH. We have relationships with the DOH HIV services; they haven’t done a whole lot in terms of getting the word out for this model. They have never funded us. Oh that’s not true – one little pilot project. The DOH HIV Services came to us and said we want to replicate your model, we want to put a small RFP out for your model. We gave them our curriculum, they went out on home visits with the CHWs, they wrote this RFP, and then they didn’t fund us. It’s a really long story. So I think it will happen. I just got an email back from the head of HIV services at the DOH here in Massachusetts saying – she wrote me three months ago and said we really want to learn from you, we’re thinking about the role of the CHW in all of our services. And I wrote her back and wrote her back, and they couldn’t fit it in. and so now that’s not going to happen until January. Which is not atypical. I mean, they just had major funding cuts in HIV services. So there’s a lot of things going on at the same time. But I think it’s a good sign. And Judy Bigby, who’s the head of HHS for the state, is a friend of PACT’s; when she worked at the Brigham, she’s one of Heidi’s mentors. John Auerbach, who used to be with the city and is now with the state DOH, knows us well, his chief of staff is a good friend of mine.
I mean, this will happen eventually. Whether we actually mold ourselves to fit in to qualify for Ryan White funding for HIV Services, which we really need to get funded these days, is a little unclear.

**CD:** Do you think that it’s possible to replicate the PACT model with integrity – the full package, once that’s more clearly set out – when coming from a place of cutting costs, and being in a very tight budget, and being motivated by the huge cost-effectiveness of PACT? Or do you think that that can’t be the mission in order to be true to the PACT model?

**JAS:** Oh, it definitely is part of the mission. It definitely is. It’s not the first goal, but it’s easily a secondary goal. And we have to think about selling or marketing this program in a way that speaks to the bottom line of these institutions. It’s cost savings, but it’s also cost shifting. It moves more of the costs under outpatient care, which is the goal, than inpatient care, which is much more expensive. So like, substance abuse treatment, mental health treatment, pharmacy, that kind of stuff. Which in general is much more affordable. And insurance companies would not be interested in us if we didn’t offer a cost savings piece. They wouldn’t. we would have none of those relationships. So I definitely think that’s a huge piece. And that speaks to the broader health reform goals; there are these development of compatible pair organizations – I don’t know if you’ve heard about these- that are springing up in Massachusetts and around the country, medical homes, which is this term that was created – so it’s kind of one stop shopping. You get all of your services in one place, you don’t go outside of your network for everything related to your health. And it’s sort of like the old community health center model, but there’s much more attached to it. And we fit in there, as CHWs attached to that, at serving the whole patient community of that clinic or that organization, that service provider.

**CD:** Thank you so incredibly much!

**JAS:** Well please feel free to email me any additional questions – or if you want documentation of stuff, or copies of outlines, or whatever.

**CD:** That would be fantastic! And would it be possible for me to email you names of who to talk to in New York? I know you mentioned a lot during our time.

**JAS:** Sure! I’d be happy to.

**CD:** This was really an honor for me to talk to you, I’ve read so much about your work since years ago.
WORKS CITED


