The Social Life of Health Policy: An Anthropological Inquiry into the Affordable Care Act (ACA) and HIV/AIDS Care in Atlanta, Georgia

Fauzia Aman Malik
Ph.D. in Medical Anthropology

School of Social and Political Sciences
The University of Edinburgh

May 2017
Abstract

The purpose of this thesis is to ethnographically explore the social life of health reform policy. This thesis focuses on the Ponce Center, a safety net HIV clinic in Atlanta. The thesis engages with a fragmented healthcare world, and the inhabitants of these worlds who are charged with rectifying the fragmentation and make care possible. They are, in technical language, service providers, whether they are policy-makers, patients, or political activists. In order to make the healthcare and policy worlds functional, the AIDS community in Atlanta perceive their first task as attempting to connect aspects of the fragmented healthcare assemblage that are otherwise disparate. The core theme of this thesis is articulations, translations, and piecing together aspects of everyday life particularly with regard to various ways of contending with fragmentation.

This thesis explores the relationship between the affective, ideological, physical and structural dynamics of inequality, poverty, vulnerability, identity, and a sense of community and belonging. This thesis is about the policy processes. It does not focus on policy-making, but policy interpretation, implementation, and enactment in Atlanta, Georgia. The thesis tracks the appropriation and contestation of the Affordable Care Act (ACA) as a site of interaction between the experience of HIV as a pre-existing condition, inequitable access to treatment through health insurance, and larger social policy and poverty discourses. Finally, it considers the processes by which major policy reforms draw in disparate actors, who are embedded in complex networks of power and resource relations – assemblages - and inevitably play a role in reshaping society.

Declaration

This is to certify that the work contained within has been composed by me and is entirely my own work. No part of this thesis has been submitted for any other degree or professional qualification.
Acknowledgements

First and foremost, I thank Allah (SWT) because without Him, I would have not reached where I am in life today.

Dedicated to Zuizz and Saad – my world revolves around you!

Zuizz, you were five years old when I left for Edinburgh to start this PhD – leaving you with dad - you were so brave and you gave me strength with your reassuring smiles everyday on Skype. Saad, you supported me for seven years like I had only imagined a perfect soulmate can do. You both patiently waited for me for these long years, encouraging me every single day to give it my best, and I am eternally grateful for that – you are the wind under my wings. This one is for you!

I benefited at every step from the experiences and labour of others who helped me understand this work and they are much deserving of my gratitude. Ponce de Leon providers, staff, and patients: Thank you for welcoming me to your world and helping me understand it. I learnt a lot from y’all.

In memory of Jacqueline “Jacque” Tucker Muther, Ponce De Leon Center, Grady Infectious Disease Program. Jacque, thank you for taking me on this journey with you, the way only you could have done. our bi-weekly meetings kept me abreast with all the connections you were part of in this assemblage. I am forever indebted to your vision, life-long passion and commitment to help others, and kindness towards me.

Thank you, Vince for being a great friend and colleague. Without your guidance, encouragement, and kind introductions, fieldwork for this research would have been very difficult. Our formal and informal discussions played a huge role in selecting the Ponce Center as my site and developing research ideas. Your review of my chapters helped me stay on the topic and corrected factual inaccuracies in my translation of data. Huge gratitude to both Jeff Graham of Georgia Equality and the late Jacque Muther of the Ponce Center, who guided me throughout the length, breadth, and depth of policy and HIV worlds. You virtually gave me ‘a seat at every table’ in the country you sat on in the HIV AIDS and health
policy world. Through you, I gained an exclusive access to the inner-most circle of major actors in health and HIV policymaking and implementation, not only in Atlanta but at a national level. Dr David Reznik, Jacque’s work spouse, who tried to fill her role once she was gone. Many of these people acted as my editors, proof-readers, and fact checkers, thank you all very much.

Thank you, Professor Dr Carlos Del Rio, for setting up the most efficient specialized HIV AIDS research unit at the Ponce Center – riding with your outreach teams on the ground, I saw parts of Atlanta, HIV policies, and treatment world, that I would have never known even existed. You are a perfect boss and I highly appreciate your unwavering support during these years.

A big thanks to Dr Sandy Thurman from Emory CFAR/former Clinton Administration HIV AIDS Czar, and Larry Leeman from Gwenith AIDS Clinic for their kind contributions to my knowledge and understanding of the history of HIV epidemic and development of related policies in the U.S., especially South. Dazon Dixon Dielo, from SisterLove Inc., who showed me how her part of the HIV and policy worlds was deeply rooted within communities, especially women of color – and opened up those connections for me. Thank you, Dr Wendy Armstrong, Director of the Ponce De Leon Center, Dr Melody Palmore, Director of Women’s Health at the Ponce Center, and Kishna Occie, Chris, Charlie, Chris F, for introducing me to your patients, answering all my questions in detail and taking me out on the rides with you in the community.

I express my profound gratitude, respect, and deep admiration to my thesis adviser, Professor Richard Freeman, at the University of Edinburgh Social Policy. Your thoughtful and judicious comments on my work challenged me and moved my work in the right direction. You have been inspirational, supportive, and encouraging throughout my final writing period - my God-sent guardian angel. I wouldn’t have reached the finish line without you.

Thanks to my other PhD supervisors, Dr Rebecca Marsland, and Professor Ian Harper. A special acknowledgement and thank you to my internal and external examiners, Fadhila Mazanderani of School of Social and Political Sciences, University of Edinburgh and Hayley MacGregor from Institute of Development Studies, University of Sussex. Thank you for reading my work
thoroughly, having a lively discussion with me during the viva which I immensely enjoyed, and providing constructive feedback on the final draft of this thesis.

Special thanks to my dear friend Kali DeDominicis for being there in toughest of times – your constant encouragement ‘you’ve got this’, meant a lot to me and kept me going. The time you spent discussing my work and helping me hash out my ideas is priceless. You provided me with substantial comments at various stages of the draft along the way. You became my intellectual buddy that I badly needed in this lonely PhD journey. Also, thank you for formatting this thesis – that was a bonus.

Professors Peter Brown, David Nugent, and John Blevins, my other senior intellectual buddies and moral supporters at Emory University Anthropology and Public Health - thank you for being there in all my academically good and bad times. Peter, especially for dropping useful hints while I enjoyed the coffee with you from the old, but very good, coffee machine in Anthropology department’s kitchen.

To my parents, Aman and Farzana, and my other set of parents – my sister Zahida and my brother-in-law Sohail Khawaja, thank you all for your unwavering moral and emotional support and unconditional love. All my achievements are the result of your prayers. I am grateful to my sisters and nieces Sajida, Naila, Maha, Mashail, Mariam Chawla, Ayesha Baber, Saniya, Faryal, Sarah. My brothers and nephew Babar, Badar, and Zohaib. Thank you y’all for your patience and being there for me when I couldn’t be there for any of you.

Last but not the least, one final shout out to my amazing crews - Kali, Diego, Koreen, Don, Laura Major, Eowyn, Kimberly, Natalie, Sarah Lopez, Chrissie, and Len – and many other friends I found in beautiful Edinburgh during these rollercoaster seven years. My life-long friends - Prachi, Filza, Claudia, Shagufta, Pratibha, Muzna, Sarah, Tanya, Farah, Shazia - I am eternally grateful for your presence in my life, your prayers, your encouragement, and your moral support.

Without the help of any single one of these people, this PhD would not have happened – it was meant to be so the universe came together!
Table of Contents

Abstract .......................................................................................................................... 1
Declaration ..................................................................................................................... 1
Acknowledgements ....................................................................................................... 2
Table of Contents .......................................................................................................... 5

Introduction: A Brief Encounter .................................................................................. 7

Chapter 1: A Critical Anthropology of Policy .............................................................. 15
‘Doing Policy’: Articulation, Meaning-Making, & Assemblage .................................. 17
Healthcare, Welfare, & Governmentality: The Intersection of Policy, Race, Poverty, & Illness ................................................................................................................. 27
Policy as an Object, Site, and Method of Study............................................................ 47
Conclusion .................................................................................................................... 61

Chapter 2: The Social Life (and Context) of the Affordable Care Act ....................... 63
Fields of Contestation: Liberal vs. Conservative Ideology & the Fragmented American Healthcare System ................................................................. 65
‘The Plan Was Too Conservative’: Clinton Era Health Reform ..................................... 75
‘We Had No Choice’: The Affordable Care Act .......................................................... 87
Conclusion .................................................................................................................... 98

Chapter 3: ‘It’s Not a Clinic, It’s a Center’: The Ponce Center as a Nexus of HIV Care for Marginalised Populations in a Major U.S. City .................................................. 101
‘The Shrubbery Negotiation’: The History of the Ponce Center & the Ryan White Program .................................................................................................................. 103
‘One-Stop Shop’: The Symbolic & Social Space of a ‘Center’ ..................................... 112
The Anatomy of Space & Social Networks at the Ponce Center .................................... 119
Conclusion .................................................................................................................... 128

Chapter 4: Being a Patient at the Ponce Center: Profiles from the Field ................. 131
‘Don't be a Dumb-Dumb’: HIV Diagnosis & the Disruption of Becoming a Patient .......................................................... 135
Performing Responsibility: Negotiating Patient Identity within a Fractured System ......................................................... 144
‘Why do I need new health insurance? I already have one, it's called Ryan White’: The Ponce Center in Patients’ Lives ............................................................................. 152
Conclusion .................................................................................................................... 162

Chapter 5: Policy in Georgia: Window onto the Modern State ................................... 165
Appropriating the ACA: Competing Narratives of Health Policy Reform & Implementation in Georgia ........................................................................................................ 168
On the Ground: Activism & the Legislative Process in Policy Implementation .......................................................................................... 178
Doing Assembling: the ACA at the Ponce Centre ....................................................... 190
Conclusion .................................................................................................................... 201

Conclusion: Tracing the Social Life of Policy .............................................................. 203
Piecing Together the Fragments: Contribution to the Concept of Assemblage ....................... 207
Glossary........................................................................................................................................... 217
Bibliography..................................................................................................................................... 219
Introduction: A Brief Encounter

‘So essentially you are leaving us to the natural progression of the disease like you did with syphilis?’ Shocked, I looked up at the pale, plain, middle-aged woman with dark, piercing eyes who had spoken. She was referencing the infamous Tuskegee syphilis experiment (1932 to 1972), when the U.S. Public Health Service declined to provide treatment to African American men in Alabama, so they could observe the natural progression of untreated syphilis. The majority of subjects were not even told they had the disease. Throughout my three years of research, most of the (predominantly black) HIV patients I encountered were aware of this study; it informed their perception of the establishment as consistently uncaring, untrustworthy, and racist. This history of profound stigma, mistrust, hopelessness, and fear is deeply engraved in the African American psyche about the relationship between vulnerable minority categories of citizens and the government institutions that hold power over them. Thus, my observations cannot be separated from the race and class dimensions of HIV’s rapid spread in the American South.

I hadn’t paid much attention to this woman during the hour-long community health education session about HIV/AIDS testing and treatment that was just ending, except that she was directly in my line of sight across the oblong table. Under renewed scrutiny, her short blonde hair and button-down collared shirt over khaki trousers marked her as out of place, as did the sweater folded on her lap and the large brown hobo bag beside her on the plain cement floor – white and middle class in the back room of this African American church in a rundown neighbourhood where most houses were boarded. It was getting dark outside. Most people were already leaving; volunteers were returning the clumsily whitewashed room to its classroom layout, but four of us remained in an informal circle. Steven, our facilitator, did not look as shocked by the woman’s statement as I felt. Neither did Raven, the Ponce Center community outreach worker who had accompanied me here.

It was the early summer of 2011, and I was trying to find a field site from which to conduct an ethnography of the new era of health policy reform ushered in by

---

1 All American place and policy names will be spelled in American English.
the passage of the Patient Protection and Affordable Care Act (ACA) in 2010. I had been introduced to Steven and Raven by a colleague at Emory University, Dr Vincent Marconi, who strongly suggested the Ponce De Leon Center as a possible field site: a comprehensive HIV/AIDS Care Clinic in Atlanta, Georgia, also known as the Emory University and Grady Hospital Infectious Disease Program. Steven and Raven mostly worked for the Ponce Center as community mobilizers, talking to communities about advancements in HIV treatment and recruiting people into clinical trials for new medications or approaches to care. As I accompanied them on occasions such as this education session, I discovered that Vince was right: the Ponce Center existed at an anthropologically fascinating nexus within a network of services, people, and organizations – from the national CAEAR (Communities Advocating Emergency AIDS Relief) Coalition, to local Atlanta charities like Living Room and Open Hand that provide housing and food respectively, to individual activists and advocacy organizations like Georgia Equality and SisterLove Inc., to their affiliation with the Grady Hospital and Emory Healthcare System. Furthermore, the Ponce Center was a site of cultural contestation; a physical space in which neoliberal policy ideologies about controlling healthcare costs struggled against public health and medical humanitarian ideologies of humanistic caring. Shadowing people like Steven and Raven not only helped me understand the everyday practices of the Ponce Center and its patients, it also illuminated the Center’s position at the core of local and national AIDS treatment, research, advocacy, and policy assemblages.

It was Raven who answered the woman’s question: Most HIV patients are dependent on Medicaid, the government safety net health insurance program, because until the ACA was passed, HIV was a pre-existing condition that excluded them from the regular health insurance market. However, they are only eligible for Medicaid if they earn under the Federal Poverty Level (FPL). Thus, Raven said, their health coverage drops as soon as their earnings move ‘even $100 above [the FPL], and they pull the rug out of your feet – just like they do with any other safety net benefits e.g. food-stamps’. An HIV diagnosis didn’t change that; the only way to get back on Medicaid was to claim total coverage
under the Disability Act, but that required a diagnosis of a full-blown AIDS, clinically defined as a CD4 count below 200. Thus, the woman was correct – she had to let the virus take its natural course until she was sick enough to qualify for treatment. I was shocked by this too; although I had thirteen years of experience in public health, I had never before directly worked on HIV. Raven explained that the Ponce Center helps people deal with those Medicaid and other safety net issues because it is funded by the Ryan White Program (RWP). Ryan White is a ‘payer of last resort’: when AIDS patients have no other resources, this federal program will cover the cost of their care. Steven suggested that the Ponce De Leon Center was specifically interesting because, as a RWP clinic, they were working on filling these particular gaps in patients’ access to care.

The woman’s poignant quote, ‘the system is going to observe me descend into AIDS’, opened my eyes to how broken the American healthcare system really is. It helped me realise the significant disconnect central to our fragmented healthcare system: we were talking about disease and infirmity as if it was a natural, unmodifiable biological phenomenon, not something that could be mitigated by social and policy interventions or informed by the embedded racial and social divisions of the American South. She was right; this policy approach was illogical from the medical perspective of preventing and controlling an epidemic. An HIV diagnosis, once a death sentence, now had advanced and proven medical solutions that were being actively obstructed by policy. This shaped my decision to structure my research around the intersection of HIV and policy as they are experienced and enacted in the physical and ideological space of the Ponce Center.

This thesis is, therefore, a work of both medical and policy anthropology; the former because it deals with the everyday realities of living with sickness and providing care, the latter because it gives special importance to the symbolic and practical aspects of policies as they impact those everyday experiences. This policy focus enabled my analysis to concentrate, or so to speak, put a spotlight, on artefacts like language, objects and actions - thus revealing cultural myths developed by people that surround contested policies in the Malinowskian sense that it conveys fundamental underlying values (Shore and
Wright 2011: 35). Similarly, my interpretative analytical framework is focused mainly on how the meanings inherent in and influenced by public policies help us understand how modern identities and ideas are shaped around conceptions of humanity and citizenship (Yanow 2000; Shore & Wright, 2011).

What makes the connection between healthcare, policy, and identity especially interesting is that it enables the examination of how policies are used to achieve cultural and political goals. Political economy of health experts, Rylko-Bauer and Farmer (2002: 478) said ‘the problems of health care, illness, are problems of society’. Unequal access to healthcare in 2017 still reflects that larger social problem: a market-based principle underlying the logic of a social world that have been guiding American society’s approach to medicine. Ethnographically understanding the ‘work’ of the Ponce Center as both ‘highly abstract and immediately practical’ (Freeman 2014: 3) constitutes the interpretive paradigm – intentions, meanings and practice – that guide healthcare policies and HIV care in the United States. Policy anthropology is an approach pioneered by Shore and Wright (1997: 4), based on the premise that ‘from cradle to grave, people are classified, shaped and ordered according to policies...the study of policy, therefore, leads straight into issues at the heart of anthropology: institutions and power; interpretation and meaning; ideology, rhetoric and discourse; the politics of culture, ethnicity and identity; and interactions between the global and the local’.

A policy finds expression through a sequence of events; it creates new social and semantic spaces, new sets of relations, new political subjects and new webs of meaning; in short, policies are instruments of government (Shore & Wright 2011). In this respect, this thesis not only tracks the debates around the ACA but also tries to capture the sequence of events before and after the passage of the policy into law. Thus, this ethnography examines the interpretation, implemented and enactment of the 2010 Patient Protection and Affordable Care Act (ACA), in Atlanta, Georgia. It investigates the fragmentary nature of U.S. healthcare assemblage and policy, focusing on the experiences of the HIV/AIDS community at a time when ‘prevention’ has become dependent on ‘treatment’.
The purpose of this thesis is to investigate the ‘social life’ (Appadurai 1988) of the policy by tracking the appropriation and contestation of the ACA as a site of interaction between the experience of HIV as a pre-existing condition, inequitable access to treatment through health insurance, and the larger social policy and poverty discourses, as localised in Atlanta – a large city in the most impoverished region of the United States (U.S. Census Bureau, 2013). This thesis documents the implementation of the ACA in real time – as it is translated and implemented in a specific location. Significantly, the ACA is one new part of a peculiar, constantly and rapidly-evolving patchwork of policies that forms the American healthcare assemblage. As a policy, it was trying to reform the nation’s fragmented healthcare system by providing coverage to as many Americans as possible, particularly the vulnerable who had not previously been able to access care. Critics of the ACA allege that by simultaneously expanding private health insurance and Medicaid (government funded healthcare for low income individuals), rather than moving towards a single payer system, the new policy keeps the fragmented assemblage of health system intact (Horton et al, 2014). This fragmentation needs to be constantly addressed through processes of articulations and assemblages. The ACA also interacted with the national HIV AIDS strategy, which identified the overlapping African Americans and HIV communities as priority vulnerable communities that must be addressed through the ACA health policy reform.

I tell the story of the ACA through the story of the Ponce Center, with a particular focus on the practices of activists and healthcare providers who must re-make the connections between the vast array of actors, organisations, disciplines, funding sources and other policies every day in order to provide care to HIV patients. This focus on providers allows me to ask a different set of significant questions about how the ACA as a policy influences the concepts, norms, or institutions within a particular society (see Yanow 1996, Shore & Wright 2011), and how people adopt, resist and negotiate the meaning of policies through their work and practice. My thesis studies what the ACA means to this particular community in this particular place and traces the connections and social
relationships between the Ponce Center and the wider healthcare assemblage. This illuminates the health system fragmentation, articulations, meanings, changing identities, and connections that ultimately make the policy implementable. Chapter 5 furthers the re-translation task that was limited to the Ponce Center in Chapter 3, in order to expand into newly created spaces and draw out those unintended consequences of interaction with other social agents.

The ethical, moral and social politics of AIDS has been largely unexamined in the recent debates about healthcare and access to treatment for the most vulnerable. Policy does not come from nowhere: it is socially and politically constructed. Similarly, policy is not merely implemented; it is enacted, resisted, exploited, re-interpreted and re-translated in the social and political spaces created by contestation about it. An HIV/AIDS clinic has a unique position in this policy/political struggle. Thus, as the central field site for my research, observing the actions and practices taking place within the Ponce Center allowed me to describe the different worlds of HIV-positive people by navigating the existing set of social and political dynamics, to examine how they interacted with the new policy. Studying how policy processes create links between agents, institutions, technologies, and discourses and bring all these diverse elements into alignment is analytically productive because it illuminates specific social forms in which integration may become possible.

I used ethnographic methods – participant observation and interviews – to primarily focus on healthcare providers and political activists as subjects of policy who act to buffer the policy’s impact on their patients by mediating and negotiating its meanings and provisions (Lamphere 2005, Waitzkin et al. 2002). My focus on healthcare providers and activists along with patient perspective – a significant part of my research, used to ground and contextualise my ethnographic analysis – is an acknowledgement of the fact that it is important to recognize how the ACA policy shapes and is shaped by different actors. This thesis is an effort to address a significant gap in the anthropology of health policy by focusing on the perspectives of the governing as well as the governed.

Chapter 1 presents a literature review on the anthropology of policy and a methodological discussion. It explicitly articulates the connections between
different strands within and between several sub fields of anthropology, medical and policy anthropology, welfare, translation, symbolism, and meaning-making that form the core of my theoretical framework. Chapter 2 follows with an examination of the historical developmental trajectory of the broader context of the fragmented American health care system, welfare and poverty discourse, and contextualizes the ACA within it. It also presents and critically analyses the trajectory of policy development that created a comprehensive ‘cocooned’ care system for the HIV AIDS in the broader U.S. healthcare assemblage. This includes an explanation of the social and ideological environment out of which these policies grew out and labelled people as deserving or undeserving of the benefits of the social contract between the state and its citizens.

Chapter 3 takes up the task of meaning-making and translation. Drawing heavily on classic symbolic anthropology, it examines the Ponce Center as a ‘One Stop Shop’ – an organizational metaphor that shaped the Center’s articulation of policy and the role of the language they used to convey their policy translation and action meanings to themselves and to broader healthcare assemblage. Based on the ideas of holistic and comprehensive care, it also considers the Center as a built space, a symbolic object that conveys the meaning of policy. It presents the perspectives of care providers, who are the direct link between broader health assemblage and the patients – individuals impacted by assemblage of policies, resources, practices, and politics. It talks about the ideas of care and the exceptionalism of care for this particular disease within the most expensive healthcare system in the world (and how it compares to the same idea practiced elsewhere in the world – e.g. one-stop shop in South Africa). Chapter 4 is a companion Chapter to 3 and presents the same process of translation and articulation of policy from the patients’ perspective. It is about identity as a multifaceted, intersectional construction that patients must articulate, negotiate, and perform that reflects both patients’ self-perceptions and their interactions with others.

In Chapter 5, this individual and organizational identity phenomenon becomes a national identity story. The appropriation, enactment and implementation at
a state level brings the ACA to a larger setting where the policy’s meanings are not just debated but put into practice, and new translations are produced to keep the existing assemblages intact. It focuses on the articulations which intensified to appropriate and implementation this policy. The processes explored in this chapter are highly politically and socially charged, but they are also deeply moral and emotionally affective for the people, as these assertions and counter-assertions shape and contest the American national identity, asserting what America should be, what it means to be an American living with HIV and seeking access to care. In essence, this chapter is about what the ACA means, what the policy does, and how it ‘lives’ in the minds of politicians, activists, patients, and healthcare providers and in the operations of the Ponce Center and the Georgia legislature.
Chapter 1: A Critical Anthropology of Policy

From an anthropological perspective, much of existence in modern societies is dictated by policies. Policies are major instruments through which governing bodies classify, regulate, shape and order people and spaces they seek to govern. Accordingly, policy is a fundamental ‘organizing principle’ of modern society (similar to ‘nation’, ‘family’, ‘class’), that helps shape social relations and makes up their realities. Wedel et al. argue that ‘even the concept of individual rights and the “private citizen” are, in effect, artefacts of policy’ (2005: 37). Thus, this ethnography of the ACA illuminates the details of what a policy does, how it works, how it is implemented, and how it is enacted. This ethnography also sheds light on broader American culture and society; the ways people, as ‘reflexive subjects’ conceptualize or question how they are being constructed and negotiate the meaning(s) of categories such as sickness, access to care, citizenship, and freedom. Moreover, it illuminates the ways people intersect with institutions and policy, and how those institutions respond to their needs (Giddens 1991). In effect, this is a study of how a policy lives its ‘social life’ from its conception and passage as a law to the point where it impacts the lives of individual people.

Shore and Wright argue that policies are fundamentally political: ‘A key feature of modern power is masking of the political under the cloak of neutrality’ (1997: 8-9). Looking beyond the ‘constraining dimensions’ of policy, where it is perceived without a conflict, can therefore help illuminate how modern identities and ideas are shaped around ‘what it means to be human’ (Wedel et al. 2005: 35). In an anthropological sense, this function of policy is comparable to ‘myth’ in the Malinowskian sense of ‘a “charter for action” or a charter conveying assumptions, values, and meanings about how to live’ (2011: 35). This connection allowed me to examine how policies are used to achieve cultural and political goals. For example, both Liberals and Conservatives present the ACA policy as a legal way to assert their translation of what American values are and how they need to be interpreted in order to shape the society (see Chapter 5).

The anthropology of policy therefore ‘takes policy itself as an object of analysis, something to be problematized, historicized and contextualized’ (Wedel et al.
to study an entire realm of modern power relations, which is why and how this focus differs from other disciplines that study policy. In Clarke et al. (2007: 139-40), policy becomes a Foucauldian mechanism of governmentality:

Inherently and unequivocally anthropological...as cultural sub texts, as classificatory devices with various meanings, as narratives that serve to justify or condemn the present, or as rhetorical devices and discursive formulations that function to empower some people and silence the others – ‘a type of power which both acts on and through the agency and subjectivity of individuals as ethically free and rational subjects’ (Shore & Wright 1997: 6).

This conception also aligns with Foucault’s (1980) concept of dispositif:

the ‘ensemble’ of practices, institutions, architectural arrangements, regulations, laws, administrative measures, scientific statements, philosophical prepositions and morality that frame the disciplinary space (Dreyfus & Rabinow 1983: 121).

Thus, it is useful to analyse policies through the lens of apparatuses of power that define populations and manage the subjects of policy (see Shore & Wright 2011, Feldman 2011, Muller 2011). In addition, while dispositif covers how ways of being and doing are framed, habitus (Bourdieu 1977) adds an appreciation of the processes by which the actors then come to internalize, embody, and become habituated to those structuring frameworks. It is unclear how the elements that constitute a dispositif or habitus come together. The previously used dichotomous frameworks in social sciences like “structure vs. agency” obscure the complexities of policy processes that form ‘assemblages’ or ‘apparatus’. Anthropological analysis of the ACA policy implementation and the existing healthcare assemblage in this thesis takes its lead from Shore and Wright’s understanding that ‘it is precisely the way policy creates links between agents, institutions, technologies, and discourses and brings all these diverse elements into alignment that makes it analytically productive’ (Shore & Wright 2011: 11, emphasis mine).

This chapter elaborates on my theoretical framework and methodology, and engages with historical literature regarding U.S. social policy development. I also consider the literature regarding health policies and HIV care in other countries in order to situate this thesis and articulate its original contributions.
‘Doing Policy’: Articulation, Meaning-Making, & Assemblage

Global forms have a distinct capacity for de-contextualization and re-contextualization, abstractability and movement, across diverse social and cultural situations and spheres of life. Such forms are able to assimilate themselves to new environments, to code heterogeneous contexts and objects in terms that are amenable to control and valuation (Collier & Ong 2005: 11).

This thesis is about healthcare and a fragmented social policy world. It is about health and social policy processes; not about policy-making per se, but about policy enactment and implementation. The American healthcare system is fragmented into dozens of different agencies, providers, and sources of funding. It is also one of the most expensive in the world. Patients must contend with both problems in their interactions with the system, especially because this fragmentation is embedded in socio-economic inequality based on race, sexuality, and poverty divisions in American culture. However, the inhabitants of the healthcare system – the doctors, health managers and care providers, activists and others from the advocacy community – are particularly charged with rectifying its fragmentation. They are, in technical language, merely called ‘service providers’. However, this research demonstrates that they are active conduits and frequently act as policymakers or patients, in part because of the fragmentation. I will refer to these groups, patients, activists, and providers, collectively as ‘the AIDS community’ in this thesis.

The AIDS community in Atlanta articulate their first task as attempting to make otherwise disparate aspects of the fragmented healthcare connect; to de-fragment them, stich them together. They do this by securing funding and trained HIV/AIDS-specialist care providers, keeping clinics and hospitals open, operating labs and facilities, and providing medications and other relevant resources; in effect, it is they who make the healthcare and policy worlds functional by providing and paying for care. The central theme of their work, and of this thesis, is assemblage and then the concept of articulation: various ways of contending with fragmentation that this healthcare assemblage requires. The patients, by contrast, describe themselves as empowered citizens who have made informed decision to pursue the continuum of care (see Chapter 4), a perspective made possible only by the
actions taken and systems created by their providers. Thus, returning to the epigraph at the beginning of this section, the focus of this thesis is not only on ‘how this assimilation is constructed – but also deconstructed and reconstructed in specific contexts of engagement’ (Kingfisher 2013: 11).

A key part of the Ponce Center’s work, function, and institutional identity is the idea of holistic care. The Center is, intentionally and by definition, central: it is the point of convergence that brings together the funding, the patients, the professionals, and the policy. Furthermore, providers at the Center are trying to care for more than just patients’ biomedical ailments – they work with their families and communities to try to provide for their practical, psychological, and social needs as well. This model of holistic care – both in the sense of bringing wholeness to the system and caring for the whole person – is seen by patients and providers as the ideal healthcare ‘assemblage’. This ‘ideal assemblage’ within the larger, fragmented assemblage is called a ‘HIV care continuum’ (or ‘cascade’) model, which outlines the progressive stages of HIV care that people living with HIV undergo from diagnosis to attaining the goal of viral suppression (a low level of HIV in the body).

This thesis offers an original application of the theory of assemblages by drawing on Deleuze and Guattari (1987) to examine how providers at the Ponce Center transform the disparate strands of the American healthcare system into an integrated, holistic program of HIV care for each individual. This assemblage framework challenges conventional ways of understanding the structures that support our world (e.g., linguistic, discursive, symbolic, semiotic). It allows us to abandon the traditional boundaries of and distinction between subjects and objects, humans and non-humans. Indeed, anthropological studies of policies are based on the understanding of policies as ‘actants’. Actants have the agency to transform themselves as they develop associations and relationships with other actors, objects and institutions in varied contexts – which makes them opposite to restrained or discreet ‘things’. This conceptualization differs from conventional policy studies in that it calls for an understanding of policies as ‘assemblages’. Thus, the ACA is not simply the words of the law; it is how people perceive those words, and how their long-
term effects will cause people to perceive the ACA in the future – and then, how the ACA might change (in text or implementation) because of those perceptions. This thesis breaks down the main argument into three interwoven aspects: first, the health care assemblage in constant flux; second, articulations, which are a fundamental aspect of the practice and provision of HIV care at the Center to maintain that assemblage; and third, translations, the meaning-making processes of social experience that happen between people or other social entities, such as the news media.

Freeman writes that ‘The assemblage, then, constitutes an associational space in which interactions and relations between actors proliferate and intensify’ (2009: 5). This provides my key framework for analysing how healthcare professionals ‘assemble’ various individuals, policies, and resources provide care. I particularly draw on Freeman’s paradigm, which emphasizes that parts in an assemblage must be put together and held together as an active, ongoing process. In Freeman’s words, an ‘assemblage is an assembling, an activity doing assembling – not what is or has been assembled’ (2014: 6; Newman & Clark 2009). Thus, elements of an assemblage are always in-the-making, always on-the-move. For example, the fragmented state of the American healthcare system changes as different organizations and policies are added or removed (e.g., Veteran’s Affairs services, the Americans with Disabilities Act, and now the ACA). Likewise, understandings of identity and marginalization (e.g. race, sexuality, gender) are all embedded in American culture – thus, attitudes towards particular groups (and, by extension, their access to healthcare) change over time. Chapter 2 especially discusses patterns of distinctions with moral and ethical implications for healthcare that are based in American cultural values; specifically, the paired dichotomies between entitled and unentitled, insured and uninsured, guilty and innocent, drug users or gay people and ‘innocent victims’, and the role of the state and federal government versus individual liberties.

Freeman also notes, drawing on Phillips (2006), that the term ‘assemblage’ is an imperfect translation of Deleuze and Guattari’s (1987) original agencement. ‘The philosophical sense of the agencement refers to the way in which states of affairs and statements made about them come into being only in relation to each
other; its literal sense in French is that of an arrangement, of fitting or fixing’ (Freeman 2018: 129; emphasis mine). Those connotations are particularly important in the context of healthcare policy, and especially with regard to my informants’ efforts to reassemble the American healthcare system (see Chapters 2, 3 & 5). Thus, this thesis focuses on what Freeman calls the ‘particularities of [assemblage] realization’, on forging alignments through the ‘work of assembling, to how assemblages are formed, to the practices, routines and arrangements of those who create and build are engaged in’ (Edquist 2008: 380-84). Freeman (2014: 7-9), draws on Strauss (1988: 176), who understands that an articulation is a way in which its elements, (such as people and resources) are made to fit together over time... what we wish to know following the processual model, is how the organization manage to achieve the degree of articulation they do, and what their members must do to maintain it.

Thus, an assemblage is a product made up of articulations; or, more properly, it is the ongoing product and process of creating, altering, and adjusting the various articulations that make up a continuous network of actions, actants and relationships – and their effects. Gerson and Star add that the ‘articulation consists of all the tasks involved in assembling...articulation is deemed prior to assembling: articulation is a critical determinant of whether and how assembling happens’ (1986: 258-66; see Chapters 3 & 5).

Livingston (2012), represents articulations as acts of improvisation; they reveal serious illness, care, pain, disfigurement and death as deeply social experiences – activities, relationships, and meanings that happen between people. She describes the cancer ward as ‘a powerfully embodied social and existential space’ where one can ‘contemplate the meanings, practices, and politics of care’ (Livingston 2012: 8). Just as Livingston understands the cancer ward as a nexus of bureaucracy, vulnerability, power, biomedical science, mortality, and hope that shape contemporary experience in southern Africa, so too is the Ponce Center a similar nexus of emotion, medicine, and policy in the American south. However, Livingston is writing in the context of Botswana, a developing country. That resource-poor setting stands in dramatic contrast to the state-of-the-art facilities at the Ponce Center, which is the biggest HIV/AIDS care
centre in the richest country in the world. It is ironic that I am still able to draw significant parallels in terms of health disparity and unequal treatment of the poor in both countries. People who need the most assistance fall through the cracks because the issue is not just health treatment, but also ‘access to care’. However, healthcare is so burdened by economic and political instability, and HIV with stigma, that, paradoxically, being diagnosed with a deadly virus is the only way many American and Botswanan citizens can acquire material support from their governments (see discussion of ‘patient citizenship’ below).

Another classic anthropological work that parallels my research is Joao Biehl’s *Will to Live: AIDS Therapies and the Politics of Survival* (2007). Biehl was working in Brazil, where health is a constitutional right rather than a privilege that must be purchased, as it is in the United States. Brazil began the free provision of anti-retrovirals (ARVs) for everyone infected with HIV in 1996, six years before the WHO added ARVs to its list of essential medicines. However, not everyone who needed ARVs had access. Biehl focused on those he perceived as abandoned subjects amidst Brazil’s policy response to the HIV/AIDS epidemic. His respondents were the poor, the homeless, homosexuals, drug addicts, transvestites, prostitutes; groups that remained stigmatized and invisible, even as Brazil provided ‘universal’ access to AIDS treatment. Biehl explains that access to medication in Brazil is dependent on a complex of rights, assertions, and negotiations between multiple actors and institutions, perspectives and alternative visions. His research subjects were residents of *Caasah*. This was precisely the situation my informants found themselves in after the implementation of the ACA, when they had to navigate the complexities of traditional health insurance for the first time. Both sets of experiences, in Atlanta and Brazil, illuminate how articulations and negotiations form the social life of AIDS and related policies. In Brazil, provision of ARVs became possible because of an ‘unlikely coalition’ between activists, government reformers, development agencies, and the pharmaceutical industry (Biehl 2007: 3). That was true in Atlanta as well: similar coalitions existed and used both formal and informal channels to create and maintain prevention, treatment, and care assemblages for HIV/AIDS (see Chapters 2, 3, & 5).
Another key process involved in the creation of assemblages is called *translation*. Kingfisher writes, drawing on Freeman (2009: 437), that all policy messages are mediated. Thus,

> In crossing boundaries, between various official and expert bodies, between themselves and texts, between institutional demands and various arenas of ‘real life’ – participants in policy travels thus engage not only in the movement of meaning, but also in its construction (Kingfisher 2013: 12).

Translation and articulation share similar roles in meaning making, because meanings are made *in* translation, and translation happens when people are articulating a concept or approach. For example, Chapter 3 discusses how the concept of the Ponce Center is described as a ‘one-stop shop’: a space that takes a holistic approach to patient care by addressing biomedical, social, interpersonal, and psychological needs in a single place. In so doing – in *translating* the policies that funded and enabled these services into the ‘real world’, and into the specific location of the Ponce Center – providers *articulated* a new and specific meaning of the word ‘care’ that in turn impacted the perception, understanding, and meaning of the relevant policies, including the Ryan White Programme, the Americans with Disabilities Act, and the ACA. Translation should also be understood to involve the processes by which actants draw on disparate theoretical frames and practices, or connect them in new ways, or devise new practices and programmes of action or linkage – thereby devising new assemblages out of extant pieces (Kingfisher 2013: 14).

The concept of translation addresses the fact that the policies and articulations and reality created by (or as) an assemblage vary from context to context. Specifically, policies are mediated, so ‘meanings or equivalent to meaning is … not prior to the translation but emerges *in* translation (Freeman 2009: 437). In other words, policies are not simply external, generalized or constraining forces, nor are they confined to texts. Rather, they are productive, performative, and continually contested; how a policy is presented by a news personality or implemented on the ground affects its functionality and perceptions of it just as much as its text or intended function. Furthermore, ‘ideas or ideologies that create and sustain policies are not static or monolithic: a key quality of policies
is that once created, they often migrate into new contexts and settings, and acquire a life of their own with consequences beyond the original intentions’ (Shore & Wright 2011: 3). As policy moves into new political and social spaces, so does the political narrative accompanying it, which is why and where it must be dealt with by other actors. I examine the moral values underlying the ACA, and its political and economic decisions about access to care and AIDS-related policies, illuminating the micro-macro power arrangements that become evident in policy’s articulation and implementation.

Chapter 3 demonstrates this aspect of the anthropological study of policy, where the Ponce Center staff’s articulations translate policy and move it into directions appropriate to keeping the care assemblage intact. Thus, the ACA’s re-translation process has two major interconnected aspects: Its narrative, and its logistics and actions. Narrative re-translation results from its move from Congress to court to the newscasters and newspapers to the pundits to neighbourhoods and waiters and taxi drivers. Its actions move the policy from the legislative sphere into the real world – to the social institutions, organizations and individuals, real people have to use and make sense of it, including its implementation in Atlanta. Each move re-translates policy from one genre to another, opening up space for further contestation, articulations, and fixing things in relation to each other – effectively maintaining the assemblage.

Yanow (1996, 2014) characterises the interpretive analysis of the policies as a strictly human activity, separate from the physical and natural world:

We act; we have intentions about our actions; we interpret others’ actions. We make sense of the world: we are meaning-making creatures. Our social institutions, our policies, our agencies are human creation, not objects independent of us’ (1996: 5).

She ties this active process of meaning making to the sociological concept of the ‘social construction of reality’ (following Berger & Luckmann 1966), whereby actions, objects, and symbols take on multiple, subjective, simultaneous meanings. Policy assemblages are also about meanings that people in a given domain and organizational field attribute to the policies that they come into contact with, and the action and interaction between various actors, human experiences, social institutions, cultural belief systems,
emotions and motivations, and the actant policy itself. In keeping with this assemblage framework, ethnographic analysis of the ACA must focus on the meaning of the policy, on the values, feelings and beliefs it expresses and the processes by which those meanings are communicated and ‘read’ by various audience. All actors in a policy situation, from legislators to implementers, are in this view active translators of policy and organizational meanings, which produces a significant degree of multi-vocality, not only its implementation, but in the conception, and in perception and discussion of it.

This thesis focusses on health providers as the main actors in terms of policy implementation and active translators and communicators of the HIV and the ACA policy meanings for them and their patients. The continuum of care – knowing your HIV status, connecting to care, staying in care, and keeping the virus in control – is all shaped by the policy. For any policy to be realized, it must be enacted, and so the question becomes what it means, and what people are doing, when they ‘do’ policy. Each chapter of this thesis focuses on one dimension of this effort to bring multiple meanings and variety of interpretations (Yanow 2014), whether shared or not shared, together through the process of interaction (Kuhn 1970). This forms a ‘social life’ of policy. Studying the social life of the ACA means tracking a process, the practices and thinking and movement around it, and it is about social change. Observations of this process in Atlanta are extended in rest of the thesis.

The ACA and its implementation add another piece in the broader health assemblage through which people can get health insurance. Thus, it cannot resolve the fundamental problem of market-based healthcare systems, where health is a commodity and not a public good or a citizen’s right. That is why social justice advocates do not like this fragmented system; they call it ‘broken’. In their opinion, a solution to this problem is comprehensive universal coverage and equal access to care for everyone: a better, more holistic assemblage. The Ponce Center uses the Ryan White policy to ensure that HIV/AIDS patients in Georgia have such coverage – forming a parallel assemblage of its own, because the Center is the only place where such holistic connections exist. In most other places, and for all other illnesses, Americans
must rely on the extant, piecemeal system, rather than the holism of the Ponce Center. As the nexus for such connections, the Center must engage in constant re-articulation work – adjusting each individual care plan as the various articulations and actants change. By focusing on both articulation and translation and the Ponce Center where they happen, this thesis uses the idiosyncrasies of health policy reform to understand how the organization of human life produces specific forms of belonging and exclusion.

By locating health policy reform within historical and social relations and the history of social policy development in the U.S. (see Chapter 2), this thesis can focus on the relationships between American ideology, structures of power, agency, and forms of subjectivities (see Shore, Wright & Pero 2011). Thus, I contextualize the ACA and its enactment within the Ponce Center not solely within the health or HIV policy world, but also within American social policy discourses. As a policy, it belongs to and is embedded within particular social and cultural worlds or ‘domains of meanings’ and ‘create[s] as well as reflect[s] those worlds’ (Shore & Wright 2011: 1). Thus, policy becomes a key mechanism by which we ‘practice’ culture, and by which the subjects of policy can exert their relative influence (Kingfisher 2013; see Chapter 5) – especially when those worlds cross and overlap as closely as social, health, and HIV policies in America do.

Significantly, as Farrugia (2014) notes, policies are also disruptive actants: being composed of heterogeneous elements, or of relationships between heterogeneous elements, they can alter boundaries or related relationships, and change perceptions of the world in certain ways. Freeman (2009) adds that the process of translation – from written law into implemented policy, or from the realm of the political into the realm of media – can further alter the meaning or perception of a policy, and its impact on the world. Medicaid, for example, both improved access to medical care for people living in poverty but also shifted people’s perceptions of those who relied on such policies, thus simultaneously increasing and decreasing their quality of life. The ACA, as a policy, has the potential to have a similar effect on society. Contingency is at the core of the health policy reform in the U.S. Anthropology of policy approaches capture this contingency when it accounts for perspectives from
both the governing as well as the governed, and allows ethnographers to explore what social policies mean, not just to policymakers, but also to the people whose lives they touch in context of the cultural logics that construct the U.S. health assemblage and social policy worlds.

This thesis focuses on both policymakers (Chapters 2, 3, & 5) and patients (Chapter 4). Among my respondents, the providers are also advocates and implementers: by providing feedback on the ‘nuts and bolts’ by which policy enacted and given direction and the lived experience its implementation, they become both the governing and the governed. My respondents, whether they were providers involved at the policy level or in the everyday running of the Ponce Center, or advocates, working beyond the Center felt strongly that they had a defining role in policy-making. Simultaneously, the patients are the ones who fully experience the impact of the final policy implementation first-hand. However, this study of providers represents a more significant contribution to the anthropology of policy, which is often concerned with either the policymakers or the citizens a policy affects, rather than the people whose job it is to enact the policy for a population.

This research captures the essential processes of the ACA assemblage; not just how it was constructed, but also its logics, how it is deconstructed and reconstructed by actors through processes of translation, and the perspectives of differently situated actors (Yanow 1996, 2014; Kingfisher 2013) and articulations (Strauss 1988; Freeman 2009, 2014). Thus, this thesis engages with a key question in anthropology about how to connect ‘local’ or ‘national’ and ‘global’, ‘macro’, and ‘micro’, in a way that captures the current dynamics and understandings of many policy processes. This is accomplished in part by presenting a critical analysis of the multiplicity of voices essential to understanding this intersection of health and inequality. I incorporate analysis and critique by activists, policy-makers, patients, and advocates regarding grassroots AIDS care services. My evidence reflects the people-centred traditions of anthropology by incorporating the plurality of local perspectives and experiences in articulating of actually happens on the ground and then linking that local context and lived experience to the national debate.
Furthermore, although the ACA is specific to the U.S. national context and policy discourse, any understanding of it must be informed by historical literature from the U.S. and existing scholarship from other countries. By locating health reform policy within historical and social relations, an anthropological analysis of the ACA enactment within the Ponce Center enables this thesis to focus on the relationships between American ideology, structures of power, agency, and forms of subjectivities (see Shore, Wright & Pero, 2011). The next section locates the ACA at the intersection between government, national culture, identity, and access to care.

**Healthcare, Welfare, & Governmentality: The Intersection of Policy, Race, Poverty, & Illness**

Over the last three decades, anthropological conceptualization of policy and governance has made dramatic progress in fundamental ways. Maskovsky and Kingfisher focus on governmentality’s limitations and situate neoliberal cultural formations in their specific contexts of occurrence to argue that the emergence of neoliberalism is a ‘fragmentary, incomplete process through which competing projects of governance are taken up and operationalized in historically and geographically situated situations where power relations are unequal’ (2001: 117-8). They understand culture as a concept continually critiqued within the discipline in recent decades, particularly if used to portray ‘a homogeneous, unitary and bounded set of practices’ (Maskovsky & Kingfisher 2001: 117-8; see Abu-Lughod 1991, Comaroff & Comaroff 1992, Gupta & Ferguson 1992, Rosaldo 1989, Roseberry 1989). Like Stuart Hall’s understanding of cultural identities as constantly evolving, Clarke calls neoliberal cultural formations ‘articulated ensembles’ that function to disarticulate traditional meanings and create new meanings (Clarke 2004: 37-8).

Recent anthropological scholarship posits that neoliberalism should not be treated as a uniform or monolithic concept, but should instead be understood as a cultural formation (Kingfisher 2002), such as personal identity, markets, and the state, that are emergent in a contested cultural field. (Comaroff & Comaroff 2000, Kingfisher 2013). This approach illuminates the shifting, diverse trajectories of government regimes and the changing nature of the
modern state itself. For example, governmentalities take many forms, including social democratic, liberal, post-liberal. Most current governmental contexts are not absolute expressions of these philosophies or concepts – governmentalities often continue to operate at the same time, in variations (Shore 2011; Kingfisher & Maskovsky 2008). As Shore and Wright (2011: 15) assert, the context in which policies are created and enacted has changed:

The post 9/11 environment has made governance more sophisticated and contradictory. Neoliberal instigated fragmentation or ‘agencification’ of the state (Pollitt et al. 2001) that entailed ‘governing at a distance’ (Rose & Miller 1992), now works to increase the centralized control.

To rephrase, the idea of shrinking government has, contradictorily, become associated in people’s lives with the state taking an enhanced role in maintaining discipline and control through risk management. This requires a new kind of ‘biopolitics…that entails new ways of controlling populations and governing the conduct of individuals’ (Shore & Wright 2011: 16), which deflects attention from the system and places responsibility entirely on individuals. As Hyatt (2011: 106; see also Sassen 2006) put it, in her study of the historical management of the poor in the United States,

we are living in a moment where the liberatory rhetoric associated with neoliberal policy, with its celebration of such values as free market, consumer choice, and ‘freedom’ appear to be in retreat, giving way to a darker vision of society harnessed to the valorisation of policing as the primary mechanism of governance.

Hyatt (2011: 106) concludes that the ‘primary purpose of this law-and-order state is...preventing crime and terrorism...even if this stance comes at the cost of compromising our liberty’. The new system is established in linguistic subjectivities like ‘responsibilised citizen’, ‘proactive’, accountable ‘self-managed’ worker and ‘calculative self’. Hyatt argues that an ideal subject for the new security state is a ‘responsibilised’ citizen-consumer who makes wiser market choices and also ‘a citizen who both polices and agrees to be policed’ (2011: 107). This is important in terms of talking about how the HIV community see themselves as the most important (and often only) advocates for their condition and refuse to be policed by a government that chose not to help.
Similarly, Epstein, in *Impure Science: AIDS, activism, and the politics of knowledge* (1996), observes in his sociopolitical history of AIDS that rejection of deviance has been a global feature of AIDS activism from the beginning. He notes that AIDS activists rejected notions of being scientific ‘outsiders’ or ‘insiders’; instead, their persistent, direct involvement in the processes of clinical-trials design and drug approval overcame their lack of scientific credibility, allowing them to create the policies around care they needed (see Chapter 2 for my respondents’ accounts of this era). HIV activists (perhaps especially the LGBTQ+ community) rejected the responsibilized patient/citizen model and challenged the contingencies that surrounded their articulations. Other anthropological studies of patient citizenship and the biopolitics of engagement make similar observations about the social categories associated with HIV and health-seeking behaviours (Doyal 2009), and similar juxtappositions of experiential narratives about living with HIV against ‘biomedical’ articulations (Davis et al. 2006, Persson 2013). These studies also understand HIV care as organized within local health practices, identities and subjectivities, which have consequences for distinct social and political contexts, particularly in resource-poor settings (Doyal 2013; Whyte 2009, Biehl 2007; Cataldo 2008; Turgeon, Taylor & Niehaus 2014). Further, they foreground the process of reconstructing life, and especially ‘identity’, around an HIV diagnosis and treatment (Baumgartner & David 2009).

Bernays’s work on achieving ‘universal access’ in HIV treatment illustrates alternate relationships between state power, technologies of the self, illness, and HIV (Bernays, Rhodes & Prodanovic 2007). In particular, she found that the Serbian government depicted PLHIV as undeserving and HIV as a constant economic, physiological, and social threat to the social fabric of their society (Bernays 2010). This directly impacted the relationship between HIV treatment and stigma in relation to the state’s funding priorities and the moral economy. That in turn had an impact on the identities of HIV-positive individuals, increasing their sense of shame, and helped to create a culture in which HIV-positive patients are inclined to be docile and thankful for whatever support is offered and disinclined to ask for or anticipate more assistance.
My participant observation of uninsured patients in an HIV safety net clinic revealed that similar linguistic subjectivities take a toll on both the care providers whose obscured work supports the broken system, and, on their patients, who are boxed in particular categories. Although care providers attempt to diminish the impacts of policy reforms on patients, language such as ‘responsibilised self’, ‘proactive patient’, accountable ‘self-managed’ become crucial to the success or failure of policy implementation, and therefore had to be re-translated to invoke the rights and liberties of all (see Chapter 2). In this regard, anthropological approaches to governmentality help capture the complex operations of modern state power and the technologies of self that produce new, self-regulated subjects to be governed, e.g. ‘neoliberal governmentality’ (Foucault 1991, Burchell 1991, Rose 1999, Shore & Wright 1997).

Over the years, anthropological conceptualization of governmentality has moved towards a realization that these approaches are not as ‘Foucauldian’ as previously imagined; for example, biopower, which is the literal attainment of subjugation over bodies and control over populations through various techniques, has been rejected as an encompassing and totalizing term (Rabinow & Rose 2003). It has become more popular to attribute a greater level of personal agency to patients than earlier paradigms, which held that people may have their identities constructed for them even when they acknowledged some space for personal agency. For example, Giddens (1991) argues that ‘reflexive subjects’ do not automatically adopt external construction of their identities unquestioningly – as Epstein’s (1996) history of AIDS clearly shows. My respondents, including patients and providers, are certainly examples of people refusing to accept external constructions of themselves as incurable or deviant, and therefore deserving of death, or of being ignored to death (see Chapters 2-5).

Hacking’s (1990, 1995) ‘looping effect’ falls between the two theories of identity: while people sometimes resist external constructions of personal identities, at other times they must adopt them. Or, if they do not adopt facets of identities in their entirety, certain categories have some effect on them, and interact with who they are. The HIV patients I interviewed exhibited the ‘looping effect’: they often reluctantly embraced their patient identity, built
around ‘CD4 counts’ and ‘viral loads’ in the biological sense. However, as AIDS patients, they could not escape incorporating some of the social stigma into their self-identities, including the associated deviant behaviours and life style choices (see Chapter 4). Hacking argues that ‘categories and counting’ define new classes of people, ‘normalize’ their ways of being in the world, and also ‘have consequences for the way in which we conceive of others and think of our own possibilities and potentialities’ (1990: 6). He conceptualizes it as ‘making-up people’. However, many of my respondents said that having HIV or AIDS did not define who they were, but rather that they embrace it willingly to build a life that may have the essentials of support and care they need.

Biehl’s analysis of AIDS patients in Brazil is more concerned with what he calls the ‘technologies of invisibility’, or ‘how the technical and political interventions make people invisible and effect the experience, distribution and social representation of dying’ from AIDS (2007: 203). He shows that the politics of AIDS treatment access were fuelled by market forces, not solely by social mobilization or an ethical principle of universal access; a reality that the Affordable Care Act policy reintroduced to many AIDS patients in Atlanta, despite its genesis in the ethical principle of universal access (see Chapter 2). Biehl found that an unintended consequence of this HIV/AIDS treatment scale up turned out to be weakening of prevention efforts, whereas public health-centred pharmaceutical distribution strengthened them. He observes (2007: 12) that the pharmaceuticalization of governance and citizenship, obviously efficacious in the treatment of AIDS, nonetheless crystallizes new inequalities. Also, promotes model of treatment inclusion that redefines some segments of population as disposable.

Biehl contends that this remains true unless ‘a different subjectivity is produced’ (2007b: 1112). Further, he argues that it is in the domain of these new subjectivities that unequal life chances are determined, and the possibility of extending life through pharmaceuticals exists. Biehl explicitly links the macro level biopolitical context and structural factors to the effects to individual experiences and meanings behind them. Biehl's interlocutors are ‘street patients’, part of the lowest strata of multitude of care networks in Brazil. They are served by Caasah, a grassroots initiative turned into a
government-funded NGO care centre; a situation that strongly resembles the Ryan White-funded Ponce Center (see Chapter 2). The Brazilian AIDS patients in Will to Live represent the new bio-citizen required by this new biopolitical system, where medicine adherence becomes tied to identity – ‘medicine is me now’, said one patient (Biehl 2007: 461) – and noncompliance means risking both the possibility of pharmaceutical life extension and the support of Caasah.

In Republic of Therapy, Vinh-Kim Nguyen (2010) tracks responses to the HIV/AIDS epidemic at the early period of antiretroviral (ARV) treatments in West Africa. He explores the question ‘what forms of politics might emerge in a world where sometimes the only way to survive is to have a fatal illness?’ (2010: 6), which was also a pressing question for my informants (see Introduction). Nguyen focuses particularly on how access to HIV care and the fact of biological vulnerability requires subjects to change their self-perceptions. He offers a concept of ‘therapeutic sovereignty’, a novel form of political power emerging in postcolonial contexts where widespread poverty and political instability result in the absence of or failure of ‘more traditional forms of sovereignty’ (ibid.: 133-4). This builds on Petryna’s (2002) original concept of ‘biological citizenship’, ‘a massive demand for but selective access to a form of social welfare based on medical, scientific, and legal criteria that both acknowledge biological injury and compensate for it’ (Petryna 2000: 6). Rabinow’s (1996) also discussed biosociality as a broader concept that encompassed social processes and social life as well as biological citizenship. Similarly, Lock and Nguyen (2010) advocate a holistic view of biomedical knowledge and practices that work to ‘make up’ selfhood, noting that this discourse often uses ‘citizenship’ metaphorically to refer to identity or political subjectivity more broadly. They all denote to forms of belonging, rights claims, and demands for access to resources and care that are made on a biological basis. The association of citizenship with identity or political subjectivity is an important lens for the analysis of my informants’ experiences as they embrace the notion of ‘patient engagement’ expected within the models of care available in the U.S.

As anthropologist and physician, Nguyen argues that we must change the subjectivity of patients in the ‘AIDS Industry’, increasing their ‘biopolitical
citizenship’ (2005: 126). This is accomplished through ‘claims and ethical projects that arise out of the conjugation of techniques used to govern populations and manage individual bodies’ (ibid.). The ACA sought to be one such project; thus, a key analytical task of this ethnography of policy was to explore the extent to which concern for the disease led to extending healthcare access to citizens who were previously barred. Therefore, this ethnography investigates how health insurance in the U.S. has multiple meanings, logics, and effects, and how it is viewed in practice, in context, and from multiple vantage points. The ACA health reform is political because it requires community action and structural changes within a broader context of policies related to reducing inequity in health, welfare and human rights.

Nguyen’s notion of ‘therapeutic sovereignty’ is a novel form of political power, emerging in post-colonial contexts where widespread poverty and political instability result in the absence or failure of more ‘traditional’ forms of sovereignty (2010: 133-4; cf Mazanderani 2013: 256-60). Nguyen describes a process of triage, by both local and international organizations, that uses ‘confessional technologies’ (Hunt 1997) in ways that ‘unwittingly sorted those who should live from those who could go without treatment’ (Nguyen 2010: 6). That is, Nguyen observed that sharing personal stories became a major element of shaping the response to the AIDS epidemic: ‘talking about yourself came to be about staying alive’, because it added an important degree of humanization to the disease (2010: 9). Nguyen particularly links this storytelling to the transformative aspects of the technologies of the self, a Foucauldian notion, and to biological and material survival (ibid.: 159). The importance of personal stories is echoed at the Ponce Center, in their understanding that medication alone is not sufficient: in order to truly benefit from the treatment, patients need access to primary healthcare, food, shelter, and mental health services.

Like Biehl and Nguyen, I seek to analyse the ‘forms of politics’ instantiated in triage and healthcare policy that create a situation in which ‘the only way to survive is by having a fatal illness’ (Nguyen 2010: 6). As the Introduction described, many AIDS patients in America find that the only way to access treatment is to allow the disease to progress to a crisis point. AIDS is the only
diagnosis for which this is true. The ‘patient citizenship’ literature provides a lens through which to engage with illness and treatment as facets of citizenship rights, and to help analyse how healthcare systems and coverage reflects on the construction of national and individual identities (see Chapter 2). Patient citizenship is a particularly useful concept for unpacking the processes that shape patients’ engagement in HIV treatment and care at the Ponce Center, because medical treatment, ARV adherence, and holistic care draw on the interlinked concepts of therapeutic and biological citizenship, and their impact on the full, holistic cascade of care (see Chapter 3).

Patient citizenship also underlies discussions of the Affordable Care Act (ACA), because the central purpose of healthcare reform was to remedy a crisis in national health and access to care. The ACA of 2010 was the first major American health care reform in fifty years, and it generated new debates about individual responsibility, the collective good, and the social contract. This generated a call for American anthropologists to participate in the conversation by studying the effects of health reform on social institutions and lives of the American people (Horton 2014). The ACA aims to reduce the number of uninsured Americans through the simultaneous expansion of the private insurance industry and government funded Medicaid. However, many criticise the fact that it expands rather than reforms the existing, costly, for-profit health care system, which is a fragmented assemblage of policies created by a small network of actors influenced by sets of special interest groups. The ACA epitomizes the compromises the U.S. government has always made with the insurance industry (Maskovsky 2000). In order to secure insurers’ support for reform key compromises were made, including the fact that single payer system was never considered, a public insurance option was quickly abandoned, and the government agreed not to negotiate pharmaceutical prices for Medicare (Oberlander 2010).

Wedel (2011) observed something similar in her analysis of how a small core of neoconservatives designed and executed the war in Iraq and shaped the Bush administration’s policies. She calls such networks of special interest groups ‘flex nets’. She argues that ‘flex nets’ influence and obfuscate the processes of accountability and transparency, and hide the onus of responsibility, with no
identifiable source of power for redress (Cruikshank 1999). They also play a vital role in creating and pushing for new subjectivities. Such groups take over policy decisions, block them or push them in certain directions in order to advance a specific agenda. With regard to the ACA, this agenda ultimately supports the pharmaceutical industry as well as the corporations that currently control the U.S. healthcare system. Given the role of these special interest ‘flex nets’, a policy analysis of the ACA must begin by examining ‘the assumptions and framing of policy debates’ and their ‘enabling discourses, mobilizing metaphors, and underlying ideologies and uses’ (Wedel et al. 2005: 33-4).

Social policy reform is situated at the centre of debates about poverty discourses and governance, and is often analysed as a conduit for disproportionate rates of impoverishment among historically marginalized social groups. Maskovsky (2000, 2006, 2012, Morgern & Maskovsky 2003, Kingfisher & Maskovsky 2008, Maskovsky & Brash 2014) documents the gradual shift in governmental promotion of private-sector, market-based strategies over previous welfare state policies, arguing that ‘the former are the most effective means of achieving economic growth and guaranteeing social welfare’ (2000: 121). This thesis illuminates numerous ways that the American the increase in poverty contributed to the rise of HIV infection in minority communities. In 2011, before the ACA took effect, nearly 48 million Americans lacked health insurance (Galewitz 2013). Furthermore, about 25 million Americans are underinsured, meaning that their out-of-pocket medical expenses amount to 10% or more of their income (Schoen et al. 2008). According to the Centers for Disease Control and Prevention, 35 million people are living with HIV/AIDS globally, an estimated 1.2 million in the United States. In Georgia, one of the states most affected, 42,067 people were living with HIV in 2013, of which 25% are women and 69% are African-American. Furthermore, there are drastic disparities in health care outcomes for black men who have sex with men (MSM) with HIV as compared to white MSM with HIV: new infections affect about 8% of the white MSM population per year, but about 32% of black MSM (Rosenberg et al. 2014). This thesis demonstrates how HIV/AIDS policies have sometimes been able to re-embed social principles of access and equity into an American healthcare
system that has been pushed towards a model of neoliberal economic efficiency. It demonstrates that neoliberalism is not a ‘thing that acts in the world’, but is instead a ‘restless and unstable process’ (Kingfisher & Maskovsky 2008: 116). I investigate this process by examining how poverty-related social policies and the safety net are often framed as a debate about redistribution, when the issue is more complex (see Chapter 5). Social policy as an organizing logic, a framework that classifies people, spaces, and ideas, can be a powerful vehicle for social change. It legitimises notions of ‘deserving’ and ‘undeserving’ people through images, interests and mutual obligations. It creates identities and constantly redefines ‘good’ citizens and ‘good’ communities, bringing different fragments of culture and society together into new social and semantic landscapes.

The discourse surrounding welfare and the safety net has, therefore, an inherently othering effect: ‘we share among us, we control and discipline them’ (Morone 2003: 138, emphasis mine). American welfare discourse is based in the ‘culture of poverty’ thesis, developed in the 1960s by Oscar Lewis, a politically influential anthropologist who tied the conditions and persistence of American poverty to intergenerational dysfunctional moral values and the behaviour of the black poor in inner city neighbourhoods. Despite heavy criticism (Valentine 1968, Young 2004), assumptions founded on this theory – like the idea that poverty is self-perpetuating – still have influence, especially on social policy research (Borjas 2001, Mead 1986). Thus, safety net policy must be understood in terms of identifying, categorising, and maintaining who is ‘deserving’ and ‘undeserving’, because welfare does not simply determine who receives what benefits, it also shapes how society perceives those people and those benefits.

American welfare discourse in the last three decades has been tied to the notion of ‘personal responsibility’ and associated conceptions of identity, society and security, with a focus on how these state-centred identities relate to law-making in the U.S. Sometimes this is done literally; for example, in the 1996 Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA). This was part of President Clinton’s ‘New Covenant’, which offered a vision of a new contract between government and the people of America where citizens were asked to do their part and be responsible. PRWORA was one aspect of a broader
welfare restructuring in which federal responsibilities for social services devolved to the states, in much the same way states taking responsibility for themselves is also a key aspect of the rhetoric surrounding the ACA (see Chapter 5). Clinton’s compromise on welfare reform prompted Republicans, the opposing political party, to shift the goal from discouraging aid to single-headed families (usually mothers who had children out of wedlock, or whose partners were incarcerated or unavailable) to enforcing work requirements in order to receive aid (Rogers-Dillon 2004: 68-9). This same logic hindered Clinton’s health reform effort in becoming a legitimate policy. The policy implications explicitly make the connection between earning benefits and taking responsibility for oneself and one’s family – essentially to reduce dependence on the government by any means necessary, whether by encouraging jobs or marriage, discouraging pregnancy, or getting relations to take responsibility for children.

Morgen and Maskovsky noted that this new policy was enabled by ‘the centrality of a racialized, demonizing dependency discourse’ (2003: 325), indicating that poverty is not considered so much an economic problem as a moral, racial and cultural one. In the 1980s, W.J. Wilson introduced the concept of the underclass. He acknowledged the economic restructuring and de-industrialisation that created huge job losses at the time, but he attributed persistent poverty to ‘cultural deficit’ and factors related to specific pathological ‘ghetto’ behaviours of the black inner-city poor (unwed teenage mothers, female-headed households, informal economy, post-affirmative action, removal of male role models). ‘The paradigm of the “underclass” still prevails in academic and public discussions of urban poverty, many of which ignore Wilson’s call to “structural” solutions (demand-side public employment) but embrace his endorsement of ghetto pathology’ (Morgen & Maskovsky 2003). Heavy reliance on these dependency and behavioural theories made it impossible for post-1960s welfare reforms to support the increasing number of female-headed households, particularly in low-income African American families, which were due to widening income gaps and power constraints related to race and gender (Moghadam 1997). Goode (2002: 288-89) writes, in her review of How Ethnography Counters Myths about Poor,
The ironic fact [is] that state welfare policy itself separates men from women and children. Stack (1974) first noted the effects that the oldest cash assistance programme, Aid for Families and Dependent Children, had on removing men from the families since it only supported single women and denied benefits to those who were discovered living with males... Susser (1999) has found that state policies actually work to breakup families by developing separate shelters for men and women, and removing teenage boys from shelters for women and children.

A defining example in contemporary discourse on poverty policies is the ‘welfare queen’: always portrayed as a sexually reckless African American woman who has too many children with different men and is not economically productive, the welfare queen is supported by hardworking taxpayers’ money (Davis 2004: 275-76) but lacks the American ideals and values that separate the ‘deserving’ poor from the ‘undeserving’. This long history of conflating race, gender and poverty has particularly stigmatized African Americans and other minorities (Goode 2002; Mullings 1997, 2013). This imaginary ‘welfare queen’ figure became a ‘controlling image’ (Collins 2000): the face of welfare programmes that socialize people into a culture of dependency, ‘depriving them of the capacity to live up to the obligations of citizenship’ (Hyatt 2011: 110). Such depictions derive from slave era ideologies of domination and sexuality. Sidel writes, ‘systematic stereotyping and stigmatizing of “welfare mothers” was necessary in order to dehumanize them in the eyes of other Americans before the harsh and tenuous lifeline of Aid to Families with Dependent Children (AFDC) and other bare-bone social programs could be shredded’ (1996: 490). Hyatt (2011) notes that poverty discourse often focuses on African Americans and their ‘inadequate’ street culture. Neubeck and Cazenave called this conceptualization ‘welfare racism that reinforces racial hierarchies and redefines the terms of citizenship to exclude poor and families of colour from even the meagre protections offered by the social safety net’ (2001: viii).

These images still underlie, inform, and shape the surface issues and the debates about American individualism, responsibility, hard work and fairness that are part of a powerful conservative narrative that equates liberalism with moral depravity and laissez-faire economics with fairness (Guetzkow 2006, Sommers & Block 2005). The production of poverty in the post-welfare era of the 1990s must
be understood as a result of policies based on neoliberal logic. This ideology justifies the existing social order by defining economic rationality and self-sufficiency as the personal responsibility of individuals and families rather than questioning the combination of ideological and political-economic structures and policies that produce poverty (see Chapter 5). Thus, when Clinton’s PRWORA policy promoted privatization by shifting many traditional state responsibilities, like healthcare, to the private sector by emphasizing the ideology of ‘personal responsibility’, this reinforced the way Americans understand many problems families encounter as matters of personal rather than social responsibility.

Much classic work on poverty in the U.S. was a rebuttal to the ‘culture of poverty’ thesis (Liebow 1967; Valentine 1968, 1978; Eames & Goode 1973; Stack 1974). Ethnographic analysis of lived experiences showed that assumptions about the personal ‘deficiencies and incompetencies’ of the poor were themselves ideological (Morgen & Maskovsky 2003). Soss (2000) brings the voices of the poor into this discussion. Unlike the sassy image of the welfare queen, he describes his respondents as exhausted, isolated, often abused and usually frightened. He characterises them as active agents, negotiating and standing up for their rights when they can, but sometimes pushed back by hostile caseworkers armed with policy. However, it is significant that particular programs have different attitudes based on the images of their beneficiaries. For example, Social Security Disability Insurance (SSDI) gives relatively more autonomy to its recipients as compared to welfare mothers, as the stories of my patient respondents illuminate clearly in Chapter 4. The disabled are perceived as people who are victims of circumstances beyond their control, whereas the ‘welfare queen’ is avoiding responsibility (Soss 2000; Soss & Schram 2006).

Racial and poverty-based stereotypes like the welfare queen inspired and justified new systems for assessing the accountability of people receiving government welfare. In the 1970s, to assure the public that taxpayer money was being appropriately utilized, strict mechanisms were created to find welfare ‘cheats’. Cruikshank elaborates, ‘new verification requirements for AFCD eligibility could include photo ID, sometimes fingerprints, two proofs of residence, verification of social security number... birth certificates, proof of
school attendance and so forth’ (1999: 112). Forty years later, such auditing and accountability techniques are the norm, used across the population to verify the legitimacy and identity of all citizens (see Chapter 3) – and, simultaneously, to imply that citizens who need such assistance are more likely to cheat.

This is particularly interesting with regard to how the dominant policy narrative judges the success of welfare reform based on the reduction in welfare caseloads. However, anthropological studies of welfare reform and urban poverty illuminate a different reality, calling the hegemonic presentation of welfare reform’s success ‘in sharp contrast with the experiences of the poor’ (Morgen & Maskovsky 2003: 316). They claim that the poor, rather than being empowered through work, were actually trapped in declining wages and faced ‘withdrawal of their citizenship rights e.g. retrenched welfare services, intensified surveillance, adaptability to new subjectivities or else the punishment’ (ibid: 329). The debates about the Personal Responsibility Act (PRWORA), ‘ending welfare as we know it’ as President Clinton said, were entirely detached from the effects of widening income inequality due to deindustrialization and outsourcing and from the biases and the systemic and structural discrimination that produced it (Morgen & Maskovsky 2003: 318; Wacquant 2009: 76-109). Hyatt (2011: 113) notes that deindustrialization has been understood as the falling fortunes of the white working class, even though African Americans have always been the last hired and first fired. Similarly, Greenhouse asserts that by constructing inequalities as a result of learned behaviour possessed by individuals socialized into a lifestyle of dependency, inequality was ‘set beyond the reach of law. That distancing of law from the status contingencies of identity became central to rationales for new legislations curtailing access to law in employment discrimination, welfare rights and immigration’ (Greenhouse 2011: 4). Goode (2002: 288) adds that dependency theorists ignored the fact that welfare benefits themselves were inadequate to support a family at poverty line. Since the initial war on poverty programs, reductions in benefits and/or failure to upgrade benefits in response to inflation have made it impossible for single mothers on welfare to make ends meet.
Existing critical anthropology scholarship examined the construction of poverty discourse through policy in terms of the safety net, access to healthcare, race, and HIV in the United States. For example, ethnographers have shown that in the absence of national health insurance, where low-paid jobs do not provide employer-based insurance, millions of the most vulnerable families are left without access to health care (Schneider 1999, Seccombe 2002, Burton et al. 2003). More than 63% of the bankruptcies filed in the U.S. are related to medical bills, and most are filed by middle-class families (Himmelstein et al. 2009). These statistics challenge how we understand low-income families’ problems, given that health insurance was never a right or a government guarantee for the people who could not afford to pay for it as a commercial commodity.

AIDS should likewise be understood as an illness that no one in power had any interest in addressing (see Chapters 2 & 5). The people who were most likely to get sick were people who were already alienated from the support systems of family and government, who were already deviant, who already had limited resources. Singer understood AIDS in connection to the broader social and health crises affecting the inner-city poor – not as a singular and distinct epidemic, but rather as a ‘syndemic’, a term referring to the ‘synergistic or intertwined and mutually enhancing health and social problems facing the urban poor’ (1994: 993). He called AIDS an ‘opportunistic infection’, an ‘undemocratic’ disease that takes advantage of the poor health and social conditions brought on by the unhealthy intersection of urban poverty and oppressive social relations structured along the lines of class, race, gender, and sexuality.

This thesis understands HIV and AIDS as an ‘epidemic of signification’ (Treichler 1988, 1999), a classic medical anthropology lens through which to examine the medicalization of social life, identity and citizenship within the diverse meanings of poverty (Singer 1994, 1997). The epidemic has evolved in so many ways, particularly in terms of living with HIV rather than dying from it, yet both scholars and medical professionals still struggle to address the complexity Treichler identified, and how this impacts each individual life as well as society as a whole. Uninsured Americans with the pre-existing condition of HIV mirror and expose the existing inequalities in social conditions and social
relations in contemporary U.S. society (Comaroff & Comaroff 2006, Comaroff 2007), and within the fragmented American healthcare assemblage. Thus, if social and safety net (read: ‘welfare’) policies determine (and reflect) which recipients are or are not ‘deserving’ in general, healthcare policy – particularly with regard to vulnerable populations such as the minorities, poor, elderly, and chronically ill – determines who deserves to live, die, or suffer.

Medical anthropology suggests an additional lens for this thesis: ‘structural violence as a conceptual framework for understanding the HIV/AIDS epidemic’ (Castro & Farmer 2005: 53-9) and its rapid spread through the poor segments of any population. Castro and Farmer argue that societies are shaped by large-scale social forces such as racism, sexism, political violence, poverty, and other inequalities rooted in historical and economic processes (2005: 59). These forces, which together define structural violence, ‘sculpt the distribution and outcome of HIV/AIDS’ (ibid.). Cataldo’s (2008) study of accessing HIV treatment in Brazil’s favelas in the light of stigmatisation and structural violence such as poor housing conditions, absence of public authorities and recurring conflicts due to drug trafficking. The marginalization and isolation of favelas inhabitants is central to the experience of accessing ART. Cataldo observes shifting individual notions of social participation explains that the ‘medicalised body-self’ is associated with the new citizenship claims for people treated for HIV in favelas. This is not dissimilar to Nguyen’s (2010) observations about ‘therapeutic citizenship’ and the capacity for individuals to derive empowerment through personal accounts and the access to resources they grant.

Working-class American citizens are also trapped within cycles of structural violence when they are required to exhaust all sources of funding and allow the disease to progress to a critical stage before they can access care (see Chapters 2, 4 & 5). This framework intersects with the political economy of health, where resources are withdrawn from policies that affect the most deserving; for example, Chapter 2 discusses how perceptions U.S. welfare and healthcare policy history and development are shaped by assumptions about who will be using the services and whether they are ‘deserving’. Farmer, by situating such narratives of affliction within wider cultural, socio-political, and economic
fields of power, suggests ‘understanding AIDS not as the inevitable outgrowth of individual pathology but as one more injustice imposed on the oppressed in the context of vast and increasing inequality’ (1991: 4). This approach highlights the connection between AIDS and poverty.

As the above literature shows, unintended implications of how market-based health reforms reshape care-seeking and caregiving practices is well documented. In the United States, this analysis has yielded critical insights into how market-based health reforms like privatizing Medicaid has negatively affected the most vulnerable in society, exacerbating health disparities, and adding burden on safety net providers (Prince 2012, Horton et al. 2001, Horton et al. 2014, Lamphere 2005, Maskovsky 2000, Waitzkin et al. 2002). Similarly, in Kenya and other similarly developing nations, structural adjustment policies and health system restructuring has diminished capacity of health systems capability to offer even basic primary care (Dao & Nichter n.d, Foley 2010, WHO 2008). Epidemiologically speaking, people living with HIV in high-prevalence, low- and medium-income countries such as South Africa are half as likely to have ART compared to HIV-positive people in high-income countries but who experience severe resource constraints (WHO 2009, cf. Moyer & Hardon 2014).

The spread of AIDS among poor and minority communities in the American South must be viewed in connection with wider political and economic changes affecting cities throughout the U.S. (Farmer 1999). People living with HIV/AIDS were particularly concerned with the implementation of the new health reform Patient Protection and Affordable Care Act (ACA) because it was supposed to integrate many of them into the U.S. health insurance market, which they had never before participated in. Access to healthcare means life and death to this group of 1.2 million people and Medicaid is the largest source of funding available for people who cannot afford to purchase private insurance. Additionally, the disproportionate prevalence of HIV/AIDS in poor African American communities in the U.S. South is a significant cause for concern.

Thus, during the implementation phase of the ACA in 2013, the biggest question was whether individual states would take advantage of Medicaid expansion provisions in the ACA to protect the most vulnerable citizens.
Georgia is one of several poor, Republican states that refused to expand Medicaid, despite its full financial backing by the federal government (see Chapter 5), thereby creating a political economy of health where resources are withdrawn from policies that affect the most deserving. Recent studies of low-income families in Atlanta show that the South was the only region to show statistically significant increases in both the poverty rate and the number of people in poverty – 16.9 percent and 19.1 million in 2010 – up from 15.7 percent and 17.6 million in 2009. Ketsche et al. (2011) found that

health care costs account for 22.7 percent of spending in low-income families, and just 16 percent in higher-income households because private premiums, out-of-pocket spending and state and local spending – which account for more than half of all health care spending – are financed regressively, taking more of lower income families’ incomes.

Iglehart (2011) reported that increasing numbers of people are pushed off Medicaid rolls, and are forced to pay out of their pockets for managed care.

Through all of these mechanisms, race, gender and poverty were conflated into a single new racialized class that Goode and Maskovsky call a ‘regime of disappearance’ (2001: 10). This term refers to fashioning a political culture that neglects, silences, and hides narratives of the poor’s lived experiences. As the income gap widens and the state pulls away from their lives, the poor become invisible, marginalized and excluded from public view (Susser 1996, 1999; Morgen & Maskovsky 2003). This ‘regime of disappearance’ is similar to what Farmer (1999) calls the ‘eraser of history’ and Biehl (2005) calls ‘zones of abandonment’ inhabited by those who were discarded by society and the medical establishment as terminal, ‘hopeless cases’. Biehl describes these zones as functioning alongside ‘technologies of invisibility’, by which

bureaucratic procedures, sheer medical neglect, moral contempt, unresolved disputes over diagnostic criteria and unreflective epidemiological knowledge mediate the process by which poor and marginalized patients are made invisible (2007: 203-4).

Horton (2014) adds that discourses of vilification may work to exclude people living with HIV/AIDS from affordable healthcare. Across America, she is correct: care subsidized by either the Ryan White Program or the ACA has become an increasingly scarce commodity, rather than a guaranteed right.
Providers at the Ponce Center were increasingly concerned that this would be the case for their patients after the ACA took effect (see Chapter 3).

Such exclusion is also accomplished by framing social welfare policy in terms of ‘welfare dependency’. In the U.S., this has led to punitive work enforcement as a new approach to poverty, where the state has a fundamental responsibility to cultivate social order and instil self-discipline. Schram et al. call this transformation ‘the rise of a “new paternalism” that is deeply entwined with the globally ascendant market-centred philosophy of “neoliberalism”’ (2010: 729). Policy related to both incarceration and welfare is becoming similarly punitive and strict. The TANF programme recipients are 90% women and the eligibility criteria to receive government assistance are shrinking day by day. A felony conviction makes one ineligible for welfare. This is parallel to Soss’s argument that welfare should be considered in terms of citizenship rights, because the welfare system offers a forum for citizens, a locus of political participation equivalent to voting or serving on juries...for many people, claiming welfare is the dominant form of political participation – compared to the understanding of Harold Laswell’s well recognized definition of politics – ‘who gets what, when and how?’ (Morone 2003: 143).

Thus, the Affordable Care Act arose out of that political and historical context. It attempted to provide an option to have the power to buy in the insurance market with government help as an equal opportunity. The logic that opposed it translated responsibilised subject and civil liberty as having the freedom not to buy health insurance – and have the dignity to make it on their own. When seen as a fluid site of cultural and political contestation, the ACA raises questions about the relationship between the state and its citizens.

Hegemony and contestation is central to...policy; political conflicts defend or unsettle established discourses and advance particular ways of conceptualizing the role of individual, social institutions and even of government itself (Wright & Reinhold 2011: 86).

Health reform policy is both a public and a private concern that asks questions about welfare, responsibility, identity, risk and security. Hence, when transporting morality into politics, it is vital to explore how governing parties construct narratives out of the subjects to be governed by their policies.
The American HIV policy-space, as shown in Chapter 2, came into being against the background of the neoliberal rise of conservative ideals and the responsibilised citizen. Further, it developed within a government eager to rationalize and minimize public services, including the safety net and attendant political economy of healthcare. Victims of exclusion have an unprecedented opportunity to claim their human and medical rights. HIV, like poverty, being a limiting, othering, discriminatory force was perceived as deviant. Narratives like the welfare queen reinforce, embody, and disseminate that function. Similarly, HIV’s association with drug users, and the moral depravity and lack of control that addiction and drug use often connote, is othering. Higher infection rates in foreign nations also contribute to the racializing and othering of the disease (Farmer 1999, Fassin 2007, Bourgois 1995, Ciccarone & Bourgois 2016). This is especially evident in the fact that African and Afro-Caribbean countries are often perceived to have higher infection rates, regardless of truth, which further conflates this issue with race. Similarly, the ‘war on drugs’ is a war on African American youth, despite the reality of other ethnicities’ drug use (Hansen, Bourgois & Drucker 2014; Netherland & Hansen 2015). The war on drugs results in high rates of incarceration, targeting 90% of black men, which impacts the economy and social life of African American families. Furthermore, because African American men and women have a greater tendency to limit their sexual networks by race than European Americans (Adimora et al. 2013, Harling et al. 2014), the low sex ratio caused by black male incarceration is a key factor in HIV transmission, and particularly in restricting new infections to within the community.

These lenses for analysing the invisibility and political detachment of the poor reflect the impact of discursive shifts that assign certain identities to individuals and thereby isolate, exclude, or include them. Similar mechanisms have rendered HIV invisible to the market-based logic of health insurance and access to treatment in the U.S. Since the very beginning, the social identity of HIV/AIDS in the U.S. was shaped and influenced by the dominant structure of social relations across class, racial, gender, and sexual orientation. For example, public health categorization of gays as a major ‘risk group’ played a contributing role in furthering disease transmission by alienating other at-risk
populations, including women and minorities of colour. Focusing on the behaviour of individuals rather than the context within which those behaviours formed and prevailed, and labelling AIDS a ‘lifestyle disease’, increased stigma for certain groups of people. Furthermore, they isolate affected groups by categorizing some as ‘deserving’ and others as ‘undeserving’.

Contemporary medical anthropology rejects the biomedical categories because they are socially constructed, not naturally given. The argument is that biomedical categories and facts are produced by combinations of institutional, technical, socio-cultural and political processes – and through these processes the biomedical world becomes real and available for interventions (Latour 1993). These biomedical processes, as a result, may mirror and perpetuate existing inequalities. Anthropology seeks understanding of how inequality translates itself into disease beyond the confines of those narrow definitions.

Policy as an Object, Site, and Method of Study

I allow the knowledge of the other to mark me.


When one takes policy as an object of study, anthropology of policy scholars believe that defining the field of research is a matter of theoretical and methodological innovation. As opposed to the traditional view of the field, in which a geographically bounded place is the site of ethnographic enquiry (Gupta & Ferguson 1997), policy anthropologists have long used the concept of a ‘policy community’ as another way of establishing field boundaries (Rhodes & Marsh 1992); they use policy as a window into processes of political transformation. Thus, ‘the field of research becomes not a particular people or organization – far less a reified policy itself – but a social and political space articulated through relations of power and system of governance’ (Shore & Wright 2011: 11). This thesis is an experiment in using these concepts to explore the social spaces where meanings are derived and practices are developed in real time throughout the implementation of the ACA. It is an innovative effort to contribute a policy as method approach to the anthropology of health field.
The anthropological analysis presented in this thesis is based on 3 years of fieldwork conducted in Atlanta, Georgia between April 2011 and May 2014. My primary ethnographic method was participant observation, involving hundreds of hours of fieldwork. I also used the extended case method, elite and in-depth key-informant interviews, and archival research to examine the dynamics of health providers and health advocates’ articulations, and their translation of policy into practice. My initial fieldnotes and conversations were primarily explanatory, proximal to what Hutchinson calls ‘nondirective’ research, following ‘questions about events and practices that people were already discussing or actively engaged in at the time’ (1996: 44).

I started recording formal, semi-structured one-on-one interviews at the Ponce de Leon Center one year after I began partaking in these ‘comings and goings’ (see Biehl 2007). I conducted 90 ethnographic in-depth interviews: 44 with care providers, 16 with patients at the Ponce Center, and 30 with outside health activists and advocates linked to the Center through the HIV care assemblage. All interviews were audio recorded and transcribed. The interviews were enabled by the trust and rapport I had built during initial participant observation. My informants were chosen from people I had observed taking a major role in the everyday practices of the Ponce clinic and related spaces. The experience gained in that first year also allowed me to identify those with a willingness to talk and to make the interviews unstructured and free-flowing, reflecting the shared experiences my respondents and I already possessed. The ‘extended case method’ allowed me to follow my interconnected respondents around access to HIV care and implementation of the ACA to study the ongoing policy processes (Burawoy 1991, 1998; Van Velsen 1967: 145; Gluckman 1961).

My ethnographic approach was informed by the notion of ‘studying through’ (Wright & Reinhold 2011). Reinhold (1994) used this approach to analyse the ideological struggle over ‘positive images’ of gay people, and contributed to studies of political transformations happening in Britain during Margaret Thatcher’s government. This is similar to the efforts to contest the narratives

---

*One year before I obtained IRB approval, which allowed me to station myself at the Ponce Center as my base field-site for another two years. No patient interviews were conducted in that first year.*
surrounding the ACA, trying to persuade the public of its merits or defects. Reinhold framed her question as a postcolonial critique of community studies; considering how to conceptualize a ‘history of the present’, and meanings of ‘events’, ‘key words’, and ‘studying through’ (Wright & Reinhold 2011). This was part of a movement by contemporary anthropologists, who were struggling with the question of how to analyze what was happening in particular ethnographic locations not as a self-contained entity called a people, village or tribe, but as part of large scale systems of power and processes of change, in which multiple actors and distant institutions could have great influence on people’s lives (Abu-Lughod 1990: 42).

This approach pushes analyses further by helping scholars identify and examine the process(es) by which ‘policy creates new social and semantic spaces, new sets of relations, new political subjects and new webs of meaning’ (Shore & Wright 2011: 1). Yanow (2000, 2006, 2011) considers taking such a broad view of the people involved in policy processes as an ‘interpretive community’ approach. Pero (2011) also emphasizes that such communities include framing not just the ones who govern but also the ones who are being governed as being possessed of an active role. All of my informants were from the self-described ‘HIV community’, though not all of them were HIV-positive. Indeed, the majority of my informants were medical and management staff: professional experts with credentials that endorse their authority regarding particular knowledge and who hold formal positions within institutional structures. I approached these experts with elite interviews, designed to study people in positions of authority (Marshall & Rossman 1999), such as health and social service providers, policymakers and bureaucrats. Other informants were HIV/AIDS patients at the Ponce Center and elsewhere. I also interviewed and observed lobbyists, political activists, and outside connections that played an important role in the life of the Center.

My focus on healthcare providers and activists should not be taken as neglect of the patient perspective. Rather, my focus on providers is an acknowledgement that it is important to recognize how the ACA policy shapes and is shaped by different actors. Patient accounts remain a significant part of grounding and contextualising my ethnographic analysis. The focus on providers and
activists, in addition to patients, is an effort to address a significant gap in the anthropology of health policy by focusing on the perspectives of the governing as well as the governed. Healthcare providers and political activists are interesting as subjects of policy because they act to buffer and create the policy’s impact on their patients by actively mediating and negotiating its meanings and provisions (Lamphere 2005, Waitzkin et al. 2002).

I saw my presence as that of an objective observer and sense-maker, developing a sensibility for organizational ethnography itself. Following an interpretive approach, I saw my role proceeding from the perspective that social realities are inter-subjectively constructed, and I was a co-interpreter of the meaning(s) of events at the Ponce Center that I participated in. ‘Being there’ ethographically was not limited to the field. Research became part of my writing as well: as Yanow explains (1996, 2013), layered descriptions of objects, events, actors, and interactions help to create a nonfictional (albeit necessarily fabricated) account of organizational life that places both author and reader at the scene. I certainly had a ‘collective’, meaning-focused outlook, centring organizational culture, identity formation, and organizational learning (see Brown & Humphreys 2002, Cook & Yanow 1993, Kunda 1992, Nicolini et al. 2003), which also included narrative or discursive approaches (see Ybema 2010) and practice studies (see Miettinen et al. 2009).

I took an interpretive anthropological stance with regard to all informants, using my investigations and analysis to bring out the ‘native point of view, i.e. “folk-model” or actors frame of reference’ (Shore & Wright 2011: 8; Malinowski 1920) with regard to policy. Drawing on grounded theory, I allowed their perspectives to guide the spaces I visited and to suggest additional informants, as well as to help shape my theoretical paradigms (Charmaz & Mitchell 2001, Glaser 2002, Clarke 2005, Charmaz 2006). In addition to ‘studying through’, using people’s practices to illuminate policy, this is a ‘multi-sited’, ‘non-local ethnography’. To study processes of transformation, Marcus proposes that researchers should select multiple sites by ‘following something (a conflict, a biography)’, or in the case of my research, a policy, ‘as it moves across the field, revealing the workings of a system or a process of change’ (1995: 96). Such
activity can also be accessed through a single site, because following policy along its trajectory rather than through hypothetical taxonomy of networks, allows the site to be dislocated (Marcus 1998, Lien & Law 2010, Bowker & Star 1999, Latour 1987). I combined this approach with more traditional ethnography by drawing on Feldman’s (2011: 45) framework of ‘non-local ethnography’, which argues that one can use a vantage point to ‘capture the processes through which apparatus [or an assemblage, in this thesis] emerges from the “spaces in between” agencies and institutions’. Gusterson (2005) calls this ‘tilting the field’ in order to study a particular site in detail, and to trace connections from there to observe their implications for the wider field.

My main physical field-site was the Ponce Center; a ‘safety net’ speciality infectious disease programme (IDP) affiliated with the Grady Hospital in Atlanta, Georgia. In the U.S., a safety net programme or health facility is one that provides services and healthcare to vulnerable, low income, un- or under-insured individuals. I examine the Ponce Center as a space and place that delivers and conceptualises care for the most vulnerable in particular ways. I also studied the Center as place where the new ACA was being implemented, which enabled me to engage with implementation as a process of translating and communicating what this new policy meant for various actors in their context. The ‘interpretive policy community’ I worked with was the health policy and HIV milieu; I accessed this by moving within the network of social, political, and interpersonal connections associated with the Center. In order to understand what made this large group of people from diverse backgrounds, locations, and expertise into a community, I considered the history, identity, purpose, and everyday efforts of people at this local safety net organization (the Ponce Center) in context of the national debate on healthcare policy reform.

From the vantage point of the Ponce Center, I ‘tilted the field’ to venture out into other physical and philosophical spaces in which the ACA policy and experiences of HIV acted on and were enacted and translated by different actors, organisations, and institutions – pieces of the American healthcare assemblage. These ‘social and political spaces’, such as state houses and political protests, created by the contesting and implementing health reform
were also occupied by many of my activist and advocate informants (see Chapter 5). I located myself at the Ponce Center, not to generate a place-bound description of daily life, although Chapter 3 examines the everyday operations of the Center, but to engage with the ‘why’ (or ‘criticality’) of the Center that goes beyond taxonomy and description. Such investigation of ‘why’ relationships or symbolic interpretations must be contextualized against historical, political, and economic factors, which is the purpose of Chapter 2. By engaging with assumptions about policy as a problem-solving device, I explored how discussions of governing influence the things people do and say. Most importantly, this is not a study of Ponce Center as an isolated entity. My purpose was to illuminate the processes of assemblage and translation through articulations and implementation of the ACA with other social policy domains. My perch at the Ponce Center enabled me to use classic participant observation to analyse how ‘bits and pieces’ of policymaking that take place in different locations – in meetings, care practices, political speeches, protests, and advocacy – converge to shape the ACA assemblage from the ‘spaces in between’.

Gaining access to an organizational research situation is an ongoing process (Smith 2007: 226), as with all ethnography. Trust must be established between researcher and informants before ethnography can begin. ‘Getting in’ for the first time may be the most daunting step, and because this was multi-sited fieldwork, I had to renegotiate access several times. When I started this research, I had been working as a public health anthropologist for ten years and had been Emory University faculty for three years. Many doctors at the Ponce Center are also Emory faculty; they teach Emory students at Grady Memorial Hospital and the affiliated Ponce Center. The fact that I belonged to the same institution and was referred to them through the Emory University Center For AIDS Research (CFAR), provided me immediate, elite access to the top of policy and decision-making circles. Thus, I was simultaneously an insider and outsider researcher (see Adler & Adler 1987, Anderson 2006, Dwyer & Buckle 2009): I was an Emory insider, but I was also an outsider for this infectious disease group. They understood my research requirements and I understood their protocols, but there were still many official and social boundaries to access that had to be surmounted.
Emory requires all research to be approved by their Internal Review Board (IRB); as a ‘Human Subject Study’, my research explicitly required confidentiality and privacy for my informants. This was necessary to gain access to the Ponce Center, and particularly to talk directly to the patients. In addition, I followed the formal ethical guidelines of the University of Edinburgh (2010) and the code of ethics outlined by the American Anthropological Association (AAA 2012). Furthermore, I was working in a medical setting, a clinical context, where ‘informed consent’ was a prerequisite. Access to my ‘field’ and respondents also depended on specific relationships and the social, cultural, and temporal contingencies around them (Dourish & Anderson 2006, Nissenbaum 2009). Mazandarani et al. (2013) highlight how reflexively analysing the centrality of context is important for contemporary healthcare research, where notions of privacy, confidentiality, and security are much discussed, practiced and politically charged topics – so research concerns are shaped by context. My IRB clearance restricted direct contact with patients, a practical precaution established by the Ponce Center to protect the privacy, safety, and security of both patients and researchers. However, this meant that respondents had to come to me, rather than me approaching them. This was accomplished by having the Ponce Center outreach team and patient navigators inform their patients every day about my research; if someone showed interest, the Ponce team gave them my phone number, so they could call me directly to set up a meeting. The AAA states that ‘the degree and breadth of informed consent’ is situational to the context in which a study takes place and the requirements of other ‘codes, laws, and ethics of the country or community in which the research is pursued’ (AAA 2004, 2012).

For every encounter and patient interview, I obtained a written record of consent. My consent form assured respondents about the voluntary nature of their participation and the lengths I had taken to protect patient safety by ensuring the confidentiality of field notes, interview transcripts and recordings, and any other related materials. I met with patient respondents only for a limited time, always on clinic premises. However, ethnography differs from many other methods in that written informed consent cannot be obtained from
every individual; for example, when conducting participant observation in a dense social context, such as a board meeting with dozens of attendees. For such scenarios, I obtained an additional IRB approval for verbal consent (this never applied to patients). This meant that I would introduce myself, my research, and my reason for attending at the beginning of such meetings, or I would be introduced by someone from the Center, at the beginning of the meetings. At the end of meetings, I would often approach people of interest, or people would approach me to have a conversation about my topic.

Research in a clinical context is also bound by the Health Insurance Portability and Accountability Act of 1996 (HIPAA), which demands special measures to protect individual patients’ identities, medical records and other personal health information. For instance, I could not directly ask respondents if they had AIDS, nor could I ask to accompany them to doctors’ appointments. This protected their privacy and maintained patient-doctor confidentiality. The doctors I interviewed also never mentioned any patient by name or other identifiable information. I could not ask the doctors about patients I had interviewed, nor did I try to access any patient’s medical or insurance records or take note of individually identifiable health information, such as name, address, birth date, or Social Security Number. I did not take photographs of patient respondents. To de-identify the data, I began conversational interviews by asking them to choose an alias and got responses like ‘Call me “Redbug”, my mother used to call me that when I was young’. I always used these pseudonyms instead of legal names, even in recordings and notes, despite the fact that many patients would have preferred to be known by their first names. This process worked as an icebreaker as well, by helping put my respondents at ease. Many patient respondents mentioned their husbands, children, or other relatives in their stories; in a traditional ethnography, I could have asked to meet them, but HIPPA compliance required the removal of specified identifiers of the individual’s relatives, household members, and employers – no contact outside the Ponce Center.

Relationships in fieldwork also have important ethical implications. Ethnographic research can harm those studied, especially in the publication of accounts of their lives (Murphy & Dingwall 2007: 341). Therefore, as part of
negotiating access with the staff at the Ponce Center – who were gatekeepers in that it was their job to protect their patients from unethical or unprepared researchers – I made certain concessions, many of which were beneficial to my final thesis. I made monthly presentations for the practitioners’ meetings. Some of these were about my research progress. Others were about the ACA itself, teaching the doctors information they might need to understand how the implementation of the ACA would impact their everyday practices, or to answer patient questions about the policy. These presentations were an opportunity to expand the scope of my research, and provided a two-way communication channel between myself and the providers. This helped assuage any fears the Ponce staff might have had about possible harm that could stem from the publication of my research. My patient respondents were especially vulnerable, as people living with a stigmatized disease, mostly in poverty, who were contending with racial discrimination. My other respondents were doctors and professionals who had chosen to devote their careers to such people, with a profound awareness of how they can harm their patients’ lives; for example, doctors sometimes signed forms that enabled patients to continue receiving social benefits despite improvement in their medical condition – overriding stringent state programs that were attempting to provide citizens with bare minimum services.

It was not always possible to protect my professional informants with anonymity; unlike patients, they had titles and reputations that are available to the public. I considered it equally important to protect the interests of colleagues, which is part of why I offered my respondents the opportunity to comment on thesis drafts and future publications. I am aware that such exchanges can cause difficulties, including issues of interpretation and emphasis. However, in this case, my informants’ feedback was not analytically or empirically divergent from my own impressions, so it merely enabled me to settle factual questions, and corroborate my conclusions about the practices and social processes I had observed. This is consistent with the paradigm of grounded analysis, which builds on the symbolic interactionist emphasis on how action and meanings are created, to provide a framework for considering the mutual creation of knowledge by researcher and informants and aims to
provide interpretive understanding of the studied world (see Dey 1999, 2004; Charmaz & Mitchell 2001, Glaser 2002; Clarke 2005; Charmaz 2006).

It was also important to protect myself, as a researcher. As discussed in Chapters 3 and 4, the Ponce Center accommodates individuals who are marked by all types of different identities and experiences. They were framed by healthcare providers, politicians, and the press as everything from ‘victims of a terrible disease’ to ‘deviants who brought it on to themselves’, drug addicts, and people incarcerated for murder, theft, and prostitution. Some of these reputations were not unfounded; many of my respondents had stories to tell, including ‘I murdered twice’. They frequently made requests, asking ‘can you lend me money’, ‘buy me food’, ‘drop me home’, ‘let’s go to my friend’s house’, etc. I occasionally had to extricate myself from these situations for my own safety; I usually told informants that ‘I have another interview scheduled, and that will take the whole day’. I also followed the Ponce Center Research Coordinator’s instructions and never carried a purse, camera, computer, cash, or other ‘fancy stuff’ that would draw attention, tempt anyone, or require storage in a safe place while I worked. My notebook and phone served as my only recording and documenting devices. These precautions set limitations on my interactions with patients, rendering me unable to access more traditional forms of engagement, such as following them to their homes/lived environments, or meet with their social or familial relations. By contrast, access to my professional informants, the main participants of this study, was not bound to the Center, so we met in bars, theatres, parties, lunches, and protests. This easier, more frequent, and more informal access made my data collection more ethnographically robust.

To observe that broader policy community and to follow the unfolding implementation processes, I nourished a network of contacts, followed practices over time, and waited for new opportunities to arise. In addition to mapping socio-spatial relationships, it was beneficial for my research to follow the geographic location or movement of events – similar to multi-sited or ‘tilting the field’ approaches. Simply being present in the times, spaces, and places where events unfold allowed me to witness sensitivities, local meanings and strategic alliances first-hand, in ways that are not evident in documents or informant
accounts. At the Ponce Center, I attended regular weekly, bi-weekly or monthly meetings between scientific, medical, and administrative staff, patients, and community advisory groups. Certain meetings were open to researchers, while others were regarded as private, at least by some. I shadowed providers and activists inside and out of the Center; in meetings, clinic waiting and treatment areas, drug houses, poor neighbourhoods where Ponce Center patients reside and are frequented by outreach team from the Center, government buildings, and cafes and bars that activists frequented. I shadowed patients in the Center’s waiting rooms, including those for both clinical and welfare services. In all these places, I talked to providers, activists and patients about their world, taking notes, and observing their daily lives and everyday surroundings.

Outside the Ponce Center, I regularly attended AIDS Community Planning Committee meetings at the Fulton County Health Board. This meeting brings actors from the larger HIV community together in one place, including service and advocacy organizations, patients, government agencies and departments, politicians and the public. This allowed me to observe different components of the healthcare assemblage while they were making decisions about policy implementation. However, gaining access to the staff of the politicians, Governor’s office, or insurance Commissioner was considerably more difficult. They often ignored my emails and telephone calls, and some individuals were completely inaccessible, even after persistent efforts. For example, the Governor’s office always replied with no availability, while the insurance commissioner’s office never replied at all. To remedy this, I had to rely on the public record of their speeches and statements. I also attended numerous street protests, conferences, workshops, meetings at the Center and various related institutions, town hall meetings, and I attended movies and science and history exhibitions with members of the HIV community. All these activities were ‘circulatory’; as Turner and Bruner (1986) observed, ‘to collect data while in motion is to give a narrative order to the flux of experience.’

My methodology thus transcended geographic boundaries, working in an open-ended and reflexive manner; piecing together links between various actors, discourses, and sites – studying through. This enabled me to explore
how small details of daily life in the Ponce Centre became part of larger processes of social and political transformations within healthcare assemblages. My research followed the trajectory of the ACA as social and health policy reform through decision-making bodies and its interactions with patient citizens. It examines the impact and effects its implementation had on safety net institutions providing services to the poorest citizens, and on those individual citizens themselves, to engage with what it means to be an American trying to access healthcare in the context of HIV in Atlanta, Georgia.

In addition to traditional ethnographic methods, I also used archival research to contextualize the history of health policy reform and contemporary responses to HIV and AIDS epidemic in America through the recollections of my respondents. My policy history research included Medicare and Medicaid, the Americans with Disabilities Act, ACT-UP, the Ryan White HIV programme, the Clinton administration’s failed Health Security Act, and of course the Affordable Care Act. Poverty- and HIV-related social policy are a function of complex political, social, demographic and epidemiological forces. Thus, archival analysis allowed me to contextualise the data gathered through participant observation and interviews by understanding the interplay among them, especially poverty discourses. Guided by my respondents, I relied heavily on the Emory University’s Stuart A. Rose Manuscripts, Archives and Rare Books Library (MARBL), and the Library of Congress for legislative history, committee hearings, and congressional testimonies and transcripts.

Randy Gue, curator of the Rose Library’s modern political and historical collections, told me that MARBL is focused on preserving Atlanta's legacy in the fight against AIDS epidemic. MARBL holds the largest collection of materials relevant to Atlanta’s LGBT history, culture, politics, and public health, and Atlanta’s response to AIDS in the early years of the pandemic. These collections include the personal papers of Jesse R. Peel (one of my respondents); David A. Lowe and Rebecca Ranson; and the records of AID Atlanta; the Atlanta Gay Men’s Chorus; Positive Impact; and the Southeastern Arts, Media, and Education Project (SAME). The AIDS Oral History Project also stores much of their data at this library. My archival data also included
federal and health department documents, policy briefs, and newspaper accounts, written materials from various health care advocacy groups, information about the changing epidemiology of the disease, and availability of the treatment and prevention options for HIV. Organizational reports such as MMR (Mortality and Morbidity Report) from the Centers for Disease Control and Prevention (CDC), Kaiser Foundation Reports, and National Institute of Health (NIH) publications also provided a historical perspective on health policy reform and health care and AIDS advocacy in Atlanta.

The final aspect of ethnographic methodology that must be addressed here is myself. I could not have analysed this data without meaningfully engaging with my own impact on the research context and what my position meant for that data. Although the process of gaining access and building rapport was relatively fast and easy for me, particularly regarding professional informants, other aspects of my identity played a role in situating me on the stranger-familiar spectrum. Most obviously, I am a brown, South Asian, naturalised American woman with an accent, born and raised in Pakistan. Ethnically, I do not look like anyone I shadowed or interviewed. This was of minimal importance in the professional community because they were used to working with international colleagues. However, I was a ‘surprise’ for many patient respondents, the majority of whom were low-income African American Southerners. Patients were often curious about me at the beginning of interviews, asking questions about who I was, how long I had been in the U.S., or about my family. I found that telling them I was a ‘PhD researcher from Scotland, also associated with Emory University’ always put me in their ‘trusted zone’, and helped establish excellent rapport during the interview. I believe some of that instant trust was due to Emory’s position within the economy and its cultural capital in Atlanta. Emory is the second biggest employer in the state of Georgia and has a long history with African Americans in Atlanta dating back to the Civil Rights Movement. The fact that I am a woman also helped build trust, because a majority of the patients who contacted me to be interviewed were women. In interviews, we would often
empathise with each other over statements of shared experience about things ‘women are expected to (or have to or are supposed) to do’.

Furthermore, sustained ethnographic engagement with the inescapability and social invention of subjects, voices, bodies, places, times, truths, and with larger political and economic complexities (Rabinow 1996: 56) calls an ethnographer to reflect that analytical work back on herself. I had never been directly involved in HIV care before. The only commonality tying my previous work and this project was my passion for social justice and the impact of marginalization on access to care for the most in need – but that understanding of ‘health disparities’ in global health served as a strong foundation for this research. Furthermore, although I was an insider at Emory University and this afforded me certain benefits, I was also an outsider in these clinical contexts because my background was as a researcher and an academic faculty: more focused on application of theoretical ideas to community-based, participatory design and evaluation of projects related to health systems, behaviours, surveillance.

Ethnography is also a moral and political engagement; it is a modus vivendi (Kleinman 1998, Scheper-Hughes 1995, Cohen 1998). As Biehl (1999) puts it, ‘I do not come out of it untouched. “I think of us.”’ Throughout my fieldwork and writing phase, I have embraced the approach Wilson (1988) calls ‘activist anthropology’ and Scheper-Hughes (1995) names ‘militant anthropology’, which simply means that I share many of my informants’ goals in the movement towards making universal access to holistic HIV care possible. This research inducted me into the policies related to clinical care provision in a developed country context. By focusing on the ACA’s individual mandate and its planned Medicaid expansion, I critically examined how the notion of health as a fundamental right is asserted, contested, and articulated by various actors and subgroups — and how they reconcile the medical fact of ART as ‘prevention’ and patient engagement as a central element to the success of discourse and practice of the full, holistic cascade of care.

Ethnographies of health disparities cannot be apolitical. I took up multiple roles – as critic, advocate, and activist – and these were not objective, because the consequences of ethnographic detachment in a world characterized by
resource inequalities is not neutral. Simply doing research is a political action. HIV in the South is increasing in pandemic proportions, with fatal consequences, and attempts to resolve this issue have been woefully inadequate. The treatment is available, so this research could not escape from the imperative to interrogate how the relevant systems, policies and politics can make that treatment accessible to those who need it. I firmly believe that activist research has enriched the empirical extent and the theoretical sophistication of this thesis, as well as the practical usefulness of the knowledge it produces. I intend for this work to be a potential resource for policymakers, health professionals, and anthropologists alike.

**Conclusion**

This is an anthropology of policy. It deals specifically with the Affordable Care Act and American healthcare reform, but more broadly it is about policy as an effort to address fragmentation in the American healthcare system. It is also about decades of policy and practical attempts to assemble this system into an unfragmented, holistic model of care for people living with HIV. This encompasses more than medical care: American social and health policies hinge upon notions of deserving and undeserving persons, based on categories such as race, sexuality, poverty and moral values surrounding reponsibilization, especially in the American South, which is profoundly marked by the history of racial segregation, civil rights struggles, and poverty. To understand inequality and health disparities within this local context and broken healthcare system, theories of patient citizenship both proclaim and problematize the concept of access to HIV treatment and care.

Most fundamentally, this thesis engages with the question ‘What are people doing when they are doing policy?’ I pursued the meanings of the ACA with regard to HIV care at the Ponce de Leon Center, a safety net welfare clinic. I explored questions like ‘How do people engage with policy and what do they make of it?’ or ‘How does a policy mean’. I draw on ideas of translation and articulation to examine ACA implementation across the healthcare assemblage and the lived realities shaped by it: the ‘social life’ of that policy from conception to individual, on the ground care, and how the ACA intersects with the
fragmented nature of healthcare funding, and the constant labour required to produce a full care and funding assemblage. That notion of assemblage offers a key framework for understanding lived human experience and how they relate to the various components of broader national healthcare assemblage and their fluid, transformative relationships with the local Atlanta HIV community.

The following chapters unfold these meaning-making practices, revealing an assemblage always in flux. The process of implementing the ACA revealed a complex, shifting networks of actors, activities, institutions, and influences that shaped both the policy and its implications for HIV care in Atlanta. Using the methodological tool of ‘studying through’ was an innovative approach in the anthropology of policy, and one that can benefit further health policy research. It allowed me to access these actors in various contexts, and to follow the genesis of the fragmented healthcare system and HIV care through to everyday, on-the-ground experiences. This illuminated the ‘relations between actors, institutions and discourses across time and space’ (Shore & Wright, 2011: 3) that enable actors at the Ponce Centre, as the physical and theoretical nexus of my analysis, to convert their articulations into work of healing. This thesis, sitting at a convergence of social policy analysis, medical anthropology, and public health, also highlights the contributions an anthropological approach to health policy can make to more policy-focused disciplines.

Conceptualizing assemblages as something always in flux facilitates awareness that the policies keeping healthcare assemblages intact are not finished texts that can be implemented through rational, linear processes. Rather, health reform and HIV policies must be understood as ongoing ‘making, working, and effects of public policy as problems of modern governance’ (Greenhalgh 2008: xiii). In the following chapter, I engage with my respondents’ narratives, as accounts of creating and mediating health policies, to illuminate the evolution of policy process. To do so, I examine both the national histories implicated in the formation of HIV and health reform and the personal and social histories of producers of this political knowledge.
Chapter 2: The Social Life (and Context) of the Affordable Care Act

Unfortunately, politics makes decisions about whether people live or die every day. That’s always the pace (Jacque, 7 Jan., 2014). The story of healthcare reform policy is one of America’s longest social, economic, and political struggles. It took almost a century of failed efforts for the United States government to offer something approaching universal health benefits to citizens in the form of the Patient Protection and Affordable Care Act (ACA). “This is a big f***ing deal,” Vice President Joe Biden was heard whispering to the President through a microphone he believed was off, minutes before Obama signed the ACA on 23 March 2010 (in Adams 2010). There were 300 citizens and lawmakers cheering and applauding in the East Room of the White House. He signed the document with the strokes of 22 pens, which were distributed to attendees as a memento of this historic event; one was presented to Victoria Reggie Kennedy, widow of the late Senator Ted Kennedy, a lifelong advocate of health reform and a hero to many of my respondents. The President’s speech acknowledged his efforts. The ACA enacted comprehensive health policy reforms that guaranteed access to care for the most vulnerable members of society. It was so complex, there would be four years between this bill signing and full implementation. After the signing, the President said in his speech that his policy enshrines the principle that every citizen should have basic security when it comes to their health care:

The bill I am signing will set in motion reforms that generations of Americans have fought for and marched for and hungered to see... Today we are affirming that essential truth, a truth every generation is called to rediscover for itself, that we are not a nation that scales back its aspirations.

The ACA was designed to extend health insurance coverage to 30 out of 50 million uninsured Americans by the year 2022. Despite being an incredibly controversial policy, about 17 million people enrolled for coverage during the first year, after the final provisions went into effect in 2014, while I was still in the field. By 2015, it had reached 20 million, and in 2017, at the time of this writing, it covers 30 million. The ACA became President Obama’s signature domestic policy initiative and a legacy of his presidency, despite considerable
opposition from the Republican Party. Following the Supreme Court’s second decision to uphold the law, on 25 June, 2015, President Obama (2015) said,

After more than fifty votes in Congress to repeal or weaken this law; after a Presidential election based in part on preserving or repealing this law; after multiple challenges to this law before the Supreme Court, we can now say this for certain: The Affordable Care act still stands, it is working, and it is here to stay.

The anthropology of policy lens asserts that policy is never just about policy, and this chapter engages with efforts to problematize policy as an object of anthropological study: ‘What does it mean in this context? Whose interests does it promote? What are its social effects? And how does the concept of policy relate to other concepts, norms or institutions within a particular society?’ (Shore & Wright 2011: 8). Within a repertoire of shared experiences, and policies as expressive statements and acts, a policy expresses its identity, and the identity of its nation. This chapter explores the ‘social life’ of the Affordable Care Act (ACA), its interactions with the existing healthcare system and how policies maintain or disrupt the legitimacy of the existing social order. This is accomplished by contextualizing the passage and implementation of the ACA within the cultural and political history of both healthcare policy and the HIV epidemic. This history provides a vital foundation for analysing the ACA policy, the constantly-shifting character of HIV care within the American healthcare assemblage, and the everyday experiences of patients and providers at the Ponce Center.

This chapter presents a combination of ethnographic observation, interviews, and archival research, all grounded in my respondents’ personal accounts of historical events regarding the development of both HIV and broader healthcare policy. It begins with a brief discussion of the conflict between liberal and conservative interpretations of deep-seated American values, and ideological differences in understanding the American cultural ‘myths’. In particular, my focus is the myths that shape American responses to healthcare, and related debates about ‘earned good’, or ‘social contract’, versus ‘public good’, or ‘human right’. It also engages with marginalized identities (e.g. race, sexuality) that are relevant to HIV/AIDS as an experience and a health crisis, and how these characteristics affect people’s experience of citizenship, particularly regarding
their capacity to navigate policy or access healthcare. Section two examines American for-profit fragmented healthcare, focusing on key distinctions that contribute to inequality in access to care. Section three presents my respondents' accounts of their historical role in shaping health policies and care for the HIV community, both regionally and at the national level. It begins with the failed Clinton health reform effort of 1993, because conflict over the Health Security Act (HSA) is a significant aspect of the social context in which the ACA was developed, and many key provisions of the HSA were adopted into the ACA. The chapter ends with accounts of the more recent context in which they supported the ACA, despite having opposed the same provisions in the HSA.

**Fields of Contestation: Liberal vs. Conservative Ideology & the Fragmented American Healthcare System**

Conflicts are natural, inevitable, and essential aspects of social life. They serve to alert individuals...and communities about underlying tensions that exist on some degree in every social relationship. They provide a pathway through which challenges to an oppressive status quo can be articulated and they give individuals and groups a vehicle for achieving desired social change. In this sense, social conflicts can be beneficial...and even improve relations between erstwhile opponents. Without struggles...organizations would remain stagnant, relationships could not mature and develop, and the problems confronting groups...could not be comprehensively considered, debated, and solved (Kriesberg & Dayton 2012: 3)

The complicated tale of the ACA and healthcare policy reform, from its historical roots and contentious creation to its ‘train wreck’ implementation and the vicious fights that persist to this day, embodies the dilemmas of recent U.S. history, ideology, and values that shape the debates around the myth of American national character; what America ought to be vs what America is. Disagreements on both sides of the aisle made the ACA a point of struggle in shaping and ordering everyday life for average Americans. For example, the notion of choice in American imagination is intrinsically linked to freedom as a core American value. By extension, the ability to choose your own doctor becomes an American value; worth fighting for, compared to maligne spectre of ‘socialized medicine’ (Markel 2014). Benedict Anderson (2006) argues that the idea of the nation is a cultural artefact with profound emotional legitimacy that must be understood as a historical entity. He asserts that to classify
national identity as an ideology is problematic; instead, Anderson proposes that *nation* should be defined as ‘an imagined political community’ that is both ‘limited and sovereign’, which should be ‘treated as if it belonged with “kinship” and “religion,” rather than with “liberalism” or “fascism”’ (2006: 7).

*Imagined* because the members of even the smallest nation will never know most of their fellow members, meet them, or even hear of them, yet in the minds of each lives the image of their communion...*Limited* because even the largest [nation] ...has finite, if elastic boundaries, beyond which lie other nations...*Community*, because...the nation is always conceived as a deep, horizontal comradeship  


Anderson conceptualizes ‘the nation’ as a story – a myth – that people tell themselves about identity, and what it means to be a citizen who belongs to a country. It reflects the people, their identities, and their needs, just as policy reflects a nation’s efforts to govern and define itself and its population, and to meet or regulate their needs. The ‘myth’ of America depicts a country that fits a peculiar political, economic, and moral narrative of freedom: freedom from government; freedom *not* to do things, rather than *to* do things; freedom of the market; freedom that must be earned through hard work, rather than being a right; freedom to choose, even against one’s own interests; and freedom that is racialized and discriminatory against certain groups within society.

Policies can be ‘imagined’ in much the same way, as part of the process by which we imagine or constitute nations. Policy anthropologists Shore and Wright argue that ‘A crucial dimension of policy is...the way it is imagined’, and in this sense, policies can be studied as ‘*contested narratives* that define the problems of the present in such a way as to either condemn or condone the past, and project only one viable pathway to its resolution’ (2011: 3). Similarly, policy is not merely implemented; it is enacted, resisted, exploited, re-interpreted, and re-translated in the social and political spaces created by contestation about it.

From an anthropological perspective, most of our existence in modern societies is dictated by policies. ‘Even the concept of individual rights and the “private citizen” are, in effect, artefacts of policy’ (Wedel et al. 2005: 37). Likewise, human health is a biosocial, political, and ecological product that is impacted by policy. The stakes involved in these conflicts over both health
reform policy and the broader myth of America are so high that their loaded and affective nature cannot be underestimated. This is a pivotal part of the processes tracked in this ethnographic study of the social life of policy.

There are at least two competing narratives of America: Conservative and Liberal, associated with the major American political parties, Republican and Democrat. These opposing emotional narratives structure how Americans create, recreate, negotiate, transform and evolve policy in relation to the core of their conception of a moral society. The lenses of identity and struggle help illuminate these competing narratives, which establish the ideology and values that create the desired or imagined identity of a ‘good American citizen’ who is *eligible* (or *worthy*) of the inalienable rights of American citizenship. The relationship between the state and the citizen is defined by the rights and duties both have towards each other. The Declaration of Independence (1776) states that, ‘We hold these truths to be self-evident that all men are created equal… [and] endowed by their creator with certain inalienable rights’ of citizenship, among which are ‘life, liberty, and the pursuit of happiness’. Libertarianism, an offshoot of the Conservative narrative, is an extreme laissez-faire political philosophy advocating only minimal state intervention in the lives of citizens. It somewhat complicates the assertion that there are only two national narratives involved in the ACA. However, while overlap between conservatism and libertarianism is imperfect, the notion of ‘small government’ is a Libertarian philosophy that Conservatives co-opt when they wish to decrease spending on social programs.

America is conceptualised by both Conservatives and Liberals as a fundamentally capitalist nation, characterized by a dedication to the Protestant work ethic (Weber 1905; Baehr & Wells 2002). America was founded by Christians who focused on the relationship between work and salvation; the elect who were destined for Heaven were identifiable by their good behaviour and hard work. Furthermore, early America was a dangerous, untamed continent; constant work was necessary for survival (Zinn 2005). Weber (1905) discusses how the capitalist ‘spirit’ of American life is centred on economic activity with deep roots in a moral universe: productivity became an American value, a desirable end in and of itself. As President Obama (2010) put it,
We are not a nation that falls prey to doubt or mistrust. We don't fall prey to fear. We are not a nation that does what’s easy. That’s not who we are. That’s not how we got here. We are a nation that faces its challenges and accepts its responsibilities. We are a nation that does what is hard. What is necessary. What is right. Here, in this country, we shape our own destiny. That is what we do. That is who we are. That is what makes us the United States of America.

President Obama’s rhetoric highlights the ways these historical concepts are represented in contemporary discourse about the ‘myth’ of America and the nature of citizenship. It re-enforces the notion that in order to attain the ‘myth’ of America, a level playing field must be created.

This is tied to the fact that America was founded on secular European Enlightenment ideals that engendered the beginning of modern democracy – the idea of one man, one vote, and majority rule. However, ‘people’ in this sense referred only to white men; women, African slaves, indigenous Americans, and other people of colour were excluded from citizenship, enfranchisement, and the idea of ‘America’. Marshall (1950) argues that the notion of the ‘citizen’ evolved through three distinct but interconnected stages. Enlightenment ideals constitute the civil element: freedom of speech, thought, and faith; liberty of the person; the right to own property; and the right to justice. The political element came next: the right to participate through vote and to execute power through holding an office. Third is the social element, which encompasses the right to certain standards of living. This is a hallmark of most contemporary western democracies, where it consists of entitlements to social benefits, particularly healthcare, income security, and housing; ‘the right to a modicum of economic welfare and security’ (Marshall 1950: 11). The Republican notion of citizenship aligns primarily with the first of Marshall’s elements, while the Liberal conception aligns more with the second and third.

This situates ‘Life, Liberty, and the Pursuit of Happiness’ at the centre of both Liberal and Conservative conceptions of America, though both philosophies have their own understanding of what that means. The Conservative narrative, which was liberal in 1776, began from the revolutionary presumption that all men are created equal, and have equal freedom to work hard and succeed.
However, Conservative conceptions of American citizens, as a class of people the government should protect, tend towards the white and middle class, like those early colonists. Social and fiscal conservative conceptions of the middle class are fundamentally tied to the assumption that all people start in the same place, and therefore have an equal capacity to ‘pull themselves up by their bootstraps’ to achieve the American Dream of success. It follows that any government involvement interferes with that freedom, ergo government must be small to avoid encroaching upon citizens’ personal freedoms and private lives. This is reflected in particular policies and the meanings attached to them; for example, Conservatives associate anti-poverty programs with notions of laziness and welfare dependency (Gordon & Fraser 1995; see Chapters 1 & 4).

Liberals concur that ‘all men are created equal’, but they recognise that not everyone starts in the same place. Liberals believe that no citizen is more important or worthwhile than his or her fellow citizens, but also understand that people with certain identity characteristics begin life with advantages, while others with different characteristics do not have an equal capacity to reach an equitable place through equivalent work. Statistically speaking, an African American man earns 25% less than a white man, and African American women earn 89% of what African American men earned in 2015 (U.S. Census Bureau, 2015). Liberalism is thus tied to notions of big government; Liberals hold that the government must work to ‘level the playing field’, to ensure that all men are not only created equal but that they begin equal, and with equal advantages. The Liberal concept of American freedom is also tied to social justice, which is represented as the project of trying to create that level field where people have the same opportunity to be able to pull themselves up from their bootstraps – which means the same freedoms for American citizens.

Jeff Graham, a long time AIDS activist, former Director of the AIDS Survival Project, and current Executive Director of Georgia Equality, talked to me about having to compromise with Conservative Christian values. He explained that Conservatives often believe hard work is a ‘calling’, but illness and suffering should be the responsibility of the church and not the government, so Conservatives tend to view government safety net programs as redundant. 'In
reality’, many key informants told me, ‘churches do not have those kinds of resources to help people and it’s the government’s role to ensuring that people who are down on their luck are taken care of’. Jeff, himself a Liberal son of Conservative parents, put it like this: for the majority of Americans, especially in rural areas, ‘church is your family, and if you need anything that is where you turn to, and it’s not helpful’. Jeff argued that healthcare in the U.S. is a commodified, market-based product that consumers must buy, and that the government has the responsibility to at least regulate this market.

And if not, which is the case because of the immense pressure from the powerful insurance and medical industry lobbyists, then [the government should] provide a better alternative than pushing the responsibility onto individuals and churches.

The Liberal view of America thus locates the social contract between citizens and government in a central place, whereas Conservatives emphasise the church, which further aligns with Marshall’s latter elements of citizenship. Conservatives do believe in such a contract but, as noted above, they believe it should be primarily predicated on governmental non-interference. For Liberals, however, the role of government is to provide certain protections, and citizens agree to sacrifice certain liberties in exchange: ‘to be governed and to be bound to one another for common goals, mainly, self-preservation, and prosperity’ (Gilmore 2009: 11; see also Obama 2008).

Both Liberal and Conservative attitudes express themselves in policy, and policy in turn expresses and reflects the nation (Shore & Wright 1997; Biehl 2007; Kingfisher & Maskovsky 2008; Yanow 1996). Accordingly, policy is a fundamental ‘organizing principle’ of modern-day society, on par with other concepts such as ‘family’, ‘nation’, ‘classes or ‘citizenship’. These principles shape social relations and constitute their realities. For example, health and related ‘safety net’ policies intended to provide support to the poor and vulnerable, entail certain rights and responsibilities – and society is ordered and reordered by the way it designates those rights and responsibilities. Furthermore, by classifying people with HIV as ‘ineligible for health insurance’ based on a ‘pre-existing condition’, health insurance policies actively create new categories of individuals. These policies impose an ideal of the ‘normal’ citizen
who has the right to access care. Furthermore, because HIV/AIDS is associated with what Conservatives term ‘life-style choices’, such as homosexuality, prostitution, and drug use it became an epidemic of intersectional inequality powered by racial, gender, class, and sexual inequities. Many Americans, especially Conservatives, believe people should work hard to earn what they need, and do not consider the government or community responsible for health, and some even feel that most illnesses that have any potential human behavioural component; i.e., ‘social diseases’ like HIV are the fault of the patient. Paul Farmer calls this ‘blaming the victim’ (1993). Policy, with its determination of who is eligible for (e.g. deserving or undeserving) the expensive healthcare required constrains the actions and perceptions of particular groups and helps illuminate how laws can impact the way modern identities and ideas are shaped around ‘what it means to be human’.

The connection between policy, identity, and practice is significant because it allows us to examine how health and social safety net policies are used to achieve cultural and political effects. For example, Medicaid is the largest safety net public health insurance program in the United States, covering health and long-term care services for over 60 million low-income individuals. Signed into law by President Johnson under the Social Security Act of 1965, Medicaid is a federal program that offered matching funding to any state that wanted to create a charity care program, in accordance with Conservative constructions of the church’s role. States have the right to decide how they want to spend those funds, which has contributed to a decades-long shift in American public assistance from the Johnson-era universal entitlement to a set of time-limited benefits dependent on eligibility criteria that are strict and narrowing in most states. This means recipients of a combination of these two funding sources are subject to income guidelines that exclude a majority of the working poor. For this reason, poverty scholars have repeatedly questioned the effectiveness of Medicaid (Engel 2006, Cohen 2007, Park 2011).

Furthermore, although there is a myth that the uninsured are unemployed (see Chapter 1), the reality is that a majority of uninsured Americans are what is called ‘working poor’. These people do not receive employer-based insurance
because they have low paying jobs with no benefits, and they don’t have enough money to buy private insurance. However, they also earn too much to qualify for Medicaid in many states. Conservative ideologies of ‘small government’ converge with American perceptions of ‘deserving’ and ‘undeserving’ citizens to create an assumption that these people must have contributed to their own plight. This paradigm inherently ties eligibility to the notion of responsible citizens/personal responsibility. This is central to discussions of public health and medicine, particularly with regard to HIV care. Specifically, the disability benefits Medicaid provides are estimated to cover half of all people with HIV in regular care. This makes Medicaid the second largest source of HIV coverage in the U.S., second only to the Ryan White CARE ACT, another Federal funding programme, but one available only to patients with no other funding sources.

However, there is significant variation in Medicaid-funded HIV care: New York State allows its Medicaid program to cover everyone who is HIV-positive, whereas eligibility in the state of Georgia requires a clinical diagnosis of fully developed AIDS. The Affordable Care Act (ACA) expanded Medicaid eligibility based on income level rather than diagnosis of AIDS, which allowed these benefits to reach millions more low-income adult Americans in many states. However, those benefits were dependent on states agreeing to receive the Federal funding and implementing Medicaid expansion, which the state of Georgia did not (see Chapter 5). These variations illuminate the lines of fracture within the U.S. healthcare system. Medicaid is only one part of the patchwork of services and sources are used to pay for HIV-related services. For example, HIV testing and prevention activities are primarily a concern of the Center for Disease Control (CDC) and local and state health departments. By contrast, HIV treatment and support services are primarily funded through the Health Resources and Services Administration (HRSA), the Center for Medicare and Medicaid Services, and private insurers – and public, private, and non-profit organizations deliver services at the local level. Varying levels of coordination exists within and between service delivery organizations and funding agencies, but the vast majority of activities are uncoordinated.

The Ryan White CARE Act, or simply the Ryan White Program (RWP), is a fragment of this healthcare system that exists specifically to serve people with
HIV/AIDS. It is a Federally funded safety net program that only takes effect once a patient has exhausted all other funding resources. Lisa, a patient interviewed at the Center, told me that she and her husband are both on RWP and have been unemployed and on disability because having AIDS for a long time rendered them incapable of holding a steady job. Being classified as ‘disabled’ and ‘unemployed’ allows them to use other benefits, such as Section 8 housing, food stamps, and part of their medical treatment, provided by the Medicaid Programme – which further demonstrates how fragmented the entire network of social welfare policies is, not just those that pertain to healthcare. Chapter 3 discusses these and other policy ‘fragments’ that the Ponce Center pieces together in order to connect people with care in the comprehensive way that patients need. This patchwork of services classifies people and only provides coverage if they belong to a specific ‘eligible group’, which leaves millions of low-paid working individuals and families uninsured or underinsured.

Significantly, RWP offers what is possibly the least fragmented healthcare experience in America, as Chapter 3 explores in detail. Even citizens with insurance struggle to piece together fragmentary coverage in order to access care, and employer-based or private insurance itself fractures the healthcare landscape further. To begin with, some citizens can access it, and some cannot; for example, undocumented immigrants often cannot purchase insurance, and before the ACA reforms people with HIV and others with ‘pre-existing conditions’ were barred from purchasing (affordable) insurance. In addition, there are state variations in eligibility criteria and ‘standard of care’ (e.g. treatment options, medical technologies). Furthermore, changes in insurance can result in disconnected services and payment, which can affect the continuity of medical records and treatments. In addition, there are often artificial divisions in the services covered by insurance; for example, clinic visits and hospital stays are covered separately from medication. This creates an obvious problem: ‘If you can go and see the doctor but can’t take the medication, then why the hell are you sending me to the doctor?’ asked one consumer advocate in a community meeting. This is a particular problem for HIV/AIDS patients because their drugs are classified as ‘Tier 4’, the most expensive, meaning they are not covered by many plans.
The examples above demonstrate how policy becomes another mechanism of Foucauldian governmentality (Foucault 1997): this section engaged in close readings of ancient and recent history to demonstrate how fragmentation in the healthcare system is a reflection and perpetuation of fundamental American values and struggles. If policy is an organizing principle in contemporary society, then health policy is about how people – and the health of the people – are organised, categorised, and perceived. This organisation reflects the values of a society; because health is about the human condition, and the boundaries between life, death, and wellness. Policy categorisation of citizens therefore takes on moral and ethical dimensions. Anthropological scholarship on poverty, health and the U.S. safety net criticizes the commodification of health as a moral issue, opposed to the notion of collective social good and social contract:

Health care as a right is not compatible with healthcare as commodity; the formal is grounded in principals of justice and social good, whereas the latter is rooted in profit motives that pay lip service to the “laws” of supply and demand. Continuing to allow market forces to unilaterally dictate the policy agenda and shape of health care delivery in this country ensures that profound inequalities will continue to grow. By default, modern medicine will have to become increasingly adept at managing inequality rather than managing (providing) care (Rylko-Bauer & Farmer 2002: 477).

This American approach differs drastically from perceptions of healthcare in countries with socialized medicine; likewise, American perceptions of AIDS treatment in diverge from developed countries where the concept of healthcare systems and insurance are less relevant. For example, in most of Europe, the movement towards universal health coverage has two objectives: access to high quality services and financial protection (Carrin, Evans & Xu 2007; WHO 2010). As Saksena et al. (2014) observe, financial protection refers to a notion of minimizing the contingency associated with future need for health services and the ability to pay for them. The purpose of financial protection as an element of universal health coverage is to both minimize uncertainty in access to health care, which can reduce wellbeing in its own right, and to ensure that no citizen is forced to choose between saving for a future healthcare event or other necessity.
‘The Plan Was Too Conservative’: Clinton Era Health Reform

My fellow Americans, tonight we come together to write a new chapter in the American story... If Americans are to have the courage to change in a difficult time, we must first be secure in our most basic needs... I want to talk to you about the most critical thing we can do to build that security. This health care system of ours is badly broken, and it is time to fix it... So tonight, I want to talk to you about the principles that I believe must embody our efforts to reform American health care system, security, simplicity, savings, choice, quality and responsibility  

(President Bill Clinton 1993)

On 22 September 1993, President Clinton spoke to Congress about the need for legislative reform of the American health care system. Former Presidents Theodore Roosevelt, Franklin D. Roosevelt and Harry Truman had all discussed this, and faced allegations of bringing ‘socialism’ to free market American society. Clinton appointed his wife, First Lady Hillary Rodham Clinton, to lead the ‘The President’s Task Force on National Health Reform’, which was to develop a plan within the first 100 days of Clinton’s presidency. This section describes the Clinton health reform effort of 1993, because the conflict over the failed Health Security Act (HSA) is a significant aspect of the social context in which the ACA was developed, and many key provisions of the HSA were later adapted into the ACA. This section will also talk about the early HIV/AIDS era and policy development, which shaped the development of the ACA and also contextualises my primary field site, the Ponce Center, and the experiences of my respondents.

Several of my respondents who were policy advisors to the Clintons recalled, in personal interviews, considerable public scepticism about the President’s choice to appoint his wife as leader of the health reform task force when many other candidates had greater policy experience and had spent their careers working on health reform. The task force, which consisted of cabinet members and several other senior officials, was responsible for refining the basic model of reform that President Clinton had proposed during his election campaign. However, despite numerous meetings with public and industry interest groups, the team was perceived as secretive and exclusionary, in part because the health industry is too large to be fully involved through meetings and in part the opposition found it fiscally inconvenient to let Clinton fulfil his campaign promises. Ultimately, members could not reach an agreement and the task force was
dissolved without making any recommendations. To control the damage to the possibility of health care reform, President Clinton adopted another strategy. His new approach focused on advertising the details of the plan to general public, in an attempt to dispel the task force’s reputation for secrecy. The publicity was also intended to combat harmful myths about the plan created by opposition-sponsored attack ads. The Health Security Act (HSA) Clinton proposed to Congress was a healthcare system in which the government provided health insurance as part of the broader insurance open market, incentivising private insurance companies to compete with the government-controlled rates. However, the HSA was far from the single payer model many liberals preferred, so Clinton faced severe opposition from his own Democratic Party as well as from the Republicans. Clinton’s struggles were exacerbated by the perception that he lacked a popular mandate; he had won the Presidency with only 43% of the popular vote against Bush's 37% and third-party candidate Perot’s 19%. It was the first time since 1968 that a Presidential candidate had won with under half of the popular vote. Clinton’s support was further eroded by the ‘Republican Revolution’ of 1994: for the first time since the 1950s, Republicans claimed 12 gubernatorial seats, 20 state legislatures, and 472 legislative seats out of 538. A movement called ‘the New Right’ emerged under the leadership of Newt Gingrith (R-Georgia), Speaker of the U.S. House of Representatives, who were dedicated to obstructing the Clinton health plan. Republicans promoted the narrative that the HSA represented ‘Big Government’, which is part of the Conservative ideological narrative about how government spending (e.g., the safety net) is unnecessary, intrusive, and wasteful. The public, conditioned by the Reagan era’s small government message, responded with fear and distrust. They also associated the HSA with misogynist mistrust of Hillary Clinton’s independent, feminist reputation; the plan continued to be branded *HillaryCare*, despite the failure of her task force. Gingrich presented his ‘Contract with America’ in a document that presented the core Republican ideology: shrinking government, particularly welfare, and promoting lower taxes and greater entrepreneurial activity. A Conservative think tank, the Heritage Foundation, proposed the Employer mandate as an alternative to the HSA: it
would require all employers to insure their employees – a substitute embraced by Gingrich and the New Right. However, the Republican Party also lacked a consensus: Republican Senator, Bob Dole, advocated for an Individual mandate instead, suggesting that each individual should be responsible for buying their own health insurance instead of relying on the government or their employer.

Democrats who opposed the HSA began presenting their own, bolder plans, although none of these achieved the popular support necessary to become viable. Speaking as a Democrat and a professional healthcare advocate who actively fought against the initial Clinton plans for healthcare reform, Jeff explained that,

We felt the Hillary Clinton plan was too conservative. [It was] more of the same thing: private, profit-based insurance. We felt...single payer...was the only approach that was ultimately going to...really make it accessible to all individuals, could be tailored to the individual needs of the communities and also create a sense of health equity.

While the HSA was before Congress, both sides began airing television attack advertisements to create and support myths that the new policy attacked the values and ideology at the core of American identity. One particular advertisement, ‘Harry and Louise’ (Goddard & Clausen 1993), was famous for turning public opinion against the policy. This ad showed a couple sitting at the kitchen table complaining about how their health-insurance coverage had been cancelled and replaced with more expensive provisions they didn't want. Louise told Harry, ‘Having choices we don't like is no choice at all’. This appealed to the Conservative base, and their perspective on freedom of choice, so the ad projected the image of ‘government takeover’ and suppression of individual freedom.

The Health Security Act never came up for a vote in the House and was pronounced ‘dead’ before autumn 1994. Several of my respondents, particularly Jeff, who worked against this effort told me the HIV community was largely insulated from the failure of this healthcare reform because the HIV activist movement was able to have other protections passed into law. ACT-UP, the AIDS Coalition to Unleash Power, was a grassroots organization that took a particularly confrontational approach to HIV/AIDS and gay rights activism. ACT-UP members chained themselves to pharmaceutical company headquarters to advocate for faster AIDS research, held kiss-ins to shock
people who were unused to seeing same-sex affection in public, and die-ins to gain media attention at hospitals that barred AIDS patients, where people lay limply on the ground, so police had to carry them away on stretchers. ACT-UP played an important role in shaping the history of the epidemic in the U.S., and healthcare responses to it, along with perceptions of homosexuality more broadly (Sontag 1988). Without ACT-UP demanding visibility and assistance, many of the current AIDS policies in the U.S. would not exist (Gould 2009). Jeff, who was an active, pioneering member of ACT-UP Atlanta, said they ‘kicked the doors open if it needed to be’. My respondents, in addition to their own stories, directed me to histories of their famous contemporary comrades, especially *The Normal Heart* (Kramer 1985), which documents the terror of an AIDS crisis that was largely ignored and ridiculed for political and ‘moral’ reasons. My informant, Dr Jim Curran, featured prominently in another history those who worked to save lives in the face of a wider political, medical, and media atmosphere that were more concerned with image and budget (Shilt 1987).

This historical contextualization of HIV policies within broader healthcare reform illuminates the intersection of policy, the role that emotion plays in activism, and the experience of everyday life and death. In earlier days, palliative care was the only AIDS treatment available, so gay rights groups started providing social aid and palliative medical care to people with AIDS, regardless of their sexual orientation. However, in 1985, the well-publicised illness and death of Hollywood star Rock Hudson made HIV/AIDS a mainstream issue in the American media. It brought attention to the disease itself and how it was affecting people on a global scale. This quickly turned into general public fear and hysteria. That was also the year that Ryan White, a 13-year-old haemophiliac, was diagnosed with AIDS and barred from attending his public school. Lawsuits by his mother Jeanne, calling out on the discrimination and hostility Ryan and his family faced in their own community, made his case national news (see below). Elizabeth Taylor, Elton John and Michael Jackson all helped bring attention and resources to the HIV/AIDS cause. 1985 was also the year Larry Kramer of New York founded the AIDS Coalition to Unleash Power (ACT UP), challenging Washington and
the medical establishment and giving birth to formal AIDS activism, which remained linked to care. Jeff shared a personal story of how he got involved in AIDS activism through providing palliative care for a dying friend:

We divided days and Tuesdays were my days. I used to go to his apartment, feed him, clean him, read him newspapers and watch TV with him, and provide him company so he can pass his time. We had to teach ourselves about what best care can be provided and how – what was out there and what was needed. We had to learn very quickly.

Although the HIV/AIDS community was broader than the gay community (or even what we might today call the LGBTQIA+ community), the two were often conflated, and many of the problems that afflicted the latter informed the fears of the former. For example, Avram Finkelstein (2009), who created the famous ‘Silence = Death’ AIDS protest slogan, explained that for the gay community, ‘Politically, institutionally, silence is about control. Personally, silence is about complicity’. Until ACT-UP, Finkelstein recalled, there was no space to talk about certain issues such as fears of sex, boyfriends, loneliness, and politics; ‘every week it will go back to institutional homophobia, access issues, and racism. We were much clued into the idea that there was a politic, that there was a political context which no one was talking about at that time’ (ibid).

ACT-UP’s achievements were not limited to protest: In addition to challenging government inaction by hurling the ash and bone of fallen comrades over the White House fence (HTSAP 2012), they educated activists about antiviral medications, clinical-trial protocols, and the Food and Drug Administration (FDA) approval process. Anthony Fauzi, Director of the National Institute of Allergy and Infectious Diseases, told the International Herald Tribune that ACT-UP’s leaders ‘cracked open the opaque process’ of drug development, altered the patient doctor relationship, and ‘changed the whole face of advocacy’ (Bruni 2012). Jeff recalled protesting outside FDA, CDC, and NIH meetings until they were invited to attend. Advocates I spoke to emphasised how important it was to have a ‘seat at the table’ where ‘decisions about your life and death were being made’. Jeff still writes advocacy pieces under the slogan ‘Action = Life’.

However, it took years for this advocacy to yield effects in terms of recognition, policy, or applicable medical and pharmaceutical research. The first drug, AZT
from Glaxo, came on the market in 1987. It was highly toxic, not very effective for HIV/AIDS, and had severe side effects including liver damage, weakened muscles and blood disorders. Despite this, AZT was approved by the FDA, and it gave hope to desperate people who had been waiting years for a treatment. However, AZT was the most expensive drug that had ever been released: one of my informants recalled its cost, unverified, at about $10,000 a year. Jeff said,

There was a real sense of community outrage that they were gouging dying people. They were preying on people’s desires to just live. And they didn’t need to price it that high... *AIDS profiteering* is what it was called. And [we were] very intentionally picking up words from World War II: this whole sense of *community good* that you didn’t want to be a war profiteer – that was a bad thing – it was un-American. So, an AIDS profiteer ... was anti-humanitarian – it was wrong and morally reprehensible.

Before and after the approval of AZT, there was tremendous anxiety among people immediately affected by the disease, recalled Jesse Peel, my respondent and a long time HIV-positive AIDS activist. Jesse was one of the founders of AID Atlanta, the largest AIDS service Organization in the South, as well as Positive Impact, a mental health program for people with HIV and their friends, family and caregivers. In the early ’80s Jesse, a successful psychiatrist and prominent member of the gay community, started seeing friends and patients ‘dropping dead left right and centre’. No one knew where this disease came from and what could be done to treat it, but Jesse recalled a sense that ‘there was nothing that anyone was doing to save us’. The community also feared that AIDS would obscure the progress the gay liberation movement had made towards de-medicalizing homosexuality as a psychological diagnosis. Mistrust of medical authorities explains in part why people like Jeff were left to care for dying friends, and to support each other.
In 1983, Jesse's personal diary became more detailed about the increasing number of AIDS-related deaths around him. 'I had begun to clip obituaries and articles on AIDS from the newspapers, order of worship from funerals of my patients and friends and copies of eulogies I gave, all of which I stuck into the pages of my journals. It was my way of remembering them and my journals were becoming adjunct to therapy I needed'. I first met Jesse at the party after he donated his papers to a project documenting the history of Atlanta and the South at Emory University's Manuscript, Archives, and Rare Book Library (MARBL). MARBL wrote, 'Dr Peel's papers demonstrate the power of courageous inquiry and collective action to benefit the lives and health of so many' (Figs. 2.1-3).

Sitting in his living room, Jesse described to me how the community was scrambling to find a solution with no help from the government, so everyone pitched in: 'Anyone who was willing found their own way to help. I was good at throwing parties, so I started throwing parties to raise money for these grassroots organizations that provided care and support to the people living
with AIDS’. They had a minimum of $20 donation, and anyone could attend pool parties at his home, ‘Camp Merton’. Some of the characters from his stories about those parties became prominent figures in HIV policy development nationwide, and were already my key informants. Jesse has raised money and served on almost every AIDS organization in Atlanta.

In my informants’ accounts, the strength of collective action in the AIDS community had very individual and personal roots. These stories illuminated for me what Biehl (2007: 16) refers to as a ‘singularity of its many lives’ that form the context of the response to this epidemic. For example, Jesse described having to leave his partner of ten years, who had ‘an out of control addiction problem’. Jeff recalled taking on the interrelated roles of caregiver, activist, and lobbyist. He said as he got to know more people with AIDS, he and other activists began to take on caregiver roles. They would work on demonstrations and arrests together, and then became the ones to take care of their first friend to fall ill:

I was Tuesday night – we each had a night of the week and we’d go and we’d chat. Joey was his name. So we’d just go sit there with Joey and watch TV and make sure he had a good meal, was clean and just talk so he wouldn’t feel alone...

One night was when he was very angry...he just talked about how I would never know what it was like to be him because I was not HIV-
positive. He felt I could turn away from this at any time if it just got to be inconvenient or stressful or I lost interest, and I could move on with my life. I would have that luxury, as I remained HIV-negative. And this was something that he wanted to be passionate about, his activism, up until the day he died. Because he knew it was always going to define him, and he knew he was going to die this way, so he wanted to die as a fighter.

In some ways, it’s really weird that people in their 20’s [were] having this sort of deep conversations about what really is life and what is your role and your responsibility… That’s why it was never all about politics. It really was about this caregiving. I’ve said to folks over the years that many ways as public and political as it has been for me, it’s also very, very personal.

I made a pledge to Joey a few days before he died that I would keep doing this as long as there was a need for it. Because he wasn’t going to be here, so it was important for me that he knew that I was not going to forget him, and I was not going to forget the importance of this cause ever. So, I’ve just really tried to lead my life professionally with that sense of integrity that I just owed this friend this promise that I had made... Of course, over the years it’s been easier and easier to keep that because there have been more and more people in my life, many of whom are not here anymore, that I really cared about [who died of AIDS].

As scientific treatments advanced, HIV care began to include both medical and social services for the people living with and dying from HIV/AIDS. This comprehensive approach seeped into legislative processes and made AIDS policy very different from the existing healthcare system by joining most disparate parts of both social and healthcare policies together. Sandra Thurman – Sandy, who was at the forefront of early activism, as Director of AIDAtlanta, and official government policy making, as the Clinton Administration’s HIV/AIDS czar – told me ‘it was unlike any other epidemics, and unlike other issues of our time’. There was no treatment at that time. They did not have infrastructure in place that could meet either the social, mental, or physical needs of these dying people.

So, we ended up creating something new. It was a complicated policy process for a variety of reasons. First, it was a sexually transmitted disease, everybody's anxious about talking about sex, it has all these religious and cultural connotations for practically everybody...then it was the gay community – homosexuality – you put that next and the American public, and many politicians – religious, political, cultural conservatives in particular – just didn't know what to do with that... and we discovered early on in this AIDS business that there was such incredible discrimination against people with AIDS.
Policies had to be designed to support a continuum of care that went from diagnosis to the psychological impact of the illness, to sickness, stigma, and discrimination (Shilt 1987, Epstein 1996, Doyal & Doyal 2013). It had to include rejection by families, abandonment in hospitals, lost jobs, homes, insurance, medical coverage, and being without food because they were unemployed. The list of immediate needs was long, so the care provided had to compensate for the absence of other social support mechanisms or protections. The Doyals highlight that inequality regarding social suffering, access to care, and patterns of morality are central issues in the social distribution of HIV infection. The response to AIDS was driven primarily by the communities affected; a bottom-up effort, as opposed to a top-down approach. Sandy called it a ‘sort of soup-to-nuts, diagnosis-to-death kind of approach’.

It was not a policy response, but, let’s say, a consumer driven response, which meant that the programs were actually designed by the people who were affected and infected for the people who were affected and infected...very different from how we normally do policy.

In the late 1980s, at a time when President Regan refused to even say the word ‘AIDS’, several Congresspersons started working on an ‘Omnibus AIDS Act’ to provide palliative care in the absence of any successful treatment. That was another thing that was very different about AIDS policy. Sandy described the nature of needs and policy changes required to ensure safety, privacy, and protection against discrimination for these sick and dying people:

Their records were not protected. People were getting diagnosed and it was ending up on the front page of the paper. People were getting fired from their jobs, getting beaten, crosses burned on their front yards, and, all kinds of slurs were written on their doors, placards, saying ‘God Hates Queers’. I mean, just the most vicious anti-gay vitriol you could- just awful! So, we had to do something about that. We had to put policies and laws in place to protect people from discrimination.

This represents policy as an explicit method of dealing with hate – of protecting people from it, and of changing people’s minds. Thus, when the Ryan-White CARE Act passed in 1990, after five years of effort, by an overwhelming bipartisan majority support from the House and Senate, it included social and medical care provisions. ‘No other effort had ever been that
comprehensive, but because of this epidemic, it had to be. It was the first bill of its kind passed to deal with a single disease in the history of the United States’. Ryan White represents a comprehensive approach to providing care for HIV/AIDS that has none of the fragmentation or gaps of the broader American healthcare system. In Atlanta, it enables people to access all the services and care they need in one place: The Ponce Center. The comprehensive policy provisions afforded by Ryan White went beyond simple healthcare.

Several other relevant policies were passed simultaneously. For example, people with HIV were unable to work, so they had no money or housing. Furthermore, they were dying so quickly after diagnosis that Social Security and Medicaid introduced a rapid assessment application process to provide PLHIV with those benefits before they died. One of the major policies they incorporated was the Americans with Disabilities Act of 1990, which included people living with HIV/AIDS in the larger continuum of disabilities, ensuring them the protections other people with disabilities received. Thus, the ADA created people with AIDS as a new category of person and simultaneously created them as the same category of person as other people with disabilities. Creating new subjectivities, a new identity, is not always a bad thing – in this case, newly identifying HIV-positive people as disabled rather than (just) sick made it easier for the government to provide them with greater benefits and rights that enabled them to live with dignity and freedom. The ADA not only changed the shape of how Americans think about disability, it changed the literal physical structures of the country – buildings must have wheelchair ramps and automatic doors, more spacious designated public toilets, special seating spaces on buses and in the cinema – it’s so integrated into our daily lives that not having it would feel unnatural.

The Ryan White CARE Act and the Americans with Disabilities Act represented significant changes to the status quo, but numerous other policies had to be developed to deal with issues like privacy protections. These changes illuminate the ways policy can intersect with lived experience, and thereby change, create and shape it. For example, hospitals had to change their ‘advance medical directives’ policies, which determine who can make life and death decisions if
patient is no longer able to consent, as well as how people sign in and designate their next of kin, which prevented estranged blood relations from overriding their wishes. Sandy said, ‘We had to make it a crime to reveal someone's HIV status without their permission’ and to this day, name reporting is still not done in all states. These HIV-related policies functioned together as a network of care; it was not fragmented like the usual American healthcare system. It was this that led the HIV advocates to oppose the Clinton plan, because the Health Security Act was far from the single payer system they considered optimal. As Jeff said, ‘we wanted Ryan White CARE for everyone’. Furthermore, the AIDS community had Ryan White and the ADA, so they were not affected by the failure of the Clinton plan; its existence or non-existence changed nothing for them.

The failed HSA was the last attempt at national healthcare reform until the George W. Bush administration attempted to introduce Medicare Part D, which was intended to make prescription medications more affordable through access to cheaper Canadian drugs. Instead, it caused a debacle known as the ‘doughnut hole’ in Medicare coverage, a massive proliferation of prescription plans so complex that most people choose poorly, and the default choice is random, not the ideal plan for their medication needs. The other significant effort was in 2006, when the Republican Governor of Massachusetts, Mitt Romney, aided by the Democratic majority in his state and the leadership of Senator Edward ‘Ted’ Kennedy (D-MA), passed an individual mandate health reform policy. In his 47 years as a legislator, which continued into the Obama administration, Senator Kennedy stood for social justice, equity, and bipartisan cooperation. He championed immigration, cancer research, health insurance, anti-apartheid, disability antidiscrimination, AIDS care, civil rights, mental health benefits, children's health insurance, education and volunteering. He called universal healthcare policy the ‘cause of my life’, and fought for it until his death in August 2009, just months before the ACA health reform policy became law for the entire country. When the Massachusetts reform (later branded ‘Romneycare’) was implemented, about 8.4% of Massachusetts citizens were uninsured; by 2010, the uninsured rate fell to 3% while reducing the costs of health care in the state. Uninsured rates fell most among minorities: Between 2006 and
2010, the rate of uninsured African-Americans in Massachusetts fell from 15% to 3.4%, and the rate for Hispanics went from 20% to 9.2% (Koebler 2013).

**‘We Had No Choice’: The Affordable Care Act**

We were much more open to incremental change...as much as I abhor the concept of private coverage as opposed to universal, at least with the ACA we could get the conversation going in the right direction – getting more people covered. Jeff (2014)

‘It’s all political, it’s all political, it’s a political problem’ said Jeff, in response to my question about why American health policy reform is such a contentious issue, in addition to being inherently complex. ‘It’s like a third rail – you touch it and you are dead’. Jeff and other informants constantly described healthcare to me as ‘political’, deliberately invoking civil rights, social justice, and disenfranchisement. This word, this attribution, was everywhere – in offices, at the clinic, in protests on the street, and in the sophisticated corridors of the state capitol. Jeff called healthcare the ‘third rail of politics’ because of how it translated into other highly charged moral, affective, cognitive, political, and identity related issues inherent in the politics surrounding access to healthcare, and especially what it meant for the HIV community (see Chapters 3 & 5).

With the exception of Bush’s Medicare Part D and Romney’s state health plan, the U.S. government made no legislative attempts to regulate the insurance and health industries between the failure of the 1994 Clinton plan and Obama’s 2010 healthcare reform. A direct result of this inaction was the skyrocketing cost of health care and drugs (Fig. 2.4), a drastic increase in the numbers of uninsured, and increasingly limited access to services by those who needed it the most. Since the failure of the Clinton plan that they so adamantly opposed, ‘things have just gotten worse’, Jeff told me. Despite spending 23-26% of its total annual budget on health, $3 trillion in 2010, America had 50 million uninsured citizens (Munro 2014), and its increasingly fragmented market-based and expensive healthcare system had too many cracks though which the disfranchised fell.

This section describes the more recent context in which the HIV advocacy community supported the current health reform and embraced the ACA, even though it is a market-based solution, not the single payer policy that they had striven for. The section also explains what the ACA provisions are, and how the
policy was appropriated and contested as part of the project of making or ‘imagining’ the myth of America (see Anderson 2006). The section lays the foundation for examining the effect this policy can have on people’s conceptions of identity and experiences of access and right to health.

The ACA became active in October 2013, when the Federal and state marketplace websites launched, where insurance companies compete for business and people get affordable rates. The law assists the individual purchase of insurance in several ways. In addition to marketplaces, it provides government subsidies (tax breaks) for low-income individuals and families to help them buy insurance plans from the marketplaces. The tax credits end at income levels above 400% of the Federal Poverty Level (FPL); thus, uninsured individuals who earned more than $44,680 in 2013 had to buy their own insurance without government assistance (Kaiser Family Foundation 2015). For a family of four, the cut-off was $92,200. If people cannot find a plan that costs under 8% of their income, they are eligible for hardship exemption. The second significant provision is Medicaid expansion for the very poor; individuals and families earning under 133% of the FPL ($14,400). This allows individuals without young children to be eligible, whereas traditional Medicaid covers only pregnant women or mothers with young children, children, and the disabled. Expanding Medicaid to include single adults with an income below 133% of the FPL has important implications for the working poor, both men and women. For example, an HIV-positive male who meets this
income threshold in a state with strict eligibility criteria, like Georgia, will not have to wait for an AIDS diagnosis to be eligible for Medicaid under disability.

The ACA also addressed the fact that the insurance industry controls access to care in the U.S. system. Prior to the law, the health insurance industry profited by excluding the sickest and most vulnerable Americans, who incur the most costs. Historically, people living with HIV could not purchase private insurance due to their ‘pre-existing condition’ of HIV. The other 83% of PLHIV either substantially depended on public programs like Medicaid, Medicare, or the Veterans Affairs healthcare system, or went without care altogether. Proponents of health reform say that their intent is to ensure that everyone in the country shares the ‘risk’, because anyone can fall sick or have an accident and need those protections. Thus, the ACA applies a fiscal penalty to people who don’t share in the risk assessed based on the income reported on tax returns, which increases with every year that they choose not to buy health insurance. This creation of a shared national ‘risk pool’ demonstrates how policy can be a fluid and shifting site of cultural and political contestation. The ACA is a symbol and site of struggle between those who believe the state should not interfere in people’s freedoms and those who believe freedom and equality are only possible when state regulations enforce them:

Hegemony and contestation is central to this idea of policy; political conflicts defend or unsettle established discourses and advance particular ways of conceptualizing the role of individual, social institutions and even of government itself (Wright & Reinhold 2011: 86).

Romneycare and the ACA reform can thus be seen as a test of the political, legal, ideological and moral aspects of government-initiated policy processes. The individual mandate, a key feature of both bills, is particularly contentious: Democrats opposed it in the 1990s, until it seemed like the only politically feasible option as part of the ACA, but then the Republicans rejected it. The Republican Party challenged health reform by arguing that the policy of universal coverage through individual mandate interferes with the Constitutional rights and freedoms of citizens and undermines the value of individual responsibility. However, in the 1990s, Republicans proposed the individual mandate using the philosophical argument that it affirmed and supported individual responsibility. The Democrats generally advocate sharing the costs of the sick across the
broader population (called ‘risk pooling’). These positions have dramatically different implications for individuals when they experience significant health problems, especially when they are from low- and lower-middle-income groups. Bourdieu (1977) proposed something similar with his concept of doxa, suggesting that traditional practices, customs, beliefs, values and institutions are represented or perceived as akin to the natural world, which helps maintain the desired, (or ‘imagined’), social order without conflict. There is no consensus about the desired social order, as evidenced by the multiple interpretations and conflict between Democrats and Republicans throughout this thesis.

Contests over the individual mandate demonstrates the conflicting Conservative and Liberal ‘sensibilities’ regarding freedom and choice. Discourse about the ACA policy is currently dominated by the ‘culture of opportunity vs. culture of dependency’ division. Proponents of this law, represented by the Liberal, Democratic Obama administration, maintain that reform is part of a social contract the government must keep with its citizens. They believe these commitments include maintaining social safety net programmes such as social security, Medicaid, Medicare, unemployment benefits, food stamps, and veterans’ benefits. These programmes all provide basic support that people who are struggling need to return to stability, particularly in times of economic crisis. By the Democratic definition, the Constitutional right to ‘life, liberty, and the pursuit of happiness’ includes access to health insurance. President Obama (2012) considered this position reconcilable with conservative principles of ‘personal responsibility’ because ‘Medicare and social security are not hand-outs, you have earned those’. Conservative Republicans, however, view health insurance not as a right but as a privilege that responsible citizens earn as the ‘fruit of their labour’.

The Affordable Care Act is part of President Obama’s Liberal legacy, and tied to his status as the first American black president. Thus, a significant political aspect of this policy that must be unpacked is the mythologized and symbolic nature of the Obama presidency, his vision of America reflected through the ACA as his signature policy, and the emotional effects this policy produced on both sides of the aisle. Race is a traumatic and central issue in American culture.
Poverty, blackness, and welfare in America are routinely conflated by politicians and the media. Welfare beneficiaries are perceived as overwhelmingly black and overwhelmingly lazy: undeserving, and generally unwilling to work to achieve the American dream (see Chapter 1). This is seen as a failure to live up to – or earn – the key aspects of the ‘myth’ of America, as detailed above.

In addition, race as a form of ‘group identity’ (Jenkins 2008) is the basis of some of the most extreme acts of discrimination and human rights violations in the U.S. This is particularly, though not exclusively, true in the American South, including Georgia, with its long history of slavery, segregation, and legislated discrimination. Some Americans, steeped in the long history of racial tension, have trouble conceptualising Obama as the President because they cannot reconcile his race with notions of legitimate authority, or the idea that a person of colour could have the power to make national decisions. These discontented citizens sought to literally delegitimize his presidency by asserting that he was a Kenyan-born foreigner, and therefore ineligible for the office – a belief that earned them the title ‘birthers’, for their insistence that the President’s Hawaiian birth certificate was fraudulent.

Williams (1999: 186) identifies race in the realm of health as ‘a central determinant of social identity and obligations (and) an empirically robust predictor of variations in morbidity and mortality’. Chapters 1 and 4 examine how race intersects with issues of care and treatment in terms of being viewed as deserving and undeserving, along with stigma and discrimination as they pertain to illness and diseases; here, it is most important to note the parallel between the perceived illegitimacy of providing healthcare to the ‘undeserving’ (e.g., ‘black’, ‘lazy’) Americans and the perceived illegitimacy of the President whose signature policy facilitated this treatment. People living with HIV must contend with similar conflated issues, including homophobic sentiment, and racial, gender, and economic inequality exacerbating the fragmentation of the healthcare system. Within that, access to care through the ACA unfolds at the place of my research focus – the Ponce Centre. If the cartoon below (Fig. 2.5) depicted a black or Latino man blue-collar clothing, he would less sympathetic than the white, male chemistry teacher. This illustrates the astuteness of
Conservative conflation of welfare and entitlement programs with poor black people, especially because the most welfare recipients are white (HHS 2012).

The LGBTQIA+ community as a collective identity was also explicitly tied to the conversation about people being deserving and undeserving. The earliest days of the epidemic were marked by loneliness, abandonment, and hopelessness for people living with AIDS. Because the first identified sufferers of the disease were gay men in the U.S., AIDS developed strong sexual and moral connotations. AIDS became associated with homosexuality, in America and around the world, and was often associated with promiscuity, infidelity, lack of attachment, and irresponsibility in terms of sexual ethics and safe sex practices. Sontag (1983) discusses how the ‘social fantasy’ of certain illnesses obfuscates public understanding of the particularities of individual suffering (Weeks 1989: 1). In the social imagination, AIDS came to stand for misapprehensions about the sort of person who contracts AIDS, which obscured the true experiences of those suffering. Thus, it is necessary to contextualize the official government AIDS policies within the role and experience of the gay rights movement in the history of the political crisis surrounding AIDS. Drug users are another category of people associated with the disease, and sometimes with the LGBTQIA+ community, which also contributed to that stigma.

Dazon Dixon Diallo is the Founder and President of SisterLove, a sexual and reproductive health justice organization, with a focus on HIV/AIDS and other sexually transmitted diseases. She said her activism had the same origin as other community-based HIV/AIDS organizations: Anger. She was particularly outraged that were no services or education in Atlanta for black women
impacted by AIDS, not even within the current HIV/AIDS organizations, nor within the reproductive rights and feminist movements. ‘First’, she said, ‘let’s get this out of the way: AIDS and HIV has never been a white gay disease – never. African American poor women always had it, but nobody was ready to pay any attention to them’. She explained that HIV was not a priority, even more so because the stigma surrounding the disease intersected with the struggles of black women. Dazon works in Atlanta and South Africa, and finds that ‘The problems are not that different. [In both locations,] you have women who are vulnerable or who are not able to get the treatment and care that they need because they are economically dependent or depressed’.

In the modern era, race, gender, poverty, and LGBTQIA+ identity remain a crisis point for AIDS transmission, especially in the South. Patients with other ‘intersectional’ statuses that render them ‘undeserving’ (see Crenshaw 1994) struggle to contend with their diagnosis of a ‘gay disease’ as well. Research demonstrates that stigma limits access to treatment and affects relationships and identity (Epstein 1996, Weitz 1990), to the point that Carlos del Rio, co-Director of the Emory Center for AIDS Research told me, ‘Downtown Atlanta has a generalized HIV epidemic that mirrors what we see in some African cities’. In 2016, an estimated 1.2 million people were living with HIV in the U.S., compared to 1.3 million in Zimbabwe, which has the sixth highest HIV prevalence in sub-Saharan Africa. Over three-quarters of HIV expenditure in Zimbabwe comes from international sources, including American foreign aid, like the President’s Emergency Plan for AIDS Relief (PEPFAR) (UNAIDS 2017). In 2014, Atlanta had the fifth-highest rate of new HIV infections in the United States (Brooke et al. 2011). Carlos often asks ‘when are we getting PEPFAR money for Atlanta, our own backyard, and a city considered the world capital of public health?’ Over 4% of all black men in Fulton County, one of the poorest Atlanta areas, live with HIV. Gay and bisexual men account for 67% of all diagnoses, and 83% of that number are African-American. ‘We should not be having an epidemic of that proportion in a country like ours. This is not Africa, we have resources’, Carlos opined.

While the main discourse associated with healthcare reform was ‘dependency vs. opportunity’, the narratives accompanying the ACA included a range of
metaphors that appealed not just for and to social and fiscal but also moral and patriotic meanings and values. For example, the Republicans put forward a narrative that Obamacare was a ‘government takeover of the health care system’. They argued that this inherently suggested that the government, once it was in control of ‘all’ health decisions, would have to create panels to decide who lives and who dies. Republicans branded these ‘death panels’ and associated them with phrases like ‘pull the plug on grandma’. The Democratic, liberal narrative responded by framing the ACA as a step towards ‘European-style socialism’, which they presented a tried and tested mechanism of fairness and social justice (see Fig. 2.5). It is notable that social insurance programs of welfare states, like the National Health Service (NHS) in Britain and Medicare in Canada, are organized on the principles of ‘social solidarity’ (Stone 1993; Dao & Mulligan 2016: 10); sharing the risk, creating a sense of community, ensuring access to healthcare, and protecting citizens from financial catastrophe in the event of a medical crisis. Studies show that in the United States, unpaid medical bills caused 62% of bankruptcy filings and affected nearly 2 million people in 2013 (Himmelstein et al. 2009, Lamontagne 2013).

A significant expansion of Medicaid was intended to be the centrepiece of the ACA. However, the Supreme Court ruled that Federal imposition of this expansion on state governments was unconstitutional, which allowed individual state governments to expand Medicaid or to ‘opt out’ at their own discretion. As of early 2016, nineteen states with Republican governors remain without Medicaid expansion. A majority of these states are in the South, a region with the highest poverty rates in the country, and thus the greatest need for Medicaid. The Georgia government framed the issue of Medicaid expansion in financial terms, saying that it ‘wipes out more and more of their state budget’ (Jeff; see Chapter 5). In fact, Medicaid expansion is fully funded by the Federal government for the first three years, after which states are expected to gradually take responsibility for up to 10% of the budget, while the Federal government will continue to fund 90%. Absent from the financial framing of this decision – or implicit in it – is consideration of how the structure of American healthcare, beyond just the services provided, shapes the social realities of those in need. An
estimated nearly 2 million Georgians (20% of the population) are uninsured – among the highest in the nation. Georgia Equality and Cover Georgia, two non-profits I followed in the field as part of the HIV advocacy community, estimate that 52% of people living with HIV/AIDS in Georgia qualify for Medicaid. My respondents explained that finances were not the only reason for the Georgia government’s resistance. Jeff said the state considers Federal assistance an encroachment on its rights. Historically, states prefer control over Federal programs, especially social welfare programs, so they can decide who deserves the resources and who doesn’t, ‘to weed off the people they think are “free loaders” and save the rights of the “good citizens” who have “earned it” – a discretion to discriminate against minorities and stigmatize the welfare spending’. The presentation of ‘Obamacare as evil big government’ (Krugman 2013) aligns with the notion that it challenges states’ rights to police the boundaries of the deserving vs non-deserving poor and control its decisions on social welfare spending accordingly. ‘States’ Rights’ is an established euphemism for blocking Federal implementation of civil rights; a connotation with direct relevance to the majority of Ponce Center patients, who were black, Southern, working poor. This is a historic conflict; the Constitution enshrined slavery as a legal and permissible part of American government in order to appease the Southern states, and so as not to abridge each individual state’s right to control its own economy, and the Civil War was fought over what the Confederacy saw as an encroachment on those rights. Policies are, then, not just symbols or ideologies. They come with complicated social histories.

The division of U.S. healthcare into multiple plans and programs — especially those, like Medicaid and Medicare, that are intended to serve the vulnerable and poor — has, in effect, categorized impoverished Americans into two classes of citizen. Medicaid, as a public assistance programme for low-income individuals, is perceived as (welfare) dependency because its beneficiaries are presumed to lack the will to stand on their ‘own two feet’. Medicare, by contrast, is understood as a social insurance programme that working people pay into for years before they access it during retirement (Obama 2012). These distinct categories used to describe the social life of related policies are also active forces shaping it
(Williams 1976; Gordon & Fraser 1995; Bourdieu 1977, 1999; Scott 1998). These distinctions, these lines of fracture evident in the conservative and liberal interpretation of values, reinforce a longstanding, insidious perception among the American public: there is a deserving and an undeserving poor. In effect, some poor are seen as unfortunate people who should be pitied while others are seen as irresponsible and blameworthy. More broadly, conflict around the ACA, particularly Medicaid expansion, demonstrates how U.S. welfare stigmatizes those in need, even while providing important services.

Jacque, a paediatric AIDS expert and Ryan White Programme Director of the Ponce Centre during my fieldwork, shared how this translates into interactions when she meets with legislators and their staff regarding funding for the Ryan White CARE Program. In the early days of Ryan White, Jacque related, Sandy ‘dragged’ her to Washington because Jacque was the Director of the Pediatrics Program at Grady Hospital in Atlanta at the time, and Sandy wanted ‘some of these hard-ass Republicans to hear about the paediatric side, because that was something they would wrap their heads around’. They met with Congressman Tom Coburn, (R-Oklahoma) who himself was a physician.

That’s really how...those kinds of conversations go: Sandy will tell them about the numbers; they’re growing...and this, that and the other thing. And he looked at me and said, ‘Tell me about the poor little innocent victims’. To him, we needed to be considering the children as the innocent victims of the epidemic, as if there were guilty parties somewhere. If...there are innocent people, then there must be guilty people. The guilty people are the gay men. And the African Americans and the ‘they should know better kind of people’.

...What goes through your mind as an advocate is... ‘I am so pissed off by what this man said that I want to smack him’. But we got to look at the bigger picture and think, what do we need from him? So, then I have to pull off my charade to an extent, and say, ‘Yes that’s one of the saddest things of all, these poor babies’.

Over the years, Jacque met many such politicians. She was briefing former Congressman John Lender about the status of HIV in his state, and Jacque said, ‘We have got to get people in care and keep them in care...that’s how we handle an epidemic’. She told him that if he blocked Ryan White funding ‘we’ll close down, and we’ll literally be stepping over sick people in the street...’ And he said, “well we’ll just have to step over them, wont we?” However, he was
very supportive of the ‘little pediatric victims’. Later, someone brought up
‘innocent victims’ to Jacque in Georgia Governor Deal’s office,

I said, you know, I can’t go there. Yeah, I work in paediatrics and I see
a lot of infected kids and its extremely important, but we’re also doing
really well at keeping them from being infected by treating their
mothers and looking after the entire family so that they have a safe
place to be. And I don’t think I can say anybody is innocent without
you telling me who is guilty. And I don’t think anybody is guilty.
This is a virus. It’s not an armed intruder. It’s a virus. It’s biological.

Attaching judgement to a disease is conflating the biological body with the
moral one. These problematic patterns, rooted in the ideology of deserving and
undeserving, are also necessary to fight with both policy and outreach. Ryan
White, the boy who gave his name to the landmark policy, was a 13-year-old
haemophiliac when he was diagnosed with AIDS in 1985. His mother, Jeanne
White-Ginder, says in her biography (1997) that her son wanted to be normal
and wanted to return to school, but their hometown of Kokomo, Indiana, refused
to allow Ryan back to school after his HIV diagnosis. She combatted stigma,
hate, and discrimination, and turned to the courts to fight for her son’s right to
attend school. In a time of intolerance and unrestrained accusations, Ryan
White gained national and international support and became a voice of reason.
His personal journey inspired millions, and his struggle became a symbol that
anyone could get the disease and that AIDS was about people. In 1988, he
testified in front of Congress. A week before his death, on 8 April 1990 at the
age of 18, Senator Ted Kennedy asked his mother’s permission to use his name
for the legislation he was trying to pass to help people living with HIV/AIDS.

However, it is significant that some of Ryan White’s success as a symbol was
that he could be perceived as one of those ‘innocent victims’ the Republican
congressmen were so willing to protect. He had not contracted HIV through sex
or drug use, but through medical treatment for his haemophilia. Like Jacque, my
respondents despised the ‘innocent’ concept as victim blaming that went against
all compassion and suffering. Jacque believed ‘it implies that if there is an
innocent victim then there has to be a guilty party – and nobody is guilty here. It’s
a damn virus that knows no bounds’. Jeff evoked the concept of identity, saying
that Ryan White’s name and face on this policy was important for the community,
...because it was also recognizing and honouring the different types of people that were mostly at risk in contracting HIV and dying of AIDS. So that it was not just all gay men. And mostly, his story was so powerful, and he was so fearless. Here you have this little boy who was a haemophiliac, and so how could you deny him? And if you can’t deny him, you can’t deny the rest. That’s why Ryan White was such an important struggle. There was all this politics and yet the humanity could come together for that - a certain type of identity neutralized everything, although you still had Elton John right next to him.

The processes of policy making, particularly healthcare reform, are highly politically charged but are also deeply moral and affective for Americans. The distinction between Ryan White as a ‘good’ and worthy AIDS victim and LGBTQ+ people or drug users as blameworthy and undeserving of help is a stark, important contrast. Likewise, the perception of white families who just need ‘a little help to get back on their feet’ as different from black, inner city ‘freeloaders’ reflects the specific interests and perspectives of particular groups of people. These narratives have been reformed and repurposed through welfare policy and public discourse many times, and they not only impact policy priorities, but also serve as a foundation of the way people appraise and perceive citizenship and associated rights.

**Conclusion**

‘The historicism of policy formation (policy turning points) demonstrates that policies do not operate in a vacuum but in contrast originate from the past time and are contextualized in place’ (Grundy et al. 2014: 151). The history of U.S. HIV/AIDS policies, when set against the background of opposing ideologies and American values, demonstrates that ‘when seen as expressive acts and not solely as instrumental ones, public policies and their enactment may be “read” as telling national identity stories’ (Yanow 1996: 29). This chapter balances informants’ accounts with traditional histories of HIV/AIDS activism in order to ground ‘big picture’ national narratives of HIV, illness, and deviance in the local realities of the American South, Atlanta, and the Ponce Center. Meta-narratives of America engage with ‘myths’ related to the power or will to grant universal access to care or provide justifications for rationing limited resources; between social solidarity and individual responsibility; between private markets and public goods. The ACA became a battleground of the ‘culture wars’ over social issues
such as homosexuality, abortion, and welfare between Liberal and Conservative ideologies – and, by extension, for contested narratives about national identity. In this sense, the ACA as a policy directly reflects the struggle over key American cultural values, particularly privatization and the politicized position of the disfranchised within the ‘idea’ or ‘myth’ of America. This chapter considers the contested appropriation of the ACA as part of the project of making or ‘imagining’ America. Likewise, the way American healthcare addressed AIDS changed over time, reflecting and shaping attitudes towards the disease.

The personal accounts and ethnographic observation of the Atlanta HIV community members in this chapter illuminate an intersection of histories, life experiences, and philosophies that profoundly influenced the evolution of health and HIV policies, both in Georgia and nationally. This collage of voices, experiences, memories, and personalities reveals how ordinary actors become architects of political and medical knowledge – and of policy. Policies, in turn, become reflections of the ‘policy worlds’ or ‘domains of meaning’ that produced them (Shore et al. 2011: 1); that is, power-laden cultural artefacts of the circumstances in which they originated and continue to operate.

Understanding the historical context of American healthcare reform is vital to understanding the ACA, in part because it reveals the complexity of the endeavour, and why it was such a challenge for Democrats to present these plans to the American people yet so easy for Republican opponents to thwart those efforts. It also reveals the complexity of the ACA itself: the policy has no a single meaning, logic, or effect – rather, it must be viewed in practice, in context, and from multiple vantage points, as the rest of this thesis seeks to do.

Understanding the historical, political, and philosophical context of the ACA provides necessary insight into the origin or trajectory of decisions by which the ACA is constantly updated and transformed. I engaged with the social life of this policy on all levels, from micro to macro and federal to individual, and to study a policy as it develops and is enacted in everyday practice.

This thesis analyses and documents the implementation of the ACA in real time and explores how this policy was understood by differently situated actors within the American healthcare assemblage. I join fellow interpretive policy
scholar Yanow in inquiring ‘how does a policy mean?’ My work demonstrates how policymaking processes are strongly entwined with the personal, the historical, and the political. Policy has multiple origins and voices, and unpacking each of these reveals more about both the policy and society than what is written in the documents. In this case, illuminating the social and historical context of HIV policy, the progressive personalities that shaped it, and the engagement with local movements revealed the foundation of a model of holistic care that grounds HIV treatment in Atlanta to this day. The Ryan White Program and related policies helped shape a progressive, community-motivated, and ideologically-driven approach in the midst of a healthcare system dominated by neoliberal, market-based approaches. The development and enactment of HIV policies is thus a distinctive example of how alternatives emerge and translate into policy, and also how they shape future policy; the holistic Ryan White model motivated the HIV advocacy community to push for the ACA to move in the direction of single payer, which may establish a more equitable care for all citizens regardless of disease or their social standing.

The next chapter is about the Ponce Center, and how these struggles and ideals translate into the everyday lives of policy, patients, and caregivers.
Chapter 3: ‘It’s Not a Clinic, It’s a Center’: The Ponce Center as a Nexus of HIV Care for Marginalised Populations in a Major U.S. City

For me, the Ponce clinic is a home away from home. We are all a family here: patients, providers and staff. It is always a place of love; often it is a place of joy; sometimes it is a place of pain and sadness; it is forever a place of belonging. If anything, we intend it to be a refuge for the hurt, for the disabled, for the lonely, for the suffering, for the disfigured, for the poor, for the discarded, for the hopeful, for the weary, for those without a home, for the outcast, and sometimes for the dying.  

Vincent Marconi (2012)

This chapter deals specifically with the Ponce Center, the core of my research and a clinic that has been serving the AIDS community in Atlanta, Georgia for over 30 years. However, as the above epigraph suggests, the Ponce Center is much more than simply a clinic. As one of my informants said, ‘It’s not a clinic, it’s a Center’; it is a site where health policies get translated into social relations and lived realities. This made the Center a perfect portal for viewing and understanding the social life of the policies implemented within it. It is laden with symbolic significance, meanings, and memories. The Ponce Center is a site of cultural struggle, in which the neoliberal, anti-regulatory policy related to unrestrained healthcare costs are set in opposition to the public health and medical humanitarian approaches in a culture of humanistic caring. It is funded by, and is in many ways a physical embodiment of, the Ryan White CARE Act, a Federal safety net program for HIV that played a fundamental role in transforming it from a clinic to a Center. In that capacity, the Ponce Center, as a major component of the HIV care assemblage, can illuminate significant aspects of the larger American healthcare assemblage.

The Ponce Center was the vantage point from which I observed how the diverse elements of the HIV care assemblage articulate each other. The Center itself is a phenomenon that moves with time; expanding, shifting, reaching out, restraining, changing, and improvising to accommodate the people it serves. In its past, present and future, the Center exemplifies new rationalities and practices of government surrounding disease, death, hope, and medicine. Similar to the concept of ‘hospital-based ethnography’ (see Livingston 2012, Prince 2012, Nguyen 2011, van der Geest & Finkler 2004, Street & Coleman 2012), the Ponce Center should be understood as an intensive place ‘where
critical moral, political and social questions arise regularly and with great urgency, and where broader political, social and moral forces in society can be witnessed in a condensed fashion’ (Livingston 2012: 25). It is a physical location where policy is transformed from a series of words that comprise a law into tangible, everyday biomedical and social practices grounded within a particular infrastructure and a social, historical, political and epidemiological setting. It is also a place where on the ground actors become part of policy making by translating a given policy and meanings attributed to its implementation by them. ‘In an ultimate sense, society is itself policy making’ (Belshaw 1976: xv).

This chapter uses ethnographic data from interviews, official documents, and participant observation to examine healthcare providers at the Ponce Center as recipients of the policies. The choice to focus on providers rather than patients was made partly because providers are often neglected in studies of health policy and partly because they are interesting and important actors in their own right. Healthcare providers are ‘active and knowledgeable insiders’ who make and re-translate policy through their ‘interactions with it’ (Kingfisher 2013: 1; Shore & Wright 2011). Accordingly, the chapter focuses on assemblage, on the processes of translation and articulation that ‘render the meanings of policies, on the values, feelings, and beliefs which they express, and on the processes by which those meanings are communicated to and “read” by various audiences’ (Yanow 1996: 8). It situates the Ponce Center in time and space and demonstrates how its physical and cultural networks developed. The chapter also maps the historical and political context in which the Center’s treatment practices emerged around specific understandings of and metaphors for ‘integrated’, interdisciplinary models of care, and examines how its institutional strengths, weaknesses and vulnerabilities reflect its complicated history, and the fragmentation and politics present in the broader American healthcare system (see Horton et al. 2014). It further examines the increasing importance of these models of care in the Affordable Care Act (ACA) era of healthcare reform.

The first part of this chapter discusses the history of life with HIV/AIDS in Atlanta beyond the clinic walls, which is necessary to understanding the Ponce Center as an embodiment of the Ryan White Program, and as a modern
enactment of the ACA policy. This contextualizes the cognitive, moral and affective interpretations, vulnerabilities, and mediations engendered by and embodied in the institutional culture and its symbolic artefacts which make articulations possible. For example, the Ponce Center is to some extent a Center simply by virtue of the connections it makes and makes possible; the opportunities it provides that allow health care providers to take care of people’s bodies, holistically in ways that goes beyond traditional patient care.

As discussed in Chapter 1, the concept of translation highlights the constructive and communicative character of policy, centred on language and fields of representation, associations and articulations (Freeman 2004, 2009, 2014). This chapter then explores the diverse ways in which ‘symbolic artefacts communicated the meanings: through particular form of language, objects and acts’ (Yanow 1996: 128). I focus on the models of care that exemplify this communicative approach by engaging with a metaphor used to describe the Ponce Center: ‘One-stop shop.’ Although not unique to my field-site, this term was used constantly by those involved with the Ponce Center, referring to its wider network and relating its alternative understandings to the evolution of their own model of ‘integrated’ care. This understanding shapes their identity and directs their vision for implementing policy. The physical building and programs it houses also are symbolic objects that the Center created and uses to convey their meaning of care in its daily operation. The final section ties together a discussion of the everyday practices described throughout the chapter; the ordinary activities and networks that comprise life at the Ponce Center.

Rather than examining the impact that policies have on people, this chapter is concerned with how people engage with policy and what they make of it. The chapter conveys not just what the policy is intended to do, but also the societal meanings developed over time (values, beliefs and feelings), and the ways they are instantiated in the ‘culture of the Center and policy issue’ (Yanow 1996: 127).

‘The Shrubbery Negotiation’:

The History of the Ponce Center & the Ryan White Program

In August 1992, two activists from the AIDS Coalition to Unleash Power (ACT-UP) broke into the empty Presbyterian Center building in the dark of an early Saturday
morning. The building had been abandoned, except some homeless occupants, for several years, and was identified as an ideal site for a permanent AIDS clinic in 1990. The clinic was to be fully funded by the then-new Ryan White CARE (Comprehensive AIDS Resources Emergency) Act. However, the Neighbourhood Association had blocked its construction with a lawsuit; they objected to another ‘ugly safety net hospital’ like Grady that might bring down local property values.

One of the two activists inside the building was Jeff Graham, Executive Director of Georgia Equality since 2008, and a long time ACT-UP rabble-rouser who became one of the most active and effective advocates for the LGBT community and health reform in this conservative state (see Chapter 2). He has led HIV service and advocacy organizations for decades while making a significant mark on HIV-related policies. Jeff asserted that the Neighbourhood Association’s opposition was not just concern for the beauty of the area, but distaste for the fact that it was an AIDS clinic, with attendant racism, homophobia, and disdain for the poor: ‘We all knew it, but nobody said it out loud. It’s the South, and people are polite here. They wanted the whole Ponce de Leon corridor to be cleaned up’. The local government bureaucracy was also causing delays, as a majority of Commissioners for both Fulton and DeKalb Counties believed they should not make a significant investment in the fight against AIDS because a ‘cure was right around the corner’ as Jeff remembered the then-Surgeon General saying in mid 1980s, ‘so there was no need to devote money to a new clinic’. President Regan’s indifference to the epidemic, until 1987 when he first publically said the words ‘AIDS’, created his legacy as one of silence, and Jeff said that this is why ACT-UP made ‘Silence = Death’ their slogan.

The activists planned to throw banners out the front window facing Ponce de Leon Avenue, the road where the Presbyterian Center is situated, before other protestors arrived. ‘To this day I don’t know who that was, but someone had left the back door unlocked for us’, Jeff told me. He was the one who actually threw a banner out of the building window which read No more red tape. Other protestors

---

Some informants who were public figures, like Jeff, encouraged me to use their true identities because changing their names would have been a meaningless exercise. However, to protect the privacy of my respondents and comply with the HIPPA Act of 1996 and Grady’s ethical IRB, the names of some staff and all patients have been changed; pseudonyms are in brackets.
held placards saying RED TAPE Kills, No More Politics and EXPAND the clinic NOW! ACT UP! (Fig. 3.1). Every local TV station covered the demonstration. The goal was to stay for at least 24 hours, but by 11:30 that night, the Grady Hospital Board, Neighbourhood Association, and both sets of County Commissioners agreed to negotiate the purchase of the building and finalize the plans for a permanent, larger home for what would become the Infectious Disease Program at the Ponce de Leon Center. The $1 purchase and generosity from the Presbyterian Church was much appreciated and is lauded to this day by the clinic leadership and staff.

The ‘Cut the Red Tape’ vigil was a turning point, but it was by no means the only effort to address the problem; numerous articulations – in the form of research, protests, advocacy, testimonies and similar efforts – leveraged an array of public and private actors and institutions together to create the Center. These efforts were a response to the fact that by 1990, the Grady Hospital AIDS clinic was in a virtual state of emergency. The clinic started in 1986, housed on the second floor and serving only 10 patients; at the time, it was considered an ‘orphan clinic’ that others at Grady ‘simply hoped might just go away’. By 1990, it was serving 2,000 patients, receiving 75 requests for new appointments every week, and the number of patients was expected triple in the next five years. When ACT-UP started advocating on behalf of the clinic in May of 1991, it only had the capacity to see 28 patients a week and the wait for an appointment was four to six months. That was too long for people with AIDS, who were ‘literally dying at the clinic’s doors’.

The effort to address this problem was not limited to outside advocacy; as Jeff told me, ‘it was definitely inside/outside strategy that we adopted’, meaning
that the protesters’ voices were supported by insiders such as Sumner Thompson, the Clinical Director, and Curtis Morris, Administrator at the Grady Hospital who advocated from within the Grady health system for expansions to the Infectious Disease Program. National Association of People with AIDS (NAPWA) and ACT UP agitated from the outside, doing ‘things like disrupt Board Meetings of the Grady Board, and the Fulton and the DeKalb County Boards, lots of civil disobedience (though nobody got arrested), phone campaigns, letter writing campaigns, picketing outside of commissioner meetings, lots and lots of one-on-one conversations with the Commissioners.’ This demonstration took the newly forming assemblage beyond ACT-UP, NAPWA, or the Grady clinic. Volunteers from Project Open Hand brought meals for over a hundred protesters who set up tents and committed themselves to be there for as long as necessary. Media took up the cause as well.

In the end, the Neighbourhood Association relented as long as there was good landscaping at the Center. Jeff said that it is still a running joke amongst providers at the Center and others in the AIDS community that ‘it was so ridiculous that at the end it was landscaping and shrubbery that kind of hung in balance for medical care’. Less than a year after the early morning vigil, the Ponce de Leon Center opened its doors for HIV patients on 10 August, 1993. The Grady AIDS clinic moved from 1,200 square-foot outpatient clinic to this 7-story 90,000 square-foot space. ‘All of these services in a beautiful building, it shows age now
but when it was opened it was absolutely beautiful’, said Jacque. The Elton John AIDS Foundation was a big supporter of the Center, and Elton John himself donated artwork and played a concert on the opening day (Fig. 3.2). Jeff was not invited; when I asked why, he said ‘We had moved on to the next issue’. He was distributing flyers outside the opening ceremony agitating against Emory University for not doing enough research on HIV. At that time, Alabama University in Birmingham was conducting almost of the HIV related research and trials. People from all over Georgia had to go there. It not only created access problems but also a bit of a disconnect between Atlanta’s big advocacy and activist community’s efforts and the possibility of treatment, or a possibility of ‘experimental care’ as some of them called it. Ten years later, on the anniversary of the Ponce Center, the providers at the Center gave Jeff framed photos of himself during the vigil as a thank you gift. They still adorn the walls in his office (Fig. 3.3).

When the ground-breaking Ryan White Comprehensive AIDS Resources Emergency (CARE) Act (now the Ryan White HIV Program) was approved in 1990 with substantial bipartisan support, it did more than resolve the issue of finances for the clinic expansion; it provided a broader framework for meeting the unique needs of the national HIV community that were neglected by the disparate fragments of the extant healthcare system and safety net. Ryan White was, and remains today, unique among American healthcare programs. The funds not only support primary medical care but also provide for essential social support services such as disability, food stamps, housing etc. It is revolutionary in a market- and consumer-oriented society: first, it pays for all aspects of HIV care, which is something the American healthcare system does not do for any other specific diseases, and second, because it requires the involvement of people living with HIV (PLHIV) in decisions about implementing different parts of the Program.

Fig. 3.3: Jeff Graham in his office.
Funding provided by the CARE Act was also revolutionary in that, when the AIDS clinic was implicated in local politics and blocked from expansion, the structure of the Ryan White Program enabled them to bypass local politics and State or local budget shortfalls to receive funds directly from the Federal government for specific sets of services. Authorized programs are divided into five parts that provide a flexible structure under which this national program can address HIV care needs on the basis of: Geographic areas (e.g. States, large metropolitan areas); Populations most affected by the epidemic (e.g. the LGBTQIA+ community, people of colour); Types of HIV-related services (e.g. oncology, dentistry, mental health); and Service system needs (e.g. technical assistance for programs, clinician training, research on innovative models of care).

For patients, Ryan White translates into medical care, medications, case management, dental care, mental health counselling, substance abuse treatment, and support services. The funds are used to serve PLHIV who are low income, are un- or under-insured, or otherwise lack the resources to access services on their own. Thus, the Ryan White Program is a ‘payer of last resort’, meaning there cannot be another payer source for HIV-related care (i.e. private insurance, Medicaid or Medicare). Financial eligibility for Ryan White services has historically been 300% of the Federal Poverty Level (FPL), based on annual or monthly earnings. There is no spend-down requirement. Jacque and Jeff told me that this eligibility is currently expanded to 400% FPL. This is directly relevant to the struggle between Conservative vs. Liberal ideals and the question of which citizens, if any, should be cared for by the taxpayers (see Chapter 1).

Atlanta has become fifth in the U.S. for highest number of new HIV diagnoses. Southern states like Georgia present 50% of the overall HIV cases in the country. These cases are mostly among poor and minorities, people working low-wage jobs and living in unstable housing situations with limited access to medical care (Rosenberg et al. 2014). In the field, many patients and providers told me that ‘HIV is the least of their problems’. My drives around town with outreach team Occiee and Kiesha were eye opening as I was taken to the dilapidated poor neighbourhoods of Vine City and English Ave with boarded and burnt houses, drug dealers, pimps and women ‘working the street’ in broad daylight, parks and
bridges that housed the homeless, outside the ‘Pink House’ Atlanta jail. During these drives, our target was to find the patients who had missed appointments, convince them and bring them back to the Ponce Center for treatment. Many are dealing with homelessness, mental illness, substance abuse, co-infections such as hepatitis C, and other critical issues. Only 3% have private health insurance, and some are undocumented immigrants. Their problems are not a ‘one size fits all scenario’ and being under one roof helps the Ponce Center to customize care according to individual patients’ specific needs. Patients are referred to the Ponce Center by healthcare providers and agencies, including community and faith-based organizations such as Sisterlove Inc. and AID Atlanta. Recently, Grady reported that one third of all newly diagnosed people in Atlanta have advanced or clinical AIDS. That means at least two or three people arrive at the Ponce Center every day who have already progressed to late-stage AIDS.

From both a health and social policies perspective, it is the segments of society that fall into categories of new citizenship and stay at the margins of socio-political inclusion (Cataldo 2008). This also refers to the earlier discussion on bio-citizenship, therapeutic citizenship and similar terms (see Chapter 1). The model of HIV care at Ponce is relatively similar to the models of ‘comprehensive’, ‘holistic’ HIV care being implemented in other global contexts, in both developed and developing nations (Brazil, Biehl 2007; West Africa, Nugyen 2011). ‘Holistic care’, which usually refers to a provider or clinic that takes all aspects of a patient’s wellness into consideration – not just the body, but also mind and spirit. ‘Comprehensive care’ can mean wraparound or end-to-end services including community-based organizations (CBO’s) and social services. This is distinct from ‘integrated care’, which usually refers to including TB and primary care with HIV-care and is much more common in low middle-income countries (LMIC) settings. Mental health and substance abuse care could be in the integrated or at least the comprehensive care.

The Ponce De Leon Center is one of the largest, most comprehensive facilities dedicated to the treatment of advanced HIV in the United States. It was created to dispense all the services guaranteed and paid for by Ryan White Program; it is both an artefact and an embodiment of the policy and the ‘wraparound,
patient-centred care model’ it funds. The struggle wasn’t just to get access to healthcare and treatment, but to ensure that PLHIV’s right to access treatment was enshrined in law-based policy. The Center fulfilled a specific social mandate that understands access to care and treatment as a social justice concern. Thus, anyone who enters the clinic and meets the eligibility requirements (see Chapter 4) is registered to receive both medical treatments for HIV and social support services. Through the long process of its implementation, people translated and re-translated the Ryan White CARE Act into practice, providing specific care to each individual: cutting, adding, tweaking, adjusting, and re-adjusting the ways services fit together. The Ponce Center became a place, a Program, a Center that embodied the Ryan White policy, and in so doing, met its patients’ biomedical and, by extension, social needs in a way that the broader system had not previously supported. In some cases, patients’ family members can also receive services through the Ryan White programs that focus on women, infants, children, and youth, even though they are not diagnosed with HIV. The clinic’s biggest achievement and greatest challenge is to reach as many PLHIV as possible and to keep them in care.

Jacqueline Muther, a paediatric AIDS specialist, was already working in Atlanta when the Ponce Center was founded. She explained how much the above approach defined the Center as forward-thinking and unique when it opened. She had been with the Ponce Center since it was a tiny AIDS clinic on the second floor of Grady Hospital’s oldest building, and admitted that ‘Actually, I was the one who identified the current location as a possibility to our Director’. In many ways, the people were around long before the new physical building. Jacque used to run the lab as well as the paediatric clinic at Grady, but a chance trip to advocate for clinic funding moved her to prominent role in ensuring a continued funding stream for the Center. Three decades later, Jacque remains a champion of that work. Jacque described some of her connections from Fig. 3.4: Dr Jacqueline Murther (right) & John Lewis, Congressman and Civil Rights Activist
those early days of the Center and epidemic as ‘lifelong partnerships’ that included grassroots organizations, hospitals, bureaucrats, volunteers, patients, politicians, and advocates. Her main responsibility at the Ponce Center was to maintain its role within the broader American healthcare assemblages (see Chapters 4 & 5).

The implementation of the Ryan White policy has been very successful nationwide. Particularly at the Ponce Center, these accomplishments are reflected in its state-of-the-art programmes emerging from cutting edge research, expert doctors and nurses specialised in HIV care, and the epidemiological statistics of lives saved. The Center is known to have high approval, both among the public and those it serves. Some patients told me that they take appointments around the schedule of their particular doctors because they have known each other for years. These social connections and trust is essential and much valued by both the patients and the providers alike. About 170 staff and on-site affiliates care for about 5,700 men, women, adolescents, and children living with HIV. Since the Center opened, the social, political, and epidemiological context of HIV/AIDS has undergone revolutionary changes. Medical advances have transformed HIV into a manageable chronic condition, making access to treatment vital; as one respondent jokingly told me, ‘It’s not so much a death sentence anymore, but consider it a life sentence’.

As a paradigm, chronic disease has its own complexities, because virus management extends well beyond biomedical management of symptoms and disease progression. HIV as a variety of biomedical citizenship functions in a particular way that is categorised by virus’s deadliness, medical complexity, stigmatization. and social embeddedness. To provide full, holistic treatment and to re-integrate HIV patients into full citizenship, all of those dimensions must be dealt with simultaneously. The Ponce Center’s ethos is positioned towards a holistic model of care; however, my respondents asserted that the Center is currently transitioning between the holistic model of care and the traditional European, or allopathic, medical tradition. Holistic care is more challenging to implement in contexts that have been dominated by allopathic medicine: issues of hierarchy and power, and the exclusive focus in curative medicine, tend to clash with the broader ethos of the holistic model. The main
framework for the delivery of this combination model is the ‘Continuum’ or ‘Cascade of Care’. Dr Carlos Del Rio, an infectious disease expert, described the cascade to me like this: ‘the outcome is treated HIV as a result of sequential care engagements: HIV testing, to diagnosis, to linkage and access to [anti-retroviral treatment], to retention in treatment, to the point where viral suppression is achieved.’ As someone who has led treatment, prevention, and research efforts targeting HIV/AIDS since the early days of the epidemic, Del Rio spoke with conviction: ‘we need to scale up these tools — including education, condom distribution, and HIV testing — as a routine part of medical care, engagement in care, and access to antiretroviral therapy’.

‘One-Stop Shop’: The Symbolic & Social Space of a ‘Center’
A symbol is a thing that represents something else – a social convention with historic and cultural specification and multiple meanings. Symbols act as boundary mechanisms (see Strathern 1982; Cohen 1985; Lamont & Molnar 2002; Zimmer 2003; Tilly 2004, 2005; Jones 2009) that distinguish insiders who share the meanings from outsiders – ‘not to know them is not to belong’ (Hunter 1974: 67). This section analyses two symbolic elements: metaphor, as a figure of thought (Lakoff 1986) and its relation to organizational action, and objects, the Ponce Center building and its programs. When policies are implemented, the symbolic language and objects of policy are interwoven and overlapping, so this is how they will be described.

Understanding the ‘work’ of the Ponce Center as ‘highly abstract and immediately practical’, drawing on Freeman’s (2014) assemblage paradigm, has implications for the meanings and practice of healthcare policies, and for understanding HIV care in the United States. This thesis follows Rylko-Bauer and Farmer (2002), and Horton et al. (2014) in understanding the American healthcare system as a highly fragmented network of policies, practices, and procedures that serve specific subsections of the population (e.g. the Veterans Administration, Ryan White HIV Program, Medicare, Medicaid, the ACA, and rarely the employment-based private health insurance). The Ponce Center staff do the work of articulating and translating and bringing those pieces together into individual assemblages of care. They deliver the cascade of care and make
all stages of the continuum of care possible for their ‘resource poor’ patient population, the providers understand that medication alone is not enough. Access to medication is equally matched with primary and specialty healthcare, food, housing, and so on. This has significant policy and practice implications. This was evident during the founding and evolution of the Ponce Center: providers developed a distinct identity for their clinic, encompassed in the phrase ‘One-Stop Shop’. Employees and patients regularly described the Center to me in this way, proudly referring to its mission to provide ‘all services that a person with HIV might need’ in one place,’ as Jacque told me. This usage was not limited to the global understanding of one-stop shop as integrated care for different diseases under the same roof, such as co-infections like TB and HIV. Instead, the Ponce Center one-stop shop model included the ‘new forms of HIV related sociality described as a product of re-shaping of existing social ties rather than of biological connections’ (Paparini & Rhodes 2016: 510). The phrase stood out particularly because both those connected to the Center and outsiders frequently praised the Center using those exact words. I initially thought this was merely a sales pitch, until I recognized that it articulates and embodies the important differences between how the Center functions and a regular clinic. These articulations over time had brought the disparate fragments of American social policies together with fragmented health policies and created a unique care assemblage.

The one-stop shop model, as the Ponce Center uses it, is particularly novel within the most expensive and fragmented healthcare system in the world. Purchased insurance can make access to specific services scattered, which is why the broad nature of Ryan White funding is the only thing that made such holistic care possible, even in the richest country in the world. Thus, ‘one-stop shop’ became a nearly unique metaphor for the HIV community in the U.S. They took the phrase from the global milieu and expanded their symbolic translation of it to include additional policy meanings that were local to U.S. Policy and to the Ponce Center’s organizational identity. Historically, Jacque explained,

The term didn’t originate with the...Ponce Center, but we referred to it in various ways as we were pulling it together: centralized services, coordinated care, etc. What we...needed to do to overcome client challenges like transportation, coordination of appointments, child care issues and other barriers was to put all patients and
services under one roof. At first, there was some reluctance to include paediatrics (since, even back in 1990s, all children born to HIV+ moms didn’t end up infected). But we knew women were bringing their kids into care but not getting care themselves. So, it was an evolutionary process to bring all the key pieces [together]. Somewhere in there HRSA used the term One-Stop Shop, I think. But it’s the concept not the terminology that is the key. It’s about removing barriers to access and utilization of care services.

The ‘one-stop shop’ metaphor gained popularity among HIV providers, and they began to adopt similar language as well, such as ‘comprehensive care’, ‘wrap around services’ or ‘one-on-one model’, in documents, conversations, and practices. This aligns not only with the logical constructs of the ‘one-stop shop’ concept, but also with the Center’s historical context, because the ‘extra’ services are all funded by Ryan White. More significantly, as Lakoff and Johnson (1987: 79) wrote, ‘metaphor is not a harmless exercise in naming. It is one of the principle means by which we understand our experience and reason on the basis of that understanding. To the extent that we act on our reasoning, metaphor plays a role in the creation of reality’. By this logic, the one-stop shop metaphor guides the vision and thinking of the providers, and has become prescriptive for the all-inclusive everyday practices of the Ponce Center. Thus, it points to what is meaningful for the group and conveys the symbolically constructed identity of the Center as a provider of ‘wrap-around services’, including nurturing biological and social services, as well as comprehensive care – by which they mean that the Center provides anything a person living with HIV needs that is unavailable outside, collected in one place. It creates an experience where people with HIV do not have to be without a doctor because they do not have the right health insurance, where they do not have to wonder whether their doctor understands the specialized care needed for their condition, they don’t have to go to several different agencies for their basic needs such as food and shelter, or have to wonder where the $2.50 bus ticket to reach the Center is going to come from. It guided the vision for what programs at the Center needed to look like and how to implement them.

Jacque explained the programs took shape over the years, ‘piece by piece and floor by floor’. Even before they acquired the new building on Ponce de Leon Ave to expand the clinic, the struggle to join the different pieces went on like this:
Paediatrics wasn’t originally gonna be part of the plan, and neither was oral health... We were still fighting our battles, even then about making it all happen. We had our first kid...at Grady... Obstetricians couldn’t really move over here, because we don’t deliver babies here, so we decided to connect with them by having a social worker that goes over there to...connect [pregnant women] to care. We just sort of built...little building blocks along the way to make it all...fit together as well as it can.

Shortly after that they received more children, and it became evident they had to put something in place, and that it had to be more centralised. Jacque said,

We applied for what they called a ‘Pediatric AIDS Demonstration Project’ at the time, and were funded for a social worker, and a part time physician, and nurse. It was a very small grant, but it grew, and became Ryan-White...Part D. So, we were doing paediatrics on the second floor of Grady hospital, the adult clinic was on another floor...then Obstetricians started seeing the pregnant women, and we would have meetings regularly... our new AIDS meetings, to talk about...what we were going to do. But there wasn’t any real treatment at that time. This would be the mid to late eighties, and we still didn’t have any meds. Then AZT came out right around...that time, at least there was something.

This was a difficult task, because paediatrics and medicine are different departments in the Grady medical system and fell under two different administrative arms at the hospital. On Wednesdays, they would load up a cart with paediatrics charts from the hospital and take them down the street to another building called Hugh Spaulding. At the Ponce Center, they made sure that it was all in one place and easier for the specialists to communicate on their patients’ cases. Jacque said another concern was childcare while the mothers attended to their appointment with the doctor. They asked AID Atlanta to locate babysitting volunteers, and ‘we got this big ol’ tumbling mat to put out in the hallways, ’cause there was no place to put it otherwise, and volunteers would sit and read to the kids and entertain ’em... So that kinda began...what we now call a ‘one-stop shop’ idea.’ Originally, only three floors were renovated. Paediatrics and the Women’s Clinic were on the second floor, just like they are now. It was about ten years later that floors three and four were renovated, to accommodate their case load. The clinic had 1,000 patients when they moved in, and now they have 5,800.

As the above quote explains, the idea of the Center as a ‘one-stop shop’ evolved over time in response to new needs regarding patient treatment and care - just
as sandy had described the evolution of treatment and care AIDS policies purely in response to needs. ‘One-Stop Shop’ gave shape to the Center, distinguishing it from previous disparate efforts to bring the essential pieces of HIV care together, thus reflecting the general state of healthcare in America. Analytically, this metaphor shaped how the idea of care was conceived and delivered and conveyed an image of what the Center should be through the implementation of various care practices. It also provided a paradigm for envisioning the building remodelling and use, it created a sense of what programs needed to be there and what the benchmarks of success should be, and it suggested the roles, responsibilities and expectations for service providers and patients. In addition, the metaphor also guided thought and action regarding administrative roles and practices, as section three discusses.

The Clinic Directors, Drs Wendy Armstrong and Vincent (Vince) Marconi, consider the holistic, one-stop shop metaphor a central part of the Center’s mandate. ‘We were asked decades ago to care for the “sickest of the sickest” because we have the most comprehensive services and experienced provider population’, Wendy told me. Both Directors focus on the importance of holistic, wraparound care, and how it can have specific, concrete medical effects (Lofgren et al. 2015). The Center’s approach, she said, is ‘to get folks successfully into care and it translates to a better outcome for individual patients. That’s very gratifying for us.’ Their leadership and vision for the Center is guided by their research, which consistently demonstrates the importance of holistic care – not just medical, but social and psychological as well.

Wendy’s career focuses on the delivery of high quality clinical care to HIV patients and other immunocompromised hosts, including transplant recipients (Armstrong 2017). One of her biggest contributions to HIV care practice at the Center is the Transition Clinic Study Project. The Transition Clinic was started by a clinic founder,
Angelle Vuchetich, and Wendy took over when she joined as the Director of the Ponce Center. This project found that patients’ health improved when they received the Transition Center’s intensive, flexible, one-on-one model of care rather than standard treatment, and their viral loads of HIV decreased significantly. This was the epitome of the ‘one-stop shop’ model of HIV care.

For Vince, Wendy, Jacque, Carlos, and others at the Center, this work goes beyond traditional patient care. Wendy says that Atlanta’s epidemic of late-stage AIDS in vulnerable populations is so profound that, despite her other research interests, ‘it became clear that my focus has to be finding people who are affected, linking them to care, and retaining them in care. If we can’t get people into care, we’ve failed this population’. Many of my conversations with Vince focused on his research into factors that impact responses to treatment, particularly reasons people have trouble taking their medication (Marconi 2017). ‘Do the problems have to do with financial or transportation limitations, health literacy, engagement with providers, or is it a biological reason?’ he asks. These insights and experiences had broad significance for providers at the Ponce Center; Vince expanded on the practical implications of these questions on their practices and policies, saying ‘we try to understand what we can do as a system, either through improving our services or through biology, for those who are already significantly challenged when they start treatment’.

Another small but important example of the Center’s holistic approach are the two small community gardens to the left of the main entrance. The Ornamental Garden, shown here (Fig. 3.6), was started by a patient, but is maintained by the Wellness Program, which also created the vegetable garden over the wall. The Ornamental Garden was inspired in part by a Palliative Care program for HIV patients living...
in Durban, South Africa at McCord Hospital and by the Transition Clinic. This program was founded by Dr Eugene (‘Gene’) Farber, director of the Behaviour and Mental Health Center for Wellbeing, and Vince in an attempt to address human beings as ‘whole.’ Its full name is ‘Mind, Body and Spirit Health and Wellness’, and the Program gives patients opportunities to engage in activities like gardening, Yoga, nutrition, Tai chi, Qigong, art, music, pets, job skills training, etc. It is associated with a Palliative Care clinic that the Center offers every other week. This Palliative Care clinic is not limited to hospice or end-of-life care, but is rather based on 1990s World Health Organisation (WHO) recommendation that AIDS care should treat the spiritual, psycho-social, and symptomatic issues of chronic disease rather than focusing solely on medical treatment.

This model of care reconfigures clinic space through relationships between the physical environment, technologies, and persons, while simultaneously considering the kinds of spatial imaginings, hopes for the future, and emotional responses that are made possible by those configurations in people at the Center. These ideas of wellness bridge biomedical care and spiritual imaginings and seek to care for peoples ‘mental states and forge connections to make them feel better and give them a place to gather’. This Center is one of those places. Vince stated, ‘We are certainly trying to create a space that is more than just healthcare, especially with our new programs that will need more patients and care providers’ involvement – more public spaces will be needed’. They believe a one-stop shop cannot just collect relevant medical treatments and services under one roof. It must also collect these spiritual and psychological services. In addition to providing comprehensive, integrated care, the Center strives to assemble or ‘bundle’ as many services into one appointment as possible so that patients do not have to make time for separate appointments, hence a One-Stop Shop. The phrase itself is a practical, almost explicit articulation that the Center exists to create assemblage. During a Palliative Care visit, a physician, nurse coordinator, psychologists, social workers, case managers, nutritionists, physical therapists, and pain management specialists, meet with patients one-on-one and then come together as a team and draft a plan of care that may work better with patients’ involvement (Farber & Marconi 2014, Ward et al. 2016, Lofgren et al. 2015).
Patients are encouraged to develop close ties with staff, since research shows that relationships with medical providers can be a deciding factor in health decisions.

The Anatomy of Space & Social Networks at the Ponce Center

The building had no signs, no name; just a number, 341, on a grey and tall building – rectangular boxy 1960s architecture. I drove by it several times before I saw the single discreet sign for Ponce de Leon Center staff parking – permit only. There was a large parking area and green grassy hill creating distance between the building and its namesake Avenue (Fig. 3.7). I called the Ponce De Leon Center to ask if I was circling the right block. I was instructed to drive around the rear of the building, to enter Visitor Parking from the North Ave side. Wendy, the Director, later told that having no signs was an intentional step towards anonymity: ‘there is no question we don’t put a lot of signs up. There is still a profound amount of stigma, and if you walk in, people assume you have AIDS’.

With its shiny marble floors, the visitor entrance foyer used to be a chapel for the Presbyterian Center (Fig. 3.8). Now it hosts the lone registration desk, high like an altar, in the Center with a three-story tall ceiling and stained-glass windows that bring in an abundance of light. The nurse behind the desk has guided thousands of Georgians with HIV over the years to take
a seat in those chairs, wait for their doctors, and get care. There is a space on the left under a low wooden ceiling, where pews are replaced by individual chairs facing a TV mounted on the front wall that serves as a waiting area for the patients. It’s a cozy welcoming nook in the bright and non-threatening large room that feels like the start of the anonymizing and purifying of identity process.

They get scared when their doctor changes. Or when the nurse that does their shots is somebody new... Add that to the fact that they’re gonna run into people here they don’t want to run into. Maybe even the person that infected them! All these dynamics that go on, it’s not just a health care issue. And it’s certainly not just a policy issue, it’s a whole dynamic of humanness that, um ... presents a challenge to us in designing the systems and keeping ’em going.

For individuals living with HIV, the Center expands beyond its biomedical function; by providing uninsured patients’ legitimate entry and access to care and treatment, it shares in their identity, stigma and anonymity, and ‘reflects and respects their humanity’, as Jacque said. It becomes a space both real and imagined (Foucault 1984, Street & Coleman 2012), but is also constructed in relation to all other spaces. As Chapter 2 discusses, the reality of most people who come to the Ponce Center is very different than that of average Americans. The absence of prominent signs marking the Ponce Center as an HIV clinic demonstrates how the Center shares in the patients’ anonymity in order to maintain their safety, and its own. The Center’s inconspicuous neutrality and blandness suggest that it might be something else; as Vince said, ‘In some ways we want this space to be more than about their HIV – it should be a place for people with HIV to heal all aspects of their life’. The Ponce Center thus exists as a place of hope and safety that functions according to a conception of HIV and wellness that extends beyond the virus; this space creates opportunities to take care of people’s bodies, mental state, and life situations. It forges connection to makes them feel better, thus creating a sense of belonging.

I map the space of the Ponce Center as similar to a heterotopic site (Foucault 1984), a framework for examining a space of multiple orderings (Street & Coleman 2012). Foucault’s conception is concerned with how people think, and how they enact and affect the material world through thinking and speaking. Thus, heterotopia is understood not as a thing or an aspect of space,
but instead as an assemblage laid over – or set into – the space through human interaction and understanding, and thus the defining paradigm of the whole chapter becomes articulations. This approach traces the configuration of hospital spaces through ‘relationships between the physical environment, technologies, and persons, while simultaneously considering the kinds of spatial imaginings, hopes for the future, and emotional responses that are made possible by those configurations’ (Street & Coleman 2012: 5). Such a space is lived through (White et al. 2012, Bachelard 1994, Foucault 1984).

The Patient Education Center is on the Patio Level. Every patient who has to enrol or re-enrol in HIV care at the Center starts by taking an elevator down and entering through the door on their left. A small reception desk in front of the entrance door forms the middle of the room. The waiting room is an open area to the left; crowded with people, this rectangular space becomes loud and congested. Nothing separates the receptionist from the high energy world of the waiting area. Most of the time people flock around her, asking questions as soon as they find an ‘opening’. There are small individual consultation rooms lined up along the left side, with doors that can be closed for privacy. Four more rooms line the right side in a tight enclave occupied by triage nurses, Peer Educators, and the Patient Education Center coordinator. At the Patient Education Center, patients’ first contacts are peer educators, patient navigators or triage nurses who interview patients to understand their needs. Triage nurses direct patients, like ‘concierges’, to wherever they need to go in order to receive personalised care and treatment. They are connected to primary medical care, Transition Center clinic that struggles with mental health, homelessness and substance abuse issues, subspecialty care in Dermatology,
Lipid Disorders, Neurology, Hepatitis C, Haematology/Oncology, Ophthalmology, and Gynaecology with cystoscopy, endoscopy, and a state of the art Oral Health Center. They can also be connected to Social services, case management, adherence counselling, nutrition, on-site radiology, laboratory, pharmacy, and peer counselling – all services provided for by Ryan White.

Access to these services is possible only if a patient meets the eligibility criteria. As mentioned above, Ryan White requires only a clinical diagnosis of HIV and proof that the patient is financially unable to pay for treatment. The Georgia bureaucratic structure has additional requirements to access the state’s AIDS Drug Assistance Program (ADAP), a state-administered, federally-funded initiative that helps low-income patients access HIV medication. More than four thousand Georgians are supported by ADAP. People are placed in treatment and care regimens depending on how they are connected with things, as one admission manager at the Ponce Center explained:

You have to come up with three pieces of evidence to fulfil the state mandate in order to get your certification: your Georgia identification card, proof of residence, income, insurance status and viral load/CD4 count. Most importantly, you need to re-certify every six months.

Grady has a similar mandate that is re-certified annually. ‘If you fail at this certification for some reason, as there is a waiting list for ADAP, then you have to go back on to the waiting list’. However, Jeff clarified that there is currently no waiting list for ADAP; in 2012, Georgia had the longest ADAP waiting list in the nation due to years of public health and hospital budget cuts. Many patients did not apply for ADAP due to those wait lists, and Jeff said ‘There were a lot of concerns that people were falling through the cracks.’ Jeff’s advocacy network for PLHIV arranged for patients to get assistance from pharmaceutical companies’ programs for low-income patients. However, even this solution created gaps if a patient had to shift to a different company’s program because of a change in prescribed medications, so ADAP was preferable.

The ADAP recertification requirement for patients at short intervals causes problems for the Center. The manager explained that majority of their patients’ lack these documents because they are homeless, suffering from addictions, or very poor. Thus, the first task of patient navigators and triage nurses is to
connect these people with community organizations who can provide them with a ‘home’ address – usually a shelter where people can receive their mail. The navigators or triage nurses then help them apply for the state ID and get them into a clinic so a doctor can get them tested. This illustrates how the Ponce Center explicitly exists within a local web of services, funding, and people and organizations that care – and these too can be brought together and used to create or facilitate healthcare and other holistic services that fit into the Center’s philosophy and remit. The articulations that support patient flow are designed to create this ad hoc order in care and services in the context of a fragmented health care system. They also bring in other local and federal services that are not necessarily HIV- or healthcare-related to participate in their assemblages. In addition to clinical services, this includes government programs for social welfare services such as Section 8 housing, food stamps, disability and specific concession and entitlements via the Women, Infants and Children (WIC), along with charities like Living Room (temporary housing support), Open Hand Atlanta (charity service that delivers healthy cooked meals to HIV patients at their homes), and a Food Pantry, which are also navigated with the help of partners like AID Atlanta, a social impact organization that works closely with the Ponce Center, provides most of the social services and is one of the network of different actors I observed during this research.

The Transition clinic provides the highest level of care for the sickest, poorest and most destitute of patients. For medical treatment options, the clinic doctors use a model of ‘combination care,’ a major component of which, as mentioned earlier, is the HIV Care Continuum or Cascade. The care continuum moves horizontally along service provision, whereas the Center’s combination of care moves vertically in terms of service intensity based on need. This model stratifies patients based on risk of worsening their condition, starting from the minimal level for patients who require basic care and already understand how to care for their health; then it moves up that ladder to a smaller portion of people who require more resources (e.g. those at advanced stages of AIDS, those with additional illnesses and long term side effects of HIV medicines as well as those with psychosocial challenges such as mental health, substance
abuse and homelessness). Such stratification is necessary because if resources are focused earlier at a preventable stage then most of the expenses incurred by treating those with severe disease can be saved and repurposed.

In addition to the Transition clinic, which treats the biological and psychosocial aspects of care, the fourth floor also contains a housing organization called ‘the Living Room.’ This organization provides housing assistance to the homeless or low-income families and individuals; they connect people to Section 8 government housing assistance program, find temporary shelters, or help patients with their rent. There are several other community-based organizations (CBO) on this floor, such as Legal Aid. Women can also get their food stamps from the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) office on this floor. WIC is a Federal safety net Programme that provides grants to enable States to care for their poor. The fact that the Center connects people not just to Ryan White funding but to other sources of Federal money emphasises the point of piecing together assemblages, thus forming additional layers of care.

The transitional care model is another dimension of what makes this space a Center and not just a Clinic. The facilities are used by more challenged patients who are coping with what Vince calls a social ‘triple whammy’: homelessness, substance abuse and mental health problems. They can come in five days a week and spend a whole day there, no need for an appointment; they get food, their pill boxes are made for them, they receive mental health and substance abuse counselling, group therapy, and they can play games and watch TV. This is where most of the Transition Center’s resources are concentrated despite the fact that only 40 out of 5,700 patients use the Transition Center clinic, while 80-90 attend the palliative care clinic. The Wellness series is open to all (including staff), though during my research there were only about 400 people using these services.

Drawing on the Transition Clinic model of care, Carlos brought in NIH funded Project RETAIN: Providing Integrated Care for HIV-Infected Crack Cocaine Users to keep their patients engaged. Studies have shown that here is an inherent paradox between the individual responsibilities demanded of people for management of HIV and the reality of the limits to agency in the context of
health practices (Paparini & Rhodes 2016). Such limits shape adherence to ART, as it simultaneously takes on an increasingly central role in HIV prevention and care efforts (Nguyen et al. 2011). For example, a pre-requisite for ARTs to work is better nutrition – people on food stamps mostly can only afford processed or junk food which compromises their health further. At Ponce, newly-diagnosed patients are sent to the retention clinic, where a navigator is appointed to each individual patient. Patient navigators give personal attention and support, helping patients work out the logistics of treatment and accompanying them to their appointments. This is an effort to keep people in care and help them navigate the system smoothly. For example, as mentioned earlier, the first thing a navigator helps most patients obtain is a state issued photo identification document and proof of permanent Georgia residency, so they can have access to medication through ADAP once they clear the certification. Navigators get involved very quickly with intimate details of their patients’ lives and their issues, so forging a close, trusting relationship is the key for a navigator trying to help them address certain issues: ‘we have to trust that the information they are giving us is right, and they have to trust that we have their best at our hearts – we have to become their guides’ (Charlie 2013).

Navigators work closely with outreach workers, who reconnect with patients who have fallen out of care. Outreach workers first reach out to people by the phone and, if that is unsuccessful, they search homeless shelters, streets, and under bridges. They know people by street names that the clinic otherwise wouldn’t learn from a regular patient registration application; so they can ask, for example, ‘Where’s DJ Johnny?’ instead of using ‘DJ Johnny’s’ legal name. I accompanied the team on several occasions. While we were driving around the neighbourhood called ‘the Bluff’, looking for patients, the team took me to boarded-up drug houses and introduced me to small-time drug dealers, pimps, or sex workers. The team members were well known within the community. Ossie, who was driving, and worked in these neighbourhoods for ten years, said:

I’ve seen brothers doing stuff and haven’t called the police on them. They know I drive around, and I know what they do, and they let me do what I need to do for HIV. We have kind of settled in a comfortable routine over these years... most of these folks are faced with the problems of having somewhere to sleep or rest, where their
next meal is coming from, making sure their kids go to school or day-care, getting money to get high and then finding their next high. Some women are worried about getting beat or abused by their John, Pimp, Boyfriend, and Daddy. Those words are all synonymous...

Some of the individuals that we came across when you were with us last month in the park are not even getting any kind of assistance from the government at all. They use a bartering system the exchange sexual favours, drugs, food and protection. It is their way of living and it works for them. They battle with staying on drugs or getting off drugs; either way is a dilemma. When these individuals need medical care, they check their selves into the Emergency Room, where they will not be turned down. From there, most of them are sent to us at the Center.

Thus, the work of healthcare providers involves a process of piecing together fragments of the American safety net and healthcare systems and policies to make biomedical care possible. In other words, people who work at the Ponce Center and provide healthcare to the HIV community in Atlanta have to re-make the connections between the different parts of the system every day; they do the work of connecting different agencies and fragmented policies, bringing them together to provide customised care to each individual that walks through their door. The emergence of meanings in translation also indicates power relations (Freeman 2009). For example, the meaning-making of the Ryan White Program policy is also part of ‘claims making’ (Kingfisher 2013: 13) – claim to ‘care’ and ‘access to treatment’ for HIV. In the process of providing healthcare the Ponce Center has thus created something new by situating the re-translated meanings of HIV and health reform policies and their implementation back into the context of broader socio-political concerns. These translation processes, or aligning involves processes of assemblages, addressing array of agendas and multi-vocality of their meanings, and creating linkages and connections across sites and issues. The acts of translation and construction by which providers ascribe meanings to policies through collective acts are anthropologically significant and therefore help illuminate how policy in general is used, understood, and implemented.

The relationships and network ties that make up the Ponce Center function at multiple levels, starting from connections and re-making processes of the fragmented health system within the Center. The Ponce Center and the people who work there were cultivating these relationships even before its inception.
as a ‘one-stop shop’ where the medical treatments are provided, and the broader work of healing is made possible. It is not merely a place that cures the disease, but one that gives patients a new understanding of who they are; it helps them make sense of this new identity within that condition, as is discussed in the next chapter. The Ponce Center forges links between health providers, patients, providers, the organizations on- and off-site, and the surrounding community for the HIV citizen in the era of treatment possibility.

More importantly, the doctors, nurses, specialists, and other care providers collaborate to provide a holistic network of physical and mental biomedical care for each individual. Those networks manifest in a physical way, as well, by having HIV, mental health, and dental care specialists all in one place, which allows them to ensure that patients can see every specialist they need in one day, saving extra trips. The Ponce Center draws into its network welfare policies and non-profit organisations that are not directly related to HIV. Nurses and patient navigators link in social services such as Federal WIC funding, food pantry, Living Room, Legal Aid, and child care, all coordinated on the premises to ensure that food, shelter, legal assistance, and other forms of social support is available to the patients. In addition, the Ponce Center brings in cutting-edge, care-related research on-site, which allows them to apply both ground-breaking and proven approaches into its practice. This includes the Transition Clinic and Project Reach, which provide resources the patient navigators need to go out into the community and bring individuals in. Project Reach is also how they also spread knowledge of the Center in the Atlanta neighbourhoods that need them – growing their networks and local reputation. The connections and relationships between these networks morph and shape the larger, national healthcare assemblage, and are informed by it (see Chapters 2 & 5).

The Ponce Center network also includes family, friends, and activists who are part of the HIV community, but do not have the disease themselves. In particular, not all the activists – or ‘champions’, as the community calls them – who have risen from the grassroots level to advocate for and guide HIV policy since the beginning of the epidemic are gay or HIV-positive themselves. The dedication of straight but HIV-positive advocates to these alliances, the urgent need to save
human lives and strong sense of community felt by people like Jacque and the Ponce Center staff comes from their shared experiences of the disease and its attendant sense of helplessness and death (see Chapter 2). Uninfected advocates often had sick friends and family; they became caregivers, so they shared that experience of suffering and struggle, hope and death. Similarly, gay and straight infected individuals all suffered and fought together; as Jeff said, the older advocates ‘remember that the only groups that were accepting to folks were LGBT-based groups so that had to get over their homophobia and many of them want to give back, to try to make life better for LGBT folks in general’.

The network of organisations and people the Ponce Center has built extends beyond its walls. The Center works closely within a local network of organizations like SisterLove, Georgia Equality, AID Atlanta, AID Gwinnett, Positive Impact, Mercy Clinic, VA Hospital, Open Hand, WIC, other state public and social agencies and departments. It is impossible to name and describe all the organizations that support Ponce Center and are supported in turn by the Ponce Center. The Center is also part of a national network; The Communities Advocating Emergency AIDS Relief (CAEAR) Coalition has agencies and organisations in all fifty states. CAEAR is the oldest and most important national membership organization that advocates for federal policy, legislation, regulations, and appropriations to serve the Medicare Part A, Part C and ADAP community mandates. The Ponce Center coordinates with them annually to lay out their policy agenda for the next year, and to discuss how to meet the care, treatment, supportive, and prevention service needs of people living with HIV/AIDS and the organizations that form their network. Chapter 5 elaborates on the Ponce Center’s efforts within the contemporary national health care evolution and the evolving role of the Ryan White HIV Treatment Program in that environment – and the dynamics of how these groups work together.

Conclusion
This chapter deals with the question ‘What makes the clinic a Center?’ The answer is that the Ponce Center goes beyond traditional patient care to focus on human suffering over the bio-citizenship model. It creates social relations, and advances a combination of integrated and holistic care that is concerned
with the full spectrum of human experience. The resulting ‘one-stop shop’ diverges from most traditional global models of limited integrated care for co-infections or reproductive health and HIV, fighting for resources to fulfil the promise of a manageable HIV epidemic. In so doing, the Ponce Center demonstrates that the fragmentation in the U.S. healthcare system can be addressed through an evolving process of articulations and translation in order to create and maintain the required assemblages of physical, mental, and medical care. To do so, providers at the Center rely heavily on relationships forged over time in order to make the ‘everyday life’ activities, claims, negotiations and alliances possible. These acts help providers produce and assemble policy in unofficial ways, and displace the notion of policy as a neutral, apolitical, top-down and linear process.

Historicizing and contextualizing the Ponce Center illuminates how the Ryan White CARE Act created HIV as an exception within the U.S. healthcare system, by creating a separate safety net for sufferers of a particular disease. Ryan White made American HIV care unique by creating a consolidated and streamlined source of funding for holistic, all-encompassing care, and the Ponce Center became a location for distributing this unique care. The Center’s core value is care for individuals, within a relationship-centered view, and it creates itself as a space where suffering is acknowledged and addressed. The constant articulatory process at the Ponce Center is a defining feature of practice and HIV care in the U.S. These everyday articulations and the resulting assemblages show that policies are power-laden artefacts. That is, these assemblages are not only responses to particular aspects of American culture (e.g., parts that are concerned with healthcare, sickness, policy, identity), they are also re-translating and re-designing that culture according to the meanings ascribed by different actors who interact with these policies.

The ‘one-stop shop’ metaphor, as well as Center’s vast social networks are the cornerstones of articulations that allow the Center to exert power beyond the building’s walls by reaching out to new patients, forming local, personal, and national networks, and asserting a conception of HIV that creates conditions under which they are understood as a community with specific urgent needs.
The Living Room, WIC federal funding, childcare services, meditation and self-care classes, Gardens, subsidized transportation, and in-house pharmacy are all connections that allow the Ponce Center to function as a one-stop-shop. In addition, navigators, testing programs, and outreach teams form a direct link with community, as do relationships with organizations like AIDAtlanta, SisterLove, and Mercy. The Center also holds a prominent position with the CAEAR coalition at a national level, including maintaining relationships with the White House and HRSA. Finally, medical and public health research, based at the Centre through the Emory CFAR program, brings in funding and cutting-edge approaches to HIV care and treatment. It also acts as another layer of social and financial networks, embedding the Ponce Center within a national and international effort to improve treatment and cure HIV/AIDS.
Chapter 4: Being a Patient at the Ponce Center: Profiles from the Field

I had to do my business. I had to go out and make my appointments and go see these people, and so that’s what I did. You know? I put my differences aside and got up and started taking care of my business - like I was supposed to, ’cause if I didn’t I’d be out there on that street somewhere. Who knows, probably dead?

(Lisa, July 2013)

This chapter is about patients’ experiences of sickness and their interactions with various health and social policies at the Ponce Center in Atlanta, Georgia. It is a companion to Chapter 3, which deals with the translations and articulations of policy mandates by healthcare providers. These providers’ fight to make the cascade of care possible understood as ‘work of healing’ and is most obvious in their experiences and practices at the Center. On the other side are the patients who are facing the implications of a lifelong treatment, its complications, and HIV-related illnesses. Patients are the primary focus of the Center, but they are positioned differently than Center employees within networks of policy and personal relationships, and they attribute different meanings to policies, policy worlds and, in effect, to the medical world they inhabit (see Shore & Wright 2011: 2). Thus, this chapter is about identity, and the experience of becoming and of being an HIV patient. More specifically, it is about identity as a multifaceted, intersectional construction that patients must articulate, negotiate, and perform that reflects both patients’ self-perceptions and their interactions with others (see Brown & Capozza 2006, Choo & Ferree 2010, Collins 1991, Cooley 1956, Glenn 2000, Jenkins 2008, Mead 1987, McCall 2005, Taylor & Spencer 2004, Watkins-Hayes 2008).

Because patients hold a different position in the policy world than other actors, they entail different research responsibilities. All patients, especially HIV patients, are considered ‘vulnerable’, meaning I required ethical clearance from both the University of Edinburgh and Emory University to study the Grady Hospital Infectious Diseases Program. My interactions with patients were shaped by time restrictions and privacy regulations set by these binding approvals (see Chapter 1). In order to protect their privacy, I have used pseudonyms for all patients whose stories are told here. As a gesture of reciprocity, I also compensated them with $20 (£15.30) per interview for their time at the request of IRB; a necessity that in certain situations entails its own
methodological issues (Grant & Sugarman 2004, Head 2009, AAA 2009). It was deemed that compensation would not pose any such problems in my study because the patients were used to being part of studies – the Centre is a hub of HIV research, and participation incentives are common as a ‘direct benefit of the research’ to their predominantly poor patient population.

During my fieldwork, I shadowed health providers, the community outreach team, and patient navigators at the Center, observing their interactions with patients. Some of those patients became my respondents and I recorded their stories. The patient narratives presented in this chapter are drawn from 16 semi-structured in-depth ethnographic interviews and hundreds of hours of observations conducted between June 2013 and May 2014. The quotes cited and analysed in this chapter denote general patterns obvious in most of those patient interviews. For example, all interviewees brought up ‘the first day with diagnosis,’ CD4 counts, adherence, social and personal relations, family, dating and sex, economic struggles, life style and nutrition, physical and emotional pain, shame, psychosocial support, their relations, and access to the Ponce Center and its staff. The intersection of HIV and their lives is central to the analysis in this chapter. At the same time, I have restricted the number of ‘voices’ or interviews here to maintain a sense of closer understanding of individual personal narratives. There are other voices present in this chapter, mostly doctors and navigators, that contextualize these patients and their accounts.

The research period covered a few months before and after the first Federal marketplace health insurance open enrolment period instituted by the ACA. My intention was to see if HIV patients who earned just enough to be eligible for government subsidies, rather than being able to rely on free Medicaid treatment, preferred to enrol in private coverage or to remain uninsured. Medicaid expansion, a cornerstone of the ACA policy, was supposed to be implemented at the same time as the insurance marketplaces; Medicaid extends insurance to the poorest citizens, and the expansion was meant to cover nearly half of uninsured Americans. This component was crucial because the majority of patients at the Center should fall into that newly-eligible population. However, like many states with Republican governors, Georgia did not expand its Medicaid program,
leaving 12% of its population with no insurance options. Georgia’s Medicaid eligibility criteria is one of the strictest in the nation and provides bare essentials only; poor, childless adults (earning up to 100% of the Federal Poverty Line) do not qualify for Medicaid or ACA insurance subsidies, even if they have HIV.

Patients’ stories help illuminate their situated experiences as contextualised within the Ponce Center, where prevention and intervention (i.e. keeping them in care) becomes a site of struggle between representations (of their identities, sickness, access to treatment, and rights as citizens to state benefits like health insurance via the ACA), and human agency – meaning patients’ capacity to make treatment decisions for themselves. The struggle is enacted within and by the culture of blame and the notion of responsibilisation, which is a market-embedded morality that reflects government categories and rationalities, stigma and suffering, local politics, scientific technologies and racial imaginaries. The American ideologies that shape the social safety net and health policies hold patients responsible for taking an active role in their own care and for the outcome of their life situations. These policies, the systems they create, and the network of related programs are deeply embedded in the ideology of work ethics, productivity, autonomy, and individual responsibility (see Chapters 1 & 2). It particularly considers how the correct performance of invoking constitutional rights may enable negotiation of entitlement (see Hyatt 2011; Jenkins 2008; Farmer 2001, 2004; Kingfisher 2013; Morgen & Maskovsky 2003; Mulligan 2017). Although laws do not explicitly state their underlying neoliberal standards of individual responsibility and self-discipline, policies – and perceptions and implementation of policies – implicitly divide people into categories according to whether they are deserving or undeserving of citizenship benefits. This ‘politics of life itself’ offers both possibilities and limitations for how the current era of treatment possibility is lived. For the HIV community, fear of ‘being left behind’ is a powerful element of shared experience that has been central in this community’s continued efforts.

Being a patient is itself an identity – one that exists between those categories of deserving and undeserving – that is informed by and intersects with these other categories of identity and stigma based on characteristics such as race, class,
gender, motherhood, welfare status, and sexual orientation. Such identity characteristics determine power relations, fuel inequalities, and shape the realities of living with HIV. Their status as patients articulates a diversity of issues related to access to care (including insurance) and various aspects of their identity, particularly in terms of their responsibilities and rights as citizens. Bob Geldoff, of Live Aid fame, used the terms ‘hooker’ and ‘junkie’ at the 2014 AIDS conference and was critical of those who rejected these terms on the basis that they increased stigma. Vince disagreed: ‘in fact, it is not just stigma but increasing blame. It creates a cognitive bias against the individuals. This is the classic attack on political correctness that results in actual harm when these terms are used.’ Thus, someone perceived as a ‘blameless victim’ – like thirteen-year-old Ryan White, who contracted HIV through a tainted blood transfusion for haemophilia – has a different experience than black, non-heterosexual, sexually promiscuous, or drug-using victims. Jacque and others at the Ponce Center vehemently opposed this false dichotomy. As HIV patients navigate policy worlds, the distinctions between those categories and their implications become a dilemma that the patients must resolve in order to access treatment – or, at least, they must make an effort to control how other people evaluate them.

This chapter examines what it means to be associated with particular categories of stigmatised identity, what it means to be an HIV patient trying to access care. This chapter focuses on three distinct but interrelated domains of patient narratives. The first section deals with diagnosis: the experience of becoming a patient, and the series of social, personal, and medical disruptions this entails. The second section examines what it means to be a patient, and how patients articulate and negotiate intersecting subjectivities and fluid identities, particularly in relation to the categories of ‘deserving’ and ‘undeserving’. This section begins from the understanding that negotiation and related performance are intrinsic part of the process of becoming and sets the negotiating a patient identity at the core of the articulation, translation, and assemblage work that patients must do. The last section is about being a patient at the Ponce Center: what the Center means for them, how it situates them within the identity spectrum and the fractured web of health policy and social services.
‘Don’t be a Dumb-Dumb’: HIV Diagnosis & the Disruption of Becoming a Patient

On a late October night, in a popular historic neighbourhood east of downtown Atlanta, hordes of people were ‘bar hopping’. Out there on the side of the street was JZ of AID Atlanta, standing beside a large HIV testing van. ‘Get tested! Get your result right here, right now!’ JZ roared as people passed him. ‘Participate! Raise awareness.’ JZ handed out condoms and lifesavers: ‘Get testing and save lives.’ He handed out Dum-Dum lollipops and encouraged people to ‘know their status and not be dumb.’ He gave away Smarties along with information brochures and condoms urging people to be smart and learn their status early so they can receive life-saving Anti-Retroviral Treatment (ART). His brochures explained that persons who test HIV-positive can access counselling, prevention education, support services, and medical care to help them stay healthy and not progress to AIDS. HIV-negative persons can access counselling and education on how to remain HIV-negative. JZ said every status is good, whether positive or negative, if it means stopping the spread of HIV. More importantly, taking a test and receiving even a negative diagnosis still serves to ‘disrupt’ these passers-by’s comfortable understanding of the world – their assumptions about who can and cannot be infected with such a morally freighted virus. This is a process that occurs on a deeper and more personal level for most patients who are diagnosed with HIV: they must learn to reconcile their image of themselves with their assumptions about people living with HIV.

‘I’m not positive, but I am HIV-impacted and -affected, and I live with all sorts of work on HIV’. Dazon Dixon Diallo, founder of Sister Love Inc. in Atlanta told me. She seemed to echo South Africa activist Adam Levin, who insists ‘It doesn’t matter if you are HIV-positive or negative: The world has AIDS, and if you give a shit about the world, you have it too’ (2004: 226). In 1989, Dazon founded Sister Love, which took up the challenge of empowering infected and high-risk African American women to take control of their lives. Dazon said,

This was the time when the major focus was on white gay men, and clinics were full of them. Nobody was paying attention to black women and men who were also suffering from this epidemic. I started Sister Love out of the same reason that everyone working on
AIDS was working on it: Anger. Anger that nothing was being done for people who were dying from it.

In the early 1990s, Sister love joined the ‘Women don’t get AIDS’ campaign, to lobby the CDC to change their definition of HIV to include women. Prior to that, women had no resources because they were not being counted, or even diagnosed in the clinics. Sister Love is one of the strongest community liaisons that the Ponce Centre has. Dazon described herself as ‘one of those fortunate people who, as I put it, didn’t meet the virus through people — I meet people through the virus’. Her organization emphasizes counselling and support groups following the medical, social and political dimensions of the cascade of care. She identified the ‘diagnosis’ as the most stressful part of the process. The first advice Sister Love counsellors give people is to ‘sit with it for a minute and think about it’. She also compared sharing the news of diagnosis with coming out, because newly-diagnosed patients must decide who they will tell in their immediate sphere. Dazon has found that responses depend on the nature and strength of relationships: ‘In some instances, coming out to a partner has actually increased or introduced violence into a person’s life where it wasn’t there before. Or if there was violence, a person may not come out ever’. This perspective is directly counter to the broad endorsement of getting tested that JZ advocated on the streets. Dazon mentioned that within her organization, and in the larger HIV community, people often became slowly active within the HIV/AIDS work as part of working to develop the strength needed to disclose to family and loved ones.

Sophie, a member of staff at Motherhouse, Sister Love’s main office, was one such person: ‘It feels like your life is over, and that’s how I felt. I had such anger towards my own self. Now I tell women you have a way to move forward. We are here for you. It’s going to be OK’. She described another case to me: A woman with three children, recently diagnosed with AIDS, was coming to the Motherhouse. Sophie was calling the Ponce Center to set up a first appointment, and had also arranged for her to meet with a person from a domestic violence shelter. The woman was in an abusive relationship, and the diagnosis had exacerbated her situation, but she didn’t want to leave her children with her husband. She had no job or money and needed immediate medical care. Sophie agreed that I could talk to the lady once she arrived at the
Motherhouse, but everything happened too quickly for that. The woman was crying and could hardly stand. After a short, private meeting, the shelter took her and her children to an undisclosed safe house as a standard procedure. To see that woman with her children, so weak and sick, and taking this brave step for their safety was a powerful experience for me as a researcher; but more importantly, it highlighted institutional violence and cycles of abuse, marginalization, and the intersection of disadvantage.

Stevie, an outreach worker from the Ponce Center, had a different kind of story. His diagnosis was when he was seventeen years old: ‘I fainted in the shower and my father rushed me to the hospital. They told me I had AIDS, and then they were asking me if I knew what that is and stuff like that. At the time, I did not’. Stevie thinks the virus was transmitted through a tattoo he got because his then-girlfriend insisted. He acknowledged that at the time he was sleeping with both men and women, but hesitated to suggest that was the reason for his infection; bisexuality and promiscuity are both heavily stigmatised identities, especially when they intersect with an AIDS diagnosis (see below). No one in Stevie’s family had much knowledge of AIDS, and whatever sex talk they had was confined to heterosexual relationships. Sex Education in his Georgia public school was ‘kind of non-existent’, so that didn’t help either. Jacque told me the same:

Pretty much within the south an abstinence only teaching in schools is done...it got worse after the (George W.) Bush Administration’s...restriction on spending Federal dollars on sex talk, which was considered ‘promoting careless sexual behaviour’. Earlier it was in relation to the issue of teenage pregnancy, but after HIV it’s the horror of spread of the disease and needs to be changed.

Stevie added, ‘I remember the weird videos portraying girls and boys having sex in steam rising side streets and catching STDs. That didn’t seem like me, so I never bothered about it’. Now, at age 27, he is not only a long-term patient at the Ponce Center but also involved in educating his fellow HIV-positive African Americans, particularly youth, about how to handle HIV. ‘There has been a kind of silence in the African American community – we don’t understand it...and we are dying from this ignorance. I feel I needed to step up to the plate and be more vocal so we don’t die from this epidemic’. All forms of AIDS education and activism are on some level a disruption; Stevie is articulating
the need for a macro-level disruption of the status quo surrounding abstinence and ignorance within poor, urban, Southern communities of colour.

Death from AIDS is still a common reality for people with those identities; Dr Carlos Del Rio, Director of the Emory AIDS International Training and Research Program, told me, ‘in many ways, Atlanta is the epicentre of the epidemic in the U.S.’. About 70% of Atlanta’s HIV/AIDS patients live within two miles of the Ponce Center, because the poorest zip codes have the highest rate of HIV. These neighbourhoods also fall at the intersection of race and other marginalized identities. Dr Wendy Armstrong and numerous other Ponce Center doctors repeatedly identified this as their biggest challenge. ‘We are diagnosing people very late and this should not be the case in 2014. We’ve had patients who were diagnosed with full blown AIDS on their first test, first visit with us’. It can take a decade for the disease to progress from HIV to AIDS, says Wendy. However, of the 15-20 new HIV diagnoses a month at Grady hospital that are referred to the Ponce Center, about half of the patients already have AIDS. Stigma and lack of access to health insurance creates perceptual realities for patients that obfuscate early diagnosis, leaving many unable to benefit from the possibilities of treatment.

Lowanda, now fifty, discovered her status when a doctor visiting her children’s daycare at the church said she didn’t look good and should take a test. Three weeks later, they sat her down and explained that the test was for HIV and diagnosed her with full blown AIDS. It was 7 January, 1993. She didn’t understand at the time what it meant, but she figured that ‘it didn’t sound good at all’. She went numb:

I could hear them, but I couldn’t respond back. They just wanted to make sure that I was taken care of so they took me to schedule my appointment. They had to lift me from my arms and were pretty much guiding me on wherever we were going... I didn’t ask why, as I was only following what I was told.

Lowanda’s experience is a classic form of disruption; she literally disassociated from her actual life and experience for several days, and the process of coming to terms with her diagnosis and treatment required her to re-form – and transform – many of her habits, relationships, and expectations. Lisa, by contrast, also experienced a disruption surrounding her diagnosis, but one that forced her to transform her life in more positive ways. The 45-year-old patient
told me her diagnosis came about because of a drug bust. ‘I was staying in a house and they did a drug bust and I got caught in the house. Thank God they did. Because if they did not, I probably woulda been dead the next day, the doctor told me’. She was so sick that her two months of incarceration were spent in the jail hospital with pneumonia. She went to the Grady hospital after her release and stayed there until she could walk again.

Keeley, unlike Stevie, Lowanda, and Lisa, suspected that her condition might be related to AIDS. She was admitted to the hospital for what doctors believed was pneumonia. She also had two knots on her neck. ‘I asked the doctor what it is and if it is related to HIV because I think I knew I had, I thought I had HIV.’ Two weeks later her doctor confirmed her worst fears. In those early years, she had health insurance through her job. She started treatment, but quickly lost both job and health insurance: ‘after I found out that I was positive, I, I quit. Yeah, I just stopped working. My mental state after being diagnosed was totally different.’ She told her husband, and he tested positive too. They wondered who infected whom. It was devastating for the couple although they stayed married. ‘It was just...really hard, mentally and emotionally...much better over ten plus years now’. This brief quote highlights many of the domains in which an HIV diagnosis can disrupt and transform patients’ lives: it altered her mental and emotional health, her attitude towards work, her marriage and her relationship with her husband.

HIV has its own stigmatized place in the social imagination. Bodies and sexuality have historically served as domains for advancing and combating stereotypes about marginalized groups, and these preoccupations have been a continuous thread in the public’s response to the AIDS epidemic. The earliest days of the epidemic were marked by loneliness, abandonment and hopelessness for the people living with AIDS. Because the first identified sufferers of the disease were gay men in America, AIDS took on strong sexual and moral connotations. It became categorized as a ‘lifestyle disease’, characterized by promiscuous sex, drugs, and the moral depravity of homosexuality; in the words of Evangelical Preacher Jerry Falwell, AIDS was ‘God’s Punishment on Fags’. Farmer (1999) studied AIDS among Haitians, another stigmatized community, and made similar observations about its moral weight.
Susan Sontag (1983) writes extensively about how this tendency of illness to become a metaphor triggers ‘a process whereby the specifics of individual suffering are lost in a welter of social fantasy’ (Weeks 1989: 1). So in the social imagination AIDS came to stand in for the assumptions people made about people living with AIDS, obscuring the actual suffering; what Treichler (1999) terms an ‘epidemic of signification’ that is revealed through processes of blaming, as well as by establishing moral connections between the spread of HIV/AIDS and larger social transformations on the community level. The providers at the Ponce Center reject these presumptions. However, their patients regularly have to contend with people with conservative ideologies who cling to morally-weighted notions of the disease. We therefore cannot understand the lived experience of HIV without considering how intersecting subjectivities can define how individuals work, love, and live. A diagnosis is a disruption to thinking, to social relationships – particularly, demonstrates concern and loss of safety in assuming that friends and family will accept her un-problematically. As Simone told me,

We were still dealing with kind of being ostracized in society. Um, putting us in a position to—to still feel...I don’t know, maybe, to just not want to talk about it. You know, now it’s a lot more...of a common conversation, you know. People are—I think they’ve come around a lot more then when I was first diagnosed.

She added,

Being positive, you sometimes feel like you’re kinda the black sheep and you don’t know who to tell. You don’t know, you know, how people are going to accept you. So it kinda hinders your thought process or the abilities to even seek the actual resources to even treat yourself.

Lowanda shared her experience of public humiliation and stigma. When she entered the waiting room in the Grady Hospital in 1993, it was full of seniors, so she wondered if she was in the right place. Lowanda mimicked the nurse in a thin voice calling out loudly that ‘I want all of you to know that everyone in this room has the same thing – you all are sick with AIDS!’ The door was wide open and people were walking up and down the corridor. The patients were all ‘still freaking out too and people started stopping and looking into the room to see how we all looked like. Later the secretary came and apologised for her behaviour and said “She [the nurse] shouldn’t have done this to you”’. Lowanda said that she felt traumatized, and that feeling stayed with her.
She tried to share the news with her family – eight siblings and her father – but couldn’t. She called her youngest brother and told him to sit down as she had some news she wanted him to share with the family on her behalf. He listened calmly and promised to do as she asked. A few minutes later his wife called, demanding to know ‘what have you done to my husband?’ as he was rolling around the floor, crying uncontrollably. After he calmed down, he told the rest of her family. The first call came from her father, ‘Why didn’t you call me first? Who did you call before me?’ She didn’t know what to say. Lowanda wondered why it mattered: ‘Who knows first, who knows second, who was supposed to know and who wasn’t – it doesn’t change the situation’. She was 29. Her family threw a surprise birthday party on her 30th which she thought was her last, as she was told she only had six months to live. Lowanda and her children do everything related to the Center as a family:

This is the doctor, this is the nurse and these are my medicines – they know everything and everybody. Now the kids want to stand for LGBT and everything else. And I have no privacy – they keep an eye on men around me. Just the other day, my son scared off a man in his 70s who was taking interest in me in the waiting room. Children do not want me to date “someone their grandpa’s age”.

Simone similarly relies on her children, but did not feel she could share with the rest of her family. Among other things, she is also guarding herself and her loved ones against the disruptions that AIDS brings. At first, she only told her elder daughter. She only recently told her younger daughter, who had an emotional moment but then came back and said, ‘I did my research. We know what to do.’ Simone said, ‘My daughters were ready to roll’. She addressed the issue of disruption almost directly, explaining that she wanted to wait to tell her mother and siblings until her treatment reaches a point when she can truthfully say that almost nothing has changed in her life:

Until I did get on my medication, get past the initial effects and get it in my system and everything is you know, one hundred percent. So that when I tell them I want to have them all together. But they can see that I was healthy and that everything was fine.

There were usually one of three reasons that patients cited of not telling their families or why their families/friends stigmatize them (1) transmissibility of HIV, (2) the person could die from the disease, and (3) association with
homosexuality. Vince told me that ‘amazingly in my experience here in the South, the biggest concern is over the second one - worrying an elderly parent that they have a “serious” disease.’

The stigma of HIV builds a discourse that limits the identities of HIV-positive people to those deserving of rejection, discrimination and avoidance. In many cases, this perceived stigma outweighs patients’ ability to fulfil roles and follow social codes that construct their identities as loyal wives and dedicated mothers, no matter how hard they try to present a positive, ‘ideal’ face to friends and family members. It is not an accident that the phrase ‘black sheep’ occurs twice, just in the data quoted in this chapter; similar phrases such as ‘outcast’, ‘rejected’, and ‘alone’ are scattered throughout my interviews, which indicates a specific variety of disruption in people’s familial relationships, which are supposed to withstand anything. The need to control information about their physical illness thus becomes a tool to negotiate identities that allow them to maintain their respective social positions.

Dazon discusses the importance of recognizing the intersectionality of these disadvantaged identities; it is essential, if she and other advocates and providers are to make the cascade of care successful. My advocate-respondents, like Dazon, are experts in their field, with decades of experience so their everyday analyses were important for enabling me to decipher the meanings they were attributing, and what was behind those practices. Concepts like intersectionality are not just tools available to them, but also leverage in their articulations, negotiations and performance. Dazon said,

> Intersectionality matters to women affected by HIV. Women’s lives are complex, complicated, layered, with many different levels of experiences: sexism, racism, religion, customary practices, cultural practices, language. All of these things are coming together in one human being who walks into the door who may happen either born with vagina or chooses to get a new one later. We have to look at all of these issues and be intentional about tackling them all, because that’s the only way we are going to tackle the HIV, because its already wrapped up in all of that.

HIV is a bigger challenge for women because they are already economically dependent... However, there are studies that have shown that for poor women or women with no or low income, who are HIV positive, disclosing your HIV status and seeking services is
actually an economic benefit. Because you are the only folks now who have the access to housing, child care, transportation, meal delivery, all those things matter that you struggled before HIV. For women with middle income and higher, HIV diagnosis has exactly the opposite. It could destroy their status, their job, their insurance coverage, how they are situated in their families.

I found men in a similar situation. Kanye, an HIV-positive patient navigator, has a complicated relationship with his mother. She often visits him and stays overnight at his place. She knows that he works at the Ponce Center, but he says there is no question of disclosing his sexuality or status to her:

You will not believe how misinformed my mother is about HIV in this age and time. She holds a firm believe that it is a curse from god and you can get infected by being near such people. She prostituted all her life, but being gay and positive will be unacceptable to her. I educate the community but I dare not mention a word in front of her.

Lisa did not tell her family because she knew she would become an outcast. Despite the fact that her family accepted her many drug busts and incarcerations, she believed they would consider her the ‘black sheep, and leave like everybody else [in her life]’. The message is implicit but clear: being HIV-positive is less acceptable to her blood relations than her drug addiction or time in jail. Instead, she highlights the support of the Ponce Center staff:

Kishna, Cathy, Charles, and Brittany. They’re my friends. They’re my best friends. And they stood by me and would not give up on me, they would not let me give up. They were there with me. Well, I needed somebody to be there. I didn’t want to talk to no person. I throw my hand up; I don’t want to talk to no people. They kill you before you die with their questions. But Kishna, she said...she was determined, Lisa, you gotta get your help ‘cause you’re gonna need it. People care about you and I’m one of the people that care about you’. And that helped me survive.

Simone felt more comfortable sharing with some of her close friends than she did with her family, ‘and they were very supportive’. Most of my respondents relied more on a ‘found family’ for moral or emotional support, like Lisa’s Ponce Center friends. This is a common theme in the LGBTQIA+ community more generally, where even today a significant proportion of the population finds that their identity (or intersecting identities, when it comes to a HIV diagnosis) is an unacceptable disruption to their family’s expectations for them. Like Lowanda’s family, Simone’s friends had questions:
Some of them were like—why did you tell me before now? I want to make sure you’re okay. But very supportive. Didn’t change anything about our relationship or anything. So it was great. I haven’t told a lot of people but, I have that small support group.

Patients’ ability to form new relationships is also transformed by diagnosis. In particular, Lowanda noted that dating is significantly complicated by the risks and stigma of HIV:

You don’t know how to date anymore after this. You want to but then you don’t know how secure it’s gonna be. And when do you want to tell them that you got infected—right at the beginning? Or do you wait till things become serious? Or do you insist on condom? Or like my friends tell me, ‘put it in your mouth and when you are going down on him, just slip it onto him’.

She kept giggling and said, ‘how do [you] even do that?’ Although Lowanda’s tone was light-hearted, these issues have legal repercussions. It is important to note that in Georgia, it is a criminal offense to have sexual relations with someone if you are HIV+ and do not disclose that to the individual even if you use a condom, are on treatment, and have an undetectable viral load (VL).

These stories show that being diagnosed and living with HIV is a profoundly social experience, a social process. The dramatic nature of illness and what is at stake, and the diversity of contexts in which it is experienced—they offer insight into how patients’ individual experiences form the overall narrative. HIV as a profoundly disruptive force that transforms their understanding of both the world and their relationships. Diagnosis is a process of translation; it disrupts existing relationships and makes them reform them. Most of their personal relationships go through some kind of profound transformation—their identities change and therefore their relationships with family, friends, partners, and lovers are changed. In essence, they are negotiating a new kind of identity for themselves that makes sense within their new condition.

Performing Responsibility: Negotiating Patient Identity within a Fractured System

On an early fall day, Lowanda, a fifty-year-old African American woman in a motorized wheelchair, enters the Center. The first order of the day, after the nurse signs her in, is seeing her doctor. Lowanda’s medication is changed in this
visit: ‘She has reduced the pills I take drastically. I need to remember to pick them up from the pharmacy downstairs – they are kind of slow here,’ smiling, she pretends to whisper the last part of her sentence to me. After the doctor, the head nurse sends Lowanda to attend a long term chronic care education session on the Patio Level. I wait in the examination room for her to return.

The majority of HIV patients I interviewed were African American, uninsured and on welfare, most suffering from drug addiction and mental health problems, of different sexual orientations and genders. Therefore, they fall within many intersecting stereotypes of stigmatized identities regarding normative standards about ideal or deserving subjects. For example, there is an expectation that the uninsured come from poverty, which intersects with the assumption that they do not work. In fact, most Georgians living in poverty work full time at jobs that pay only minimum wage: they are working poor. There is also an assumption that poverty is synonymous with race – which, in turn, is associated with laziness, drug-addiction, welfare, crime, sexual and familial irresponsibility, and similar. This was reflected in the way my respondents tried to disassociate themselves from being identified as ‘poor on welfare’, despite using every safety net benefit available to citizens living in poverty. During one search ride, when we went out to look for a young homeless girl, Ossie, an outreach worker, described the situation like this:

All their problems are the problems society looks down upon and they are blamed for it – race, poverty, single mothers, drugs, prostitution – these people have so many stigmas attached to their lives that at the end of the day, HIV is just another thing they have to deal with – it means nothing to them. With adherence and multi-resistant virus issues – this becomes a big problem for the Center.

As Chapter 3 discusses, providers at the Center call this a ‘double or triple whammy’, and consider it as important to incorporate into care as treatment for the virus itself. However, there are others – including, significantly, the conservative lawmakers who control Georgia policy – who take the opposite position on these intersecting stigmas. They hold actual patients to an idealized notion of a ‘perfect patient’: a blameless victim, who bears no responsibility for their infection or for prior moral infractions that might compromise their innocence or credibility as people who deserve treatment.
Very few patients can live up to this ideal; Ryan White, the white teenaged haemophiliac boy infected by his medical treatments comes perhaps closest of anyone. Patients at the Ponce Center, who have to contend with the inherent stigma of their other identities, as well as their personal health or criminal histories, struggle to live up to this impossible standard.

However, to some degree, patients cannot escape the implications of the ideal subject or an identity worthy of consideration. Goffman’s theory of identity (1956) is a significant concept to understand this. In his classic work ‘The presentation of the self in everyday life’ he identifies the three aspects of identity, what you know about yourself, what others know about you and what’s essentially requires of you. Goffman’s work suggests that best approach to understand human action is to see people as actors on a ‘social stage’, actively creating an image of themselves to influence the intended audience (and, ultimately themselves in terms of their own impression of who they are). Enough of the people in power and the policies they enact subscribe to this illusion – as do the ordinary citizens who comprise patients’ networks of family and friends – that it became a necessary part of how my informants negotiate and perform their embodiment of a patient identity. In other words, in order to access care, uninsured patients must ‘perform’ as patients who are ‘deserving’ of citizen benefits. One of the ways they engage with the impossible standard is by substituting the concept of ‘responsibility’ for the unattainable perfection of an innocent victim. If they cannot be perfect and blameless and free of identity-based stigma, then they can present themselves as responsible and hardworking and deserving – to me, to their doctors, to their families and, most importantly, to themselves. Even (or perhaps especially) those patients whose stories had less than ideal beginnings considered it important to emphasise the fact that they were now taking responsibility for their lives and treatment. As Lisa told me,

I’m almost a year clean (of drugs) now...I like coming here to this hospital ‘cause they give me a lot of encouragement and I take care— I’m taking my medicine like I’m supposed to. I come to my doctor like I’m supposed to. Things that I didn’t do, I do now.

Of all the patients I interviewed, Lowanda most exemplified the standards of an ‘ideal’ subject, even by Conservative definitions. The first of these standards is
how a patient contracted the disease; this is both the beginning of their experience as a person living with HIV/AIDS and determines where they fall on the spectrum of this new identity. Lowanda is certainly what Conservatives consider an ‘innocent victim’ and therefore a person ‘deserving’ of treatment. She met her husband in college, married him shortly before he joined the U.S. Navy, and became a trailing military spouse. Lowanda blamed her husband’s family for encouraging risky sexual behaviour. Her mother-in-law, especially, allowed her four sons to use her bedroom for sexual activities after family parties: ‘one would go in with a girl and then the second will go in with a girl – sometimes two of them will go together with one girl, it was crazy. Who allows that in their own home?’ He was also sleeping with a sixteen-year-old boy in his mother’s street who died of AIDS. He knew he had infected her but told his family that she gave it to him, and claimed their children were not his. Despite this, she was a faithful wife; she even wanted to stay with him so they could help each other out.

This was a common experience among my informants. Simone told me a man she had been seeing ‘called me and told me that he got tested and was positive. So he suggested I got tested too.’ She later learned that he had been infecting women on purpose. ‘He was on the news. I had been celibate for a year before we met. It was about a month and a half before he and I actually slept together and I saw him put on a condom. So, I am just going to safely assume that at some point he took it off.’ She was ‘devastated’ to learn he had infected her on purpose because she was not even looking for anyone when she met him. He swept her off her feet, constantly telling her how much he cared about her. She wasn’t expecting deception from him and was totally taken by surprise. She sarcastically said, ‘And I thought, WOW, this is how you show how you care...so you know, I had to deal with that. And I have forgiven him because I had to move on with my life. So I got past that.’

Their emphasis on fidelity – and, in Lowanda’s case, loyalty to the man who infected her – is an important way patients assert their ‘ideal’ nature, and their right to care. Even patients with slightly less straightforward circumstances do this. For example, Stevie, the African American youth educator, preferred to assume his infection was the result of a tattoo than of his bisexuality and active
sex life – thus disassociating himself from the stigma of promiscuity associated with both bisexuals and HIV-positive individuals.

Lowanda comes from what conservatives would deem a ‘decent’ family background – which allows her to disassociate herself from assumptions about people of colour, broken homes, and criminality. Her father was a pastor in a small town, so as a child she was kept very close to the church, and her upbringing was centred on God and a middle-class work ethic, and the idea that parents will set certain rules that children were not supposed to question. Even after moving to the city, she goes to church and encourages her children to have a personal relationship with God. She is also a devoted mother; fiercely protective of her children, sometimes to the point that her neighbours call her ‘a mean person on the block. They say I don’t let my child come out to play, but it’s not true’. Her policy is that her daughter ‘can only go where I can see her’, and must come inside ‘when the moon comes out’ around 10 pm. This does not precisely combat the racial stereotypes about absent black fathers and overworked mothers, but it does emphasise her loyalty and her devotion to meeting familial responsibilities. Simone, likewise, justified her use of welfare her devotion to her children: ‘I didn’t ask for any financial assistance, just the food because I have kids. So I wanted to make sure I am able to feed my kids, and then now having the illness, making sure that I can still eat healthy and keep myself going’.

Lowanda also has college education and work history. She graduated in apparel design from Illinois University, did bridal showers and prom dresses and worked for a big cleaners’ company. She also designed theatre costumes in Washington DC, and made flags and uniforms for the army. This enables her to exemplify and present herself as an ideal citizen and a responsible patient; a hardworking Good Samaritan who ‘gives back to her community’ and doesn’t complain. She may have had to rely on others for support sometimes, but she describes herself as someone who never thought about what she didn’t have, and did what had to be done so her kids could eat and go to school. And when she could, she always ‘paid her dues’ and returned the favour. Referring to herself in the third person, she says,
Lowanda is the one that’s always trying to save everybody else. I’ve taken in a lot of people in who were trying to pull up themselves, trying to go back to school and trying to get a job and just do something positive with their lives vs just being out there and doing nothing.

Lowanda’s narrative might appear to contrast with many of my other informants, but in fact they all had definite opinions about ‘giving back’ and ‘taking responsibility’, and the immorality of welfare, regardless of their financial circumstances. For example, although Lisa freely admitted to me that when she was first diagnosed, ‘I was on drugs. I didn’t care. I didn’t work. I didn’t do nothing. I didn’t get no income no kinda income. But I got my disability and I got my house, my apartment…and I’m getting my food stamps and things like that’ she had only contempt for government assistance or the people who relied on it. She had no idea that her Medicaid, food stamps, disability payments, or housing assistance were welfare, telling me ‘I’m not on welfare and I don’t think that people should get on welfare.’ Later in the interview, she softened this judgement:

I advise people to not be so...dependent on it. Because it’s just laziness...Some people need [welfare]. A lot of people don’t. You know ‘cause a lotta people use it, use the system up and make it bad for the people who already do—because they don’t want to go out and be dependent. They don’t want to go out and get it, they’re dependent on free money.

Simone said, similarly,

At any point someone can be placed in a situation not of their own will, where they may need the help. I do not like, um, individuals who use that, who abuse it, rather. Um, because there are people who really need it. For example, elderly people who may not be able to work and are dealing with health issues, may not have family...So I don’t have a problem with [welfare] from the perspective of it being available. I just have a problem with how some people abuse it.

She then digresses to other welfare services, such as food stamps:

Especially those individuals who are dealing with illnesses, if you need the assistance to get the food you need to stay healthy, then of course, do that. I don’t have a problem with them either. Because, again, it can be a struggle especially if you don’t know about these service[s] and you’re trying to pay for medicines. For example, an HIV patent medicine can be expensive if you don’t have any assistance to get them. So if those types of government resources can assist you, then I say, use them. But use them wisely. At the point that you’re able to handle things on your own, you know, make them available for someone else who may need them. Kinda like paying it forward, you know? Allow someone else to take advantage of those resources.
That last point is particularly important. Both Simone and Lisa are already framing not relying on welfare as a positive moral action – but the last quote reframes welfare independence as not only positive in the sense that it emphasises ‘good’ American values like hard work and self-sufficiency (see Chapter 1), but as a social imperative. As Simone put it, ‘Me making the money available [by giving up government support when employed] will open the door for someone else to be able to use it’. It is perhaps telling that both Simone and Lisa use words like ‘encourage’ or ‘advise’ when talking about pressuring others not to rely on welfare; that they should, as Simone said use welfare ‘as a stepping stone, as a tool to help you get back on track. Not to live off of it forever’.

Interestingly, Lowanda was the only one of my respondents who did not denigrate welfare at any point, or place caveats on the morality of its use. She said, ‘I am thankful that the help was there when I needed it; I happily took it. It allows me to focus on myself and my kids, which I need the most right now.’ Unlike Lisa and Simone, Lowanda is comfortable with being on welfare; she has no trouble understanding herself as an ideal citizen who has ‘earned the right to be taken care of respectfully’. She is confident that she did her part, and is ‘at a point where I cannot save the world anymore and it’s too much for me now so...I’m just trying to find out where I belong, sort of what it is that I’m supposed to be doing and that I need to continue to do something positive at all times.’ Historically, poor black people in the South have been taught to feel ashamed of needing welfare, whereas Lowanda’s attitude resembles that of middle class white people who understand they have paid into the system and now they have a right to rely on it until they are back on their feet. Simone has some of that understanding: she says I only take it when I need it and I always drop it when I get back on a job – but she still feels immoral for relying on it.

However responsible Lowanda or my other informants might be – and however much they may successfully disassociate themselves from the stigma of their positive status and other marginalised identities – they still fail to live up to Conservative notions of an ‘ideal citizen’ and ‘deserving’ patient in one key way: they are black. They are ignored or disrespected by white privileged men in power who set the laws, who listen to (or disregard their constituents. For
example, advocates like Jacque and Jeff have an annual ritual where they take patients who represent treatment ‘success stories’, particular communities or groups, and/or are advocates, to State or Federal lawmakers’ offices for lobbying. On one such trip, a group of heterosexual African American women representing the black community was visiting a Senator’s office in Washington DC with Jacque. The senator commented on having no sympathy for people who ‘brought it onto themselves’ – the implication being that they had contracted HIV through adulterous behaviour, and were not deserving of help. He refused to shake their hands or look at them at all during the meeting. By contrast, during another meeting where Jeff was accompanying a mixed group, a white heterosexual HIV positive woman – one of Jeff’s colleague who was HIV-positive herself – jumped in to explain life with HIV in a meeting with the Senator. She received a considerably more positive and thoughtful hearing than the black men and women in her group who had been speaking before.

White women’s voices advocating for treatment are also more welcome at Republican Conventions; Mary Fisher, a rich Republican woman from a strong political family, spoke at the 1992 RNC. She worked in the Ford administration herself and was infected by her unfaithful husband. All patients share extreme stigma and exclusion, but their stories are set apart by their race, which dictates how their experiences end or what they lead to. Similarly, Ryan White’s case was ideal for national attention because he was a young, white, blameless ‘victim’, and his mother was fighting for in the basic citizen’s right of attending school, which set in motion the laws that protect people living with HIV to this day. All of these white women and ‘innocent victims’ compel some sympathy and material resources from powerful, victim-blaming politicians, and divert them towards people living with HIV. This process of self-articulation is one that patients use, not only to convince case managers and doctors that they have a right to access care, but as individuals who are equally inculcated in normative neoliberal narratives, to justify their need for care to themselves as this section demonstrates – the most important relationship they have to rebuild and take back the control of how people and social institutions see them.
Dressed in old white collared shirt and black trousers, Quincy came to the Ponce Center through SisterLove Inc. He had recently relocated to Atlanta from Birmingham, Alabama, and his small jazz music group played at different events in the city. Stephanie, a counsellor from SisterLove, was accompanying him. She had arranged for him a next-day appointment with the doctor; normally this took three weeks, but the Ponce Center accommodated him because he was very sick and nowhere else would take him. He had a health insurance plan for which he was paying $140 every month, but it was a pre-Obamacare ‘junk’ insurance policy that was abolished by the ACA for failing to meet a basic standard of care. At other clinics, Quincy had encountered problems in getting specific care for HIV and related complications for months resulting in dropping his CD4 count to 17, a level at which almost any opportunistic infection can invade the body and kill. ‘My cold is not a common cold,’ he said.

CD4 count and viral load, two medical terms, were additional markers of identity and performance that located patients within the network of policy – who is and is not in need of the treatment. CD4 count – the chief measure of the immune system for HIV-positive people seemed the key to this claim. 200, the point below which doctors in the U.S. used to dole out another diagnosis: AIDS (they now prefer calling it ‘late-stage HIV infection now’). Vince said, ‘I think it is a bit hard to say how they understand the meaning of the CD4 count differently from how we explain it. We try to make it as straightforward and simple as possible’. For doctors, the CD4-related numbers are informational diagnostic criteria: ‘For providers, the VL and CD4 response is how we measure success with therapy - suppressing virus replication and improvement in the immune system respectively,’ Vince continued. Patients have a similar understanding, but they describe it in personal terms: A high CD4 count is the experience of really sick – it means this is how awful I feel – worry about what my prognosis is – what I need to do- what I need to improve in order to die, or wish, I was dead.
The significance of CD4 was universal: doctors, nurses, patients, managers, navigators all mentioned CD4, and this number was central to the experience of being ill with HIV/AIDS. At the Ponce Center, CD4 count had relevance beyond the actual experience of being sick or a diagnostic number: it affected the varieties of funding the providers could access for their patients, or when a patient became eligible for from different programs, different funding streams. On a more abstract policy level, CD4 count is how patients are located and categorized within the government assemblage. Wendy, the Ponce Center Director, told me that ‘200 is when a patient must go on a treatment, though 500 is the new recommendation and we are trying to get that implemented’. Lisa’s experience illustrates the importance of CD4 to a patient’s location within health assemblage. She confided ‘my numbers (CD4 count and viral load) are going up, and I’m doing better now. But I might lose my disability benefits if they reach undetectable level’. She wanted to ask her doctor to sign the disability forms in any case, as a favour to her. The doctors had already told me that this is a consistent dilemma for them: many patients ask for such favours, which they morally cannot oblige. Patients themselves face a dilemma: take medicines and be healthy – or don’t take medicines, remain sick, and receive disability benefits. The Center also recognises that HIV-positive people in low-income jobs cannot afford to pay for their medical care, which prevents them from taking slightly higher paying jobs that would put them above the poverty line and make them ineligible for even Medicaid unless they claim disability. This reinforces stereotypes about lazy people of colour on welfare. Or, as Lisa put it, if her disability expired, then ‘I can’t afford even this clinic and it’s free’.

The Center explored ways to fill such gaps: for example, Quincy was put on the treatment immediately. His policy did not cover his medication, which cost $3,000-$6,000 a month. He did not qualify for either Ryan White funds or the AIDS Drug Assistance Program (ADAP) because he had ‘some form of insurance’, despite its inadequacy for meeting his medical requirements. It was only in a recent meeting with us at the historic Motherhouse, a Sisterlove headquarter on Abernathy Ave that he learned about his possible ADAP eligibility and new ACA plans which covered HIV as a pre-existing condition. He
was interested in exploring the health plans offered by the new ACA marketplace online. The health navigators at the Ponce Center advised him to drop his old insurance and use the Federal health exchange to enroll in a comprehensive plan with subsides that would make treatment affordable. After overcoming the initial challenges of website glitches that marked the first enrollment period, he was able to buy a new marketplace plan with a $50 tax rebate. His new ‘Bronze plan’ cost $190; $50 more than he was paying before, but it covered all clinic visits, hospital stays and most medication after paying $2000 deductibles (out of pocket expenses after which the insurance starts paying your medical expenses). While the staff helped him to enrol online, he was connected to the Patients’ Assistance Program and received his medication for the next three months from one of the pharmaceutical companies participating in the Center’s programs – after which his coverage from the ACA plan started. He said that the expense was ‘challenging but doable.’ Quincy was grateful that the Center ensured that his treatment was not hindered by ‘paper work’; he was able to see a doctor, get medication, and sign up for a new plan within a week’s time at the Ponce Center, despite the fact that his insurance covered nothing.

I did not meet many patients like Quincy at the Center who were seeking guidance to learn about newly available health insurance opportunity through the ACA. Only about 3% of the patients at the Center have any kind of health insurance. Some are undocumented immigrants who have no way of accessing either private or employer based health insurance or government provided benefits for the poor. Patients don’t know what different policies are called. Many of my informants from the Ponce Center could not believe that they did not have health insurance – they insisted, ‘I have Ryan White and that IS my health insurance’. For example, Keeley said that all she knew about Obamacare was that it was a new policy that will provide insurance to a lot of people.

Um, just as far as…it just being available. That’s all. And I really wasn’t inquisitive about it because I am in a position now where my health care has been taken care of. So it doesn’t really, really concern me at the moment. If it was something that I had to check into, I would, if I didn’t have any, um, insurance. Or being able to see a health care provider.
This ignorance about where Obamacare and Ryan White exist within the policy structure of the safety net is part of why my informants could be so self-righteous about welfare. They truly believed that they already had health insurance and that everything they needed for their care was already entirely covered by it.

However, once health insurance started becoming available, it began to fill different gaps in treatment and funding. For example, a young man I met outside the Ponce Center whom I will call Jonnie. He discussed his life openly with me, from being positive and sick most of the time to getting engaged to his boyfriend and moving to Miami with him. His partner had a violent temper, playboy lifestyle, and a substance abuse problem. Not only did Jonnie suffer physical abuse at his hands, but his partner also got him off of his health insurance – Jonnie was still looking for work in new town, so he was dependent on his partner. No insurance meant no healthcare. Jonnie became very sick, so his partner sent him back to Atlanta with no return ticket. He was almost dead when he went to his father in Alabama who took him to emergency. The ACA allowed his father to put Jonnie on his health insurance, because he was under the age of twenty-six, and it saved Jonnie’s life. He and his father spent months on regular doctor’s visits, treatment, nutrition, and physiotherapy. When he visited me in Atlanta, I took him to the Ponce Center where we got guidance on locating a Ryan White Program HIV Center in Alabama, since he had decided to stay in his hometown.

The Center is a place of cohesion for policy networks as well. Part of their purpose is to ensure that patients are as insulated as possible from the fragmentary nature of the system. Instead, what patients are presented with is a cohesive whole, from experience to policy assemblages: a nurse tells you to see your doctor, explains how to make taking medication easier in terms of remembering or keeping it down, guides you to child care or pharmacy, to Labs, to see your dentist, to volunteers who will help with housing assistance applications, etc. Thus, all of the work that goes into taking this piecemeal fragmented system of government welfare and health policies that the Center staff struggles to bring together into individualised assemblages relevant to the unique situation of each individual patient, is quite invisible to the patients who just see a really cohesive united front (see Chapter 3). Lowanda, for example, needed a
wheelchair and had no idea how to acquire one or how to get government funding; the Center simply put her in touch with the Emory Rehabilitation Center, where she finds resources to get her perfectly customised wheelchair.

In other words, patients at the Center do not interact directly with policies; rather, they interact with people at the Center who interpret and negotiate the policies for them, and then tell them how to benefit from them. Health providers give them checklists, follow-ups, and personal support – providers become the face of policy to patients; the people they know, who mean something to them. As Lisa put it, ‘Kishna, Cathy, Charles... They’re my friends’. The patients get an opportunity to build new relationships – and to replace the relationships with families and friends they may have lost – with people at the Center. Their relationships at the Center help them facilitate Social Services and medication refills. Patient navigators give personal attention and support, helping patients negotiate the logistics of treatment, accompanying them to appointments, and assisting them with struggles related to disclosure, stigma, housing, transportation, childcare, relationships, food, employment, and well-being. Section one presents diagnosis as disruption, a point where people’s lives are wrecked, transformed. The Center is where everything changes with diagnosis, but the experience of the Center carefully shaped so as not to embody disruption for most patients. Instead, the Center disrupts the disruption; it starts helping them piece things together, and becomes a site of cohesion in patients’ lives. The Center connects them with other people like them, helps them overcome feelings of despair and disconnection, advises them on their life situations and families, and how to engage with treatment and the positive transformation and reclamation of agency it can represent.

Patients do a lot of work, but not in the realms of policy. Their ‘hustle’ as few of them termed the articulations they have to make, is in the context of their lived experiences. Their responsibility is to turn up, participate in activities, and take care of themselves. This is more than some of them can manage; one research coordinator told me, when I scheduled my first patient interview, ‘not all HIV patients at the Center can say that – may attend few appointments and then disappear. This is just the reality and nature of their illness experience. They
might turn up or they might not; keep an open mind and be ready to move on’. The relationships at the Center depend on flexibility, on a deeper understanding of patient experience, and constant follow-ups for those who cannot meet these responsibilities alone. At that moment, I understood that the researcher meant significantly more than the medical concept of adherence issues – a concept that, while important from the perspective of treatment success, can seem to hold patients responsible or irresponsible in terms of their own care. What I understood later, as I got more involved in the life at the Center, is more humane and social in nature. Her assertion highlighted the extreme efforts patients must make to learn about their illness, to get up in the morning, attend appointments, or take medications. Because this is not policy work, lawmakers and politicians who allocate resources do not consider it enough effort on part of the patients: as most believe that all that the patients have to do is to adhere to their treatment and it’s all good. Keely, however, said:

This cannot be farther from the truth. I was struggling not only with HIV, but also mental illness, and substance abuse. My initial medication did not suit me. It took me years to develop a relationship with the Center and people here. Nurse Kenda sat me down and repeated every single time I was here how to take my medication: “have it with evening meal, same time every day” etc. etc. She had a story like mine and we bonded. She understood me.

As she explained her experiences, she stressed that when people come here, they are changed from sick and ignorant person to a person who understands that they have hope; that there is treatment. Lisa shared that her family’s reaction was fear, ‘scared! All of them were scared. You know I probably woulda been distanced from my family. They (are) asking all these questions like they scared of me or something.’ She said that she wanted ‘let everybody know that HIV is not as bad as you think it is. You know! When I first heard about my diagnosis, I was like ooh!’ but at the time she didn’t know anything about HIV until she learned about it from one of the Ponce Center related community-based research called Project Hope. Lisa said, ‘when I learned about it I said I’m all scared of y’all healthy people out there than I am of myself. So, I’m alright.’

The Ponce Center changes patients by changing what they know. The Ponce Center takes them in and transforms them into a person who is educated about
their condition, who understands how to actually take control of their well-being, their treatment and of their life. It also educates and transforms their families – Lowanda’s family integrated entirely into the educational process and treatment decisions is really important. Because it means that the Center is taking part in the process of transforming those relationships.

Modern patients who enter treatment early lead lives that would be unrecognizable to PLHIV 20 years ago. Many do just take a pill. What goes unmentioned, however, are the side-effects, the stigma and related conditions that are triggered by the virus or ushered in by it. The Center’s staff believe that developing close relationships between patients and medical providers can be a deciding factor in health decisions. As discussed in Chapter 3, the Transition Center’s intensive, flexible, one-on-one model of care is probably more successful at bringing patients’ viral loads of HIV down than traditional care. Many of my respondents expressed that this place of care, and the relationships they developed here, whether they have been coming here for decades or just starting, were very important. As Lisa said, ‘they may know you better than anybody else.’

Both Lowanda and Keeley are long term patients at the Center. ‘I plan my appointments on the days when Kenda is here’ said Keeley.

I was immediately put on combination therapy when it was very new and I had to take almost 20 pills a day. It was difficult. Side effects were quite bad, regular diarrhoea, a common symptom that emerges soon after infection, irregular vomiting, and periods of not being able to get out of bed and ‘descending into feelings of worthlessness.’

Lowanda strongly believes the Center resurrected her from her death bed. Her current life on ARTs is unrecognizable from twenty years ago, when she started with AZT:

Zidovudine is the proper name for it, and...it has a lot of side effects. You are off balance, falling over, can’t climb stairs or cross the road – takes you several light[s] to get to the end of the road, and you hope that no car runs you down until you reach the end of the crossing. So AZT breaks your body down. It does help with AIDS, but it was also harming a lot of people, a lot were dying from it. So I ended up in the hospital and ended up in a wheelchair. I was like what is this? I didn’t know how to use it (the wheelchair) initially.
The Ponce Center and its extended network of services changed how she managed everyday problems, and immensely impacted her quality of life for the better. Providers at the Ponce Center try to teach patients not only about their disease but also about all of the community and governmental resources available to help them manage their illness and live their lives. For example, Lowanda has been in the wheelchair since 1995. Her first chair was a compact chair for the house. She seemed much more pleased with the current custom model: ‘Folks at Emory Hospital weigh you, measure you, and find out your movement requirements, and then build a custom chair for you. They built it with the thought for what was best for me.’ She likes to be on the couch to receive guests, so hers has an additional part that extends the chair into a reclining chair. It is hard for her to move from the chair to bed and back frequently. So during the day she can also sleep in her chair and has a head rest to protect her while moving around. The chair also has pockets and zippers so she can take her belongings with her. She still falls back and often has muscle spasms, migraines and seizures, so she wears a seat belt on her chair so she doesn’t fall out of it. She is on fewer pills and her body has a better tolerance for her new treatment. Coherent plan helps them believe that they are not on ‘government handouts’ but are doing the best they can do given their situation. They get absorbed in the Ponce centre – they appreciate these services, and like mentioned in the previous section, they believe it’s their responsibility to rely on themselves more than outside help.

Many patients shared that when they see someone in their situation they take it upon themselves to say, ‘do you know you can go to the Ponce Center for help?’ That aspect of patient integration into the social and political network of this policy apparatus of the Ponce Center in Atlanta and nationally is important. Lisa compared other clinics and resources with the Ponce Center,

You know, it’s hard to go in and say hi, my name is ‘so and so’ and I am HIV positive, you know. So I think that was really the biggest thing. But once I came here and found out about the Ponce Center and Grady, it made me a lot more comfortable, I would say, about saying hey, here’s what’s going on with me. I need some help with this, and you know, these are some of the resources, so I can actually reach out. Because here, they made it seem... like it was nothing. You know? It was—I could—I am a normally person. And I am just getting healthy. Other places, they make you feel not so good. So... Yeah.
She used to go to another collaborating organization, AID Atlanta, which she found ‘a bit slower’. She was so impressed with the resources at the Ponce Center, I’ve definitely started to let more people know about resources at the Ponce Center and that Grady has in general that are specialized for HIV patient. Because, you know, it’s needed. I see so many people that are not dealing with their illness but other social issues like, you know, homelessness. Even if they have a residence then they’re kinda struggling with being able to buy food, pay utilities and those type of things. So to have to deal with your daily life, and then also to have to worry about how you’re going to get health care—that’s a lot - here’s a place that can really help you with a variety of things that’s going out make life easier for you.

Like Quincy and Redbug, other patients were aware that the Center, treated them differently than other places. The Ryan White HIV/AIDS Program is a linchpin in their lives, without which many feel their HIV care would be compromised. Most of those profiled had been uninsured for years before the ACA and were only able to get their HIV care through Ryan White, including accessing medications through its AIDS Drug Assistance Program. Today, for those in states that have not expanded Medicaid, Ryan White remains their primary vehicle for accessing HIV care and treatment. Ryan White also continues to support many who gained new coverage under the ACA, including by providing premium support to make insurance more affordable for those in private marketplace plans, through the provision of wrap-around services such as case management, and by offering assistance during gaps in coverage. Almost all talked about the critical role Ryan White plays in their HIV care.

Not many have a relatively straight a path to health insurance like Quincy. I only encountered two patients, both men, who had or were interested in buying health insurance. These two men also barely reached the lower eligibility limit for government subsidies via the ACA. Quincy, like many of the patients I spoke to, didn’t want to be on welfare and felt he was in a position to pay for his care as much as he was able to. He wanted to take charge of his health and responsibility for his payments. He told me ‘God has been good to me, I survived and I’m blessed. I need to help myself. How do I sign up?’ From the patient perspective, one of the most important things that the Ponce Center does is teach them how to act on what they are already trying to do, how to re-assert control and agency over their own lives and illness.
Simone was diagnosed in 2005. Until now, she had not been involved in any type of actual treatment. ‘I had visited doctors off and on, you know, because as I am working I’ve had insurance, so I would go and they would check my numbers, and they would say oh, as long as they’re two hundred or better, then you’re okay.’ she has never been on a treatment. ‘I would just eat right, exercise. The same things that I would normally do.’ She was only hospitalized once with Hepatitis B and dehydration. She lost work and the health insurance that came with it three years ago, and her condition deteriorated after that. She said,

I think it was mostly because I did not know the options that were there for HIV specialized care, for example, the Ponce Center, and the resources that Grady has. Being positive, it can be tough...to...let people know. So that you can get the information that you need. I think that was one of the biggest things that when I came here, I felt at ease. Everything was explained well to me. It is important to let people know that these resources are available specifically for individuals who—with HIV. I think that’s one the biggest things for me, just getting the information out there.

Most of the patients at the Center that I interviewed did not know or cared about Affordable Care Act/ ‘Obamacare’. Even outreach workers believed it did not apply to ‘our patient population,’ essentially sharing in their patient’s confusion. One because of poverty level and secondly because this population has never been part of the regular health insurance market. I thought it was astonishing that people who needed coverage the most did not know about how the landscape was changing for them.

Meanwhile, these women don’t live out their days as a death sentence. Lisa said she feels good. She is taking her medications and ‘living her life in the moment.’ Lowanda tells me she went to the session to ask about dating and sex, which she considers a ‘big issue: people want to know what they can do, but doctors don’t talk about it unless you specifically ask’. The group is part of the Education Department. Patients who have been diagnosed for a long time attend, but any patient is welcome to attend that is enrolled at IDP. The group is comprised of a core group of patients who have been coming here for years. The schedule is set for the 1st and 3rd Thursday of each month. They do activities like cookouts, zoo visits, etc. a case manager co-facilitates the meetings and acts as a Liaison from the Center. She complained that the support group leaders provided no
'satisfactory answers', only 'very vague talk', that didn’t help her deal with the fact that ‘most people with AIDS lose their sex drive’. She knew that ‘you can hold hands and you can talk’, but did not consider this sufficient: ‘intimacy is important for relationships HIV people have...they want that part of the relationship to be safe and happy. After all, life goes on.’

**Conclusion**

Identity is a complex phenomenon, shaped by our experiences of social interactions: it is relational and translational – identity is formed in relation to others. Part of the symbolic work of the Ponce Center is to translate the diseased body of these individuals into a healing one through a process that is as much social and administrative as medical and biological. This chapter explored the social interactions through which patient identities are challenged, maintained, negotiated and performed, for self-presentation and for role-making. The patients represented here are relatively similar in terms of categories. More importantly, they all share the need for constant negotiation in their everyday lives; they must negotiate and perform aspects of the articulations – they articulate themselves as patients, they articulate their illnesses, their care, their blackness, or sexuality, and their location within policy, among other things. Furthermore, these patients are all in a constant process of becoming – negotiating what it means to be a patient. And this process of becoming and negotiating is also very fragile. Eligibility can change at any moment because funding for treatment is provisional, based on whether a patient’s CD4 count has reached undetectable levels, whether the Center has run out of grant money, or the Ryan White reauthorization is halted by Congress.

These patient negotiations and performances are ‘not just meaning-making, but meaning-making in the interest of claims making’ (Kingfisher 2013: 13; see also Shore & Wright 2011) Furthermore, coping with an illness is about more than managing a physical disease or treating the symptoms of that disease; it is about managing the social relations and negotiating the context, assumptions, meanings, experiences and actions that surround that specific illness (Nichter & Lock 2002). Living with an illness like HIV is also about the social, political, and economic conditions that determine the presence, distribution, and
transmission of the disease within a local area, ‘as well as the priorities and
titlement to resources people can claim in a community, household, or family
concerning...treatment’ (Dilger 2010: 7; see also Kleinman 1980, 1995; Baer,
Singer & Susser 1997; Watkins-Hayes 2008). In interaction with these policies
and associated stereotypes, patients must produce their own meanings and
articulations – hence, systems of meaning and practice are actively disarticulated
and rearticulated in new ways by different actors (Kingfisher 2013: 14).

Despite difficult circumstances, the Center has for years enabled patients to
balance their needs within the fragmented health care system. However, the
reality beyond the boundaries of the Center is that the fragmentation of the
healthcare system has not gone away – rather, the fragments themselves are
changing. Thus, there is disturbance and resistance; most prominently, the
perception that the Ryan White Program is their health insurance (rather than
a source of Federal funding), so patients respond to being asked to buy health
insurance as having to contribute money they do not have. In addition, the ACA
is perceived as a welfare program because it empowers the government to provide
subsidies to low- and middle-income people for purchasing health insurance, or
pays through the Medicaid program. The assertion ‘I am not that poor’ reflects
notions of personal responsibility and stigma that are attached to entitlements,
as well as a desire to present themselves in a positive light – disassociated from
any negative stereotypes about race, sexuality, gender, or illness that might
otherwise attach to them. Third, some patients view the ACA as an opportunity
to assert agency over their health and treatment. Thus, patients with a certain
income level, who were out of the market, did not mind enrolling in Obamacare.

Finally, the ACA is disrupting the equilibrium of the Center and its services.
Thus, the Center is beginning to take a new form in order to respond to and
enact the provisions of this new policy. Whether the result will be better, worse,
or equivalent remains to be seen. Thus, articulations in actual policy-related
terms and provisions as well as the terms in which people talk about the ACA
point at the reshaping or changing assemblage discussed in the next chapter.
Chapter 5: Policy in Georgia: Window onto the Modern State

Ideas or ideologies that create and sustain policies are not static or monolithic: a key quality of policies is that once created, they often migrate into new contexts and settings, and acquire a life of their own with consequences beyond the original intentions (Shore & Wright 2011: 3).

During my 2012-14 fieldwork, my respondents among Atlanta’s health service, advocacy, and patient community were hopeful that the Governor would eventually allow the expansion, though perhaps not until after his re-election campaign. They expected ‘compassion’ because they believed they had kept him well informed about all the Georgians who lacked access to healthcare. Jacque was a storyteller. In our bi-weekly update meetings she would relate several stories from previous years about how health, and especially HIV, had ‘never been’ an apolitical issue; ‘It’s a political disease…. From the very beginning of the epidemic…the “AIDS world” has counted onto our elected officials to help us address the urgent needs of the clients we are serving’. She was speaking of the ‘volatile’ nature of the healthcare community’s’ hold on the resources and the crises they must routinely manage to continue operating, particularly ‘all these years we had spent talking to Congress members to bring the disparate pieces together to make it all work for the ones who need it the most’.

On 16 November, 2012, Governor Nathan Deal of Georgia officially informed the Obama Whitehouse that his state was not interested in establishing its own Health Insurance Marketplace; that is, a state website where residents could compare insurance plans and purchase them using federal tax credits. Deal (2012) said,

I remain committed to common sense health care solutions that empower consumers to take responsibility for their own health, motivate the private sector and drive efficiencies for consumers, employers and governments alike. I continue to hope that we might finally engage in a serious conversation about restoring meaningful flexibility to states around health care programs.

Governor Deal also publicly maintained that he ‘would not have any intention’ of expanding Georgia’s Medicaid Program, a crucial element of the Affordable Care Act (ACA) that channelled additional Federal money into the state. He decided this despite the fact that the American South has the highest poverty and uninsured rates in the country, and Georgia, with 22.5% of its population
uninsured (roughly 650,000 people), is not far behind Texas at 24%, with the highest rate of uninsured citizens in America.

As an ethnography of policy, this thesis seeks not ‘just to focus a new lens on particular fields of policy but, in doing so, to reveal the larger processes of governance, power and social change that are shaping the world today’ (Shore & Wright 2011: 1). The ‘social life of policy’ explored in this chapter expands out from the physical bounds of the Ponce Centre and into the broader world of health reform and its assemblages; interacting and observing the influence of public events, politics, elections, and practical considerations that lawmakers make about how particular policies will affect their own political capital and that of their party. This chapter is about how different actors translate and enact their understandings of the ACA and the right to health in one place. It is about what the policy does and how it ‘lives’ in the worlds of politicians, activists, patients, and healthcare providers connecting the operations of the Center to the Georgia legislature. The chapter examines the ACA as a space, as the site of ethnographic inquiry. It follows the policy’s implementation over time, examines its translation from one context to another (e.g., from Federal bill to state policy to healthcare assemblage component, or from political to media battles), and as different actors contest its articulations. This chapter explores the ‘social life’ of the Affordable Care Act (ACA) as a vehicle for social change, as it took on a life of its own with consequences that went beyond its original intentions. This ‘domino effect’ is apparent in my observations of the articulations, negotiations, and performances present in health reform debates; in compromises on the ACA; and in appropriations and enactment of the policy.

This chapter investigates how ‘the particular systems of meanings and practices, seemingly sedimented, can be actively disarticulated and re-articulated in new ways (Kingfisher 2013: 14). The chapter presents two primary domains where the process of translation occurs, and three broad categories of actors. First is the state government, which is mostly Republican; second, the healthcare advocates, which includes HIV communities; third is the Federal government, which was mostly Democratic. The ideologies of these disparate groups come together through this policy in the work of
implementation on the ground. The Republican government is trying to advance two ‘meanings’ or ‘translations’, founded on a view of healthcare framed mostly in terms of cost – so these narratives are dominated by numbers and budget-related actions. However, Democrats and advocates in the health community frame healthcare as a social justice issue; a social contract that the government has with its citizens for the provisions of the basic human rights (see Chapter 2). Each group is trying to produce a narrative that will convince the public of their meaning – and the work they do to achieve that is the focus of this chapter. It is significant that the assemblage they produce through this symbolic contestation is not a finished product. It must be made and re-made constantly through a mutually constitutive and enunciative articulation process that enables this policy assemblage, and the particular systems of meanings and practices it represents, to be actively disarticulated and re-articulated in new ways. That process of policy articulation, and how it maintains the assemblage in a manner that provides care for HIV patients, is the focus of this chapter.

Drawing on Yanow (2013: 14), I start with the description and analysis of how legislation is the interpretation enactment of prior debate and idea history; that implementation is at once the interpretation of policy “texts” and the creation of a “text” (in the form of agency actors’ enacted interpretations of the policy texts) which itself will be interpreted, together with legislative texts, by clients, community members, policy-relevant publics near and far, evaluators, legislators, policy analysts, and potentially many others.

This chapter is based on ethnographic interviews, ‘shadowing’ key informants, and participant observation at the Ponce Center and the Georgia Capitol. It moves between various domains of policy to bring attention to the processes and ‘sub-processes’ of translation, re-translation, and articulation to illustrate ‘how organizations manage to achieve the degree of articulation they do, and what their members must do to maintain it’ (Strauss 1988: 179; Freeman 2009). Observations about the communication of policy meanings as one form of interpretive analysis are extended in this chapter. It takes a view of the policy process that brings policy communications (oral, visual, and textual) and dramatism together to observe the various actors acting in and enacting the play of societal meanings, communicating them to through actions that validate or undercut various values, beliefs and feelings.
Section one follows the translation of the ACA from the Federal level to the states. It is a critical analysis of ACA implementation over time, particularly how the policy was contested and articulated in Georgia, and the problems anticipated or caused by those contested articulations. It is an account of ACA politics in Georgia, and of the various ways Georgia ‘translates’ Federal Medicaid politics, particularly with regard to the Ponce Center. Section two is about the work of ‘doing assemblage’ that the Center and its allies engaged in through their efforts to shape and maintain a stable healthcare assemblage for patients. It considers healthcare professionals, advocacy groups, and related industries, and their responses to and efforts to implement or influence the ACA on the ground in Georgia. This is an account of the struggle in the Georgian state Capitol, particularly with regard to how budgeting intersects with social issues, advocacy, and policy priorities. Section three examines the re-translation of the ACA back to the Federal level after Republican governors like Nathan Deal contested specific components of the law. It discusses the Federal shutdown of 2014, which was an effort to delay implementation of the Federal online exchange website in response to local pressure placed on politicians who represented conservative states, and it considers the shift in narratives surrounding both the ACA policy and other related policies that were integral to my informants, such as Ryan White.

**Appropriating the ACA: Competing Narratives of Health Policy Reform & Implementation in Georgia**

The passage of law is one moment in a process of appropriation and contestation when a political coalition succeeds in silencing others, making their version authoritative and embedding it in the precepts and procedures of the state. But the dominant version can be immediately contested as it is translated into concrete situations (Shore & Wright 2011: 13).

Policies are not simply external, generalized or constraining forces, nor are they confined to texts. Rather they are ‘productive, performative, and continually contested’ (Shore & Wright 2011: 3). As policy moves into new political and social spaces, so does the political narrative about why and where other actors must interact with it. Each move re-translates policy from one genre to another, opening up space for further contestation. When the ACA health
reform policy passed, the President and Democratic members of Congress envisioned that it would work in a certain way: it was supposed to cover 20 million Americans, expand Medicaid in each state, and establish online marketplace exchanges in every state. It was also intended to provide subsidies to people at certain income levels, so that everyone could afford to fulfil the ‘individual mandate’, which required that every American adult purchase health insurance. The story told in this chapter is, in part, how that vision failed to be realised. The discrete yet interconnected nature of what Jacque referred to as the ‘AIDS world’ provides a unique opportunity to explore the ACA policy through an anthropological lens, as shaping and re-shaping an assemblage made of multiple pieces – or assemblages within assemblage. Significantly, the crisis my informants faced is not the existence of the ACA, nor is it entirely the failure of Medicaid expansion; their problem is grappling with how the ACA – both the ideal ACA and its implementation in their state – fit into the assemblages that enable individualised HIV patient treatment and care.

Congress and the President released the ACA to fifty governors and their legislative bodies, made up of State Senators and Representatives. However, thirty-three of these governors were Republicans with a different vision of how health reform should function. Given that ‘a crucial dimension of policy is...the way it is imagined and such imaginaries can be thought of as moving through time and space’, policies can therefore ‘be studied as ‘contested narratives’ which define the problems of the present in such a way as to either condemn or condone the past, and project only one viable pathway to its resolution’ (Shore & Wright 2011: 3). Governor Deal presents the dominant (and Republican) narrative in Georgia, arguing that the law’s high cost and ‘one-size fits all’ approach is unacceptable for the state. Opposing Governor Deal are Democratic lawmakers, a minority party in the State legislature, along with their supporting constituencies. They note that Georgia has the fifth-highest number of uninsured people of any state in the union, and demand that the Governor allow the state to take part in expanding Medicaid, the Federal health insurance program for the poor, thus providing health coverage to 650,000 low-income Georgians. Their narrative is that this issue is about human suffering and social justice:
‘the kind of society we want as Americans or who we are as Americans’ (Jeff).

It also includes the empirical assertion that if Georgia took the proffered 100% Federal government funding for the first three years of Medicaid expansion and 90% thereafter, the state could receive about $34 billion in Federal funds over 10 years. Governor Deal’s response to this in a media interview was,

We have to understand that Medicaid is an entitlement program. It is federal and state money that goes into it. Depending on the poverty level of the state, the Federal participation varies. But even though the Federal government is offering to pay 100% of the cost for three years, it will decline after that. We estimate that it will cost the state of Georgia billions of dollars over the course of that time even when the initial period will be paid by the federal government. Plus, the fact the being an entitlement program it doesn’t really matter what the state’s budget calls for in terms of Medicaid cost, if it sees that we will be required to pay that extra even though our budget does not contemplate it (O’Hayer 2013).

Tim Franks, the BBC interviewer Deal was speaking to, is from the UK, where single payer has been an institution since 1948. He later shared that he found this debate ‘poisonous’ and ‘phenomenally complicated’ for an outsider, and that he considered the ACA the single most important piece of legislation to emerge from the Obama administration (O’Hayer 2013). The complications of the fragmented American healthcare system are equally baffling to insiders; many health reform activists felt there was a need to educate lawmakers, because comments made by a majority of Atlanta legislators at public town hall meetings showed that both Democrats and Republicans believed Medicaid already covered everyone who makes 100% of the Federal Poverty Level or less.

Jacque forcefully objected: ‘This is not true and it’s misleading! The Medicaid system in Georgia is designed for children, pregnant women, and for select people contending with extreme poverty, illness, or disability – so not everyone living in poverty is eligible in its current form’. She added that even for those who qualify, Medicaid in Georgia only ‘provides the bare minimum required by the law’, in contrast to the more generous funding of states like New York or California. Jeff, a veteran healthcare and AIDS activist, concurred:

Where the real challenges lie moving forward, is that many [legislators] think that the program is already working in the way that expansion would allow it to work. So they are hesitant to throw more money into a system that, they then would argue, creates an incentive for people to not want to take responsibility for themselves.
Thus, the most immediate effect of Governor Deal’s decision to opt out of the Medicaid expansion provisions of the ACA was expanding what is called the ‘Coverage Gap’ for Georgia’s poor. To illustrate, the vast majority of my patient informants from the Ponce Centre fell into the category of ‘working poor’: people who make too much money to qualify for Medicaid (or are otherwise disqualified from receiving pre-ACA Medicaid benefits as single, childless adults), but earn too little to qualify for affordable subsidized health insurance from the exchanges, because the ACA presumes they will be covered under the expanded Medicaid eligibility provisions. Only 4% of Ponce Center patients had some kind of insurance, while the rest depend on the safety net. According to Kaiser (2011, Garfield & Damico 2016) estimates, there are some five million uninsured nationwide who fall into this ‘Coverage Gap’ in states like Georgia that have strict Medicaid eligibility criteria and have refused expansion. Three-quarters of these people are single, childless adults, and 9% of them live in Georgia. As Jacque put it, ‘it’s very difficult sometimes, particularly now when we do have the ACA but we also have the “haves and the have-nots” where Medicaid expansion is concerned. And so, again, in the South we have our own historic issues with the disfranchised’.

In addition to ignorance, many of my informants believed the Governor was not considering these factors ‘because of politics’, as Dr Jim Curran, a leader in AIDS Research and a former Director of the HIV/AIDS Division at the CDC put it. Noting that the South tends to vote Republican on both the state and Federal level, Dr Curran explained that ‘the Republicans hate the Democrats and they hate Obama. So, anything Obama wants to do, they don’t want to do. It has nothing to do with ground reality’. Indeed, he noted that the latest polls suggest that 60% of Georgians want to expand Medicaid. Furthermore, in American politics, the personality of elected officials is often key to the implementation of policy; the American understanding of executive power ensures that one man and the political ideology he represents can make a single decision that deprives thousands of people of care. The circumstances of those political personalities are also important, particularly their election status. My informants frequently quoted the adage ‘A politician’s full-time job is to get re-elected’. Governor Deal
was running for re-election in 2014, and this impacted his willingness to commit to highly controversial issues like healthcare. When asked about her expectations for the future, Jacque said, ‘Who is the in-charge of the state? Some people say next year if the Governor wins the election, maybe after that he will expand Medicaid because it won’t be a political issue for him anymore - it is now. That’s just how it is!’ Jeff, a long-time activist and political operative, told me,

What we were hoping...is that we would make it through this legislative session and once the Governor felt safe that he had secured the Republican nomination for re-election, come this mid-summer we might see the Governor begin to float some proposals of how we would expand Medicaid here in Georgia.

This was the prevailing opinion among advocates and influential healthcare voices I spoke to during 2012-14. Jacque described them all as being in a ‘cautiously hopeful waiting mode’, adding that they were ‘hoping for some compassion from the Governor.’ Dr Curran viewed it as a matter of necessity; voters had to convince the legislature to expand Medicaid, ‘cause the rural hospitals are the ones going broke. The state is facing increased pressure from hospitals to sign up or spend its own money on them, so they can stay open’. Both were confident that they had kept Governor Deal well informed of on-the-ground reality of people in need and were hoping that he would be sympathetic to institutions already strapped for resources.

However, in the spring of 2014, Deal was projected to lose to his challenger. Jason Carter, the Democratic candidate and grandson of Former President Jimmy Carter, was another ‘son of the South.’ In anticipation of his loss, Governor Deal signed several laws in late 2013 and early 2014 that Jeff described as ‘doomsday scenarios’. Democratic State Rep. Pat Gardner, reiterated the Democratic argument at a Chamber of Commerce conference, saying that

Denying the opportunity for Georgia’s adults to take advantage of Federal reimbursement for their care simply shifts the cost to hospital emergency rooms, or state- and county-funded mental health treatment programs, or county jails. Improving the health of our low-wage working families and those living in abject poverty is essential to building a strong workforce, but instead Federal taxes paid by Georgians will be used to pay for hospitals’ and doctors’ services in other states, while our families, hospitals, and doctors continue to struggle to survive.
This is a direct attack on Deal’s Republican narrative that the state must be more fiscally responsible, and is more capable of making the best decisions for its citizens when it is free of Federal interference. Despite hundreds of meetings between majority and minority lawmakers, as well as representatives from community groups and concerned hospitals, the Governor’s decision remained the same. He repeatedly told his constituents that the truth is this has nothing to do with politics and everything to do with fiscal responsibility. In fact, the state of Georgia would have benefited from Medicaid expansion. A study from Georgia State University estimated that expanding the public program would create up to 70,000 new jobs state-wide (Cluster 2013).

The ACA policy allowed states that participated in Medicaid expansion to opt out after the three fully-funded years. Governor Deal (Franks 2013) called this an ‘old gimmick’, asking ‘Have you ever seen somebody given something for free? And then elected officials beginning to take it away from them?’ To refute these arguments, Democrats make several key points. First, Georgians pay Federal taxes every year that return to them in the form of programs and services – so, in fact, expansion is not free, but paid for by taxpayers, including Georgians. Independent experts at the Kaiser Family Foundation (Garfield & Damico 2016, Holahan et al. 2013) say this is a ‘huge pot of money’ that can improve healthcare for the working poor; they estimate that expansion would bring in $34 billion to the State from the Federal government, whereas taxes paid amount to $24 billion. This was the point that my informants were most upset about; Jacque explained, ‘the first three years are essentially free federal funds, which if we don’t claim will just go elsewhere.’ She stressed the need for this money to come back to Georgia, highlighting the already underfunded safety net programs like Medicaid and food stamps that already have strict eligibility criteria and provide only the bare minimum of support required by the federal policies. She pointed at a notice posted all over the centre informing recipients that they were required to attend appointments in November, or their food stamps benefits would be further decreased (Fig. 3.9). The issue was raised at length in Ponce Centre planning council meetings and discussions held by other organizations. The general public was also concerned about Georgians
taxes benefiting other states and not Georgians. Advocates of the ACA, including Democratic candidate Jason Carter, used independent analysis from sources like Kaiser to support their narrative of its economic viability. Carter told a rally,

> It’s incredibly important for us to look at the fact that the Federal government has $9 million of our tax money they keep every day. There’s $30 billion in expansion funds that we’ve paid – it’s our money and Nathan Deal wants Washington to keep it. That doesn’t make sense to anyone, certainly not here — (Bluestein 2014).

The second Democratic argument is that the Governor claimed that if more Georgians enrolled in Medicaid through expansion, the Federal expansion money ‘dries up’ and the state will be left ‘holding the bag’ (Hunt 2014). In fact, this seems to have been a self-fulfilling pronouncement: Since the ACA was passed, many people who were already eligible for Medicaid have enrolled now that coverage is mandated. Thus, Georgia saw a 5.8% increase, or about 98,800 new enrollees, between October 2013 and March 2014 – but, because Governor Deal did not expand Medicaid, the state must bear increased costs from new enrollees while losing 100% of Federal financial support. Dr Curran suggests that Republican arguments like this one

> ...are only good at a very high philosophical level.... Saying we can’t and we don’t trust the government because they might charge us more, so we’re going to turn down the 100% for three years and the 90% after that because we can’t afford the 10% – and we’ll let our hospitals go broke? It’s not rational, it’s all just politics.

However, as a compromise between those Republican arguments and the Federal drive to achieve national universal coverage, the White House allowed twelve Republican governors who requested permission to customize ‘alternative’ Medicaid expansion plans for their states. This is not a change in the ACA itself but in the details of its implementation and regulations; an explicit example of the translation of this debate and the unique policy provisions from the Federal level to the local and back to the Federal. This flexibility in regulation is legal as long as the states comply with the limits of what the actual law says they must do for vulnerable citizens. The secretary of HRSA is responsible for approving applications for such exemptions. The most successful example is Arkansas, where the rate of uninsured dropped from 22.8% to 12% within a year. Their customized expansion, called the ‘private
option’, uses Medicaid dollars to pay private premiums. The poorest citizens remain in traditional Medicaid, while thousands of other newly-eligible low-income people are routed through the state exchange. Conservatives found this acceptable because the state expansion worked through private channels and not a public programme, despite the fact that Medicaid is still paying the bill. It’s significant that the meanings conveyed through these contested narratives manifested, on the one hand, in a difference between the local Georgian advocates’ priorities, which were getting expansion funding for Georgia and refuting the Republican narrative. On the other hand, these meanings manifested in Federal compromise with Republican ideology in an attempt to find common ground, and through that a workable political solution. Governor Deal did not even consider the option of an alternate plan, saying,

Forgive me for being a sceptic, for having a little over 17 years in the US Congress. I know how difficult it is for the Federal government to try to come up with those dollars... they are running deficits every year. And this is a promise by the Federal government; it is not an actuality because it has to be put into Federal budgets every year.

Governor Deal was effectively highlighting the fact that the Federal government cannot guarantee that the funding it wants to provide will be fit into the budget. This is a new and partisan issue; an extremely contentious relationship between the Democratic President, Obama, and the Republican majority in the Legislative branch. Operating under drastically different ideologies (see Chapter 2), Republican lawmakers made the decision to govern through absolute resistance to all policies proposed by the Obama administration. For example, in October 2010, Senate Minority Leader Mitch McConnell (R-KY) famously said, ‘The single most important thing we want to achieve is for President Obama to be a one-term president’ (Kessler 2010). Even before implementation, Republican politicians regularly attempted to discredit the ACA by comparing it to socialist medicine like the NHS. They intentionally evoked images of President Obama as a socialist running ‘death panels’ to determine whether citizens should live or die – a narrative popularised by Republican donors and grassroots activists during the Obama campaign, which they revived during the Congressional process of enacting the law. Former Speaker of the House, Republican Newt Gingrich, said in April 2010 that if Republicans won back control of Congress in
the upcoming election, they should cut any funding for the Affordable Care Act in all appropriations bills; a threat they carried out. Gingrich said Republicans needed to ‘be ready to stand on principle’ even if this led to a government shutdown. President Obama insisted in response that he would not cave in to ‘ideological’ demands (Talev 2013). However, when the government shutdown finally occurred in 2013, it was at great cost to the Republicans’ image (see below); they created a debt ceiling crisis at the cost of $24 billion according to international financial services company, Standard and Poor (Perlberg 2013).

Republican resistance to the ACA itself on financial grounds also seems to have been unfounded; the Congressional Budget Office (Banthin & Masi, 2013, CBO 2012) projected that the law will save an estimated $109 billion over the next decade. Nobel Prize-winning economist Paul Krugman (2013) explains in the New York Times that this may be partly due to the fact that the ACA takes advantage of extant Medicaid cost control measures:

\[
\text{Medicaid is the piece of the US health care system (aside from the VA) that does the best job of controlling costs. It does this by being able to say no. For example, it’s able...to say that it won’t pay for me-too drugs that are far more expensive than equally or almost equally good alternatives. This ability to say no, combined with its size, means that Medicaid covers people far more cheaply than private insurance...}
\]

One way to think about this is that Medicaid is actually the piece of the US system that looks most like European health systems, which cost far less than ours while delivering comparable results. Now, expanded Medicaid is a key part of Obamacare — and so far, despite GOP obstruction, Medicaid enrolments have outpaced insurance through the exchanges. This is often reported as if it were a bad thing — as if Medicaid were somehow a fake solution, as if only purchases of private insurance count. But Medicaid is good, very cost-effective coverage! And rising Medicaid enrolment is, aside from a huge benefit to the previously uninsured, a step toward better cost control in the system as a whole.

Krugman’s editorial debunks many social and economic assumptions, or ‘imaginings’ (Shore & Wright 2011, Hyatt 2011, Morgen 2002) about entitlement programs, which render further expansion problematic in general public opinion. This is then leveraged by (usually Republican) politicians and policymakers to garner support for their efforts to limit or de-fund Medicare and other safety net programs – a position that liberal activists like Dr Curran,
Jacque, and Jeff vehemently opposed. Jeff refuted the Republican argument that safety net programmes are unnecessary (see Chapters 2 & 4), saying:

Medicaid expansion actually serves as a bridge so that people can get to the point that they can take responsibility for themselves. Maslow’s hierarchy of needs is something that most legislators don’t understand and have never heard of, so they’re never going to understand why safety nets exist. This is why basic infrastructure must be there for really extreme poor people... it’s not that people decide that being poor is a fun way of life. ...How do you pull yourself up from your bootstraps if you don’t have boots? They don’t understand that.

As with Medicaid and other safety net programmes, initial hostility towards the ACA engendered numerous myths about it, especially when it is referred to as ‘Obamacare’. However, since coverage began in January 2014, the debate had been inverted, as people discover that they may hate the idea of ‘Obamacare’ but they love the provisions of the ACA. This necessarily affected the way ‘spin’ is put on the policy to ‘sell’ it to the general public. In previous elections, most Democratic candidates distanced themselves from the ACA, while Republican candidates competed to produce the most Conservative attack on Obamacare. In 2014 and 2016 it was the opposite: Republicans struggled to answer questions about Medicaid expansion, which had become popular, while Democrats proudly touted their role in health reform. In the Republican stronghold of Arkansas, the Democratic candidate ran a political advertisement detailing the law without using its name. In the ad, the Senator’s father tells his son’s story: ‘Mark’s insurance company didn’t want to pay for the treatment that ultimately saved his life.’ The screen shows Mark Pryor sitting next to his father. ‘No one should be fighting an insurance company while you’re fighting for your life,’ he says. That’s why I helped pass a law that prevents insurance companies from cancelling your policy if you get sick, or deny coverage for pre-existing conditions’ (Dionne 2014).

The struggle between Republican ideals, the shifting popularity of the ACA, and perceptions of Republican efforts to thwart the policy was especially evident in late 2013. Republican lawmakers felt obligated to keep campaign promises to obstruct ACA implementation by shutting down the Federal Government. The healthgov.com rolled out on 1 Oct., 2013, the same day as the ACA Federal Exchange website went live. The standoff lasted 16 days. It did not defund or
stop the ACA rollout, but it did shut down most other government services; as many as 800,000 of the nation’s 2.1 million federal workers were furloughed, meaning they were ordered to stay home by the Office of Management and Budget as there was no money to pay their salaries.

At the centre of the ACA controversy is the question of what role the government ought to play vis-à-vis poverty and citizenry. The rise of the Tea Party in the last few years put particular pressure on Republicans to shrink the government. This push for smaller government is mainly focused on dismantling the safety net: cutting food stamps, removing unemployment benefits, and refusing to provide health coverage to millions of uninsured through the ACA. The issue of the uninsured is at the heart of the fragmented American health system — and it is deeply rooted in the American values of productivity, autonomy, and personal responsibility (see Chapter 2). Traditionally, health insurance has been tied to the employment and the uninsured are associated with the unemployment, falsely linking ‘productivity’ with health citizenship (Becker 2004, 2006; Horton 2007), thereby establishing the uninsured as ‘undeserving,’ of scarce government resources. However, the HIV advocacy community’s counter-narrative consistently debunked this myth and exposed its ideological foundations while asserting their alternative ‘moral economy’ (Scott 1998, Zinn 2011). My respondents felt that neglecting the most vulnerable in the society was yet another ‘policy’ through which Republicans were undermining the social contract, thereby narrowing choices, eroding personal freedoms, and normalizing a lack of basic healthcare.

**On the Ground:**

**Activism & the Legislative Process in Policy Implementation**

The State Capitol building in Atlanta, called ‘The Golden Dome’, is a space where law-making, the ultimate state action, takes place. In its halls, bills are presented by the members of the state Senate and House of Representatives, debated, and then passed to the Governor for signing. This is a sphere where laws are transferred, translated, and contested; a place where actors (politicians, advocates, and lobbyists) converge to express their opinions to legislators – lobbyists promote specific ways of implementing policy’s provisions and legal
actions, activists protest, and citizen advocates attempt to communicate with their representatives. This section primarily considers the 40-day legislative session of the Georgia General Assembly that began on January 10, 2014; the first after ACA implementation began. In the wake of the immediate, visible impact of the ACA, healthcare advocates decided to focus on convincing state legislators to expand Medicaid and work with them on implementing other parts of the law. Thus, studying this session and talking to the actors involved helps illuminate the ‘appropriation’ and complex interactions between the state-society-market, HIV care, and access to treatment.

As many of my respondents feared, this was the session in which Governor Deal signed all bills intended to impede or interrupt ACA implementation. Jeff particularly described House Bill (HB) 707 and HB990 as ‘doomsday scenarios’. HB990 removed a governor’s discretion to make decisions about Medicaid expansion, instead granting that capacity to the legislators. Thus, even if Democrats won the gubernatorial race, any future Medicaid expansion would probably fail to be approved by the state legislature, which was expected to be Republican. This allowed Governor Deal to avoid discussing Medicaid during the general election, and to shift blame onto the legislature by saying his hands were tied. The other ‘doomsday’ law, HB707 or the ‘Georgia Health Care Freedom and the ACA Non-compliance Act’, made it illegal for any organisation to engage in activities that support the implementation of the ACA in Georgia. HB707, passed in a late-night vote of 115-59, undermines the ACA in five ways that correspond to Republican narrative and ideology. It:

1. Prohibits state agencies, departments or political subdivisions from using resources or spending funds to advocate for Medicaid expansion. This provision supplements the efforts made in HB990 to hamper Medicaid expansion by prohibiting the governor from expanding Medicaid by executive order.
2. Prohibits the state of Georgia from running an insurance exchange.
3. Refuses federal grant money for the purpose of creating or running a state insurance exchange.
4. Ends the University of Georgia Health Navigator Programme.
5. Prohibits the Commissioner of Insurance from investigating or enforcing any alleged violation of federal health insurance requirements mandated by Obamacare.
The immediate effects of the bill were obvious – like forcing the Federal government to run Georgia’s health insurance exchange – but its more obscure provisions were no less detrimental. For example, Georgia State University’s Public Health Department had to abandon a well-funded program that trained health navigators to guide people through the health insurance enrolment process on the online Federal marketplace. This exacerbated national confusion surrounding the disastrous launch of the Federal website, which was impeded by technical glitches. This, in turn, exacerbated poor perceptions of Obamacare in general; and the false but widespread belief that Obamacare was different from the popular ACA may have contributed to the Republican Presidential victory in 2016 (Calfas 2017). To my informants, HB990 seemed like the politicians identified every problem the broader health community was protesting and turned each piece into a law. Jeff especially noted that both House Bills made it harder to do advocacy work. In particular, as resources and manpower are diverted to handle the healthcare crisis caused by their rejection of the ACA, HB990 made it necessary for the health community to engage in more public contests to exert pressure: ‘imagine convincing 236 members of the Georgia legislature now instead of just a single person, the Governor’.

In addition to the traditional politicians and lobbyists who occupy the physical space of the capitol and influence the legislative space of the policy, there are also citizens, activists, and advocacy groups that do the same. Two of these, Georgia Equality and Moral Mondays, were an important part of the advocacy assemblage of Georgia. I worked most closely with Georgia Equality, Jeff’s organisation; their main focus is LGBTQ rights, but they also work with the HIV/AIDS leadership and community on issues of treatment rights and access. They are part of the Communities Advocating Emergency AIDS Relief (CAEAR) Coalition, a proactive national leadership group focused on the nation’s response to HIV/AIDS. Jeff, who has a long history of radical activism that includes ACT-UP (see Chapter 3), learned early that although big rallies and community mobilization are powerful tools, successful movements require people who can dress and act professionally, and who understand the legislative process. However, he emphasised ‘the power of bringing people from the grassroots in’ to do this:
We didn’t want it to be paid lobbyists; we didn’t want pharmaceutical companies doing this. We wanted it to be a grassroots effort...we knew that we needed to play on the same field as the professional lobbyists — and earn the same respect. So that’s what we train people to do.

Moral Mondays are a more classic multi-state grassroots movement; made up of politically liberal pastors and headed by Rev. Barber from North Carolina, Moral Mondays also hold social justice and health as a human right and a public good. However, they take the opposite of the suit-wearing, rules-following approach preferred by Georgia Equality, and they have a disparate view of how activism should be practiced and what its goals should be. Moral Mondays came to Georgia in 2013, where the movement is led by Reverend Dr Raphael Warnock, senior pastor of the Ebenezer Baptist Church in Atlanta, the spiritual home of Dr Martin Luther King Jr. They describe themselves as ‘seek[ing] to contribute to the creation of a more just and peaceful society where dialogue, debate and discussion prevail, and will work to achieve consensus in our group without silencing minority voices.’ They believe in disruption of power through nonviolent civil disobedience and follow Dr King’s assertion that ‘Of all forms of inequality, injustice in health care is the most shocking and inhumane’. By April 2014, their advocacy received considerable public attention and participation every time they called a demonstration at the State Capitol steps. During the legislative session, their focus was on budget cuts to safety net programs, including Medicaid expansion, and access to abortion facilities. They especially hoped to dissuade lawmakers from passing HB990. In a media interview, Rev. Warnock said:

Dr King said that ‘the time comes when silence is betrayal’ and that time is now. The issue is affordable healthcare for all in the richest country in the world. Moral Mondays movement embodies what our vision of America is: the beloved community, that brings us together rather than divides us, helps us to see that we are stronger together...we are tied in a single garment of destiny, caught up in an inescapable network of mutuality (Goodman 2014).

On 18 March, 2014, the day House Republicans finally decided to move on HB990, Moral Mondays staged a rally to stall all activity in the upper chamber, before being arrested in the classic tradition of civil disobedience. A diverse group of religious leaders, students, labour, reproductive and health advocates, progressive activists, and elderly residents started gathering on the steps of the
Dome around 8:30am. They had been protesting outside the capitol for days, and the passage of HB990 in the House prompted them to take the ‘party inside’ where it was now under discussion by the Senate. Protestors chanted ‘Medicaid Expansion Now,’ and ‘Our Lives Matter’ and held placards. Rev. Warnock and other community leaders and concerned citizens began making speeches summoning the moral argument for universal healthcare. Around 11 o’clock, a large group moved to viewer’s gallery overlooking the Senate upper chamber. Three protesters rolled out a large banner, loudly shouting ‘Medicaid expansion, our lives matter!’ This stopped the proceedings for a short time, while police removed them from the gallery. After another group of women did the same, the Lt Governor ordered everyone to clear the gallery. This is when I left the protest, as I had promised my husband I would not be arrested. In the afternoon, another group of protestors blocked the entrance to Governor Deal’s office, precipitating the next round of civil disobedience arrests. Finally, a blockade of the Senate chamber (Fig. 5.1) resulted in several more arrests; one protestor in handcuffs was heard saying, ‘I don’t want to see people in Georgia die because of lack of health care’ (Culp-Ressler 2014). Rev. Warnock was also arrested along with the other protesters for nonviolent civil disobedience. ‘Dr King said that the time comes when silence is betrayal’, Rev. Warnock said. ‘That time is now. The issue is affordable healthcare for all in the richest country in the world’ (Goodman 2014).
By contrast, Georgia Equality was inside the Dome, as part of months of meetings with prominent politicians and committees. Jeff acknowledged that ‘The Moral Monday folks [are] morally correct, and it is outrageous that the state has not expanded Medicaid.’ He added, ‘What they have been able to do that the coverage Georgia Coalition has not been able to do is get the public much more aware’. He further noted that Moral Monday protests were widely covered by the mainstream media programmes that people actually watch and listen to, as opposed to the in-depth policy analysis of the Health Rider for the Atlanta Journal Constitution, which is read only by ‘policy wonks’ and other specialists. Jeff said that he didn’t know what would have happened if Moral Monday had not been so successful at bringing voice and urgency to the situation. However, although Jeff appreciated much of their work, he could not fully support it:

My concerns are...that having people get arrested in the gallery of the senate may have caused some short-term harm... We can never know what might have been, [but] there were internal conversations and rumours that House Bill 990 was set to die silently in the Senate. That the Senate was fighting with the House and that they were going to use that as a leverage point.

If that is true, then two months of Moral Mondays activism may have disrupted the eighteen months Jeff and Georgia Equality spent exerting pressure in non-confrontational ways; what Jeff called the ‘grass-tops work’ of ‘Educating lawmakers, educating county commissioners, educating hospitals, trying to get the medical association of Georgia to make a statement in support of Medicaid expansion...things like that. It is said that the politicians don’t run things the lobbyists do.’ However, the mistrust is mutual; Jeff said that when the Cover Georgia coalition learned about the planned Moral Monday protests, some people them reached out to them, saying ‘We’re concerned you’re going to make it worse, please don’t’. Moral Monday responded, ‘We don’t trust you, [or] your lobbyists. You’re insiders, we’re gonna do what we’re gonna do.’ There has been little communication between the two coalitions since. However, Jeff was careful to emphasize his admiration for ‘the spirit of the Moral Monday folks...I mean I would be a big hypocrite if I didn’t say it was great, that what they’re doing. But in the short term I don’t know that it was all that helpful’.
Instead, Georgia Equality operates ‘strategic and focused’ lobbying efforts that concentrate on LGBT issues, HIV/AIDS, and Medicaid expansion. They occasionally invite other non-profit organizations to participate in lobby days before legislative sessions. They also invite people living with HIV: 25 or 30 committed ‘citizen advocate’ volunteers who must be highly trained to communicate effectively with local, State and Federal elected officials about updated information on issues regarding healthcare law and HIV. Citizen advocates come from all across the state, though many are drawn from districts represented by politicians on the appropriations subcommittee (a powerful group responsible for setting specific government monetary expenditures). The volunteers put a face on healthcare and HIV/AIDS issues by talking to their district representatives about what citizens need. On Awareness Days, Georgia Equality pays for transportation and hotel accommodation, hosts a banquet, and trains the citizen advocates on Sunday before taking them to the Capitol for the lobby day. Jeff said that four years of this strategy have provided social pressure that safety net institutions like the Ponce Centre use to help secure vital Ryan White funding through the appropriation committee. Their established reputation for professionalism ensured their continued success, even after the Democratic state government was replaced by a Republican majority in 2002:

We had learned to work with the pharmaceutical industry when it benefitted us, oppose them when we were upset with them. It gave a whole different tone and tenor to this partnership...to be able to sit down in situations like that and then talk through what the issues and the challenges are.

The number of lobby days varies. In 2013 Georgia Equality turned their usual AIDS lobby day into a ‘Cover Georgia’ day that focused on Medicaid expansion under the ACA. They brought some 110 people to Congress, about half of whom were HIV-positive. Jeff said,

Advocacy is so engrained in what it means to be living with HIV, what it means to be a part of the HIV community and provide HIV services, that it is, pardon the pun, it’s in our blood. So it’s easier for people to understand why they have to do this...and they are willing to do it. So it’s not uncommon when we have some of these broader goals of a lobby day that aren’t necessarily HIV-specific, we still get a lot of people living with HIV that show up.
I shadowed Jeff, a constant presence under the Golden Dome, at numerous State Capitol events and a few Senate meetings, whenever I could get special permission to attend as an observer. During this chaotic legislative session, the Capitol was full of people from across the state; every representative and senator was in attendance, various bills were at different stages of review, and lobbyists crowded the corridors and offices, trying to make favourable deals in closed-door meetings. The morning HB990 passed the House, there was an email exchange between myself and five of my key informants: Jacque, Wendy, Carlos Del Rio, Vince, and Jeff. Vince tried to be positive, saying the legislature might bend to popular opinion and protests. Carlos did not see it that way, ‘The only hope we had for Medicaid expansion in Georgia was that Deal would do it post-election. With the legislature taking it away from him, we are toast!’ Wendy agreed: ‘Yes, I think our best shot had been with Deal. He would have been able to make the decision on economic grounds with less fall out post-election.’ Jacque pointed out that the bill had only passed the House and still had to go through the Senate. She shared an invitation to a Roundtable Discussion on the Affordable Care Act being held at the State Capitol, and suggested that I obtain special permission from the Senator’s office to attend. A number of their colleagues would be attending, including Jeff. Matt Hicks, Grady’s Sr. VP of Government Relations would also be there as ‘the voice for Grady overall as well as for the IDP’. Jacque pointed out that the email included the line ‘we support Governor Deal’s decision not to expand Medicaid’. She considered this a warning that they shouldn’t expect much from this discussion; the decision was already made, and HB990 would probably pass the Senate:

Some of our friends, like Steve Henson and Nan Orrock and others [democrats in the Senate], will probably fight it to no avail. Many individuals and organizations are having town hall meetings and other discussions about this, but getting to the State Senators is the key. Talking amongst ourselves isn’t going to impact anything at this point except make us all frustrated, unfortunately.

On 7 March, 2014, I attended that roundtable discussion organized by a pharmaceutical company for hospitals and community advocates to meet Republican Senators, which allowed me to observe interactions between the health community and lawmakers. The meeting was intended to inform
Senators about the status of ACA implementation in Georgia, and about the concerns and problems experienced health professionals and their patients, as part of the effort to convince lawmakers of the potential harm to citizens caused by bills like HB990. Senator Rene Unterman, as the chair of the Health and Human Services Committee, represented the key committee that considers legislation regarding safety regulations and healthcare and social services for the citizens of Georgia. On my way to the meeting, two senators walked ahead of me – well-dressed older men with long, expensive winter coats on their arms – engaged in an intense discussion of a bill up for a second review. Food was on tables outside every room, and aides ran around with clipboards. Security guards in suits and obvious earplugs were everywhere in the long wood panelled and carpeted corridors. The scene was of chaos and high energy. Three people with a clipboard stood outside room 375 where I was to attend. I showed them the invitation letter and was shown to my seat, where Jeff was already sitting.

Senator Unterman (R), one of the three senators attending the meeting, made only a brief appearance to greet participants before she left to head a budget meeting. The organizers introduced the other Republican senator: Senator Burke, who is a physician. One by one, different representatives spoke: Matthew Hicks, the Gwinnet county Representative; a representative spoke for Mercy Care, a member of Saint Joseph’s Health System and Trinity Health – another Federally Qualified Health Center that caters specifically for the Homeless program; people representing the concerns of individual cities, including one from a hospital in Augusta, Georgia who feared they would be shut down like the other two hospitals in the area; a patient serving as ‘a consumer rep’; and Jeff, who spoke as a health advocate. Finally, Matt Hicks, the Grady representative, described challenges the hospital and the IDP at the Ponce Center already faced, and how they were exacerbated by the state’s refusal to expand Medicaid. The Senators did not speak a single word in response – though they did express appreciation for the wonderful sandwiches that had been catered by a famous bakery before exiting the room. It was obvious that the meeting had merely been a formality, to give the impression of a due process followed. Everyone was disappointed by this lack of communication,
though Jeff was not surprised. After that display of Republican indifference, I asked Jeff what factors were effective when lobbying for stigmatized communities (e.g., poor, uninsured, HIV-positive, LGBTQ+) in a conservative political environment. ‘As simple as this may sound,’ Jeff answered,

...understanding how the budget process works was our first key to success...The legislative session starts in January, goes through April or May. The Governor presents his budgets in January but the budget process actually starts in May the year before — with different divisions within each department making their requests to their supervisors. Then their supervisors and their commissioners take a look at what are the needs, what are the impacts, and what are the politics —because at the end of the day it’s all about politics.

In September and October, budget requests are taken to their respective boards, which are usually appointed by the Governor as necessary. Final requests from each department reach the Governor’s office in mid-November, where the Governor’s staff finalizes everything and releases the budget in the first week of January. Thus, citizen lobbyists had to learn that they needed to start the process in May the year before. Jeff emphasized that this is difficult for many local groups, especially for grassroots efforts: citizen lobbyists do not have the tools to do 18-month projections for pharmaco-economic studies and ‘economic modelling. That’s where a partnership of the pharmaceutical industry really helped’, Jeff explained to me, because ‘That’s their business!’

Thus, the second key to Georgia Equality’s success was

Learning how not to give up your ideals and not give up your passion and your power, but to work with [pharmaceutical companies]. ’Cause so much of the relationship between AIDS activities and the pharmaceutical industry was very oppositional throughout the 80’s and most of the 90’s. It’s probably a little too cozy over the last 15 years. But it’s also a real benefit to be able to tap into that power of the business.

The third key was hiring a professional Washington DC lobbying firm to train and advise them, including suggesting simple but high impact practices like dressing professionally (see Fig. 5.2). He explained,

People think ‘We’ll wear the t-shirts’, or ‘This is what I wear normally’, ‘This is me, I want to have self-expression’. And all of those things are great and fine. [But] When we do our lobby days, we specifically say ‘If you want to be effective, you dress like lobbyists’...The very first thing that happens when you approach the lawmakers is they’re going to look at you. They’re going to make a value judgment before
you ever open your mouth...You want that value judgment, at the very least, [to] be neutral... So the more you can look like someone that they can do business with, the more they’re going to be receptive to the words and messages that come out of your mouth.

Much of their success depended on learning about the legislative process, effectively delivering a message, and developing alliances with people who had political clout with lawmakers and could give them the data that they needed. Once that framework of networks and practices was set in place, Jeff explained that effective lobbying involves two steps. First, activist groups like Moral Mondays apply populist, grassroots pressure to politicians. This, Jeff said, is

... about gaining or losing power. With elected officials, it’s always a question of; will this hurt me in my next bid for election? Will this help me get the committee chairmanship that I want, or placed on the committee that I want? Or am I willing to buck the leadership and what the leadership says to make a point...because I’ve got a constituency that will support me, and I will have a lot of power, if I am seen as contrarian within that. So it’s all about gaining or losing power.

Jeff confessed that the activist in him appreciated the Moral Monday tactics. However, he argued that activist groups often lack the expertise required to effectively utilise the pressure they generate. Thus, he maintained that the second step must involve advocates like himself, with professional demeanours, legislative expertise, and political connections, to handle negotiations:

Someone has to do that role. Because, as much as I can have all the respect and admiration in the world for Reverend William Barber II [of Moral Mondays], he is not going to be able to negotiate drug pricing, drug protocols or regulations around preauthorization. I am the guy who has the responsibility to do it.
However, Jeff has found in his 25 years of advocacy that this is only how the system works in times of dissention. Periods of good communication with the legislature are significantly more common, where ‘everybody is on the same page and things happen much more naturally’, and there is no need for outside pressure from activists. The political stalemate of the 2014 legislative session was a disruption of this status quo: politicians were more concerned about advancing their careers by talking about cutting taxes than in governing. Jeff added that most politicians from both parties have a limited understanding of how public health works. Drawing on his experience as a disruptive 1980s AIDS activist, he said ‘That’s when you do need a movement to do that, and that’s where ACT UP was successful, being able to bust down the doors because it was an organically grown social movement’. Jeff argued that ACT-UP

...had the right media messages that scared the right people. That people came out in droves. Those were people that came out because they were scared, and their feelings were very genuine. It was a very genuine social movement, although it may have been orchestrated from up on high.

The competing narratives among advocacy groups, despite their different techniques and priorities with regard to achieving the same ends – essentially disrupted the certainty of the dominant state narrative based on conservative ideologies. The local nature of this fight is significant: both Moral Monday and Georgia equality, by centring their advocacy on social justice and social contract, made the ACA policy jump scale. This was happening in Georgia and must be fought on Georgia’s terms, but also it was a national fight. Moral Monday’s local chapters in several states were all active and coordinating at the same time. Jeff’s Georgia Equality was not only coordinating with the CAEAR national agenda, but also strengthening local network with organizations like Cover Georgia and others. This fight takes place on a local and national level at once – and the battle is fought on multiple fronts, and multiple scales. Cordially, between political insiders and advocates who disagree professionally; antagonistically, perpetrated on politicians by activists who believe they do not have their best interests at heart; and at a distance, by actors like Jacque and the Ponce Center, who send activist and advocate agents to try to promote their agenda, but who then try to fit the assemblage pieces together regardless of whether they achieve
a positive or negative outcome – and in so doing, produce the actual state of healthcare in Georgia that patients experience during their everyday lives.

As Wildavsky observes, ‘In the most general definition, budgeting is concerned with the translation of financial resources into human purposes... [it comprises] a series of goals with price tags attached’ (1964: 1). Certainly, each of the groups highlighted in this chapter associates different meanings with the budget. Jeff’s approach especially prioritizes the capacity to have a say in where the money is going to come from and where it is going to be spent; in his words, the purpose of his advocacy ‘to have a seat at the table and talk and get hold of the resources – money – budget’. The meanings generated by budgets, and access to budgets, are not merely instrumentally rational, but are also expressive of the different aspects of the communication of these meanings. Yanow argues that a budget ‘emphasizes policies’ role in the public expression, inculcation, and validation of values, beliefs, and feelings, as well as in the distribution of material goods, there by validating self-esteem, respectability, and other “status goods”’ (1996: 22). Thus, achieving Jeff’s goal of ‘having a seat at the table’ is not just about literal access to money and resources – it is about legitimizing the claims, the citizenship rights of PLHIV.

**Doing Assembling: the ACA at the Ponce Centre**

Early in 2013, months before the health insurance exchange rollout, the social and political environment in Atlanta, Georgia was rife with uncertainty. This confusion was caused by the political actions detailed above. Hundreds of meetings took place between supporters, hospital employees, consumer groups and politicians. Rallies were assembled, protestors gathered in front of hospitals, and Moral Mondays held a sit-in at the Governor’s official residence to advocate for Medicaid expansion. At the Ponce Center, two miles away from the Golden Dome and its politics, the environment on the surface seemed calm. None of the outside city buzz permeated the Center’s serene corridors, busy waiting rooms, or clinics. Patients came and went as usual. Concerned voices discussed preparing for ACA implementation, but they could only be heard in meetings attended by the top Center administration, Community Advisory Board, researchers, staff, and doctors. Meeting after meeting, the same questions were
repeated but no one had answers, despite their contacts among high-level state and Federal officials. The law was there, agreed the Center’s senior management, but the rules and regulations to implement it were incomplete.

The greatest impact the ACA had on the Ponce Centre was the overwhelming complexity of the law and its interaction with their existing services and funding from a different Federal source, the Ryan White Program (RWP). Jacque said, ‘it really hasn’t changed anything at the moment except made more work and more confusion’. In the early stages of implementation, employees feared the ACA would jeopardise Ryan White, the Center’s main source of existence. RWP has been kept largely discrete from other health reform policies, and it plays a momentous role in HIV care for both insured and uninsured people (see Chapters 2 & 3). According to my informants, it is ‘arguably the most important law for HIV/AIDS patients’ ever passed. The Kaiser Family Foundation (Garfield & Damico 2016: 19) reports that in 2009, 40% of all PLWHIV received medical services, medications, and other services through this Program. This included 31% of insured people who received services not covered by traditional insurance.

However, in the ACA era, RWP faces considerable uncertainty; Jacque explained that program managers and HIV/AIDS advocates didn’t want to associate Ryan White with the controversial ACA, thereby opening it up to attack by ‘vengeful’ politicians who might ‘pull the plug’ on Ryan White funding in the mistaken belief that it is redundant now that the ACA purports to offer health insurance for everyone, regardless of pre-existing conditions like AIDS. In fact, if Ryan White were eliminated, most Ponce Center patients would entirely lose access to affordable treatment and care – but, Jacque said, ‘We can’t bring up the fact that everybody on Ryan White isn’t covered by the Affordable Care Act, which includes people, um, who are black for the most part, homeless and sick, or undocumented immigrants, because that’s not a popular subject either in Washington’. The HIV community was certain that even patients who were deemed capable of buying health insurance with the aid of government subsidies would not receive all the services RWP covered (e.g. dental care, mental health).

My informants’ concerns about Ryan White were exacerbated by the fact that it had to be re-authorised in early 2013, only months after Governor Deal
refused to expand Medicaid. The CAEAR Coalition was working to keep it funded, despite the fact that this involved the Federal Congress, which was in a deadlock and had not approved an official budget in two years. The Federal government was instead relying on annual appropriations from different Congressional committees to renew partial budgets. Dr David Reznik, Director of Oral Health at the Ponce Center, and Dr Wendy Armstrong, the Medical Director, worked alongside Jacque on their annual budget proposal in January; this is always done in consultation with the national CAEAR Coalition to ensure that the HIV/AIDS community sends a consistent message to Washington. Jacque was disappointed that the White House had excluded the health community from the decision-making process, so they had little impact on the overall ACA policy development. Consequently, they were still fighting for RWP renewal, rather than working on other necessary projects. She was also dejected about having to do the same work over and over, year after year, because politicians couldn’t seem to remember why it was important to ensure that Ryan White continues to fund care for people with HIV, the majority of whom do not have other payer sources. Their strategy, she said, for

...the hard-headed Republicans is that this isn’t just money...we don’t need [to spend] anymore, now that everyone is going to have health insurance. This is money that is addressing an epidemic of huge proportions. If you want us to keep a handle on this epidemic, you gotta keep this funding in place so that we make sure those who are infected get their medicines, so we can keep their viral load down, so they won’t transmit. That’s the basic message we take, and always have...There are some places, like John Lewis’ office, who actually care about the human beings involved. But most of them don’t.

This was part of a broader effort by the CAEAR Coalition to reframe the issue as a ‘common sense’ question rather than a political one. Thus, Jacque said, the HIV community has to think rationally about what they need, which is to ‘get appropriated’; that is, funded by the Federal Appropriations Committee. In 2014, she invited an influential staff person working for Jack Kingston, Congressional Representative for Georgia's 1st district, on the Appropriations Committee, to the Ponce Centre. She discussed the budgetary issues with the staffer, and gave her a detailed tour of the Ponce Center – showing her the facilities and telling her patient stories. Jacque was employing a set of tactics similar to those used by Jeff
in his advocacy. They were participating in a ‘grass-tops’ insider political game, talking to Congress people and taking practical steps to achieve political goals. Jacque thought the staff member must have been paying attention because, ‘I don’t know what happened in that room when it was being discussed but they left Ryan White in there [the budget]. They appropriated it, and decently’.

However, these successes do not mitigate the uncertainty of the ACA, or of the broader, fragmented assemblage of healthcare policy, even for patients who can benefit from the ACA rather than (or in addition to) Ryan White. Freeman discusses this in terms of the ‘multidimensional complexity’ of assemblages intended to provide individual services, which calls special attention to the ‘particularities of its realization’ (2018: 129). In practice, this meant the Center had no idea how the ACA extended to other components of the care assemblage or how coverage would work once it began. For example, the week before marketplace rollout, they did not know which treatments and drugs would be covered by specific insurance plans. An email from Grady to all senior administration said,

Grady participates in several Exchange insurance plans, but not all. If an established Grady patient has accidentally selected a plan in which Grady does not participate, we can provide them with information on switching to an in-network plan. Patients may call 000-000-7165 to receive information on switching plans.

HRSA, the Federal agency responsible for advising healthcare providers, would only say ‘do your due diligence to try and get people enrolled’. However, Ponce Center employees were, Jacque said, ‘not in any big rush to do that, because we don’t want [the policy to cause] them to fall flat on their face’. She meant that if the new health insurance provided by the ACA didn’t work perfectly the first time their patients used it, they would say “I can’t go to my appointment today. I can’t afford to buy my medicines.” That’s the last thing we want to happen’.

This was an issue that went beyond mere confusion; as Jacque pointed out, in the AIDS community, instability like that can kill. Around 40% of the Ponce Center’s patients are on Medicaid, 4% have private insurance, and 5% are undocumented; the latter are covered by RWP along with other uninsured patients. When new policies like the ACA disrupt this careful assemblage, the result is what Jacque described as a ‘simple’ phenomenon:
If we can’t keep people in care and keep them on their medications, then we have a problem caused by the fact that people have enrolled in these exchanges, but they can’t afford ’em so they’re not coming in. We need a lot more retention and client tracking and all that stuff over the next couple of years to keep people from getting discouraged by all this change? Change scares our patients.

The HIV/AIDS community is not new to fear and uncertainty. However, as one patient told me, ‘facing fear as often as we do doesn’t make it any less scary. Nobody gets used to it’. This manifests in many ways, including treatment; Jacque explained that it takes time for HIV patients to reach a level of comfort at which they’re willing to receive care, and the clinic plays a vital role in facilitating this. However, ‘If we...don’t have the money, then we can’t keep them going...We’re not gonna have suddenly income from insurance companies that will take the place of Ryan White. Because it’s just not really that quick. All of this is going to take time.’

Thus, my informants’ greatest concern was how to afford keeping existing patients on the rolls, because the Governor’s decision to reject Medicaid expansion not only left more than 650,000 people without health coverage, it diminished the resources of Grady Hospital and the Ponce Centre. The ACA included Federal subsidy cuts to a policy called ‘Disproportionate Share Hospital’ (DSH), which has, since 1985, covered the cost of uncompensated and undercompensated care at safety net hospitals in poor states like Georgia, with high rates of uninsured. The Federal cuts were based on the assumption that after the ACA was implemented, hospitals would recover the lost revenue from patients who were newly covered by either Medicaid expansion or insurance purchased using the new health exchanges. In Georgia, for example, Medicaid expansion was supposed to bring in $34 billion over a decade, which should have partially offset the $48 million DSH cut to Grady’s funding, as the largest safety net hospital in Georgia. However, neither the Center nor Grady Hospital expect an influx of insured patients capable of paying their co-pays and deductibles in the near future. Jacque said that most of their patients are too poor to qualify for subsidies, and patients who make below 100% of the poverty line are covered by Ryan White. Indeed, as Chapter 4 demonstrates, patients are often unaware of the ACA and related forthcoming changes. Thus, hospitals in states that opt
out lose both the new Medicaid patients and the old subsidies, which Matthew Hicks, Grady’s vice president of government relations, considers critical to the mission of caring for the poor. Now, more than 27,000 additional uninsured patients will seek free care at the hospital, which already saw 600,000 uninsured patients annually. In one newspaper interview, Hicks called this ‘a double whammy’: ‘You lose DSH funding, you don’t have insured patients, and somehow you’ve got to make up the difference’ (Advisory Board 2013).

Grady is only one example of this story; most hospitals in rural areas are in a worse situation and incur significant uncompensated costs in services provided to uninsured patients. The Robert Wood Johnson Foundation, a non-partisan healthcare organisation, estimates that the twenty-four holdout states will lose almost $600 billion in Federal funding and hospital reimbursements by 2022. They calculate that for every dollar a state spends expanding Medicaid, it receives $13.41 in Federal funding (Dorn, McGrath & Holahan 2014). Meanwhile, the budget shortfall in Georgia caused the closure of three rural hospitals during my research, and others faced layoffs and drastic reductions in services. The Governor claimed his decision was based on fiscal responsibility and reducing the size of the government, but the practical effect of his decision has been to strip Georgia of important health infrastructure. Dr Curran calls it irrational:

There is more HIV in the South, and the South in general still is poorer...It’s actually much more in need of Medicaid expansion than the rest of the country. The irony is that the Governor takes state money to give to the rural hospitals to keep ‘em going because they haven’t expanded Medicaid. So he’s doing exactly the same thing he said he didn’t want to do. He should expand Medicaid and help everyone in the state, and not just rural areas.

However, some aspects of ACA implementation affected the nation equally. For example, in the months between the rollout of the online health insurance marketplaces and the start of actual coverage, Jacque told me that patients at the clinic could not enrol in anything. HRSA allowed the Center to use Ryan White to pay for patients’ health insurance through exchanges, co-pays, and deductibles, but those health insurance plan dollars would not be immediately available even if they enrolled by 1 January. Thus, until even after people were able to start registering for plans on 1 October, 2013, nobody knew who would
pay newly-insured patients’ premiums for the first few months of 2014. My informants also had doubts about how this new arrangement of diverting dollars from RWP would work in practice, since the clinic was required by law to direct all eligible patients towards the exchanges. Ryan White, Jacque explains, ‘first and foremost is the payer of last resort, always...but that’s for us to figure out as well. And there’s a lot of figuring out going on, or supposed to be going on. The time frame does not line up very well’.

In addition, Jacque was unhappy with how slowly HRSA responded to queries made by herself and other CAEAR Coalition members nationwide. At one of our bi-weekly meetings in late February, she was fuming. She had just returned from the CAEAR Coalition meeting in New Orleans and ‘all hell’s breaking loose there’, because Louisiana’s Blue Cross Blue Shield insurance company refused to take RWP payments for clients enrolled in the online exchange, saying they could not take payment for administrative costs from what they considered a ‘third party’. This had the effect of leaving those clients uninsured because they could not afford to pay. The ‘Louisiana incident’ caused speculation among the HIV/AIDS community that Blue Cross was trying to find reasons to not insure these very sick, very expensive patients. This was especially troubling because Louisiana implementation was slightly ahead of other states and their patients began using the coverage earlier, so this incident was a possible indication of broader future expectations. Furthermore, Louisiana and Georgia are highly comparable, as Southern states that opted out of the exchanges and Medicaid expansion for similar reasons. After the Louisiana incident, the worried HIV/AIDS community called for national level meetings, where the Federal Government forced all insurance companies to accommodate these special arrangements.

These concerns were important, but they led the advocacy community to neglect some issues. Most significantly, they were caught by surprise in January 2014, when people collecting their prescriptions were informed without any warning from the pharmaceutical companies that their medication was not covered by their new health insurance plans. ‘The AIDS community has been so good about taking care of itself that we just dropped the ball on this one’, Jeff said, adding that ‘I don’t think any of us saw what was coming...if we had any inkling about
this, we could have put on some pressure on the Federal government, saying that
the law didn’t go far enough, or to do a “specialty carve out” for all antiretroviral
medications. Federal law requires that antiretrovirals as a class of drugs be
covered by all plans, but most AIDS medications are classified as ‘specialty tier’
drugs. Thus, although each plan must offer at least one drug in each class, and
the pharmaceutical companies followed the letter of the law, the most expensive
drugs are combination drugs from multiple classes, which fall outside the ACA
guidelines. In theory, someone willing to go from taking one composite pill a
day back to taking up to 20 pills will be covered. However, Jeff told me,

That’s not how it’s prescribed. That’s that fine nuance that we just
missed. When it was going through DC, I do remember we were
signing on letters and people were concerned about it, but people
kind of let it go and now we’re in this situation—and it’s not just
limited to Georgia. It’s popping up all over the place.

For those with private insurance, this results in high out of pocket costs that
were not affordable for low-income people who could barely afford even
government-subsidised insurance – which quickly became clear after
implementation. Jeff noted that even California missed this finer point, despite
being ‘one of the strongest areas of AIDS activism on ensuring access to
medication’ and the first state to embrace Medicaid expansion. Jeff suggested
that another reason activists ‘dropped the ball’ was that Ryan White drug
assistance money had allowed the HIV/AIDS community to feel secure for
decades. Many respondents agreed that the problem was exacerbated by the
fact that most of the community had never dealt with private insurance before,
and did not realize what they didn’t know. Until the Affordable Care Act
passed, only a small number of people living with HIV ever had a private
insurance plans from the big organizations they worked for, which negotiated
it personally; the insurance market excluded other people living with HIV. Jeff
said the last time he did advocacy with insurance companies was ‘probably
1995, 1996’. Thus, the infrastructure necessary to do advocacy has been scarce
for some time, especially in Georgia. Jeff was Director of the last agency that
focused entirely on advocacy, which created a void when it shut down in 2009.
Jeff said that the last eighteen months of advocacy in Atlanta were primarily focused on making sure that current Ryan White service providers, ‘the HIV experts who provide care to the most number of vulnerable people’, were prepared with the infrastructure and knowledge required to accept insurance. They were training Navigators to set up billing systems and acquiring state approval to help enrol people in the networks of different providers. These concerns were not without merit; issues of payment certainly added unique complexities and uncertainties to the implementation process. Health Departments in Georgia, including at safety net facilities like the Ponce Center, had never done ‘diverted third party’ billing before. Ryan White clinics were suddenly required not only to enrol patients in exchanges but to instate billing with no prior infrastructure for doing so and no funds to build one. The state, which already opposed implementation, would not help. Jacque called it

A huge nightmare, particularly from the Grady perspective. It’s one thing to look at it from a small community organization: they pay out for one patient and they wait a few weeks to get that $100 back from this third-party company and they recycle it, and it’s easy. But their billing systems aren’t like Grady’s. Grady doesn’t have any kind of system in place to handle these ‘diverted’ payments. And we [the Centre] haven’t talked to them about it yet, because we don’t know what the system’s going to be...and here we are, in the middle of February.

Dealing with expected issues such as billing ensured that advocates had no capacity to pay attention to finer issues like drug pricing. Jeff said even if they had anticipated the issue, they could not have resolved it in Georgia because of politics: ‘Our insurance commissioner self-declared himself to be the biggest ‘obstructionist’ to the implementation of Obamacare’. Indeed, in August 2013, Commissioner Hudgens boasted to a Republican audience in Floyd County, ‘Let me tell you what we’re doing [about Obamacare]. Everything in our power to be an obstructionist!’ (Kessler 2010). The commissioner’s office approves and monitors insurance policy regulations. Thus, Jeff continued, ‘The natural place for us to turn for action was very clear that they were not gonna be interested in doing anything with us’.

The October 2013 rollout of the Federal exchange, the website run by HRSA for 36 states on which applicants could enrol, was anything but smooth. It
crashed on the first day. Two weeks after the sites went online, glitches still prevented people from setting up accounts and logging onto the system. Consumers saw that the website would not let them proceed to finish the applications, while insurers complained of having incorrect information for the people who had completed their online applications. The Federal government claimed high traffic was the cause of website crash. All claims were true. The failure of the Federal website is symbolic: it, too, is unable to translate different insurance arrangements into commensurable terms.

At the Ponce Centre, Jacque had scheduled the first week of health insurance exchange rollout for the analysis with formularies, the list of covered drugs provided by every insurance company’s Prescription Drug Plan. There were spreadsheets that the HIV policy log group had helped prepare for the analysis, and Jeff thought they were ready. Instead, the rollout was a disaster; they couldn’t get on the website to see the forms, the plans, or the formularies. ‘So there was this horrible situation and now we’re scrambling trying to figure out, what are we going to do with it?’ The media frenzy over the malfunctioning exchange website only added to the uncertainty and sense of chaos. The confusion about where to guide the patients increased. The handouts about the website that Jacque had instructed her staff to share with every patient seemed pointless.

What the Center heard from their worried patients was even more troubling. During neighbourhood outreach, the staff heard stories about predatory insurance signing practices by some of the ‘big name’ insurance companies. These companies had hired ‘street agents’ were ‘nailing people’ – inviting them to come have breakfast, meet with other folks, and get health insurance. Some established patients at the Centre who enrolled in this way discovered that their insurance did not cover the Ponce Center because it is a specialised HIV/AIDS clinic. Instead, their providers’ network sent them to a general practitioner, which caused them to drop the plans. Jacque said that people were confused, ‘although some of our patients might be very interested in getting coverage for themselves if they can afford it. They have asked their doctors questions about it but they are in very small number who can actually pay their insurance plans’. As a well-informed lobbyist, Jeff was painfully aware of the loss of room to manoeuvre,
Because compromises get made in a time of crisis. Part of the promise is lower prices now, so that when the economy turns around we can up the prices again... all of these competing interests create situations like what we’ve got right now where expanding Medicaid is only part of the challenge, the other challenge is to make sure the Affordable Care Act, it’s private insurance and the Medicaid program is going to work for people that need it the most.

Jeff was right; his assessment manifested in actual reality. This was a difficult time because of the political stalemate: State legislators were putting pressure to contain ACA-related costs on all departments and divisions involved with healthcare delivery in Georgia, particularly the safety net institutions. These institutions, such as the Ponce Centre, were then obliged to help greater numbers of people with the same amount of money – which, over a period of years, becomes a type of cut, even without accounting for increasing drug prices. This movement of policy from Federal to State level, its translation to a ‘costs and numbers’ framing from a ‘needs and rights one, emphasizes how all healthcare policy exists in an assemblage – not just with other healthcare policies, but also with the full body of law, especially that regarding safety nets.

Almost all actions in the Ponce Center networks up until this point have been about preparing for the ACA – about uncertainty leading up to it, uncertainty about how its provisions were going to be paid for, anticipating and failing to anticipate specific insurance industry problems – while different actors tried to assert their own meanings to what affordable health care meant to them. Shore and Wright question, ‘if a policy is a narrative in a continual process of translation and contestation, then we might ask when can a policy be said to exist?’ (2011: 14). They illustrate this with Latour’s study of a new Paris construction project. Latour traced all phases of research and development and found that,

At each stage, the project had to be recreated with a new range of experts, new financial and institutional backers and new political supporters. For example, when they had overcome serious engineering and had prototype yellow cars running round a field, they thought they had a viable project. But to translate that into a logistical scheme that could operate on the roads and rails of Paris required bringing in new professions with new criteria and ways of seeing the problem. Suddenly the viability of the project had to be proved once again. Latour asks, at what point was it possible to say that the project actually existed?
Similarly, it can be asked at what point health reform in the United States can be said to have come into existence. Even after implementation, which was supposed to be when the ACA ‘became real’, it was not real for many people, either practically speaking, or in their conceptualizations. While I was in field, almost no patients from the clinic had enrolled; there was too much confusion about which plans covered Grady and Ponce Center. Medicaid was not expanded, and state impeded any support to get people enrolled in the Federal exchange, which made the ACA inaccessible to millions of Georgians.

**Conclusion**

The American health care system is highly fragmented, and the ACA only increased its complexity. This analysis engages particularly with the fractures in the national healthcare system using Freeman’s (2009, 2018) conception of assemblages and translation at different scales. I also rely on Shore and Wright’s (2011) conception of policy analysis as a window onto processes of political transformation, as well as Wright and Reinhold’s (2011: 88) method of ‘studying through’, which allows ethnographers to chart the process of contestation as it tracked ‘back and forth across different sites in a policy field and over time, so as to reveal how a new governing discourse emerges and becomes institutionalized’. The ACA itself is tied into and relies upon the other parts – and policies – of the healthcare assemblage and its quasi-reality, which is in a constant state of in-the-making. The aspects of the social life of the ACA revealed in this chapter are its changing meanings and articulations – efforts to enforce those meanings as institutionalized reality through law. However, the chapter also demonstrates that translations often fail or move in unexpected directions. At a metanalysis level, policy emerges in this chapter as an intricate set of interrelationships – between the state, institutions, and citizens. Each of those elements and the relationships between them are formed and broken, are subject to interpretation and alteration – another kind of translation. Thus, it is not just about what relationships are formed and which inherited, but what they are made to mean by various actors through certain varieties of governance, regulation and accounting.
For my respondents within the HIV community, the ACA is not the complete solution that its creators intended, but it is ‘a first step in the right direction’. However, if one aspect of the assemblage is missing, such as Medicaid expansion in Georgia, this has a continuing effect that destabilises other aspects of the policy assemblage, on both a state and Federal level. Creating this additional fragmentation in health policy advantages Conservatives by allowing them to fulfil their promise to obstruct ACA implementation to ensure its broader failure. They know that if they agree to one provision, such as the employer mandate, but refuse another, such as DSH payments, that jeopardizes the viability of the entire policy. Thus, the 2013 legislative session and early ACA implementation was a test of political, legal, ideological and moral aspects of policy processes that must function at both the Federal and state level. It was an opportunity for state lawmakers, elected officials, and ACA advocates to assert their vision of governance and action, present their cases about how policy should respond to public opinion and human need and be ‘appropriated’ accordingly.
**Conclusion: Tracing the Social Life of Policy**

A guiding premise of this thesis is that policy is a fundamental organizing principle in modern societies (Shore & Wright 2011), a ‘building block of culture’ by Kingfisher (2013: 179); it shapes the world we live in and the *habitus* (see Bourdieu 1990) we live by. This thesis explores the social life of one of the most consequential American public policy initiatives in modern history. Health reform in the U.S. was designed to amend the basic social contract of health – to remake persons, markets and public-private relationships by re-shaping the underpinnings of the society. If policy classifies and regulates its subjects, then one must understand the ACA policy as classifying and organising people, systems, and ideas in order to enact social change. This thesis is an account of ACA implementation in Atlanta Georgia - at a safety net organization, the Ponce de Leon Centre, an Infectious Disease Program that works within the fragmentary healthcare system to provide HIV care for the ‘sickest of the sick’ and poorest of the poor.

Care is a domain of culture, dependent on other impinging systems of rationality, commodity and instrumentality – ‘so we must take care, it seems, of care itself’ (Freeman 2017: 194). Freeman calls care a burden, ‘a set of obligations distributed unevenly among men and women and according to the prejudices of race and class, a source of exploitation and a means of control’ (ibid). Care policies are not only steeped in *power within* but also hold *power over*, for good or ill – and this is why questions about conceptualisations and commodification of health and health-related policies are important. I put the Center at the centre of this research because the fundamental anthropological question of this research is *What makes the clinic a Centre?* In another sense, the question becomes what sets the holistic approach of care at the Ponce Center apart from more medicalized approaches to healthcare represented by other spaces, policies, and apparatuses.

The purpose of my research was twofold: first, to take an anthropological approach to documenting how ACA implementation and related health and social policies are articulated and enacted in everyday life, and how they shape our world and experiences. Second, to explore and articulate the role of the ACA in access to HIV care as it developed – whether the new policy expanded, contracted,
improved, or disrupted the existing assemblage. This thesis is concerned with HIV as a chronic disease, health disparity, social justice, interdisciplinary holistic modalities of HIV care, social conceptions of HIV, access to treatment in an era of treatment as prevention, the promise of a manageable HIV epidemic, and health reform policy in the broader context of poverty discourse in Atlanta. I investigate the convergence of these themes through the paradigm of articulations: by exploring how people contested, asserted, and implemented the ACA policy through their discourse and practices. I was fortunate to be able to observe as new processes of articulations and translations emerged through the engagement of various actors with the policies – and particularly through the eyes of Ponce Centre providers and the HIV advocacy community in Georgia.

I am finishing this thesis in 2018, and contemporary reality is very different from the era of my fieldwork. During Obama’s presidency, and the first six years of the ACA policy, Republicans tried to repeal it sixty-six times. Regardless, the ACA was implemented and provided health coverage to 30 million Americans. Today, Trump is the President of the United States, and the Republicans control all three branches of government. Their efforts to repeal and replace the ACA are more immediate; on 4th May 2017, the House passed a bill to repeal the ACA and replace it with American Health Care Act (AHCA), which strips several major provisions of the ACA, including mandated coverage for citizens with pre-existing conditions, such as HIV. The new policy was defeated in the Senate, but fifty-two million adults with pre-existing conditions under the age of sixty-five, or 27% of that population, were nearly rendered uninsurable.

This thesis contributes to the anthropology of health policy reform in several important ways. First, discussion of this issue is pertinent to the modern era; I have captured ‘what the present is producing’ (Shore & Wright 2011: 3). Bringing anthropology into current public dialogue about critical social and contemporary policy debates is not just an academic exercise. Bringing attention to the relationship between the social contract and the fragmented nature of the American healthcare system, particularly as it pertains to the most vulnerable in society is, I believe, a moral responsibility. Thus, this critical medical anthropological deconstruction of the impact of ACA reform,
and the ideological assumptions surrounding its repeal or continued existence, is incumbent. Horton et al. (2014) emphasises that such analysis is relevant not only to the United States, but also to the developing countries that are moving towards neoliberal forms of health policy. I heed their call to begin

...dissecting assumptions about health, risk, choice, value, and responsibility that undergird the insurance industry—determining how the inequities and inefficiencies of market based medicine are naturalized and reproduced. With the implementation of the ACA comes the need to examine how old and new inequalities are enacted and embodied. We must evaluate how policy initiatives aimed at levelling inequalities heed or ignore social determinants of health, and whether they legitimize unequal care on the basis of ‘cultural reasoning’ (Briggs 2001 in Horton et al. 2014: 15).

Second, this thesis is important as a documentation of the ACA as it unfolded on the ground in real time in a particular local context. It is a snapshot of the processes involved in ACA implementation, and its translation by various actors into various contexts, and it furthers our understanding of the inner workings and impact of health reform, particularly on safety net institutions and vulnerable minority groups. As such, the thesis has an enduring relevance; it may last longer than the ACA. Its significance is further located in the Ponce Center, in the innovative everyday practices of the healthcare workers and the things they do in relation to patients and policy; in illuminating how the program emerged from the Ryan White policy, and how it evolved in relation to that history and the various policies that enable it to function, as well as the locations, people, and organizations that surrounded it.

This is an ethnography of place, people and policy. It examines how the ACA and similar legislation impacts places like the Ponce Center – or, conversely, cities like Atlanta that lack specialized HIV centers. This ethnography is not and was never intended to be a work of distant objectivity; instead, I took the model of activist anthropologists like Shepher-Hughes (1995), Farmer (1999: 2003), and Maskovsky (2005). My ethnographic sensibilities encouraged me to take a critical and questioning disposition; to understand that simply engaging with this topic and documenting the challenges and assumptions on which the ACA is debated, formed, and implemented, necessitated that I shared in the social movements my participants have been fighting for all their lives. I could not observe or
analyse without taking part in their project of changing the current, for-profit based model of American healthcare, and working towards ideology and single payer policy model that understands health as a right. This ethnography is intended to be read, to be applied to other similar centres and cities, and to become a resource that activists across the country can use to talk to their senators about what access to care means and what people living with HIV need. Policy shapes society, and it is often hard to predict the effects it will have. One interesting thing about this ethnography is that the Ponce Centre is a lens, a reflection of the experiences of people living with HIV. It was built around a holistic conception of their lives and the policies that impact them. This ethnographic, observational analysis of the appropriation and articulations involved in health care reform illuminate how the processes of caregiving might be reshaped to be more effective and supportive. The way the ACA unfolded at local, state, and national levels provides a window onto the fragmented state of access to treatment and care and onto the context and circumstances in which people’s lives are moulded, for better or worse. Policy shapes society, and therefore what the practices of Ponce Center must be, but the Ponce Centre also seeks to consciously and actively reflect the structures of policy, and to (re)shape the functions of policy in order to use it most effectively. These processes in turn inform how people understand both the policies and the Center. The Ponce Centre exists as a nexus of people, policies, services and organisations. It is located in Georgia, but it also sits at a nexus of national policies and social networks, and serves as a model of care that reflects and transforms the structure of the policies that gave it existence. It informs how people understand and live their own lives – and that is true of the patients, but also of the caregivers, of people like Jacque, Vince, and Jeff. All of my interviews with healthcare providers emphasise how many different policies, how many fragments – organisations, people, policies, and funding sources – they must assemble to make it possible to provide treatment and to ensure that patients can access that treatment. Their task becomes making and re-making connections as each new change comes their way – improvising as they go, because the policy landscape is constantly shifting.
Piecing Together the Fragments: Contribution to the Concept of Assemblage

This ethnography captures the immense scale of healthcare assemblages; the everyday effort required to constantly piece together a fragmented healthcare system that is considered the ‘most expensive and inequitable in the developed world’ (Horton et al. 2014). Mapping the topography of HIV policies and broader healthcare reform, I observed a range of organisations and actors who became involved in the process of contestation over the ACA. One of the most recurrent themes of my research is the set of articulations related to the ideas, beliefs, and the meanings that people attach to policies. My focus was on the healthcare providers, HIV community advocates, and federal and state governments – as well as patients – because they are all socially situated and influenced differently with different historic contexts, resources and agendas.

“This tension between powerful intent, on the one hand, and contingent process and outcome, on the other, constitutes the “social life of policy”” (Kingfisher 2013: 180). My meta-story, consistent through every chapter, is that while some articulations produce the desired results, others do not. Following other policy anthropologists, (Kingfisher 2013; Yanow 1996, 2013; Shore & Wright 1997, 2011), I accentuate the fact that the prominent markers of policy as a translation and assemblage deviate from the linear and rational models. To contextualize policy and assemblage we must understand that the processes of articulation are not seamless, and they produce and communicate different meanings, by and for different actors, according to their vantage points.

Many such divergences are present in the story of the ACA at the Ponce Center. First, as Chapter 2 outlines, there are actively contested narratives – disputes about the ideological underpinnings of policies that also function in ways that reflect and shape the identities of individuals, institutions, and organizations. Such disputes form the scaffolding around which social and health policy debates have always been constructed in the United States. Furthermore, adding the ACA to the already-fragmented healthcare system was a disruption for the Ponce Centre and the American state as a whole – and it was an additional disruption for the patients, for whom diagnosis had already been a disruption (see Chapter 4). Thus, studying the ACA, or any policy that impacts
the experiences of PLHIV, illuminates these everyday lives and highlights the complex challenges that surround access to HIV care and the socio-economic situations of people who live without health insurance. Chapter 2 therefore intertwines what is essentially a cultural history of AIDS politics with a cultural history of health care reform politics.

The concept of identity plays a significant role in how the ACA functions as a policy, and also the effect it has on people and organisations’ everyday lives. Various identities – especially marginalised identities, such as those of most of my informants, including all those living with HIV – are a further source of fragmentation that networks with the structural fragmentation of the American healthcare system. Chapter 3 examines the organizational identity of the Ponce Center as a unified interpretive community, while Chapter 4 is about the intersecting identities that patients must negotiate and perform. Chapters 2 and 5, by contrast, are about places where the ACA intersects with notions of social change and national identity. They discuss the ways people and organizations are conceived and constructed as specific subjects, and illuminate the processes of piecing together, of making and re-making an assemblage of policies and actors by and through their struggle for narrative. The struggle for narratives of identity was a common theme in the events, discussions, and contestations of the ACA this thesis tracked; if policy is a building block of society that shapes and sometimes dictates social orientations, then the dichotomous Liberal and Conservative narratives of America reveal what shape this policy should be able to give to the American society. The Liberal narratives articulate perceptions of health as a social contract – a human right that should be guaranteed by their government. The second set of narratives, usually Conservative, articulate the complex political and budgetary aspects which they assert are too limited to support such a policy. These narratives flow into each other but do not represent a clear view of the impact of health policies in the daily lives of the people with whom I worked, in part because they misunderstand and misrepresent certain portions of the population that health policy is intended to serve.

The primary Conservative discontinuity in representing the experiences of my informants is the construction of certain citizens as being ‘deserving’ or
‘undeserving’ of welfare. This can be framed in terms of attribution theory, which asserts that those who always locate blame externally, who blame others – be they individuals, providers, or the system as a whole – for the problems in their life, tend to do the worst (Heider 1958; Weiner, 1974, 1980, 1986; Bowling 2014). I often discussed this notion with the providers at the Ponce Center. Those who are resilient, who have an internal locus of control but not blame, tend to have a more positive attitude, fewer feelings of shame or guilt about the help they receive, and are more appreciative of that help despite having the same barriers as the other patients, and they end up doing much better. I found this to be true, in that patients who had internalised Conservative notions of themselves as ‘undeserving’ tended to avail themselves of assistance less frequently and, later in their sickness, to perceive themselves in a more negative sense (see Chapter 4).

This process of self-categorisation, I found, is intimately linked with the categories and labels associated with an individual’s location at the intersection of different marginalised identities and the specific ways those identities are denigrated. Ponce Center patients, and even providers or other members, all have different ‘cultural domains’ that set them apart from most of ‘normative’ society: (1) ethnicity/race, (2) age, (3) gender dysphoria/identity issues, (4) non-conforming sexual orientation, (5) addictions, (6) HIV or other diseases, (7) poverty/homelessness/unemployment, (8) incarceration. This creates a cultural clash and sense of ostracization from the majority of society and the ‘dominant’ culture, and even their own community. For example, Bob Geldoff using the terms ‘hooker’ and ‘junkie’ at the 2014 AIDS Conference (see Chapter 3), and being critical of those who rejected these terms on the basis of increasing stigma, offended many of my respondents from HIV community because those words – and others like them – do confer stigma. Additionally, they increase the blame assigned to the individuals who fit them, both by others and in terms of their internal self-conceptions. It creates a cognitive bias against the individuals. For example, Vince shared that, ‘still my patients are fired from their jobs for HIV and even my HIV clinic nurse at the VA (who is African-American) recently moved into a white neighbourhood (outside the perimeter) and they burned her front yard. She ended up moving out right
away.’ Thus, Bob Geldorff’s classic attack on ‘political correctness’ fails to account for the actual harmful effect those terms can have on the social conversation, and on individuals’ self-perceptions and treatment success.

The concept of ‘human rights’ is another recurrent theme of this thesis. This is in part because it deals intimately with peoples who are already engaged in a struggle for civil and human rights denied them by the aforementioned marginalised identity categories. It is also because the debate about healthcare is often framed as a matter of rights versus practicalities. Both sets of struggles are constructed in relation to the concept of ‘Human Rights’ that evolved after the United Nations Declaration of Human Rights (1948) and its later adoption of the International Covenant on Economic, Social and Cultural Rights (1966). Paul Farmer (2013) characterized these two international agreements as two cultural perspectives. He describes the Political and Civil rights guaranteed by the UNDHR as ‘Negative’ rights, whereby a government has to ‘remove’ efforts to restrain certain groups the freedom to practice their political, civic and religious duties or beliefs. This he perceives as a very Western perspective. The East, he argues, are more supportive of ‘Positive’ rights, whereby a government must actively apply effort, resources and money to support certain groups who do not have the necessary social, economic and cultural freedoms and standards of others.

This aligns somewhat with Libertarian versus Liberal values in the debate about healthcare; many Americans in general, especially Conservatives, support the ‘bootstrap’ philosophy that a person should work hard to earn what they need and that the government or community should not therefore be responsible for health and also feel that certain ‘social diseases’ – illnesses that have a potential human behavioural component, like HIV – are the fault of the patient. Farmer calls this ‘blaming the victim’ (1993: 1999). Instead, a central tenet of AIDS and Accusation (Farmer 1993) is that one must understand and treat infectious disease in marginalised communities or impoverished nations by carefully examining the social, historical, and political context. Margaret Lock and Vinh-Kim Nguyen (2010) add that it is a mistake to use cultural beliefs and practices to explain continuing poor health and the spread of infectious diseases:
Efforts to portray the way in which people seek to survive and reproduce human and social existence historically and in the present, are often glossed as products of ‘culture’. From there, it has been a short step to see culture as a monolithic force that determines people’s identity and behaviour. [...] doctors and public health professionals have often used the culture concept as the key in linking social factors and disease (Lock & Nguyen 2010: 103).

Chapters 2 and 5 further the conversation about the translation of policies that affect and intersect with identity on both a small and large scale. They also explore what is meant by ‘translation’ itself; how, why, and by whose agency policies are moved and transformed in the context of national identity and the role of government. There are numerous aspects of healthcare reform that illuminate the political ideologies of various groups, which in turn reveal how they conceptualise America. For example, quality protection, price regulation, and the individual mandate repelled Libertarians, though not necessarily Conservatives. By contrast, the single payer government option repelled both Libertarians, who do not want government run programs or interference, and Conservatives, who want to protect insurance business interests.

The debate over the ACA also highlights the fact that Republicans and Conservatives do not actually oppose mandates and government control or regulation under all circumstances; in fact, they support so-called ‘big government’ with regard to issues of protection (i.e. the military and defence budget) and their own policy priorities (e.g. citizenship, family values, religion, corporate interest, tax cuts). Regarding the ACA, their objection to big government is protecting corporate and wealthy interests, as well as the status quo by maintaining their business interests and preventing the degradation of the white, middle class population and values they believe are the bedrock of US society. It is important to recall that the individual mandate was a Republican idea in during conflict over the 1990s Health Services Act, in part because Republicans objected ideologically to the proposition that ‘good’ citizens should have to pay for the uninsured – whom they saw, or indeed ‘constructed’, as undeserving – through higher healthcare costs, insurance premiums, and taxes to support government programs like Medicaid.
These categories of citizenship exemplify how this thesis contributes to our understanding of how policy sheds light on social realities, how people construct identities in relation to sickness, sexuality and race and relationships specifically in the context of living with HIV. The thesis supports the existing scholarship, which says that, in the U.S. context, the right to health has been reconfigured as a right to consumer choice with regard to health insurance plans, physicians, and pharmaceuticals (Horton et al. 2014). Narratively, this aligns American healthcare policy itself (in most forms, policies, and incarnations) with Capitalist, free market ideals, and constructs patients as ‘consumers’. It is partly on this basis that the ACA’s individual mandate has become a battleground for cultural war. That is to say, the patient-as-consumer model upholds the Conservative view that freedom is about the right to choose, but the individual mandate’s assertion that consumers must choose something contradicts it – while the mandate is both the mechanism by which Liberals seek to control the costs of the bill and a mechanism they hope will ‘level the playing field’ by ensuring that healthcare is extended to all Americans.

To understand how the ACA reflects the social contract between the state and citizens, I deconstructed the notion of market-based medicine by dissecting assumptions about the individual mandate. Coverage through the mandate still revolves around the notion of individual responsibility: rather than ‘socializing risk’, as promised by the policy, or protecting a public obligation to provide care, the individual mandate is presented as the individualized approach to public policy. The ACA constructs health care neither as a social good nor as part of the voluntary shared-resource system of the ‘commons’ (Nonini 2006), because it is an individual's responsibility to purchase coverage in the marketplace. While my informants’ experiences emphasised the notion of healthcare as a social good, my data does little to illuminate the problems of the ‘commons’, because HIV policy in America is highly specialized and the experience of care at the Ponce Center and within the HIV care assemblage is unique. However, my research highlights the fact that the success of healthcare reform depended on how the ACA was designed and implemented, with three major provisions depending on each other to succeed. The absence of Medicaid
expansion in Georgia set the whole policy at odds with the context of the lived experience of the patients I had an opportunity to involve in my research.

This debate, and the thesis more broadly, illuminates how policy is produced and contested as part of the project of making America; that is, producing a country that fits a peculiar – and highly contested – political, economic, and moral narrative of freedom. The thesis frames a certain way of understanding America through policy in general and the ACA in particular. It pays special attention to how the notion of health as a fundamental right is asserted, contested, and co-opted, and how Georgia — and various actors and subgroups within Atlanta and Georgia — defined the notion of health as a personal responsibility versus a public good. Again, it is important to classify the main thematic elements of the argument to show that both sides have internal debate: as one reader of this thesis, Claudia, Vince’s wife, who herself is an anthropologist commented, ‘If the Obama White House had a nudge team, why did they “punish” [with fines] and incentivize [with tax subsidies] those without insurance...whereas now the Republicans are looking to nudge and incentivize insurance [no punishment]?’

In a more specific sense, my thesis engages with how marginalisation is produced by policy, and by policy discourse around economics, morality, and freedom. Biehl (2006) and Nugyen’s (2010) work in Brazil and West Africa has been a particular inspiration, and provided much-needed comparison to establish that the direction American health policies are taking is not in isolation. A right to health study in Colombia shows similar opposition to health reforms that diminish access and equity (Abadia-Barerro, 2012). In the U.S., the aligned notions of personal responsibility and responsible citizenship reconfigured the right to health as an issue of consumer freedom. Analysis of my respondents’ translations and articulations show how they have asserted, contested, and co-opted the conflict between personal responsibility and public good. Following Wacquant (2013), I have argued that policy is designed primarily to fragment, exclude, and contain – which together produces marginalisation. This becomes especially interesting if AIDS is understood as a disease that has a disturbing tendency to bridge and muddle certain comfortable distinctions of class, race, gender, and sexuality (Comaroff 2006);
policy thus becomes a way of reasserting those divisions and hierarchies. Advocates for the HIV community must then engage with those policies – contest them, work around them, disrupt them, ignore them – in order to resist that effect of fragmentation, exclusion, containment, and marginalisation.

Although there has been certain success in reframing an HIV diagnosis as less of an inherently deviant ‘social disease’ (Farmer 1993), these efforts often merely re-position the margins and zones of exclusion so that they affect other aspects of the community instead. This can be seen in the differing perceptions of ‘innocent’ HIV victims, and in the varied framings of white cis gay male with HIV in opposition to the working-class people of colour who predominated the patient population at the Ponce Center. The Center itself represents a discourse of hope that is one way members of the HIV community resist marginalisation and connect with others. Networking and joint lobbying involving the Center and other local and national organisations, as well as allegiances between policymakers and agencies, are the other ways in which certain aspects of this fragmentation are resisted. These resistances also link into the project of ‘imagining’ America (per Anderson 2006) in terms of freedoms guaranteed by the Constitution to ‘legitimate’ and ‘deserving’ citizens.

Chapter 4 considers how the ACA functioned in people’s everyday lives with regard to the discourse around victim blaming the ‘undeserving’. It is important to emphasize that poor (0-44% FPL), childless adults do not qualify either for current Medicaid or insurance subsidies in Georgia, even with HIV. Most people, including Senators, believe any one of those conditions might qualify a person for Medicaid; in fact, in most states in the South, like Georgia, citizens must be pregnant, disabled, in need of nursing home care, older than sixty-four, or under eighteen. Thus, numerous people are still neglected by the system; their experience does not fit the construction of healthcare as either a social good or part of the commons, so often it cannot benefit the people who need it the most. Chapter 5 demonstrates the potential of the ACA or to change that; as previous HIV policy demonstrates, holistic healthcare reform can shift understanding of the myth of America or what it means to be an American citizen seeking access to care, particularly at safety net institutions like the Ponce Center. This
is significant because it highlights why it is more helpful to discuss the ‘social life’ of policy, which means also considering how policy impacts people’s actual lives and experiences, not just the legislative process or political debates. The social life of this policy includes the experiences of people with HIV, people working with HIV, and people affiliated with the Centre or the Centre’s network. As Shore and Wright (2011: 13) write,

The passage of law is one moment in a process of appropriation and contestation when a political coalition succeeds in silencing others, making their version authoritative and embedding it in the precepts and procedures of the state. But the dominant version can be immediately contested as it is translated into concrete situations.

It is easy to decipher how much the Republicans want to have this silencing power over the Democratic policy – even if they actively or passively hurt people, or only marginally improve the existing policy. Governor Deal, like many Republican Governors, would not set up the Georgia state exchange, despite the fact that Republican Congress members lobbied for the state exchanges to be instated in order to maintain a ‘free market’ ACA rather than the single payer option. Governor Deal never lived up to my informants’ hope that he would expand Medicaid by passing this decision on to the legislature. Thus, even though we did not benefit from Medicaid expansion, Georgia lost its safety net hospital (DSH) funding as part of the ACA in 2013-14, severely disadvantage hospitals like Grady, while rural hospitals continue to close.

This thesis should end by emphasizing the fact that HIV, and the issues of policy and healthcare access that surround it, epitomises an aspect of the human condition that society must be concerned with. Many people fail to understand that to be part of the HIV community – as a patient, but also as a caretaker, friend, family or provider – is to be an activist in the fight for human rights and social justice. Furthermore, that fight is not limited to the halls of government. Policies are contested, appropriated, articulated, dis-articulated, translated, and re-translated every day by people who engage with them in ordinary life. We shape our society with the policies we work for and we have a responsibility – just like the fragility of Ponce Center is articulated every day – to do so in such a way that the care assemblage remains in place.
Glossary

ACA Patient Protection and Affordable Care Act.
ACTUP AIDS Coalition to Unleash Power.
ADA Americans with Disabilities Act ADAP.
ADAP AIDS Drug Assistance Program.
AIDS Acquired Immune Deficiency Syndrome.
AID Atlanta An Atlanta-based organization that provides HIV/AIDS-related services, care, and education.
ARV Antiretroviral drugs are referred to as a combination ARV therapy (cART) is referred to as highly active ART (HAART).
AZT Azidothymidine. An HIV drug.
Blue Cross/Blue Shield A large U.S. insurance company.
'B Buyer's Club' Groups organized for obtaining unapproved (HIV) medications and information.
CBO Community-based organizations.
CD4 count The number of CD4 T lymphocytes (CD4 cells) in a blood sample. A laboratory test used as a predictor of HIV progression.
CAEAR Coalition Communities Advocating Emerge AIDS Relief (CAEAR) Coalition is the oldest national organization with a primary focus on the Ryan White HIV/AIDS Treatment program. CAEAR is a membership organization that advocates for Federal policy, legislation, regulations, and appropriations to serve the Part A, Part C, and ADAP community mandates to meet the care, treatment, support, and prevention needs of PLWHIV and the organizations that serve them.
CFAR The Center for AIDS Research (CFAR) program at the National Institute of Health provides administrative and shared research support to synergistically enhance and coordinate high-quality AIDS research projects.
Co-insurance* A fixed percentage of the total cost of a health service, such as a doctor visit, laboratory test, hospital visit, or a prescription drug that an individual enrolled in a health plan pays “out-of-pocket” towards that service. Co-insurance is sometimes covered by a third party, such as the Ryan White Program.
Co-payment* A fixed amount an individual enrolled in a health plan pays “out-of-pocket” toward the cost of a covered health service such as a doctor’s visit, laboratory test, hospital visit, or a prescription drug. These may vary by type of service. Co-payments are sometimes covered by a third party, such as the Ryan White Program.
Deductible*  The set dollar amount an individual enrolled in a plan must pay before the health plan starts to pay for services. Depending on the plan, an issuer may pay for certain services before meeting the deductible. Deductibles are sometimes covered by a third party, such as the Ryan White Program.

Georgia Equality  Lesbian, Gay, Bisexual, and Transgender rights advocacy groups in Georgia.

Grady  The largest hospital in Georgia and the public hospital for Atlanta; affiliated with the Ponce Center.

Health Exchanges  Entities – online websites – that facilitate the purchase of health insurance through the ACA.

HIV  Human Immunodeficiency Virus.

HRSA  Health Resources & Services Administration.

Insurance Commissioner  State official charged with regulating the insurance industry in a state.

IRB  Institutional Review Board.

Medicaid  A federally funded U.S. healthcare program for those with limited resources.

Medicare  A U.S. national social insurance program administered by the U.S. federal government for older individuals.

SisterLove  A volunteer group of women interested in educating Atlanta, especially communities of women, about HIV prevention, self-help, safer sex techniques, policy, and advocacy.

PLHIV  People Living With HIV.

Premium*  The amount owed to an issuer (health insurance company) on a monthly basis to keep a policy active, typically paid by an individual or a third party, such as an employer or the Ryan White Program.

Ryan White CARE ACT/Program  Ryan White Comprehensive AIDS Resources Emergency Act

Voter ID laws  Laws that require official identification before an individual can vote (or register to vote).

Viral Load  The quantity of HIV virus in a blood sample. Also used as an indicator for monitoring HIV disease progression.

*Key Insurance Terms Kaiser Family Foundation website
Bibliography


*Journal of management inquiry* 2(4): 373-90


Declaration of Independence (1776). Available at 
[https://www.archives.gov/founding-docs/declaration-transcript] [Accessed 16 May, 2017]


Horton, et al. (2001)


Lamphere, L. (2005) ‘Providers and Staff Respond to Medicaid Managed Care: The Unintended Consequences of Reform in New Mexico’. Medical Anthropology Quarterly 19: 3-25.


16th Conference on Retroviruses and Opportunistic Infections, Montreal, February 8-11, 2009.


