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March 21, 2024

Community Organizing in Atlanta:  
Perspectives from the AIDS Crisis and COVID-19 Pandemic

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An abstract of  
a thesis submitted to the Faculty of Emory College of Arts and Sciences  
of Emory University in partial fulfillment  
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Bachelor of Science with Honors

Anthropology

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## Abstract

### Community Organizing in Atlanta: Perspectives from the AIDS Crisis and COVID-19 Pandemic

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The purpose of this study is to explore and compare the experiences of community organizers in Atlanta during the early years of the AIDS epidemic and COVID-19 pandemic. Both public health crises created a pervasive sense of fear and uncertainty in communities across the United States while revealing gaps in our social support structures. The AIDS epidemic demonstrated the devastating effects of neglect and stigma, and the COVID-19 pandemic exacerbated existing inequalities in our healthcare, employment, and economic systems. Using the social determinants of health as a theoretical framework, this study provides insight into the growing needs of affected communities and the response of local leaders.

In order to place the community responses in conversation with each other, two sets of interviews were analyzed: ten with local leaders from the AIDS epidemic from the Atlanta AIDS Legacy Project (AALP), and nine that I conducted with local leaders from the COVID-19 pandemic. Both groups of community organizers responded with versatility and innovation to address their respective challenges, taking into account the unique history and characteristics of Atlanta. AALP interviewees created or supported new organizations, as existing organizations were hindered from action due to the stigma associated with the virus. They faced challenges with inexperienced leadership and building new organizational structures, while also exhibiting significant creative freedom and capacity for collaboration. In contrast, most COVID-19 participants were already leaders at their organizations when the pandemic began. They drove the coordination of partnerships and new programs when faced with societal shutdowns, social distancing guidelines, public health hesitancy, and staff turnover. By directing attention to the community organizer experience, this study unveils critical lessons that can be applied to future public health crises.

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## Acknowledgements

I would like to acknowledge everyone who helped make this thesis possible. Thank you to my adviser, Dr. Rachel Hall-Clifford, for providing consistent and constructive guidance throughout the entire process. I deeply appreciate all of your support, and I have undoubtedly grown as a student and as a researcher because of you. Thank you to my committee members, Dr. Jodie Guest and Dr. Craig Hadley, whose impactful courses have inspired me to pursue a project at the intersection of community health and anthropology. Thank you to Ms. Heather Carpenter for supporting my experience in the Anthropology program during my four years at Emory, and to Dr. Bobby Paul for leading the Anthropology Honors cohort. Thank you to Sandra Thurman for capturing such important stories through the Atlanta AIDS Legacy Project. Thank you to my interviewees for sharing your inspiring and impactful perspectives. Thank you to my family for always being there for me and putting a smile on my face. I am so grateful for your support in all that I do. Finally, thank you to my friends for the endless laughs, countless coffee shop study sessions, and for making my time at Emory so special.

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## 1. Introduction

Public health crises shift social dynamics, create tension, and reveal weaknesses in existing health services and social structures. At the same time, public health crises have demonstrated the remarkable impact that individuals can make on their community – even while confronting tragedy and uncertainty. This study aims to highlight the experiences of these community organizers in Atlanta during the AIDS epidemic and COVID-19 pandemic.

Specifically, this study narrows in on the early years of each health crisis. The first case of what would later be called acquired immunodeficiency syndrome, or AIDS, was reported in 1981. As the crisis worsened, this “unknown” disease was mainly concentrated among gay men, injected drug users, and hemophilia patients. Even after the virus was identified and spread speedily throughout the country, the government and general public largely neglected AIDS during the 1980’s. This was further complicated by the powerful stigma associated with the disease, leading to discrimination against those suffering from AIDS and preventing action from politicians and corporations.

This widespread fear and tragedy was also present during the early years of the COVID-19 pandemic. One year after the first U.S. case in January of 2020, there were nearly 470,000 deaths from COVID-19 (CDC, 2024). Just as the AIDS crisis caused immense suffering among affected communities, the transmissibility and deadliness of COVID-19 left a huge emotional toll across the United States. COVID-19 existed alongside a backdrop of heightened political polarization, healthcare inequality, and economic disparity, which were all exacerbated over the course of the pandemic.

Atlanta is a diverse and growing city that was heavily impacted by both public health crises. In order to address the neglect and stigma of the AIDS crisis, and the polarization and



inequality of the COVID-19 pandemic, community organizers in Atlanta stepped up to fill in gaps of inaction. As an exploratory project, this study analyzes and compares interviews with local leaders from both time periods. The interviews center around four themes: Atlanta's distinctive context, challenges the interviewees faced, strategies they implemented, and their reflections on community organizing during the respective crisis.

There exists a gap in the research on community organizing during public health crises. This is especially true for the AIDS epidemic, of which scholarship generally focuses on the epidemic in San Francisco and New York through ACT UP's activism. By directing attention to the local community organizer experience, this study demonstrates the importance of considering a community's unique history and context when responding to a crisis. Additionally, this study places AIDS and COVID-19 organizing in conversation with each other. It accomplishes this using the concept of social determinants of health (SDOH) as a theoretical framework, as nonmedical factors played a significant role in exacerbating existing disparities and necessitating action from community organizations during both time periods. This thesis centers the voices of local leaders to understand how community organizations addressed these escalations of unmet needs

## 2. Literature Review

### **Social determinants of health: A lens for understanding disparity within HIV/AIDS and COVID-19**

The World Health Organization (WHO) defines health inequities as “differences in health status or in the distribution of health determinants between different population groups” (World Health Organization, 2018). These disparities are impacted by a variety of nonmedical factors such as education, income, and food security – otherwise known as the social determinants of health (SDOH). The SDOH affect individuals’ living conditions and access to resources, creating a gradient in health outcomes that often correlates to factors such as socioeconomic status (World Health Organization; Braveman and Gottlieb, 2014). As such, medical solutions alone cannot improve health outcomes permeated with social and environmental disparities (Braveman et al., 2011). In “The Social Determinants of Health: Coming of Age,” Braveman et al. reviews upstream social determinants (education, socioeconomic status, employment, racial discrimination) that shape downstream determinants (behaviors, attitudes, health-related knowledge) (Braveman et al., 2011). McGinnis and Foege found that half of all U.S. deaths in 1990 involved behavioral causes (McGinnis and Foege, 1993). This is an example of the devastating effects of downstream determinants, which are often the target of social and community programs (Braveman et al., 2011).

Scholarship on social determinants began increasing in the late 1980’s and early 1990’s. This was due in part to the establishment of the Task Force on Black and Minority Health at the U.S. Department of Health and Human Services, the task force’s monumental report on minority health, Michael Marmot’s and Richard Wilkinson’s book entitled *Social Determinants of Health*, and increasing conversations about addressing SDOH at the WHO (Braveman et al., 2011;

Osmick and Wilson, 2020). Since then, focus on the SDOH within the literature has rapidly grown (Braveman et al., 2011).

*Epidemic Inequities: Social and Racial Inequality in the History of Pandemics* is a historiography of disparities during public health crises over time (McGovern and Wailoo, 2023). It reveals how epidemic inequities have been occurring for generations, orienting around race, class, and empire. Though health disparities are not new, recent scholarship over past decades (including that related to AIDS and COVID-19) has broadened our understanding of these inequalities and provided greater nuance into the conversation.

#### *Disparity and Marginalization in the HIV/AIDS Epidemic*

On June 5, 1981, the CDC published an article in its *Morbidity and Mortality Weekly Report* that described five cases of *Pneumocystis carinii pneumonia* (PCP), a rare lung infection, in previously healthy gay men in Los Angeles. Five cases of Kaposi's Sarcoma (KS), a rare and aggressive cancer, were also reported among gay men in New York and Los Angeles on the same day. Both diseases are associated with weakened immune systems (HIV.gov).

This unknown syndrome, increasingly reported among gay men, led to the establishment of the CDC's Task Force on Kaposi's Sarcoma and Opportunistic Infections. The CDC first used the term "AIDS," or Acquired Immune Deficiency Syndrome, on September 24, 1982 (HIV.gov). By early 1996, there were an estimated 650,000-900,000 cases of HIV in the United States (CDC, 1990).

Dan Royles emphasizes how the AIDS epidemic "is deeply enmeshed with everything from the war on drugs to urban planning to malnutrition" (Bell et al., 2017). In their previously mentioned historiography, McGovern and Wailoo discuss how the AIDS crisis exposed the recurring issue of blame and social stigmatization within minority groups, and the lack of policy

from the state to address the needs of stigmatized populations (McGovern and Wailoo, 2023). Gay, bisexual, and other men who have sex with men are known to be at the highest risk of contracting AIDS. Black/African American and Hispanic/Latino communities are disproportionately affected by HIV; the former represent 12% of the U.S. population but 40% of individuals with HIV, and the latter represent 18% of the U.S. population but 25% of individuals with HIV (CDC, 2023). This reveals the consequential impacts of gaps in political, economic, and social systems that “open a lens onto the structural inequalities of society” (HIV.gov, 2023; Kanazawa, 2023; Bell et al., 2017).

*And the Band Played On*, the 1987 book by Randy Shilts that was later developed into a popular film, has served as a popular narrative and educational resource on the origins and causes of AIDS. The book has received criticism for perpetuating blame-the-victim narratives, reducing the advocacy from gay communities to a solely a “white gay response.” Furthermore, the book establishes an “origin story” of patient zero, creating an oversimplified paradigm that has since been shifted onto Haiti as the source of the virus’s introduction to the United States, prompting widespread discrimination and prejudice against Haitians (Bell et al., 2017). In “Interchange,” Emily K. Hobson writes that this search for the origins of the epidemic has demonstrated how HIV/AIDS is fueled by “histories of colonialism and globalization, capitalism and poverty, drugs (and their criminalization), sexuality (LGBTQ and otherwise), conservatism, social welfare, and public health (especially structural racism and other inequalities in health)” (Bell et al., 2017).

Today, there continues to be significant disparities among persons with HIV (PWH) in the United States. One study found that over 80% of PWH experience at least one SDOH indicator and 25% experience four or more SDOH indicators, with poverty as the most prevalent

indicator (experienced by 43% of PWH). Other significant SDOH indicators present among PWH are intimate partner violence, the need for transportation assistance, the need for help completing medical forms, food insecurity, and education level (Menza et al., 2017).

Furthermore, the southern United States experiences a disproportionate number of new HIV cases. This may be influenced by SDOH such as social attitudes and socioeconomic deprivation stemming from the enduring legacy of Jim Crow segregation and racism (Jeffries and Henny, 2019).

### *Disparity and Marginalization in the COVID-19 Pandemic*

On March 31st, 2020, New York Governor Andrew Cuomo tweeted that COVID-19 was “the great equalizer.” However, this has not proven to be the case. In “The impact of the COVID-19 pandemic on marginalized populations in the United States: A research agenda,” Neeta Kantamneni debunks Governor Cuomo’s blanket statement, reviewing the pandemic’s differential impact on historically marginalized groups in the United States. The pandemic has shed light on previously-existing, yet hidden, inequalities – a key characteristic of crises. While completely uprooting daily life, social distancing measures and societal shutdowns revealed inequities in access to decent work and discrimination (Kantamneni, 2020). The most impacted employment sectors included restaurants/bars, travel and transportation, personal services, and certain types of retail and manufacturing (Vavra, 2020). Women, African American/Black, LatinX, and Native American individuals represent a high percentage of employees in these sectors, resulting in people of color and women being disproportionately displaced from their jobs during the pandemic (U.S. Bureau of Labor Statistics). This means that social distancing exacerbated the already higher unemployment rates and lower wages of African American/Black and LatinX employees (compared to white employees) that was present before the pandemic.

Similarly, these populations are underrepresented in white-collar jobs that provide work-from-home accommodations, health benefits, paid sick leave, and decent salaries. Those in precarious positions, such as grocery store workers, had to choose between their health (due to potential viral exposure) and the need to earn wages for basic necessities (McNamara et al., 2021).

Kantamneni's essay calls for greater research that "fully explores the economic and psychological consequences of workers of color in the United States during the COVID-19 pandemic" – particularly among these already marginalized groups. Additionally, the pandemic created a multiple role conflict for women, who were more likely to assume the burden of educating and providing 24-hour care to their children during the shutdown, increasing strain and affecting wellbeing (Kantamneni, 2020; Nohe et al., 2015).

These bio-social disparities, influenced by SDOH, manifest in COVID-19 health outcomes. Low income is a leading predictor of COVID-19's most common comorbidities, which include obesity, hypertension, cancer, metabolic disorders such as type 2 diabetes, and pulmonary disease (Brinkworth and Rusen, 2022). Black/African American, Indigenous, and non-White Hispanic groups suffer the greatest economic marginalization in the United States, causing these populations to suffer disproportionately from comorbidities and contract and die of COVID-19 (Brinkworth and Shaw, 2022). According to a CDC report on February 1st, 2022, those identifying as Black or Hispanic had a 2.5-fold higher risk of hospitalization than those identifying as White. Additionally, those identifying as American Indians/Alaskan Natives had a 3-fold higher risk of hospitalizations compared to those identifying as White (CDC, 2022). Non-White, non-Asian individuals in the U.S. are nearly twice as likely to die from COVID-19 than White individuals (Brinkworth and Rusen, 2022). Bhuiyan et al. explores the disparities found within undocumented immigrants, finding a strong positive correlation between the prevalence

of COVID-19 and deaths in this population (Bhuiyan et al., 2021). McGovern and Wailoo explore the ever-present role of social vulnerability in the coronavirus pandemic, emphasizing that recovery will be uneven since “epidemics do not end evenly” (McGovern and Wailoo, 2023). Their historiography calls for historians to grapple with questions of voice, perspective, uneven recovery, and enduring trauma and pain when writing pandemic history. In his essay in *The Lancet*, Horton writes that “unless governments devise policies and programmes to reverse profound disparities, our societies will never be truly COVID-19 secure” (Horton, 2020).

### **Leadership during Public Health Crises**

#### *Crisis: Defined by Anthropology*

The exact definition of *crisis* is often contested, further complicated by discussions that aim to designate when crises “start” and “end.” Ulmer, Sellnow, and Seeger define a crisis as a “specific, unexpected, and non-routine event or series of events that create high levels of uncertainty” (Ulmer, Sellnow, & Seeger, 2022). Crises pose “a significant threat to high priority goals such as life, property, security, health, and psychological stability” (Sellnow and Seeger, 2020). The resulting shock, stress, and novelty from unfamiliar problems, or familiar problems at an unprecedented scale, create an urgency for innovative solutions (Kaiser, 2020).

Taking an anthropological approach when studying crises, particularly public health crises, allows for new “innovative conceptual directions” to understand various underlying forces (Barrios, 2017). Anthropological methods such as ethnographies dive deep into the human aspects of disasters, diversifying the perspectives from which we can view and analyze them. For instance, an anthropological study of forest fires challenges the previous notion of these phenomena being purely natural disasters, leading to a greater understanding of human-environment relationships. Using an anthropological lens, we can recognize that so much

depends on the “sociopolitical vantage point from which the beholder problematizes disaster.” Public health crises impact and are impacted by the social structures of a community, and anthropology can be used as a tool to understand them (Barrios, 2017).

### *Crisis Leadership: Applied to Local Leaders*

Just as crises are explored through multiple vantage points, there are multiple approaches to understanding crisis leadership. Using an anthropological perspective, Peter Redfield engages with questions surrounding organizational models of humanitarianism and ethicality throughout his research on Doctors Without Borders (Redfield, 2013). Additionally, ethnographic and qualitative research provides insight into the leadership structures of community-based organizations, such as the interdisciplinary team at the Nuevo South Action Research Collaborative (Contreras and Griffith, 2011).

Kaiser notes that humans are “disposed to seek leadership in times of confusion, chaos, and threat as an adaptive solution for coordinating a collective response” (Kaiser, 2020). Organizations, in addition to individuals, rely on leaders for their survival during a crisis, as their ability to continue operating is primarily determined by the organization’s response rather than the severity of the crisis (Garcia, 2006; Mitroff, 2005). Leaders are often expected to simultaneously develop new solutions while also providing stability and predictability to their organization (Kaiser, 2020). The body of literature surrounding what qualifies as effective leadership during crises is varied and dynamic, changing over time and contexts. Early theorists on crisis leadership, such as Charles Perrow and Ian Mitroff, emphasize decentralized leadership and proactive planning to address threats that may arise. They acknowledge that it is impossible to prepare for every possible crisis, but continue to emphasize anticipation as a means of crisis management. Fred Fiedler’s Cognitive Resource Theory claims that more experienced leaders



perform better under times of stress and crisis since they can act quickly to initiate well-rehearsed strategies, while intelligent leaders perform better under non-stressful conditions due to their greater ability to weigh various options (Riggio and Newstead, 2023).

Drawing from complexity science, Uhl-Bien et al. proposes a new conceptual framework for leadership models called Complexity Leadership Theory (CLT). CLT focuses on leadership strategies and behaviors that “foster organizational and subunit creativity,” allowing the context of the system to influence direction and viewing leadership as a process. They argue that Complexity Leadership Theory is better suited for the adaptive challenges common in the Knowledge Era than previous leadership models, which are tailored for the technical challenges common in the Industrial Era (Uhl-Bien et al., 2007). Riggio and Newstead expand on Complexity Leadership Theory as a form of crisis management:

In a crisis situation, regardless of its type or source, organizational members need to work together to develop adaptive and creative solutions. This involves rapid sharing of information, generation and consideration of possible courses of action, functional and constructive conflict from diverse members, and the ability to quickly change direction. According to complexity theory, leadership does not start with the leader in a top-down fashion. Instead, it emerges from the complex interplay of people, leaders, followers, and other stakeholders—and the rich contexts in which said interplay occurs. (Riggio and Newstead, 2023).

Versatile leadership is a model rooted in CLT, drawing on the central role of context and adaptability. It emphasizes the ability to read uncertain situations and respond to this change with “a wide repertoire of complementary perspectives, skills, and behaviors” (Kaiser, 2020).

Drawing on the wide range of leadership theories, with a particular concentration on CLT, Riggio and Newstead propose five key competencies for effective leaders during unforeseen crises: Sensemaking, Decision-making, Coordinating Resources and Teamwork, Facilitating Learning, and Communication (Riggio and Newstead, 2023).

Sensemaking refers to how a leader gives meaning to an unfolding crisis as revealed through their actions (Riggio and Newstead, 2023). As Karl E. Weick states, “people often don’t know what the ‘appropriate action’ is until they take some action and see what happens. Thus, actions determine the situation” (Weick, 1988). Sensemaking is also a leader’s ability to “[create] a mutual understanding of what is happening, what it means, and what must be done” (Riggio and Newstead, 2023).

Decision-making involves how the leader gathers relevant (and often incomplete) information, seeks advice, balances trade-offs, and weighs consequences of a variety of stakeholders (Riggio and Newstead, 2023).

Coordinating Resources and Teamwork encompasses how the leader fosters trust and resilience within their organization, delegates responsibility, collaborates with leaders from other organizations, and provides direction, alignment, and coordination. Riggio and Newstead argue that effective leaders during a crisis “encourage diverse groups and individuals to work together to address the crisis, and the leader should empower these members to act and make decisions as appropriate, always ensuring that members are monitored and that communication lines are open and flowing” (Riggio and Newstead, 2023). It is natural for people to crave an authoritative leader during times of distress (Gerada, 2021). However, delegating leadership and encouraging collaboration in the face of unfamiliar problems (rather than relying on top-down organizational

models) allows community members more directly involved with their respective populations to be involved in the decision-making process.

Facilitating learning corresponds to how a leader acts during and after a crisis. Rather than avoiding or directing blame, Riggio and Newstead state that leaders should direct their energy towards reflecting on what worked well in managing the crisis, what worked poorly, and carrying forward lessons learned. Additionally, their paper highlights how “the disruptive nature of crises often requires rapid and dramatic adaptations to work and organization, which can provide rich opportunities to learn possible new-normal practices” (Riggio and Newstead, 2023).

Finally, leaders must be adept at Communication during crises. Communication encompasses how a leader distributes information as well as how they listen, tapping into the shared humanity and making stakeholders feel reassured. The communication must be open, clear, sincere, frequent, emotionally appropriate, and multidirectional (Riggio and Newstead, 2023). Hassan A. Tetteh establishes a framework for *what* and *how* leaders should communicate during crises (Tetteh, 2020). The three “W’s” of *what* to communicate are *what happened?*, *what are you doing about it?*, and *what does it mean to me?* The four “C’s” of *how* to communicate are through Credibility, appropriate Context, Compassion, and Commitment. Tetteh connects this framework to communication during the Ebola outbreak, using this 2014 crisis as a case study for how we can apply lessons in communication to the COVID-19 pandemic (this also serves as an example of the “facilitating learning” competency) (Tetteh, 2020). Clare Gerada, a physician at the Hurley Clinic in London, underscores the importance of language during public health crises. She highlights the pervasiveness of war metaphors when discussing COVID-19 and its divisive impacts. Gerada also applauds New Zealand Prime Minister Jacinda Ardher’n’s

impactful language during the pandemic, emphasizing her consistent “clarity, honesty, and... compassion” that created a sense of unity and successful viral containment in New Zealand (Gerada, 2021).

Riggio and Newstead’s five competencies will serve as a framework for understanding the response of Atlanta leaders during the HIV/AIDS epidemic and the COVID-19 pandemic. Though Riggio and Newstead seem to discuss these competences in the context of high-profile leaders, this framework successfully applies to local leaders who made significant impacts through exhibiting these qualities at their community organizations.

### **COVID-19 and Complexity Theory**

These five competencies proved to be extremely important during the COVID-19 pandemic, as leaders often had to communicate, make critical decisions, and create shared meaning in a period of ongoing uncertainty filled with more unknowns than knowns.

In *SARS-CoV-2 Is Not Special, but the Pandemic Is: The Ecology, Evolution, Policy, and Future of the Deadliest Pandemic in Living Memory*, Brinkworth and Rusen discuss COVID-19 in the context of previous disease; specifically, they focus on reemerging patterns and unique features (Brinkworth and Rusen, 2022). Compared to SARS-CoV, SARS-CoV-2 is more infectious and reaches peak levels of maximum infectivity sooner – often before symptoms appear. Since January 12, 2020, COVID-19 has caused over 7 million deaths globally, over 1 million deaths in the United States, and nearly 37,000 deaths in the state of Georgia (WHO COVID-19 Dashboard; COVID Data Tracker).

Uhl-Bien discusses the concepts of complexity, emergence, and adaptive space in relation to the pandemic. Organizations experience *complexity* when faced with an adaptive pressure, in which “a) there is no known solution, b) people must work together in new partnerships who

haven't worked together before, c) these partnerships are characterized by conflicting views (i.e., high heterogeneity), and d) agents have high interdependence such that, in extreme cases, they must adapt together or they will die." These complexity pressures enable the *emergence* of ideation processes for creative solutions that would not have been conceptualized otherwise. This *adaptive space*, or "conditions that enable the adaptive process to occur," is necessary to advance new ways of thinking and unprecedented solutions. It is a product of the tension between pressures to change and pressures for stability, requiring adaptive outcomes to balance both. Adaptive space naturally opened up during the COVID-19 pandemic, loosening various systems and organizations for change. This took several forms, such as how distilleries repurposed their facilities to produce hand sanitizer, communities began drive-through food lines for those who lost their jobs, and hospitals turned to crowdsourcing and 3D printing to make up for supply shortages (Uhl-Bien, 2021).

Riggio and Newstead argue that in Complexity Leadership Theory, the role of leader during times of crisis is "less about providing direction and more about providing adaptive space for stakeholders to generate novel responses collectively" (Riggio and Newstead, 2023). When expertise, experience, and data are limited during crises such as COVID-19, it is important to involve multiple stakeholders with various contributions to adaptive space (Tetteh, 2020).

The social determinants of health encompass all of society, including education, economic resources, nutrition, housing, and access to healthcare. With its embedded complexity, incorporating the SDOH into conversations naturally invites greater emergence, adaptive space, and innovative solutions into the conversation.

## **Community Organizing in Public Health**

### *HIV/AIDS Activism during the 1980's-1990's*

Reiko Kanazawa's 2023 historiography of AIDS scholarship explores the relationship between the weak government response and early stages of AIDS activism (Kanazawa, 2023). President Ronald Reagan did not publicly mention AIDS until September of 1985, four years after the first announced cases in Los Angeles (Georgia State University Library). By this point, there had already been nearly 12,000 reported cases of AIDS and almost 6,000 deaths (National Library of Medicine). Furthermore, Reagan fought to protect private providers from liability from AIDS, placing the burden on the already overwhelmed public welfare system and limiting avenues of healthcare. Without significant support from the federal government, funding often came from independent donors such as the Rockefeller and Ford Foundations (Bell et al., 2017). Angered by this lack of a coordinated government response, vulnerable communities – most visibly, white gay men – mobilized to advocate against the indifference of public health institutions to sexual minorities. During this time, African American Studies and feminist scholar Evelyln Hammonds revealed the neglect of black queer men and women, highlighting the racial and gender politics at play during the epidemic (Kanazawa, 2023). While AIDS activism during the 1980's focused on increasing drug research and accessibility, its messaging and strategies shifted in the early 1990's towards an analysis of structural violence affecting AIDS vulnerability and outcomes in the United States and globally (Bell et al., 2017).

A key organization in the history of AIDS activism is the AIDS Coalition to Unleash Power, or ACT UP. Formed in March of 1987 in New York City, there have been over 80 chapters of ACT UP nationally and over 30 internationally (Gould, 2009). ACT UP utilized methods such as civil disobedience, raucous demonstrations, die-ins, and meetings with

government officials, and they made a tremendous impact in attracting attention to the needs of various populations, increasing treatment accessibility, and influencing legislation (Gould, 2009). Amaro et al. describes one of the first federal funding initiatives that addressed HIV/AIDS in minority groups (Amaro et al., 2001). This Minority AIDS Initiative, established in 1998, reveals both the power of community advocacy and the federal government's delay in addressing the structural forces shaping disparity within the epidemic. Reflecting on this public health crisis in the context of future emergencies, Kanazawa emphasizes that "each sector, institution, professional, and individual has a role to play in an effective response" (Kanazawa, 2023).

Dan Royles highlights how AIDS activists, such as those at ACT UP, "had to be disruptive and disobedient in the face of a society that didn't believe that their lives... mattered, and a society that blamed them for the disease that was killing them." These individuals drew on traditions of activism from previous decades surrounding antinuclear and environmental advocacy, gay liberation, women's rights, black power, and civil rights (Bell et al., 2017).

During the early 1980s, protestors commonly compared HIV/AIDS to war, particularly the Holocaust and Vietnam War, to highlight the scale of the epidemic, call for government action, and reinforce the social value of those who were suffering and dying. Emily K. Hobson has explored how antiwar organizing earlier in the twentieth century shaped HIV/AIDS activism. Strategies to evoke this response included activists' citing of death tolls in the context of war losses ("by 1990, almost twice as many Americans had died of HIV/AIDS related causes than U.S. soldiers lost during the Vietnam War") and initiatives such as the NAMES Project AIDS Memorial Quilt, which echoed the Vietnam Veterans Memorial (Bell et al., 2017).

The AIDS Memorial Quilt is one example of creative approaches taken by AIDS activists and community organizers. Performance and theater played a significant role among cultural activists, including productions by Latino performers at Teatro Vivo! in Los Angeles and by the Black performance group, Pomo Afro Homosin, in the San Francisco Area (Bell et al., 2017). In *Acts of Intervention*, performance scholar David Román traces the role of theater in the larger cultural politics of race, sexuality, citizenship, and AIDS in the U.S. beginning in the 1980's (Román, 1998). Experimental videos by activists such as Marlon Rigs have documented underrepresented histories of AIDS that centered women, queer, and trans people of color. In New York City, the provocative “Let the Record Show” window installation at the New Museum flashed images of “AIDS criminals” preventing necessary governmental action and text displays such as how “the Pentagon spends in one day more than the government spent in the last five years for AIDS research and education” (Crimp, 1987).

Among the extensive research on AIDS activism and community response, there exists significant gaps. There is limited research on the role of the philanthropic sector during the beginning years of the epidemic, despite how they shaped early financial responses to the AIDS crisis due to the lack of government action. Furthermore, a large proportion of literature on AIDS activism centers around San Francisco and New York City, with a particular focus on ACT UP. The richness of archives on this topic varies greatly between states, depending on how actively the respective state governments have prioritized these collections (Bell et al., 2017).

### *Community Organizing during COVID-19*

There is currently a gap in empirical evidence investigating the efficacy of community organizing in reducing health inequalities (Nouman, 2023). The COVID-19 pandemic shed light on the significant disparities within health outcomes in the United States, prompting community



organizations to step up and address the social determinants of this health gradient. Furthermore, in the summer of 2020, there was a national reckoning with racial inequality in our country, prompting mass Black Lives Matter (BLM) protests, corporate gestures of solidarity, and an aftermath of conversations surrounding the American policing, education, and criminal legal system, among others. With the backdrop of BLM and a deadly pandemic, community building and organizing was heavily used to create movements, undo systematic power imbalances, and promote equality in health outcomes and beyond (Minkler and Wakimoto, 2021).

In the past few years, scholarship on the pandemic has covered some community initiatives that sought to address the needs of vulnerable groups. Mansfield et al. describes the Get Out the Vaccine program in California, which was a government-funded canvassing program that partnered with community-based organizations to conduct COVID-19 vaccine outreach, registration, and education. The authors highlight the necessity to leverage trusted entities and understand the sociopolitical, geographic, and cultural factors of communities (Mansfield et al., 2023). Pacheco et al. also demonstrates the importance of strategically partnering with local public health and social service partners to achieve health equity, particularly in rural and under-resourced urban communities in Kansas (Pacheco et al., 2023). Community organizing often shifted to virtual spaces due to social distancing guidelines, as exemplified by a mutual aid network that used information communication technologies to connect two separate towns in Boston, providing opportunities for members to request and fill needs (Wilson et al., 2022).

As research on community organizing during the COVID-19 pandemic continues to grow, discussion of community building, addressing structural barriers, and online methods are emerging as prominent themes.

### *A History of Multiorganizational Partnerships in Public Health*

A community-based solution evident during both the HIV/AIDS epidemic and the COVID-19 pandemic is the establishment of partnerships between organizations. In general, public health activities in the United States combine efforts from various government and private organizations with different missions, resources, and types of operations. Through collective action, organizations agree to coordinate activities rather than act in isolation or compete with each other, pursuing objectives that may not have otherwise been possible (Mays and Scutchfield, 2010).

Mays and Scutchfield review the strengths and challenges of multiorganizational partnerships in improving community health, defining partnerships as “social networks formed among organizations.” They review social network theory as a means of understanding the dynamics of organizational collaboration. Network breath reflects the array of different actors (affecting the resources available), network density measures the amount of interconnectedness, and network centrality describes the relative influence of a single organization within a partnership (Mays and Scutchfield, 2010).

Partnerships can be beneficial in decreasing duplication among organizations that would otherwise perform the same actions independently, realizing new goals that were unachievable by a single organization, and creating a larger combined level of impact. Potential challenges of multiorganizational partnerships include goal alignment, sacrificing organizational autonomy, opportunity costs, and the risk of exacerbating inequities (Johnston and Finegood, 2015; Mays and Scutchfield, 2010). If the partnership lacks strong coordination between parties, it may create greater inefficiencies that decrease effectiveness and perpetuate gaps within public health activities (Mays and Scutchfield, 2010).

The role of partnerships over time is evident in previous literature. Baker et al. reinforces the importance of partnerships between hospital systems/public health agencies and non-governmental organizations, citing key examples in the 1990's that proved highly impactful. This includes a successful collaboration in 1992 between the Dekalb County Board of Health and the Antioch Baptist Church North, in which the church resourced a block of their low-income housing facility for patients with Tuberculosis requiring directly observed treatment. Due to financial and programmatic governmental constraints, health departments in the early 1990s sought out partnerships, coalitions, and shared resources to achieve their objectives rather than working through the restricted bureaucratic channels. Public school systems, non-health governmental agencies, hospitals, churches, university institutions, and nonprofits worked together to adapt to the difficult political and budget environment (Baker et al., 1994).

More recent literature, such as that by Johnston and Finegood, establishes diverse partnerships as a core practice within public health, deeming it necessary to address the many determinants of health that fall outside the reach of healthcare organizations. In the past, public health practitioners have been distrustful of the private sector due to prior disasters, including those in the tobacco and baby formula industries. More recently, cross-sector partnerships have gained momentum in response to the epidemics of obesity and non-communicable diseases (NCDs). The WHO has also shifted its stance to support cross-sector partnerships within the field of public health. Johnston and Finegood set the foundations required for successful collaboration, which include trust (emphasizing the importance of the socio-psychological aspects of partnership), transparency about conflicts of interest, and monitoring and evaluation (Johnston and Finegood, 2015).

As a rapidly-changing public health crisis, the COVID-19 pandemic saw the formation of many partnerships. Park and Chung analyze South Korea's response to the coronavirus through the lens of its structured web of public-private partnerships (PPPs). Early in the pandemic, South Korea's leadership turned to PPPs to conduct widespread testing across the country, drawing on lessons learned from testing failures during the 2015 outbreak of MERS, another highly infectious disease (Park and Chung, 2021). This serves as a key case example for leveraging cross-sector collaboration to address public health issues.

This thesis explores the role of multiorganizational partnerships in Atlanta during both HIV/AIDS and COVID-19. One prominent sector in these collaborations are faith-based organizations. Previous literature emphasizes the importance of African American churches during public health crises, as they have a long history of influence, accessibility, and trust within their communities. This is due to their high attendance, established infrastructure, active health ministries, and influential and trusted pastors (Berkley-Patton et al., 2022). In December of 2020, African American adults were over two times more likely than Hispanic or White adults to know someone who was hospitalized or died from the coronavirus (Brewer et al., 2020). This reinforces the need for community-based efforts to mitigate these disproportionate impacts. By leveraging existing infrastructure, such as the networks built by African American churches, culturally-relevant resources and materials can be disseminated to economically and socially marginalized communities (Brewer et al., 2020).

### **Setting the Scene: Atlanta and the U.S. South**

In a 2012 paper in the *Annual Review of Sociology*, Richard Lloyd situates Atlanta within the urbanization process of the southern United States. The South has experienced dynamic

population growth for decades, uniquely influenced by its specific history and contemporary conditions. Southern cities have taken shape during the struggles for black freedom in the 1950s and 1960s, creating geographic divisions between White and Black areas. Furthermore, most southern cities, including Atlanta, experience sprawling growth as opposed to high-density urban areas. Rather than concentrated in inner-cities, the majority of African Americans in the Atlanta metro area live in the suburbs (Lloyd, 2012).

Lloyd argues that urbanization in the South played a significant role in creating the conditions necessary to challenge Jim Crow, as “cities catalyze social movements; they are sites of struggle, and, in many cases, they are the objects of struggle as well.” At the same time, urbanizations created the conditions for the “ultimate limits” that the Civil Rights Movement could reach (Lloyd, 2012).

Atlanta undeniably played a central role during the Civil Rights Movement, serving as the backdrop of several mass protests and the birthplace of the Southern Christian Leadership Conference (SCLC), which coordinated protest activities across the South. The city was also home to leaders such as Dr. Martin Luther King, Jr. and John Lewis, who grew the movement across the country (Atlanta History Center).

As a southern city in the state of Georgia, Atlanta has long been surrounded by conservative politics. However, during the last few decades of the twentieth century, it became known as a sanctuary for LGBTQ+ individuals in the South and received new residents who sought safety and community (Emerson, 2021). As of March 2021, there were an estimated 194,000 individuals who identify as LGBT in the metro Atlanta area – about 4.6% of the population (Conron et al., 2021)

Additionally, Atlanta is characterized by its immigrant population. Immigrant residents make up 14% of the metro area's total population, with over half at risk of deportation (Vera). Clarkston, a city within Dekalb County, is known as the "Ellis Island of the South." Immigrants from countries such as Vietnam, Bosnia, Ethiopia, Somalia, Nepal, Burma, and more recently, Iraq and Syria, are attracted to the city due to an established population of foreign-born residents existing social networks (Kim and Bozarth, 2021).

Despite its centrality to the Civil Rights Movement and reputation for serving as a refuge city, Atlanta remains a center of inequality within the United States. Kim and Bozarth found that one third of Clarkston foreign-born residents experience difficulty receiving health care due to high costs and lack of insurance. They also found higher rates of poverty among foreign-born residents in Clarkston compared to native-born respondents in the city (Kim and Bozarth, 2021).

In 2019, the U.S. News Report ranked Atlanta as having the second greatest income inequality gap (following San Juan, Puerto Rico) (Bach, 2020). Sjoquist names this "the Atlanta paradox," as there exists substantial racial segregation in a community with a reputation for good race relations as well as "high inner-city poverty in the face of substantial economic growth" (Sjoquist, 2000).

The foundations for this disparity are evident in recent decades, such as significant gentrification that has displaced Black residents and provided the majority of economic opportunity to White residents moving in (Lloyd, 2012). Orfield and Ashkinaze analyze how conservative policy in Atlanta during the 1980's – despite electing its first African American mayor – has contributed to current manifestations of inequality along racial and socioeconomic lines (Orfield and Ashkinaze, 1991). Combined with Atlanta's sprawling growth, this contributes

to the “suburbanization of poverty” – a trend of particular importance to community organizations who seek to address the needs of marginalized populations (Lloyd, 2012).

### 3. Methods

This study explores the community organizer experience in Atlanta during the AIDS crisis (narrowing in on 1981-1990) and the COVID-19 pandemic (narrowing in on 2020-2022). For the purposes of this study, “community organizer” is broadly defined as a leader who brought individuals together to achieve common goals. Community organizers are sometimes referred to as “local leaders” in this paper. In order to investigate the dynamics of community organizing during these public health crises, I analyzed two groups of interviews.

The first group are interviews from the Atlanta AIDS Legacy Project (AALP). These ten interviews were conducted between 2009-2014 by Sandra L. Thurman, the former Director of the White House Office on National AIDS Policy and Presidential Envoy for AIDS Cooperation under President Clinton. The AALP began as Thurman’s master’s thesis with the purpose of documenting Atlanta’s initial response to the AIDS crisis from the perspective of those who spearheaded the city’s efforts. These interviews are stored digitally in the Emory University Stuart A. Rose Manuscript, Archives, and Rare Book Library, which I am able to access as an undergraduate student at Emory. Each interview was moderated by Thurman and lasts about one hour in length. I selected the AALP because these ten interviewees represent a diverse group of local leaders who responded to AIDS from nonprofit, government, and public health perspectives.

I organized and conducted the second group of interviews, titled “COVID-19 interviews.” These nine interviewees, referred to in this paper as “COVID-19 participants,” were recruited through email outreach and references from those I already interviewed. The COVID-19 interviews were one hour in length and took place over Zoom. These interviews were semi-structured, based on the interview guide included in the appendix. I began by reading through the



consent form (see appendix), and participants provided verbal consent to participate in the study.

### *Breakdown of AALP interviewees*

AALP interviewees represent federal and state government bodies (four), nonprofit organizations (five), and faith-based organizations (one). Of the five interviewees at nonprofits, four worked at organizations that started during the AIDS crisis. Two of the ten interviewees are HIV-positive.

Name	Sex	Age (at interview)	Organization	Position	HIV positive?
Bruce Garner	Male	60+	The Episcopal Church	LGBTQ+ advocate	No
John Lewis	Male	60+	U.S. House of Representatives	Georgia congressman	No
Alicia Philipp	Female	60+	Community Foundation for Greater Atlanta	President	No
James Curran	Male	60+	Center for Disease Control	Leader of the task force on HIV/AIDS	No
David Sheppard	Male	60+	Design Industries Foundation Fighting AIDS (DIFFA)	Executive Director	No
Jesse Peel	Male	60+	AID Atlanta; Positive Impact	Founding member	Yes
Jim Martin	Male	60+	Georgia General Assembly	State representative	No
Nancy Paris	Female	60+	AID Atlanta	Hospice care director	No
Stephen Woods	Male	60+	Open Hand	Executive Director	Yes
Jane Carr	Female	60+	Georgia Division of Public Health	Director, Office of Infectious Disease	No

### *Breakdown of COVID-19 Participants*

COVID-19 participants represent nonprofit organizations (six), public counties in Atlanta (two), and a private university (one). Participants 2 and 4 work for the same humanitarian nonprofit. All organizations represented were in existence prior to COVID-19.

Participant number	Sex	Age (at interview)	Organization Type	Position
1	Male	20-40	Crisis response nonprofit	Area Director
2	Female	40-60	Humanitarian nonprofit	Regional Donor Services Executive
3	Female	40-60	Youth-focused nonprofit	Chief Social Impact Director
4	Female	40-60	Humanitarian nonprofit	Regional Medical Director
5	Male	60+	Rollins School of Public Health	Dean
6	Female	40-60	Public county	District Health Director
7	Female	60+	Funding nonprofit	Communications Executive
8	Female	40-60	Nonprofit for HIV services	Communications Executive
9	Female	20-40	Public school system	Health Services Director

In order to analyze each set of interviews, I first transcribed them by using Zoom's closed captioning feature. From here, I downloaded the transcriptions into Delve, a qualitative coding software, and coded each interview for four main themes: disease in the context of Atlanta, challenges faced by community organizers, leadership and community organizing strategies, and reflections of community organizers. The following Results section is divided into two chapters

(one for each set of interviews), and each chapter walks through these four coded themes for their respective set of interviews.

#### 4. Results from Atlanta AIDS Legacy Project Interviews

##### **The AIDS epidemic in the context of Atlanta**

###### *The juxtaposition between Georgia and Atlanta*

Several AALP interviewees discussed the social and political environment of Atlanta during the early stages of the AIDS crisis. During the 1980's, Atlanta was known to be a safe haven for LGBTQ+ communities in the South. However, located in the state of Georgia, Atlanta was still functionally southern and conservative. One focus of the AALP is the implications of this sociopolitical context on the HIV/AIDS epidemic.

Georgia's conservative environment contributed to a delayed public health response. The general public and majority of leadership was disinterested in taking action due to the notion that AIDS was a "gay disease;" it was an isolated issue that it wouldn't affect them. Jim Martin described how topics of sexual orientation and sex "was not considered appropriate conversation" in those days (J. Martin, AALP, July 7, 2009). Bruce Garner and Nancy Paris discussed how this apprehensiveness deterred effective education about the disease. While sex education models existed in the more liberal California and New York, the Georgia legislature blocked initiatives that included sexually-explicit information. This inability for the state government to be publicly upfront and promote preventative measures created a unique challenge for Atlanta, whose growing young population did not fully align with the conservative values of the greater state. David Sheppard noted this juxtaposition between the city, with civil rights leader Andrew Young as its mayor, and the state, with politicians enforcing AIDS denial and homophobia.

The United States lacked a coordinated federal response as AIDS cases increased during the 1980's, reflected in President Reagan's unwillingness to publicly discuss the epidemic until

prompted by reporters at a press conference in 1985. This reluctance was mirrored in the state of Georgia. At a high level, Georgia contained a conservative legislature that controlled the state health department and streams of funding. Due to the stigma surrounding AIDS, government and corporate organizations were hesitant to associate themselves with the epidemic. Without their support, there was a scarcity of funding and support programs to assist impacted groups.

### *The power of Atlanta community members*

Though the state and federal government neglected the rising AIDS crisis, passionate individuals and organizations navigated this conservative environment by taking action outside of the political sphere. They drew on Atlanta's "tradition of local initiatives," in which "leaders of individual communities within the city [work] together to solve problems" (J. Martin, AALP, July 7, 2009). Jane Carr believes that "we were able to do things in Atlanta that I think, maybe didn't happen in other places because we had forceful, intelligent, compassionate people of integrity who were respected" (J. Carr, AALP, June 21, 2009).

It was the community members of Atlanta driving the response against AIDS, rather than those in the highest positions of power. They were the "heart and soul of the professional healthcare response to HIV/AIDS," shaping the consensus of "what was acceptable care, what was appropriate care, how our definition of the continuum of care needed to expand and grow and be more holistic and be more inclusive" (N. Paris, AALP, July 7, 2009). They utilized their social networks, high level of involvement with non-profits, and, among the wealthy, elite social clubs to involve more members in the community in the response to AIDS.

*Building on the civil rights movement*

Another theme discussed by participants is Atlanta's history in the civil rights movement. Nancy Paris referenced "The Atlanta Way," which broadly refers to Atlanta's history of Black and White communities working together on racial issues. More specifically, "The Atlanta Way" is a term for the city's urban governance strategy in the mid-1900's, in which coalitions were formed between Black and White political and business elites (Edget and Abdelaziz, 2021). One participant discussed how Atlanta's AIDS response was benefited by this previously existing, highly-participatory corporate community. This process has been lauded for creating a desegregation process without intense White violence, but criticized for promoting a false narrative of economic and residential equality (Edget and Abdelaziz, 2021). Serving as the foundation, this history has led to other nicknames such as "the city too busy to hate" and the "Black Mecca," demonstrating how enmeshed Atlanta is with its past (Edget and Abdelaziz, 2021).

The Civil Rights Act, prohibiting discrimination on the basis of race, color, religion, sex or national origin, was passed in 1964 (U.S. Department of Labor). When the AIDS epidemic arrived two decades later, the civil rights movement and its legacy were still fresh in the minds of community members. AALP interviewees reflected on the lessons learned from the civil rights movement that were applied to the AIDS epidemic, as both time periods were characterized by heightened potential for conflict, divisiveness, and uncertainty. Nancy Paris discussed how Atlanta could have "crossed the line" and become a "hotbed of conflict" and discrimination during the AIDS crisis, but never succumbed due to lessons learned previously and the ability to integrate various perspectives (N. Paris, AALP, July 7, 2009).

Alicia Phillips provided a contradictory perspective to “The Atlanta Way,” describing an “inability to talk about race” and an “inability to really figure out how we're gonna work around race” (A. Philipp, AALP, June 20, 2009). This was evident in hesitant discussions about whether separate organizations were necessary to address HIV/AIDS in African American populations in Atlanta.

Among those determined to collaborate, group organization and joint action were not immediate. Community organizers faced a variety of challenges during both the early and later stages of the AIDS epidemic, both related to the nature of the disease and the social structures the virus interacted with.

### **Challenges faced by community organizers during the AIDS epidemic**

#### *Lack of understanding and empathy*

A primary challenge faced by communities impacted by AIDS was getting others to pay attention to the severity of the disease. Jim Martin noted that the virus was “more or less neglected than being divisive initially” (J. Martin, AALP, July 7, 2009). Nobody knew much about the disease during the first year after the reported cases – just that it affected gay men. As a result, it was easy for those who were unaffected to pay little attention to AIDS and its impacts. Denial circulated in Atlanta when AIDS was initially concentrated in New York and San Francisco, with the popular scapegoat that the disease only affects gay men (“them, not us”) in “those cities far away.” In reality, when the first five cases were reported in 1981, there were already an estimated 250,000 people infected with HIV across the United States (J. Curran, AALP, June 16, 2009). This created a sudden shock and atmosphere of fear when the virus inevitably amplified in Atlanta. As the crisis progressed from indifference through “othering” to alarm, fear became a guiding force in the community reaction. This fear manifested in two

diverging ways: 1) discrimination and stigma against affected groups, and 2) the drive to take action.

### *Stigma against LGBTQ+ communities*

Several AALP interviewees described the terror and uncertainty within the community, especially when the virus was discovered and it became visible in other groups, such as individuals with blood transfusions. People didn't know how the virus spread or who it would affect next. While AIDS was concentrated in LGBTQ+ communities, it was easy for the wider public to focus less on the emerging health crisis and more on the rising unemployment and inflation of the time period. HIV/AIDS was "something that happens to other people," a sentiment reinforced by the stigma against LGBTQ+ populations in the early 1980's. Jim Martin described the resulting discrimination in Atlanta, such as hospital rules that prohibited families from visiting their loved ones dying of AIDS and dentists who refused to see patients infected with the virus due to fear of transmission (J. Martin, AALP, July 7, 2009). Bruce Garner recounted a man calling AID Atlanta, one of the city's most comprehensive HIV/AIDS service organizations, to pick him up from the airport because the airline had rejected him from flying.

This stigma is also apparent at the organizational level, as companies were hesitant to "be tainted by treading into AIDS-related waters" (N. Paris, AALP, July 7, 2009). David Sheppard, founder of Heart Strings in Atlanta, reflected on cold-calling experiences where the phone was slammed in his face – an immediate reaction fueled by homophobia. Local major corporations who did want to donate money to fighting AIDS would do so anonymously through the Community Foundation, ensuring their name was not attached. Even the United Way of Greater Atlanta, a community investment organization with a long history of impact in public health, was initially reluctant to fund AIDS initiatives. Alicia Philipp recalled it taking five to six years



before corporations were willing to directly support AIDS organizations (A. Philipp, AALP, June 20, 2009). Those held back by this bias could not separate AIDS as a public health crisis from their stigma against LGBTQ+ populations.

#### *Limited funding for AIDS initiatives*

During the first decade of the epidemic, federal, state, and county support was sparse. Georgia did not provide state funding until the late 1980's, leaving community organizers without a consistent source of money. Jane Carr described how organizations such as AID Atlanta were working to provide social services and education about transmission, yet “we in public health [Georgia Division of Public Health] were basically forbidden to communicate with the organization, much less provide them any funding. That went on for several years” (J. Carr, AALP, June 21, 2009).

Lacking federal or state funding, early community organizers instead directed their energy towards seeking out philanthropic benefactors. Nevertheless, the size of grants was rarely enough to keep pace with the need, as organizations were often “pulling from the same pool of money” to support and grow their initiatives (B. Garner, AALP, June 19, 2009). The challenge of securing funding was an underlying theme across all AALP interviews.

#### *Inexperienced leadership*

John Lewis states that “the response to AIDS in the US was actually not a government response, but a community response” (J. Lewis, AALP, November 26, 2013). Many of the most impactful organizations and initiatives in the fight against AIDS can be attributed to the passionate activists who decided to take matters into their own hands. These “unusual characters” came from all sectors of society with a wide range of backgrounds; however, very

few had experience leading public health initiatives, growing community programs, or running nonprofits – they were starting from scratch. This posed various leadership and management challenges; though the determination and passion were unwavering, there was limited prior experience to ensure successful execution. Nancy Paris reflected on her initial involvement with AIDS organizations, claiming that she was naive and uninformed. Even though she had a professional health background working with hospice care, she felt ill-prepared and had to learn lessons on crisis response in the midst of the epidemic, such as how to present AIDS-related issues to funders and volunteers in a boardroom who had differing reactions (N. Paris, AALP, July 7, 2009).

*Creating organizational structures with no precedent to follow*

As discussed previously, the community response to AIDS changed as the nature of the disease became increasingly apparent. New information about who was at risk, how the virus is transmitted, and how specific needs should be addressed was constantly evolving. This required local organizations, which were still in their early stages of development, to adapt as they were growing and building a presence in the community. Nancy Paris emphasized the chaotic nature of these early years:

It was helter skelter. You couldn't finish writing a letter [for things to change] in that period of time. I remember at an early board meeting that we had someone around the table who was a stickler for details and she said, you know, we're out of compliance with the bylaws, and I said I don't give a rip. I mean, bylaws be damned, you just couldn't put a structure or a funding mechanism or a program in place that could absorb the growth in

the epidemic, the trajectory that we were on. It was like we had been shot out of a cannon (N. Paris, AALP, July 7, 2009).

As the disease progressed, there were many conflicting pressures within organizations as individuals expressed different opinions on approaches they should take. Nancy Paris described this as a constant “back and forth” where “there were so many forces at work that people couldn’t always behave in the way that they thought was best” (N. Paris, AALP, July 7, 2009). This included the need to respond to the needs of management, funders, the governor, and the legislature, among others – resulting in crucial questions about who to trust, who to work with, who to “call our own,” and who to depend on.

The continuously-changing state of the AIDS epidemic exacerbated other issues, such as the lack of leaders with prior nonprofit experience and the extremely limited funding sources. This meant that improving the management systems of organizations was often not a priority:

All the time we kept thinking this was temporary. This disease was gonna be cured.

These organizations were only going to be needed for a short period of time... so do they really need personnel policies and long range strategic plans and you know all the things that we would expect of other organizations? (A. Philipp, AALP, June 20, 2009)

In addition to an ever-evolving community health landscape, it was very difficult for young organizations to measure success. Bruce Garner explained how they were providing services to those infected with HIV, and “you measure success usually in the healthcare community by the fact that somebody recovered. Well, nobody was recovering” (B. Garner, AALP, June 19, 2009).

This disease was especially tragic during these years of uncertainty, fear, and lack of recovery from the virus. Even though many of the individuals leading these community organizations were learning on the spot, they brought grit and stamina in working through challenges. This included the need to work through difficult conversations with varying opinions about how to address the needs of different populations in Atlanta, such as African American communities. On organization boards, there was a conscious effort to share the leadership with members of the African-American community; however, there were varying levels of success in accomplishing this – with lots of room for improvement. Bruce Garner highlighted the unanswered question of who should be serving this population, as there was “a certain group of African Americans who did not think they could be served by anybody but an African American organization” (B. Garner, AALP, June 19, 2009). In this sense, progress often came not from immediate consensus, but from intense discussions fueled by differing viewpoints.

#### *Tension between community organizations*

As discussed previously, a lack of funding was a significant obstacle for community organizations. This already limited stream of money was narrowed by the reluctance of some funders to make grants to organizations that were less than three years old – constituting most AIDS relief organizations. As a result, organizations were all applying for the same few funding opportunities available.

As someone responsible for the distribution of funds from the Georgia Division of Health, Jane Carr faced intersecting issues of funding competition, lack of management experience, and determining what was an effective number of organizations to support (J. Carr, AALP, June 21, 2009). Some AALP interviewees noted that Atlanta was unique in avoiding competition or overlap between organizations during its early stages of AIDS response. They

celebrated the avoidance of significant duplication, which would have decreased efficiency if multiple organizations were trying to solve the same problems. On the other hand, others, such as Nancy Paris, revealed an underlying aura of competition between organizations. She described how some people would see new AID Atlanta programs, then decide to create their own initiatives and boards to “do that on our own” (N. Paris, AALP, July 7, 2009).

In reflecting on these challenges, Nancy Paris also reiterated the necessity for multiple entities to work together simultaneously:

In retrospect, it was just completely unrealistic to think that one organization could grow and handle all this. It would have imploded. It would have become its own bureaucracy. So other responses were needed, innovation was needed, creativity was needed, and I think that may have created a better service delivery system (N. Paris, AALP, July 7, 2009).

Faced with an unraveling epidemic, funding restrictions, and a lack of instructions for effective AIDS community organizing, local leaders were in a constant battle with the challenges they faced. This required them to continuously adapt, honing in on their own strategies that ultimately enabled these community organizations to make a significant impact on the city of Atlanta.

### **Leadership and strategies of Atlanta’s AIDS community organizations**

#### *First to act: the LGBTQ+ community*

AIDS initially appeared in the LGBTQ+ populations of urban areas. These communities were tired of seeing their friends and family dying from the growing yet neglected disease, and they became the first to respond to AIDS (including many who were infected with HIV, who

knew just how isolating infection felt). Early on, a key initiative was the buddy program, in which volunteers would provide one-on-one support to those suffering from AIDS. Jesse Peel highlighted the importance of the buddy program during a time in which those infected often lost their jobs, were restrained from their family, and lacked any treatment (J. Peel, AALP, June 21, 2009). Many of the volunteers were infected with the virus themselves or had a close friend or family member with the virus. As a result, this community work came with a very significant emotional toll for those involved. It commanded tremendous courage, strength, and resilience to relentlessly advocate for their communities and provide support for those suffering from a disease very personal to themselves.

The drive to take action among the LGBTQ+ population in Atlanta coalesced in 1982 with the creation of AID Atlanta, which grew as additional needs surfaced such as food delivery and housing. It became the central organizational body for AIDS relief in the metro area.

One strength of Atlanta's LGBTQ+ community was its far-reaching network within the city. Several AALP interviewees highlight how these broader relationships allowed those unaffected by AIDS to encounter LGBTQ+ activists in other sectors of their lives, with a prime example being in the business sector.

During the early stages of the AIDS crisis, Atlanta's community action was primarily driven by volunteers. Alicia Philipp described the early AIDS organizations as the most volunteer-centric community response she can recall (A. Philipp, AALP, June 20, 2009). Since the LGBTQ+ community in Atlanta was quite heterogeneous, the foundation of volunteers and community organizers were, on their own, a very diverse group of individuals:

One of the strengths of the gay community is that it knows no socioeconomic status or race or ethnicity. So, while it is a minority based on sexual orientation, it has members in

every other subset of society. Politicians, government workers, scientists, bus drivers, the unemployed... (J. Curran, AALP, June 16, 2009).

Since the LGBTQ+ community was not confined to a specific population, their influence was evident across many aspects of society. After this community's initial advocacy and response to the AIDS crisis, the base of community organizers began expanding outside of Atlanta's LGBTQ+ community.

#### *Expanding community leadership outside of the LGBTQ+ community*

Jim Martin underscored that the AIDS crisis in Atlanta brought together a "cast of characters" that would not have been the usual suspects for collaboration and community engagement (J. Martin, AALP, July 7, 2009). At the onset of the epidemic, there was an absence of an established network of public health organizations sufficiently equipped to address AIDS. When young organizations sprung up to fill this gap, they recognized the necessity to recruit leaders with a diversity of backgrounds and experiences.

This shift did not happen seamlessly. A few AALP participants discuss the tension that arose within organizations when more leadership was given to those outside of the LGBTQ+ community. Some early community organizers were reluctant to let others get involved, maintaining that the LGBTQ+ community was responsible for initiating much of the early response and should be the ones guiding further initiatives.

The expansion of community involvement led to the development of more structured operations, such as volunteer management systems that some early volunteers were not fond of. They wanted the agency to help in the ways that they chose, rather than through delegations from higher leadership.

Ultimately, broadening of community leadership was highly beneficial to the AIDS response, as almost all AALP interviewees discuss how this advanced their respective organizations. David Sheppard believes that bringing in members of the medical, business, and nonprofit communities to serve on the board of Heart Strings was a significant door opener and key to their success (D. Sheppard, AALP, February 18, 2014). Furthermore, though it was formed two decades before the AIDS crisis in 1951, the Community Foundation for Greater Atlanta initially felt unprepared to tackle the epidemic's impact. In response, they established an advisory committee with those who could do site visits and bring additional knowledge on the organizations being funded (A. Philipp, AALP, June 20, 2009).

In addition to accumulating expertise, including new communities in an organization's operations was beneficial for strengthening fundraising initiatives. In his AALP interview, David Sheppard discussed the Heart Strings performance at the Fox Theater and how the broad base of supporters from the political community, corporate community, and social community made this a successful philanthropic event.

### *Organizational boards*

The boards of AIDS organizations, including AID Atlanta, were unique in that they were "working boards" in which "board members are actually providing services in addition to managing the organization" (J. Peel, AALP, June 21, 2009).

Though tension and competition between AIDS organizations has been acknowledged, there was also a significant degree of cooperation and coordination. For instance, Jesse Peel described a monthly meeting of executive directors from a variety of organizations in which they sought out to "complement each other rather than being in direct competition" (J. Peel, AALP,



June 21, 2009). Leaders would ensure they did not plan fundraisers on the same date and maintained a stream of transparent communication amongst one another.

### *Task forces*

Task forces also served a central role in the AIDS response in Atlanta. During a tragic public health crisis flooded with stigma, uncertainty, and fear, these groups discussed the large amount of information (and lack of information) related to AIDS and how to best move forward at their respective organization. Task forces were intentionally created to provide a space for open dialogue between individuals with differing areas of expertise and varying opinions. In his AALP interview, Jim Martin spends a significant amount of time reinforcing the importance of the task force at the state legislature, as it improved legislation by providing a space for the debate of issues at the intersection of science and policy. Jane Carr attributes much of the legislature's early success to this task force, adding in details about their beneficial media coverage in Atlanta newspapers, television stations, and the radio to get out information. Jesse Peel describes the AID Atlanta task force as a place where people from "all over the state and all walks of life" could come together through purposeful discussion.

### *The influential role of the individual*

Legislative wins in the late 1980's and early 1990's were the culmination of years of advocacy by community members. This securing of funding was certainly a group effort; however, it simultaneously highlights the important role that specific individuals played in enacting change during the AIDS crisis.

Outside of Atlanta, and especially in rural areas of Georgia, there was a "desert" of services for AIDS with few resources to provide those infected with the virus. This resulted in an

influx of people to Atlanta. Alicia Philipp discussed how within the state of Georgia, AIDS became known as “an Atlanta disease.” This placed a strong pressure on Atlanta political leadership to speak out on the state level.

These influential political figures advocated tirelessly for the necessity of federal and state support. Jane Carr, former Director of the Office of Infectious Disease at the Georgia Division of Public Health, was a key figure in creating a funding structure for AIDS organizations. She described her experience sitting down with various organizations, creating goals and objectives, and monitoring benchmarks of success (J. Carr, AALP, June 21, 2009). In the Georgia Legislature, Jim Martin helped secure some of the first public funding in the fight against AIDS in 1988-1989 (University of Georgia Special Collections Libraries). After the political advocacy surrounding a teenager with hemophilia barred from attending his school due to his AIDS diagnosis, the Clinton Administration passed the Ryan White Care Act in 1990, which provided funding to states, communities and families suffering from the impacts of AIDS.

High-profile figures also played a significant role in increasing attention and funding towards addressing the AIDS epidemic. A notable example in Atlanta is the advocacy work of Elton John, who established the Elton John AIDS Foundation and has funded nonprofit organizations across the Southeastern United States (Wooten, 2018).

As an increasing number of people became involved in AIDS relief initiatives, multiple sectors started overlapping and collaborating in innovative approaches. Community organizers developed creative solutions to tackle the difficulties created by public neglect, stigma, limited funding, and working without a precedent.

*Creative strategies for community organization*

This paper has established the LGBTQ+ community in Atlanta as the first ones to act in the fight against AIDS. With its 10 interviews of local leaders who were deeply involved in addressing the AIDS crisis in the 1980's, the AALP paints a picture of what this early response looked like. These community organizers implemented creativity and unconventionality in raising awareness and money for the cause. This included opening up their own wallets and homes for events ranging from dinners to pool parties to sophisticated musical events.

Several AALP described these parties as a defining factor of the very early response to AIDS. These events, with its festive atmosphere, served to bring people from across the region together in the same room and provide a place to both plan future action and serve as a positive outlet during the tragedy of the epidemic. Jesse Peel reflected on his parties around his pool or on his boat as “the beginning of the long history” of people coming together in the AIDS response (J. Peel, AALP, June 21, 2009).

With limited funds available, community organizers ensured that what money they did have was spent in impactful ways – which often meant creative applications to let their funding stretch as far as possible. A key characteristic of the AIDS response across the country, including in Atlanta, was the involvement of the arts. David Sheppard first created Heart Strings, a musical that portrays narratives of those affected by AIDS, in 1986. After its first production in Atlanta, the show evolved into a highly successful fundraising event and toured nationally, with Jimmy and Rosalyn Carter as the national honorary co-chairs, as well as the mayors of each city the tour visited (Spearnak, 1990). David Sheppard discussed with pride how the initial Heart Strings performance served as a template that “would help not just Atlanta, but communities all over” (D. Sheppard, AALP, February 18, 2014).

As more people joined in the effort against AIDS, community organizations began to utilize pre-existing resources to further their impact. One key example is the Georgia Division of Health's hiring of the network of health educators in the state to improve awareness among teachers and caretakers about transmission routes and prevention efforts. Jane Carr believes that this initiative was key in preventing the high levels of discrimination against those with AIDS that were seen in other states (J. Carr, AALP, June 21, 2009).

These collaborative relationships are also seen within community organizations, who would partner with other entities to assist with marketing, fundraising, and reaching new areas of the community. Stephen Woods described Open Hand events that provided ways for restaurants and others to get involved without having to take on a significant burden of work (S. Woods, AALP, February 18, 2014). At AID Atlanta events, external parties would often donate resources such as flowers, music, and entertainment.

Just as community partnerships were extremely important to programs at the Georgia Division of Health, Open Hand, and AID Atlanta, they were central to the operations of the Community Foundation for Greater Atlanta. The Community Foundation for Greater Atlanta served as a critical resource for expanding AIDS relief operations in the city. Alicia Philipp attributes this to the organization's advisory committee, which included affected individuals, business and medical professionals, and long-standing relationships with other organizations in the community. This allowed the Community Foundation to help these other organizations integrate the HIV/AIDS message into their work and think about the health crisis in a different way.

## **Reflections on community organizing during the AIDS crisis**

### *Lessons learned from the Atlanta AIDS response*

A key theme among the reflections of AALP interviewees is that epidemics reveal weaknesses in our social structures. By exploiting the gaps in society, AIDS reinforced the need to proactively strengthen our existing structures, even (and especially) when there is no health crisis to test their limits.

Additionally, John Lewis reiterated the importance of those in visible positions of leadership to serve as a “national light,” – speaking up about emerging crises and painting a picture about why their constituents should care (J. Lewis, AALP, November 26, 2013).

The necessity for earlier collaboration between politics and public health surfaced as another key lesson. Though the lack of initial government action was a significant hindrance, several AALP interviewees took time to acknowledge the powerful effects and legacies of early individuals, such as those that established the buddy program and delivered meals on wheels.

Additionally, a few AALP interviewees noted how the leaders who emerge during crises may not be the expected figures. For instance, liberal activists initially did not want to work with Tom Murphy, the Speaker of the Georgia House of Representatives who was notably very powerful and very conservative. However, Murphy ended up being an important ally in the legislature during the AIDS movement, underscoring the importance of bipartisan leadership and not ruling people out in collaborative efforts. Jesse Peel highlighted the need for diverse perspectives in leadership groups, as the AIDS response grew in scale and success when the circle was broadened to include individuals from all backgrounds and sectors of society (J. Peel, AALP, June 21, 2009).

Another common reflection on the AIDS epidemic was the importance of utilizing existing structures during public health crises. This includes taking advantage of the variety of expertise in a community, particularly in the development of task forces. Task forces allow agencies to incorporate new goals into their operations, rather than requiring the development of entirely new entities. Jane Carr is an especially strong proponent of this strategy, as it encourages people from all aspects of the community to become involved (J. Carr, AALP, June 21, 2009). Recommendations derive from this joint effort, and they carry greater credibility from the public and from policymakers.

One AALP interviewee noted that the AIDS crisis created an overall change in how health care institutions perceive themselves.

Because health care institutions didn't necessarily see themselves as by and for the community, they did not necessarily define themselves as being accountable to the community. And I think AIDS really brought that into institutions and also helped create partnerships between service providers or community-based organizations and traditional mainstream healthcare delivery programs (N. Paris, AALP, July 7, 2009).

The AIDS epidemic helped healthcare institutions realize the necessity to be integrated into their communities, collaborating with other organizations to maximize their impact. This reveals another lesson from the epidemic: connecting various organizations and developing partnerships early on. Jane Carr emphasized how the AIDS crisis paved the way for cross-sector partnerships in the future, as it was “probably the first time in a public health epidemic that this had been so critical, because the scope of it was so large and we had so much to do with not a lot of staff, not a lot of money in the early days” (J. Carr, AALP, June 21, 2009).

The new organizations that emerged to combat the AIDS crisis served as “parallel systems” with organizations that had already been in place, yet did not want to take on the burden of addressing the stigma-ridden epidemic. Alicia Philipp argued that future responses to health crises will benefit if existing organizations can push past stigmas and take early action (A. Philipp, AALP, June 20, 2009).

These organizations were also limited by their monetary resources, as government funding was greatly delayed considering the gravity of the crisis. When legislation such as the Ryan White CARE Act in 1990 was passed, it revealed the significant and far-reaching impact enabled by consistent streams of money. When the government is funding a crisis response, legislatures need to understand that there is no “cookie cutter response” to crises such as an epidemic; rather, governments should consider every community’s unique challenges and opportunities, and develop policy that encompasses this heterogeneity.

Regarding funding, a couple AALP interviewees from funding agencies (such as the Georgia Division of Health and the Community Foundation) suggested that they would have utilized a different funding blueprint. For instance, Jane Carr states that “we would have been better off to have maybe a maximum of say three [organizations], and then have branches of those organizations that were funded to do different things,” rather than providing funds to almost anyone who applied (J. Carr, AALP, June 21, 2009). This would have also benefited the clients seeking out AIDS services, preventing them from navigating a very diversified system of organizations.

Overall, the AALP highlights how the AIDS crisis is still highly relevant in our society today. Nancy Paris summed up this takeaway, framing the epidemic as an important case study to reflect back on:

Well if you look at AIDS if you examine AIDS you're able to see the best and the worst of health care. Of religion. Of voluntary community response. Of political action. It's a wonderful sort of microcosm of all the societal responses and systems that exist to address any big problem (N. Paris, AALP, July 7, 2009).

Community organizers, including all AALP interviewees, realized these lessons after navigating the uncertain times of the epidemic to the best of their ability. This required grit, determination, and stamina during a period of time filled with so much tragedy. Considering this, it is also important to discuss the subjective experiences of these local leaders, including their motivations and the personal identities they brought to their work.

#### *Personal experiences as a community organizer*

Like other early community organizers, many AALP interviewees became involved after experiencing fear and frustration with the growing epidemic. Several mention stories about close friends who were getting sick, and they underscore both the emotional toll and call to action this created. Affecting many different populations in Atlanta, the epidemic fostered shared grief within communities. John Lewis described how those in the African American community “were in the same boat,” with so many knowing a friend or relative who was affected by AIDS, resulting in a steadfast effort to be there for one another because “what hurt and pained one, hurt and pained all of us” (J. Lewis, AALP, November 26, 2013).

Other AALP interviewees described how they were intrinsically motivated to contribute to the early AIDS response, rather than sit idly by as the infection rate grew. Each of the ten AALP interviewees are part of the group of activists and community organizers who refused to



neglect the growing crisis, which so many across the country were doing. Nancy Paris characterized her early action as a calling that “just struck something in me that I couldn’t not respond. It would not have been within me to sit on the sidelines” (N. Paris, AALP, July 7, 2009). Bruce Garner discussed how his strong faith as part of the Episcopal Church serves as a key tenet of his identity and prompted his early community action (B. Garner, AALP, June 19, 2009). Furthermore, several AALP interviewees were influenced and inspired by the advocacy of those around them. Jim Martin was moved to action after a powerful conversation with a constituent, who explained the various challenges of those affected by AIDS (J. Martin, AALP, July 7, 2009).

In addition to the individuals who approached him, Jim Martin attributed his entry into the AIDS response to the progressive constituents in his neighborhood who allowed him to “take positions that other legislators couldn’t take.” In becoming a public advocate in the legislature, he learned that “sometimes [the] fear of doing something that's greater than actually doing it. And...once you start taking actions, and you see that you can be successful, and you can make a difference, it encourages you and encourages others” (J. Martin, AALP, July 7, 2009).

Many AALP interviewees were inspired by their own life experiences. Nancy Paris was a director of hospice care in Atlanta when she first learned about AIDS. In her AALP interview, she also discussed her grandfather, who was taken away from his home once infected with TB and later died at an institution in isolation. These elements of her personal background contributed to her advocacy in allowing AIDS patients to receive hospice care (N. Paris, AALP, July 7, 2009). Additionally, Stephen Woods had previous experience in the food service business. When he was diagnosed with HIV and could no longer work, he had a strong desire to give back to others suffering from the virus and began volunteering at Open Hand, where he

became Executive Director and grew their programming in meal preparation and delivery (S. Woods, AALP, February 18, 2014).

In a crisis as overwhelming and large as AIDS, it could be difficult to know where to start. Jesse Peel talked about how he and his peers tackled this challenge by discerning what the perceived need was. After this first discussion, he could implement steps to help address the need for basic, yet deprived, necessities such as meals or housing (J. Peel, AALP, June 21, 2009).

Community organizers built on their strengths, whether it was engaging their wide social network through festive fundraising events (“certainly having a party was something I knew how to do”) or navigating politics and the democratic process (“you’ve got to be able to work with people to decide those areas where you can achieve consensus”) (J. Peel, AALP, June 21, 2009; J. Martin, AALP, July 7, 2009).

As part of the AALP, these ten interviewees discussed the challenges they faced, lessons they learned, and steps they would have taken in hindsight. However, there is a general consensus that they did everything they could with the information and resources available at that time. They feel pride in the impact they achieved and the legacies they left on the greater Atlanta community. Stephen Woods reflected on his initiatives in this light, as he “[took] what was a volunteer-based organization that was born out of a need to respond to a crisis, and then [built] an infrastructure around that, that has carried Project Open Hand and the Meals on Wheels program into the future” (S. Woods, AALP, February 18, 2014). Each of the ten AALP interviewees left a tangible impact on Atlanta and hold important life experiences that provide lessons for the future.

## 5. Results from contemporary COVID-19 Interviews

### COVID-19 in the context of Atlanta

#### *Diversity and inequality in a growing city*

The COVID-19 pandemic impacted the entire United States and the individual communities within every state, city, and county. This holds true for Atlanta, whose unique makeup drove how the pandemic played out after Georgia confirmed their first case on March 2, 2020 (Norder, 2020).

Atlanta is a city with significant diversity, and “for the most part, it celebrates that diversity” (Participant 5). When discussing their organization’s pandemic response, participants brought up different aspects of the city that they considered, including populations experiencing poverty, homelessness, and the variations between counties. Several participants acknowledged this diversity and included these demographic aspects in conversations about their organization. Participant 3 referenced this in her interview, stating that “you have to constantly reevaluate [operations]... we still have a long way to go, but we’re making progress.”

Atlanta is a consistently growing city, which means that “anything that happens, happens in the context of growth of a large city,” including gaps in health care patterns, poverty, and “any type of pandemic coming in and exploiting those gaps” (Participant 5). Several participants particularly emphasized the inequality in Atlanta as a key consideration when evaluating the COVID-19 pandemic’s impact. One participant brought up attending the 2023 “State of the Region” address at the Atlanta Regional Commission, the community planning agency that works with local governments in the metro area. She discussed how poverty that already affected certain pockets of the city is now “off the charts” in these neighborhoods; there may be a 10-year difference in life expectancy between neighborhoods that are two miles away. Additionally,

another participant explained huge discrepancies between emergency room wait times in south Fulton County and other areas of the county, with averages ranging from 20 minutes to four hours.

Community organizations seriously considered this inequity when shaping their response to the pandemic, as community responses run the risk of exacerbating inequalities rather than addressing them. Conscious solutions included mobile testing and vaccination sites at convenient locations for disadvantaged groups, as well as drive-thru food distribution events to help struggling families. One participant reflected on a misstep taken by their organization, in which none of their grants to struggling arts organizations were led or founded by people of color. Another participant described discrepancies in the scheduling of vaccination appointments. Early on, those in certain regions of the city, such as the north, were more successful at securing vaccines compared to other regions. This occurred because appointments were in limited supply, and scheduling a vaccination required the time and ability to constantly be on the internet and refresh the page. Over time, community leaders recognized this concerning pattern and adjusted their operations to provide more equitable outcomes.

As the capital of Georgia and the state's largest city, Atlanta benefitted from its reservoir of resources. This is particularly true in the healthcare field, as the city is home to the Centers for Disease Control (CDC) and many affiliated infectious disease experts. Furthermore, Atlanta is a center for a variety of businesses, providing organizations with plentiful opportunities for partnerships with corporate offices.

### *Political Landscape of Georgia*

Across the country, the COVID-19 quickly became highly politicized. Dr. James Curran was not surprised by this, as it follows previous public health patterns:

Public health has always been political because it involves populations. And in order to be effective with populations, you have to win over the population. You have to understand the population. You have to understand the diversity and cultural aspects of many different populations. But in a pandemic, it shouldn't be political, shouldn't be partisan. But unfortunately, with COVID it was partisan in part because it was a presidential election and in part because it was handled both at the federal and state and local [levels], so it became very divisive and remains divisive to this day (Participant 5).

The city of Atlanta was led by a conservative Georgia governor during the public health crisis. Governor Brian Kemp was the first to allow businesses to reopen after the shutdown, which lasted less than a month. This quick shift in policy forced community organizers to act strategically when transitioning out of lockdown.

### **Challenges faced by community organizers during the COVID-19 pandemic**

#### *Public health hesitancy, communicating uncertainty, and building trust*

Georgia faced the challenge of public health hesitancy, which could manifest as distrust towards the government, distrust of healthcare, or a strong sense of independence. One participant highlighted the presence of vaccine hesitancy, noting the small but vocal percentage of people in Atlanta who see not getting vaccinated as a “badge of honor.” Participant 1 contrasted his work to those in other cities such as Chicago and Los Angeles, as “the hurdles are very different” for community organizers serving those in Georgia. Before the vaccine, the challenge of many community organizers was getting people to understand what the virus was. The health director of an Atlanta county described the laborious, draining process of responding

to a flood of angry emails from community members who were distrustful of the vaccine and supporting research:

I would spend like an hour putting together, you know, an email with links [to the CDC site and research studies] and then there'd be back and forth with this particular person, whoever it was... it rarely happened that somebody said, oh yes, you're right. I'm, I am convinced. In fact, I don't think that ever happened. Because by the time it's somebody's writing to the head of the health department during a pandemic. I'm sorry. They have their ideas (Participant 6).

This hesitancy stemmed from a ubiquitous truth of the early stages of the pandemic: nobody knew all the answers about the virus. In this sea of unknowns, public sentiment towards government guidelines and CDC recommendations was complicated by the stream of mixed messages. Officials were constantly working with incomplete information, and often updated or changed previous statements when new information was presented about the virus. With guidance of this nature, “you're always gonna have a big group of people are gonna say ‘well what but you told us before XYZ and now you're telling us ABC’... we try to say ‘well we've learned more,’ but that doesn't often resonate with people” (Participant 6).

There were two contrasting forces at play: ensuring that new information was accurate, and getting out new information as quickly as possible, even though it was subject to change. One participant emphasized both the difficulty and the necessity of communicating this uncertainty, relaying this as a skill our public officials should improve upon in the future.

Another participant, who led health services at a school system, described the variation of reactions to their vaccination events. She explained the necessity of building trust in order to successfully provide resources and education to parents and students in the county.

Within organizations, solidifying trust is also of the utmost importance. Several participants discussed this challenge and reinforced the necessity to be transparent with their teams, address concerns, and ensure that team members feel confident that the organization leadership was putting their safety first.

*Difficulties presented by COVID-19's restrictions and widespread scale*

COVID-19 restrictions and high transmission rate significantly interrupted society, including how community organizations functioned. These challenges were clearly illustrated by two study participants who work for a humanitarian nonprofit that organizes blood drives. These participants discussed how the first sectors that closed – including high schools, colleges, businesses, churches, and sporting events – are where they conducted most partnerships for blood drives. Oftentimes, these blood drives are scheduled months in advance. This means that if an event is shut down with one day's notice, it will be practically impossible for the organization to fill that need. Additionally, this organization was not immune to staff members and donors getting sick or being exposed, requiring quarantine and backing out of commitments at the last minute. Facilities used for blood collection could only be booked if they could accommodate six feet of separation between donors. This combination of requirements made it significantly more difficult for the organization to meet their expected number of blood donations. It also complicated their ability to communicate expected numbers of units to the hospitals relying on them.

Another participant, who ran the Georgia branch of a crisis response organization, also described this constant shuffling of staff and resources to try to cover previously-scheduled events. This issue was exacerbated by the reality of resources being in short supply. For instance, both this participant and the director of health services at a school system struggled with how to distribute their limited number of COVID tests and vaccines, balancing both their limited inventory and community expectations. Furthermore, one participant noted that the online system they used to schedule appointments could not handle the demand. They faced several issues with a software that was designed for 20 appointments a day, yet was quickly expected to handle over 500 appointments.

#### *The ongoing nature of COVID-19*

A key theme across all interviews was the need to keep track of continuously changing information. This variability didn't disappear in the first couple of months of the pandemic; rather, it became a defining characteristic of this new reality. As such, community organizers had to constantly keep track of all pandemic updates to keep themselves, their staff, and the people they were serving safe and informed (pertaining to masking, social distancing, quarantine length, and vaccination eligibility, among other considerations).

With these changes often occurring abruptly, individuals at community organizations were often overwhelmed with a huge amount of work and responsibility that would be abnormal during non-pandemic times. For instance, one participant recalled working seven days a week, handling case investigations for an entire school district all on her own. Another participant explained how their organization's senior leadership had two calls a day – one from 8:00am-9:00am, one from 4:00pm-5:00pm – seven days a week.



*Navigating internal organization challenges*

An additional reality of the pandemic was the emotional toll experienced by staff members at local organizations. One participant, who works at a comprehensive health agency for those living with HIV, described this ever-present truth:

When you're meeting with patients sort of in especially mental health providers and recovery specialists and any the medical writers, you're sort of absorbing that secondary trauma of that person too... I mean, I was in charge of actually sending sympathy cards... and sometimes sympathy cards to the same person a couple months apart... I don't think we were prepared for... what effect [the increasing death toll] would have within the organization (Participant 8).

Just as society was disrupted by the COVID-19 pandemic, so too were community organizations, resulting in adaptations in organizational structure. These internal changes presented several challenges to local leaders, with staff turnover serving as a common struggle. Since most of the participants' organizations required work on the front lines of the pandemic, they lost employees who were concerned about their safety or preferred to work remotely.

One participant described how her organization relied less on volunteer work due to these same obstacles. As a result, their staff members took on the responsibilities traditionally delegated to volunteers. When the pandemic hit, they reorganized their operations and focused on two initiatives: food delivery for the community and free childcare for frontline workers. Staff members were delegated away from their normal jobs and funneled into one of these two programs. In some cases, this created culture strife and unhappiness within the organization, as some individuals did not want to shift responsibilities to a new area they didn't choose.

Additionally, due to changes in revenue, this organization was forced to let go of their part time staff.

## **Leadership and strategies of Atlanta's COVID-19 community organizers**

### *Partnerships*

Across all COVID-19 interviews on community response, the implementation of partnerships was a central theme. Organizations collaborated with each other to expand their reach. Since each entity in these collaborative efforts were already integrated into the community in their own unique way, organizations could utilize each other's networks to impact more people, preventing the need to "reinvent the wheel." This strategy of community response allowed for the expansion of health services, such as testing and vaccination efforts.

Several participants described a general openness among community organizations to establish partnerships during the pandemic. Participant 2 explained how "you know [the benefits of partnerships], but throughout the pandemic, it really solidified the fact that our partnerships and our relationships in the community are so important to our organization." She attributed her organization's ability to stay afloat and provide services during the pandemic to these community partnerships.

Participant 1 also believes that partnerships were integral to his organization's operations during the pandemic, as the organization was new to Georgia and previously had little familiarity with the community. He emphasized the importance of reflecting on one's abilities during crises and reaching out to others to fill in gaps:

When it comes to any sort of crisis, especially a public health crisis, it's no one agency that's going to respond. It's gotta be a very, very tight response from the vision/beginning.

I'd say the most important things as an organization or as members of an organization is to not just know what your strengths are, but more importantly, know what your weaknesses are, know what your gaps are... we don't know a lot about the minority population. How can we bring in people that *know* these groups that can advocate for them and be a fair representation of them given this time of crisis because a lot of times you can go in and provide a service, but a service that is uninformed. So I will say that collaboration is key, but so is introspection of yourself and as an organization... if you try to do it all and not bring other parties, you're going to in one way shape or form provide injustice to others.

He explained how state vaccination efforts had difficulty reaching undocumented individuals since many testing sites were run by the National Guard or other government bodies. His organization stepped in to fill this gap, partnering with community organizations like a Latino-serving funding agency to create mobile vaccination sites that were in accessible and familiar locations.

Sometimes, COVID-19 partnerships were utilized to fulfill other needs in an area. For instance, a county health director was asked by a community to bring resources such as a dentist or car seats, along with vaccines, to their COVID-19 events.

Partnerships described in the COVID-19 interviews include those with the public sector, faith-based organizations, community-based organizations, and corporate organizations.

Examples of collaborative efforts involving participants' organizations include:

- A partnership between a crisis relief organization and local churches to amplify a vaccine incentive program
- A health agency leveraging already strong relationships with the state health department

- A nonprofit organization collaborated with existing community partners, posting on their website when in need of volunteers
- An organization that hosts blood drives leveraged already-existing corporate relationships, as the business offices would share opportunities for donating to community blood drives with their employees
- A youth-focused nonprofit organization created a widespread food distribution program by partnering with food banks, restaurants, grocery stores, and professional Atlanta sports teams
- A crisis relief organization partnered with a local Latino community organization to better serve Spanish speakers in Atlanta

The diversity in partnerships reflects the importance of this theme. Two participants spent a relatively long time discussing the importance of faith-based partnerships, as organizations such as Atlanta churches already have highly established networks with a significant amount of trust from their members. This increased the effectiveness of public health messaging and attendance at COVID-19 events, particularly vaccination events. Participant 1 underscored the importance of “finding that trusted individual and leveraging their influence” – not through coercion, but by serving as the messenger of information from a reliable source.

Partnerships provided benefits in staffing events, funding, and managing cumbersome administration responsibilities. They often arose organically, established through phone calls, zoom meetings, and references to other organizations to partner with. Multiple participants also discussed how partnerships established during the early COVID-19 pandemic enabled an immediate, effective community response to the mpox outbreak of 2022.

### *Implementing new models*

In order to respond to the challenges of the COVID-19 pandemic, community organizations in Atlanta introduced a variety of unprecedented operations. For instance, Participant 1's organization (with its many chapters worldwide) focuses functionally on crisis response. However, since its inception in 2020, the Georgia chapter has primarily provided public health programming. This has led to the expansion of public health initiatives in other chapters across the world.

A comprehensive health agency started providing drive-up HIV testing and pharmacy services, as well as a condom mailing program that allowed them to continue providing preventative services while keeping people out of the physical building. This organization, which focuses on individuals infected with HIV, also provided food cards so that those who were immune-deficient could make fewer trips to the grocery store.

Furthermore, a humanitarian organization that runs blood drives was heavily affected by the closure of schools and the switch to remote work. Rather than concentrating efforts (and receiving the most blood donations) from school and corporate blood drives, the humanitarian organization switched to a community model with open facilities at public locations.

A nonprofit organization created a philanthropy-matching system, in which donors can learn about various options to give back to and "match" with one that most resonates with them. This program ended up raising 170 million dollars.

As discussed earlier, the ability to make a vaccine appointment often depended on consistent internet access. In order to make vaccination opportunities more equitable, an Atlanta county instituted outreach teams and free Uber transportation for certain groups, such as residents at senior centers. Several organizations began vaccination efforts specifically for their

staff members, along with new safety protocols implemented consistently across locations. These new initiatives often occurred as a result of an individual's drive and creativity within an organization. For instance, one participant recalled making several calls to the president of the United Way to work out her national organization's first COVID-19 rescue and recovery fund in the country.

In addition to new operations, many organizations saw changes in their internal structure. One example is the creation of teams that brought in individuals with a variety of areas of expertise. For instance, the health services director of a school system built a team that for the first time, consisted of a district epidemiologist, a school health coordinator, a district case investigator, and a district RN. This participant also described a task force that included communications, HR, health services, nutritionists, students, and families.

Many organizations allowed employees to work remotely when possible or redistributed staff members to work where the need was the greatest. One participant discussed how his organization transitioned to a new organizational model entirely – specifically, the Incident Command System.

Another change was the increase of communication, both internal and externally. The health director of an Atlanta county recalled increased contact between her office and hospitals, as well as spending a significant amount of time on Zoom calls during 2020 educating community groups. Participant 3, the Chief of Social Impact at a nonprofit organization, recalled a pivotal meeting among hospitals that benefitted families across the city:

One of our leaders who really kind of came up with the idea said, what if we got all the hospitals in Atlanta on a conference call? You know, Emory and Northside and Wellstar and Piedmont and Children's. All these hospitals that honestly probably weren't great

friends because there's an aura of competition, but how do we get everybody on the call and find out what are the needs? How can we help their staff? How can we step into that space of providing childcare where people need it?

In general, participants reported a higher frequency of internal meetings, with several participants having participated in daily meetings with the leadership team at their organization.

With in-person gathering severely limited, technological solutions became central to many organizations' operations. Several participants reported introducing or expanding telehealth opportunities for community members, particularly for mental health services. Across all interviews, there was also an emphasis on the transition to Zoom and Microsoft Teams communication. Though this was difficult to get used to, video calls enabled organizations to continue operating while keeping their staff safe.

### *Building on previous models*

While many community organizations in Atlanta established new operations to address COVID-19, they also adapted their existing models to the pandemic. For instance, a comprehensive health agency for individuals infected with HIV was already highly familiar with the impacts of a tragic epidemic. This includes the toll on mental health, influenced by factors such as social isolation, job loss, and stress. With this preemptive knowledge, the agency increased their number of mental health providers and telehealth opportunities early on. They also easily reinstated masking mandates – already a common practice for the organization during flu season. They also utilized their vaccine educational programs, previously used to teach patients about the flu vaccine, and a network of medical suppliers for resources such as gloves, masks, and vaccine refrigerators (which the staff already knew how to regulate).

Organizations capitalized on their own strengths when deciding which previous models to build on. An example includes how the Chief Social Impact Director at a nonprofit knew they were well experienced in child care, and subsequently decided that this was an area they could uniquely contribute to the challenges faced by community members, particularly front-line workers. The humanitarian organization that manages blood drives expanded their preexisting relationships with hospitals to establish a more comprehensive inventory planning schedule. Additionally, the area director of a crisis relief organization described how they leaned into their ability to address the needs of vulnerable, underserved populations. At first, his organization primarily helped organize the massive testing sites at locations such as the Mercedes-Benz Stadium, which served hundreds of people. However, he soon realized that these initiatives did not reach some disadvantaged populations in Atlanta, including undocumented immigrants. As a result, this organization shifted to focus on the creation of sustainable mobile health platforms for testing and vaccination. Participant 8 stated that COVID-19 “really just accelerated stuff that we were already thinking about doing.”

Partnerships, as discussed earlier, were always integral to many community organizations. This fact was greatly reinforced during the pandemic, as collaboration efforts proliferated. One participant claimed that the pandemic “didn’t necessarily change the fundamentals of the process;” rather, it increased utilization of already-existing resources and relationships.

Several participants highlighted the necessity of the services provided by their organization – a necessity unchanged by the onset of a global pandemic. As a result, these organizations adapted so that they could stay open during the lockdown and continue serving



their community. One participant described expanding their hours for HIV testing – even adding evening and Saturday hours – so that patients would be spread out during the day.

Another theme present across several COVID-19 interviews was organizations' reliance on the "goodness" of people in Atlanta. This sense of care for others in the community was key to volunteer-based organizations before the pandemic, and the consistent desire among community members to give back allowed many organizations to keep serving others. An executive at the humanitarian organization attributed their ability to meet quotas to the dedication of blood donors to continue giving blood, even as the pandemic worsened.

#### *Leadership attributes of Atlanta community organizers during the COVID-19 pandemic*

The COVID-19 pandemic abruptly altered daily society, including the operations of community organizations. In general, many local leaders who played a role during these early months were already in their respective positions when forced to grapple with the changes. One local leader demonstrated this true perseverance and commitment in the face of pervasive uncertainty and tragedy:

In the throes of it, I didn't know if it was Wednesday or Saturday. I didn't know if it was day or night other than I could look outside, you know. I had absolutely no concept for what was really going on in the world other than the fact that people were dying and it was our job to get money out that would help save them (Participant 7).

Most participants shared similar sentiments of completely dedicating themselves to their work during this time period. They often had to juggle a variety of priorities. These priorities often conflicted, as discussed by a participant from the HIV comprehensive health agency who

“didn’t want to close any of our doors. But we also wanted to make sure that we were keeping specially newly diagnosed people safe because their immune system is so low.”

Atlanta leaders at community organizations also took on outreach to elected officials for support. One participant described how this resulted in the Surgeon General of Georgia putting out a message about the need for blood donors, contributing to the organization’s ability to rebound from shortages during the pandemic.

If not incorporated previously, organizational leadership was often expanded into teams of individuals with diverse areas of expertise. There was a shift away from individual decision-making to the involvement of collaborative task forces. Partly due to the CDC being headquartered in Atlanta, infectious disease experts were often readily involved in decision-making. Some organizations already had these professionals on their teams.

At the same time, some leaders assumed new responsibility with minimal experience in the respective field. Participant 3 highlighted this experience at her nonprofit, stating that “I will never forget our CEO calling me on March the twelfth and she said ‘I would like you to run our food effort.’ And I remember thinking: okay, I’ve never done this before, but let’s figure this out.”

As an infectious disease expert with experience during both the AIDS crisis of the 1980’s and the recent COVID-19 pandemic, Dr. James Curran reflected on the importance of trustworthy leadership that unites the community:

Well, you know, in any epidemic, leadership is crucial. And leadership involves consensus building. You don’t have leaders without followers. So it’s not just somebody with the bullhorn and somebody. We will listen to people, and also be listened to. So you

have to be culturally appropriate, and you have to be able to see over the hill and convince people that you can do that so they'll listen to you (Participant 5).

Here, Dr. Curran highlighted the importance of clear, consistent communication. With information about the virus constantly changing, this proved true for community organizers, both in their external messaging to the general public and their internal communication among staff members. Similarly, a couple participants discussed initiatives to provide community members with channels to discuss their questions and concerns about the pandemic, such as an online platform for families in a school system.

### **Reflections on community organizing during the COVID-19 pandemic**

#### *Lessons and legacies of the COVID-19 pandemic*

COVID-19 increased pressure on our healthcare system, and “when you put pressure on something, the weakest points will manifest themselves.” Leaders at community organizations stepped up to address these areas, learning many lessons along the way.

A key lesson was the importance of building trust in communities. This is evident in how the LGBTQ+ population was one of the most vaccinated communities due to their previous collective experience with HIV. Participant 8 described how members of that population have pre-established trust in medical providers and have been hearing about HIV/AIDS vaccine research their whole lives, so “when [COVID-19] vaccines become available, they will get them in their arms.”

Additionally, participants learned that approaching the public from a purely science perspective doesn't work, as simply reciting data will not change minds. Community organizers must understand the communities they are working with, include them in the story, and act with

transparency. In order to build this trust and resonate with diverse communities, organizations should be representative of their communities and employ individuals with a variety of backgrounds and perspectives.

The pandemic reinforced the need to make resources equitable and accessible, with strong systems at the local, state, and federal level. Dr. James Curran stated that “you can have a safe and effective vaccine, but it isn't safe and effective unless everybody gets it. You can have treatment. But it isn't any good if people can't afford it” (Participant 5). Furthermore, participants reflected on the central role of partnerships, as COVID-19 reinforced that “we can mobilize things quickly if you work with already existing channels.”

Multiple participants discussed how they were able to apply these lessons to an effective response to the mpox outbreak of 2022, promoting equitable access to the mpox vaccine and establishing mass vaccination sites at preexisting locations from COVID-19.

While the pandemic's impacts on society are still becoming evident, participants highlighted several legacies it left at the organizational level. The pandemic instituted a mindset of flexibility among local leaders, creating a lasting willingness to try different things in their work. Organizations are not rigid entities; they can adapt to various pressures and implement changes in order to better serve their communities.

Additionally, several operational models introduced during the pandemic have remained active. This includes expanded telehealth services, diversified leadership teams, remote work opportunities, ventilation systems, innovation teams, and drive-up testing.

#### *Personal experiences as a community organizer*

In the midst of shutdowns, contact tracing, changing CDC guidelines, and a rising death toll, participants of the COVID-19 interviews spearheaded initiatives that benefitted populations

across the Atlanta community. They were motivated by the desire to minimize barriers to health, as well as a dedication to their organization's mission. This is reflected by an executive at a humanitarian organization, who explained how "I can put my head on the pillow at night and know, as bad as my day might have been, we did a lot of really incredible work. That's what keeps me coming back every day. I just love our mission" (Participant 2). These participants saw opportunities to impact others from within their organization, and they decided to be one of the individuals that ensured these initiatives came to fruition. One participant even came out of retirement to be part of Atlanta's community response to the pandemic.

Several participants also felt a personal responsibility to educate the public about the virus and how to keep the community safe. They viewed themselves as a resource for the community, which needed guidance and clarity in the midst of the pandemic's chaos.

Even with this trend of persistence and dedication, community work was often draining and left an emotional toll. Participant 3 explained how "in the first six months there wasn't time to self-analyze or reflect very much. It was just go go go go and never stop." She explained how constantly pouring oneself into their responsibilities can lead to moments of questioning one's work or feeling stuck. She also reinforced the necessity to practice self-care during these times.

Most participants sought to translate previous experiences into effective leadership during the pandemic. Many had worked previously in public health or infectious disease (including HIV) and felt a "natural progression" when moving into COVID-19 work. As a result, these participants were not stunned by the patterns revealed by the pandemic; rather, the pandemic activated lessons learned from past professional work.

## 6. Discussion

### *Atlanta*

Throughout all interviews, the city of Atlanta served as an important character in the greater narrative of the community organizer experience. The social and political environments of the city and state were highly relevant during both time periods. While the COVID-19 pandemic was driven by politicization, the unfolding of the AIDS crisis was influenced by political neglect. The backdrop of Atlanta, including the legacy of the civil rights movement, contained two counteracting forces: a tradition of highly engaged, collaborative community members and a location within a traditionally conservative state. This affected the timeline and manner in which community organizations could operate; they had access to the resources and energy of a passionate community, while forced to work inside the parameters of state policies. These parameters were more constraining for AALP interviewees, as the nature of state policies in the early 1980's included funding denials and obstacles to preventative education. On the other hand, the COVID-19 participants faced government policies that included the early lifting of shutdowns and masking requirements. Even though these policies may have contributed to rising COVID-19 cases, they did not directly serve as a hindrance to the COVID-19 participants. At least one individual in both the AALP and COVID-19 interviews believed that Atlanta was in a unique position during their respective public health crisis, facing different challenges than cities such as Los Angeles and New York due to the conservative context of the south.

Furthermore, both AALP interviewees and COVID-19 participants were impacted by the lessons and legacies of previous Atlanta histories. AIDS community organizers felt like they were "building a plane and flying it at the same time," creating their AIDS relief efforts from scratch without a precedent to follow. Among AALP interviewees, the civil rights movement

was an anchor that reinforced what was possible to achieve in Atlanta. Specifically, these interviewees strongly believed in the city's ability to collaborate across populations and its potential for mass impact. Multiple AALP interviewees mentioned civil rights leaders in Atlanta, incorporating their names into discussions about the AIDS response. In this sense, civil rights leaders served as a source of inspiration, and local Atlanta leaders in the 1980's aimed to model their ability to unite communities and enact change. While the legacy of the civil rights movement in Atlanta and community organizing continues to this day, COVID-19 participants primarily referenced public health crises (especially AIDS) as the most relevant histories they drew on. These participants were more specific in describing the lessons they learned and applied from the AIDS crisis. For instance, several COVID-19 participants discussed the necessity to utilize existing, trusted networks to effectively reach specific populations in Atlanta. This specificity is likely due to how AIDS and COVID-19 are categorically similar, as both are infectious diseases that filled society with ample unknowns and fear. At the same time, COVID-19 participants emphasized the important differences between the two public health crises, such as their routes of transmission and level of stigma.

### *Challenges*

The AIDS crisis and COVID-19 pandemic did not uniformly impact society. Rather, social determinants of health contributed to a gradient of health outcomes, levels of disruption to livelihood, and access to resources. The literature identifies how Black and Hispanic communities are disproportionately affected by both HIV and COVID-19, revealing the influential role of SDOH such as discrimination, income, education, and geographic region (CDC, 2023; HIV.gov, 2023). Additionally, the stigma associated with HIV may have prevented certain groups, such as members of the LGBTQ+ community, from receiving care, which

demonstrates how the downstream determinants of discrimination and attitudes affect health outcomes. Furthermore, the pandemic's social distancing measures and shutdowns had a differential effect on American workers, creating a divide between those who could shift to remote work and those who could not (Kantamneni, 2020; McNamara et al., 2021; U.S. Bureau of Labor Statistics). This further exacerbated existing inequalities, as illustrated by the COVID-19 participants. For instance, one COVID-19 participant described how early phases of vaccine distribution disproportionately favored those who could be home, constantly refreshing their computers to book a vaccination appointment. This activity was impossible for those working in precarious positions, which was largely made up of people of color. Consequently, the demographic landscape of those initially immunized against the virus was affected by social and structural components of society. Community organizers sought to address these gaps created by disparities in access to health resources, access to food, socioeconomic status, and race- or sexuality-based discrimination.

The nature of each virus presented unique challenges for community organizers. COVID-19's high rate of transmission created societal shutdowns, social distancing guidelines, and quarantine procedures, which necessitated immediate reworking of organizations' in-person operations. AIDS was incurable during the early years of the epidemic, and its primary modes of transmission, including sex and injected drug use, were stigmatized topics. This resulted in an inability for the general public and government to be upfront in conversations and urgent in their response. Both the COVID-19 pandemic and AIDS epidemic created a significant emotional toll on community organizers, as they were affected by the disease in some capacity and knew others who were suffering and dying.



Furthermore, the AIDS epidemic and COVID-19 pandemic alike were characterized by unknowns. This created the necessity for trust between the medical community, government, and general public, as well as significant difficulty in attaining it. This state of uncertainty manifested in different ways. During the AIDS crisis, the disease became heavily stigmatized, known as a “gay disease” that businesses did not want to fund or be associated with. The fear generated led to infected individuals being othered and discriminated against, such as how some dentist offices refused to see HIV-positive patients. During the COVID-19 pandemic, the unknowns led to hyper-politicization and public health hesitancy both within Georgia and across the United States. Community organizers sought to address the needs of communities throughout Atlanta, yet their efforts were sometimes complicated by the vocal distrust expressed among certain groups.

The disparity associated with both health crises, driven largely by SDOH, necessitated the involvement of community organizations. During the COVID-19 pandemic, many organizations adapted their pre-existing operations to incorporate community relief efforts. Alternatively, new “parallel” organizations had to be created during the AIDS epidemic due to neglect from existing organizations. As a result, the main challenges described by AALP interviewees involved inexperienced leadership, navigating young, changing organizational structures, and trying to grow their operations in scale. On the other hand, the main challenges described by COVID-19 participants involved adapting their organization’s operations to the growing pandemic while facing societal shutdowns, social distancing guidelines, and staff turnover. Both groups of interviewees faced difficulties in accessing resources. For AALP interviewees, this primarily meant the ability to secure funding. For COVID-19 participants, this

meant sourcing enough vaccines, COVID-19 tests, and locations to hold socially-distanced operations.

### *Leadership and Strategies*

Local leaders during both the AIDS crisis and the COVID-19 epidemic were faced with conflicting responsibilities: developing new solutions while providing stability for their communities. Early literature on crisis leadership emphasizes proactivity. This approach is beneficial by highlighting the necessity to reevaluate social structures during times of non-crisis to address structural inequalities. However, Complexity Leadership Theory (CLT) better encapsulates the adaptive and resourceful nature of the AALP interviewees and COVID-19 participants. In some capacity, all of these individuals discussed the importance of Atlanta's unique context and tailored their operations to fit the needs of specific communities – a defining feature of versatile leadership.

Newstead and Riggio's five key competencies were highly evident among AALP interviewees and COVID-19 participants as they navigated the complexity of their respective crisis. Sensemaking within their organizations and communities was among their primary responsibilities. In the face of uncertainty and fear, local leaders brought an unwavering dedication to continuing their organization's mission, communicating transparently and frequently with other staff while validating their needs. Since information about both AIDS and COVID-19 was constantly evolving, community organizers had to make meaning out of each stage of the disease. During the COVID-19 pandemic, many community organizers led daily meetings (with one COVID-19 participant having meetings twice a day) to create a mutual understanding among staff members on new disease updates and discuss how to adapt current operations. During the AIDS crisis, many community organizers were either infected with HIV

or knew those who were sick and dying from the disease. There was no treatment at the time, which meant that nobody with AIDS was recovering. Rather than being discouraged by disease outcomes, leaders such as Jesse Peel drew on personal experiences and centered the meaning of community initiatives around efforts to combat isolation and loneliness, mobilizing individuals to support projects like the buddy program.

Decision-making was another competency exhibited by all AALP interviewees and COVID-19 participants. In tangent with Sensemaking, community organizers had to consider a variety of perspectives and reflect on incomplete information in order to make choices on how to proceed – such as which AIDS organizations to fund or how to keep staff safe during COVID-19 vaccination events.

Through Coordinating Resources and Teamwork, AALP interviewees realized the importance of diverse task forces and organizational boards. These groups provided a space for different points of view to not only interact, but strengthen the organization's operations. Many COVID-19 participants applied this lesson during the pandemic and discussed the benefits of having a variety of perspectives on their team, including the expertise of infectious disease experts. The enthusiastic increase in partnerships also falls into this competency, as it takes structured and strategic coordination to collaborate impactfully.

A central part of both the AALP and COVID-19 interviews was reflection on the lessons learned from the community organizer experience, exemplifying how local leaders played a key role in Facilitating Learning. The takeaways from this competency will be discussed later in this section.

The fifth key competency is Communication. A core part of this practice was listening to community members and providing them spaces to voice their concerns and unique perspectives.

During the COVID-19 pandemic, effective communication meant using transparent language that acknowledged the uncertainty of the situation and the need to change operations as new information became available. In the face of public health hesitancy and political divisiveness, this proved especially important. During the AIDS crisis, it was important for AALP interviewees – many of whom were public figures – to use language that united groups in a collective fight against AIDS as opposed to language that contributed to stigmatization of infected individuals.

Through this exploratory study, several similarities and differences in community organizing strategies emerged between the AIDS crisis and COVID-19 pandemic in Atlanta. Partnerships were an important strategy discussed by both AALP interviewees and COVID-19 participants. However, this theme was much more common across the COVID-19 interviews than the AALP interviews. This could be due to the nature of each set of interviews; I prompted COVID-19 participants to expand on their partnership efforts if mentioned, which often led to them emphasizing the centrality of collaborating with other entities. On the other hand, Thurman's interviews were conducted more than two decades after the initial AIDS community response and aimed to provide a sweeping overview of the interviewee's experience during AIDS in Atlanta, rather than explore the details of partnerships. Generally, AALP interviewees instead focused more on the growing collaboration of diverse individuals within organizations and the expanding of leadership to those outside of the LGBTQ+ community.

When discussing partnerships, COVID-19 participants particularly emphasized the need to utilize existing channels of trust within communities. The massive gap in income inequality and significant diversity within Atlanta means there is no one solution that can be applied to the entire city. Partnerships that fostered trust were crucial in addressing many social determinants of

health. For instance, Participant 1's collaboration with the Latino Community Fund to create mobile vaccination sites for undocumented immigrants helped combat poor access to health care and the fear of deportation. African-American churches, with a history of highly-trusted pastors and engaged communities, were unsurprisingly another powerful partner in the spreading of public health information and services.

Historically, the performing and visual arts have played an influential role in community organizing and activism. Within the sample of this study, AALP interviewees referenced more artistic initiatives than the COVID-19 participants. This may be a byproduct of how AIDS organizations were starting from scratch with no roadmap to follow, providing greater space for unconventionality and risk-taking. Since each of the COVID-19 participants' organizations were already in existence prior to the pandemic, they may have been less likely to initiate operations in areas that they were less familiar with, such as the arts.

Nevertheless, all AALP interviewees and COVID-19 participants exhibited creativity and versatility within their organization, implementing steps to understand the context of their communities and address unmet needs. They dealt with the tension between pressures to change and pressures for stability, and they allowed adaptive space to open up and loosen the expectations of what systems and community organizations "should" look like. Ultimately, this led to the emergence of unprecedented solutions. Among AALP interviewees, adaptive space led to initiatives such as Heart Strings's Atlanta production and national tour, the Georgia Division of Health's statewide network of educators for AIDS prevention, Open Hand's robust food delivery program, and Jim Martin's resilient advocacy for AIDS relief funding in the Georgia House of Representatives. Among COVID-19 participants, adaptive space allowed a youth-focused nonprofit to redirect their efforts to food distribution and providing childcare for front

line workers, a crisis relief organization to establish mobile testing sites for vulnerable communities, and a school district to create an online forum to address family concerns. The use – and challenges – of technological solutions was also a prominent theme among COVID-19 participants that was not present in the AALP interviews. This is likely due to the advances and ubiquity of mobile technology since the AIDS crisis, as well as how social distancing measures necessitated the ability to communicate and work with others while physically separate.

### *Reflections of community organizers*

Many AALP interviewees and COVID-19 participants discussed similar lessons learned, including the importance of early responses from existing organizations and the ability to communicate uncertainty while maintaining trust. It is unlikely that these lessons were coincidentally discovered in both time periods. Rather, leaders during the COVID-19 pandemic turned to previous histories of public health crises that had significant implications across society.

Many COVID-19 participants referenced the AIDS epidemic when describing their decision-making. As one AALP interviewee highlighted, the response to AIDS was the largest community organizing movement that a public health crisis had ever produced. This unprecedented response, complicated by a variety of challenges, was a learning process. It took several years before organizations arrived at their most effective community organizing strategies. When the COVID-19 pandemic began in early 2020, several local leaders immediately implemented lessons they learned from the AIDS crisis. Among these lessons are the importance of fostering trust within communities, intentionally establishing collaborative spaces for diverse perspectives, and acknowledging the emotional toll experienced by staff members within community organizations. This translation of takeaways from AIDS to COVID-

19 was particularly prominent among COVID-19 participants who had worked with HIV patients in the past.

Similarly, multiple COVID-19 participants discussed how strategies from the pandemic were directly applied to the next public health crisis – mpox. The mpox response benefitted from pre-established vaccination sites and educational campaigns centered around the importance of getting immunized in order to protect the community.

These direct applications to future crisis response underscore the importance of capturing the lived experiences of community organizers. At the same time, reflections by AALP interviewees and COVID-19 participants reinforce that public officials and local leaders cannot begin to implement learned solutions only when a crisis emerges. Both the AIDS crisis and the COVID-19 pandemic increased pressure on various aspects of society, revealing existing gaps in our social support structures that exacerbate inequalities in healthcare, education, nutrition, socioeconomic status, and employment. It is imperative to address societal gaps during non-crisis periods, ensuring our healthcare, political, social, and economic systems will be prepared to support all communities when under strain. This proactivity could include the strengthening of public health funding networks and maintenance of culturally-competent health educator networks throughout the state.

Within each group of interviews, the interviewees came from a wide range of backgrounds and perspectives. Their unwavering dedication to the health of the Atlanta community was motivated by a diversity of factors, but all converged on their refusal to sit idly by while vulnerable members of the community were becoming sick and dying. Whether the local leader was the founder of a new AIDS organization or a long-time executive of a public

health agency during the pandemic, they were motivated by a deep, intrinsic desire to relieve suffering in their communities.



## 7. Conclusion

The purpose of this exploratory study is to shed light on the community organizer experience in Atlanta, specifically through the lens of two monumental public health crises. Though the precise definition of “crisis” is contested, these events contain a consistent element of societal disruption – often with disparity among vulnerable populations. In order to be an effective community organizer during times of crisis, leaders must be adept at identifying gaps created by SDOH, recognizing the unique needs of different communities, and collaborating in the implementation of solutions. Furthermore, organization leaders must communicate internally and externally with transparency and humility.

During years of extreme fear, uncertainty, inequality, and tragedy, community organizers played a pivotal role in advocating for the health and wellness of the Atlanta community. Regardless of these challenges, the local leaders who took part in this study demonstrated true resilience and grit. They were not isolated from the crisis at hand; many AALP interviewees were infected or knew someone suffering from HIV/AIDS, and many COVID-19 participants were experiencing the emotional toll of thousands dying each day from the pandemic, including friends and family. These remarkable individuals refused to sit idly by while so many were suffering. There was no hesitation in their decision to act.

The AALP interviewees were responsible for shifting the dynamics of the AIDS epidemic from pervasive neglect to supportive advocacy. They redefined the disease, convincing the Atlanta community of the virus’s gravity in their city and countering the rampant stigma that plagued it. The COVID-19 participants were instrumental in coordinating resources and multi-organizational partnerships. They strove to balance the need for change and the desire for stability within their organizations, and they relied on a mixture of previous and new models to

achieve this. Both the AALP interviewees and COVID-19 participants were deeply involved in their city, influenced by Atlanta's unique history and characteristics. These local leaders employed versatility and creativity in navigating the complexity of their respective public health crisis.

### *Limitations*

This study consists of ten AALP interviewees and nine COVID-19 participants. Their interviews do provide a range of perspectives and experiences through which common themes are found. However, further research would benefit from a larger pool of interviewees in order to capture nuances that were unrepresented in this study. Additionally, perspectives from populations such as transgender and indigenous communities were not included in this study, yet their perspectives are necessary additions to the greater conversation on community response to public health crises.

All 19 interviews involved community organizers who were addressing the needs of those impacted by HIV/AIDS or COVID-19. However, both of these time periods saw a much wider breadth of community organizing, from advocacy for LGBTQ+ and women's rights in the 1980's to the Black Lives Matter protests of 2020. Though these social movements fell outside of the scope of this study, they are also crucial to the greater conversation of community organizing during these time periods.

Lastly, both AIDS and COVID-19 are referred to as public health crises in this paper. However, these diseases are still present globally with significant impacts on people's lives. This study does not aim to reduce the ongoing implications of HIV/AIDS and COVID-19; rather, it

narrows in on the early years of each crisis to compare initial societal reactions and community responses.

### *Future directions*

This study reinforces the importance of retrospection, and this can reveal valuable lessons to apply to the future. We see this in how COVID-19 participants translated learnings from AIDS to the pandemic, and lessons from the pandemic to the mpox outbreak. It is critical that these takeaways do not fade from our memory, and that continuous, intentional, and documented retrospection becomes a routine part of an organization's crisis response.

Furthermore, the AALP and COVID-19 interviews highlight the influence of community history and unique features on crisis response. With this finding, organizations should spend greater time during non-crisis periods understanding the context of their city. For instance, the Atlanta Regional Commission provides interactive data dashboards and mapping tools for the general public. One COVID-19 participant emphasized the usefulness of this data on understanding nuances within the city. All community organizers should become familiar with these types of resources in order to build effective programs for their respective populations. This can help ensure that community programs address needs rather than exacerbate inequalities.

Community organizations should also conduct conversations about crisis response during non-crisis periods of time. These discussions should aim to understand their organization's place within the community and specific strengths that they uniquely contribute. When community organizations leaned into these strengths during the AIDS crisis and COVID-19 pandemic (such as food distribution or childcare), they were able to utilize previous knowledge to provide a specific, effective solution. Promoting a deeper internal understanding of an organization's

abilities and mission may also reduce the influence of stigma on decision-making. Additionally, community organizers should make a conscious effort to maintain relationships with their partners even after collaborative programming has ended, as existing relationships were highly valuable to return to at the onset of public health crises.

Among the sentiments shared by AALP interviewees and COVID-19 participants, there was a common theme of satisfaction in what they were able to achieve. Though many shared regrets in some decision-making, there was a general sense that they did what they could with the information available at the time. These community organizers' lived experiences now contribute to the pool of knowledge that future leaders can draw upon during crisis response. This makes it critical to carve out spaces for community organizers to reflect and center their stories in the greater narrative of public health crises.

## 8. Appendix

### *Consent Form*




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#### Emory University Oral Consent Script For a Research Study

**Title:** Community Organizing during the HIV/AIDS Epidemic and COVID-19 Pandemic: A digital perspective

**IRB #:** STUDY00006541

**Principal Investigator:** Dr. Rachel Hall-Clifford (PhD, MPH, MSc)  
Assistant Professor of Human Health and Sociology

**Faculty Advisor:** Dr. Rachel Hall-Clifford (PhD, MPH, MSc)

#### Introduction and Study Overview

Thank you for your interest in our community organizing research study. We would like to tell you what you need to think about before you choose whether or not to join the study. It is your choice. If you choose to join, you can change your mind later on and leave the study.

The purpose of this study is to understand how community organizing occurs during a public health crisis. Specifically, this study focuses on the HIV/AIDS epidemic and the COVID-19 pandemic, with a particular focus on the role of digital technology during the COVID-19 pandemic.

If you join, you will be asked to participate in a 1-hour interview.

Risks include loss of time, loss of privacy, breach of confidentiality, and any psychological discomfort that may be caused by talking about your personal experiences

You may not benefit from joining the study. This study is designed to learn more about how community organizing occurred during the HIV/AIDS epidemic and COVID-19 pandemic, and the legacy that these time periods continue to leave behind. The study results may be used to help others in the future.

Study records can be opened by court order. They also may be provided in response to a subpoena or a request for the production of documents.

#### Storing and Sharing your Information

All interviews will be audio-recorded and transcribed by the researchers. These recordings will be kept on a password-encrypted account in Emory OneDrive.

Once the study has been completed, we will send you a summary of all of the results of the study and what they mean. We will not send you your individual results from this study.



### **Confidentiality**

Certain offices and people other than the researchers may look at study records. Government agencies and Emory employees overseeing proper study conduct may look at your study records. These offices include the Emory Institutional Review Board and the Emory Office of Compliance. Emory will keep any research records we create private to the extent we are required to do so by law. A study number rather than your name will be used on study records wherever possible. Your name and other facts that might point to you will not appear when we present this study or publish its results.

### **People Who will Use/Disclose Your Information:**

The following people and groups will use and disclose your information in connection with the research study:

- The Principal Investigator and the research staff will use and disclose your information to conduct the study
- Emory may use and disclose your information to run normal business operations.
- The Principal Investigator and research staff will share your information with other people and groups to help conduct the study or to provide oversight for the study.
- The following people and groups will use your information to make sure the research is done correctly and safely:
  - Emory offices that are part of the Human Research Participant Protection Program and those that are involved in study administration and billing. These include the Emory IRB, the Emory Research and Healthcare Compliance Offices, and the Emory Office for Clinical Research.
  - Public health agencies.
  - Research monitors and reviewer.
  - Accreditation agencies.
- Sometimes a Principal Investigator or other researcher moves to a different institution. If this happens, your information may be shared with that new institution and their oversight offices. Information will be shared securely and under a legal agreement to ensure it continues to be used under the terms of this consent.

### **Contact Information**

If you have questions about the study procedures, appointments, research-related injuries or bad reactions, or other questions or concerns about the research or your part in it, contact Emily Silver at (240) 385-7160.

This study has been reviewed by an ethics committee to ensure the protection of research participants. If you have questions about your **rights as a research participant**, or if you have **complaints** about the research or an issue you would rather discuss with someone outside the research team, contact the Emory Institutional Review Board at 404-712-0720 or 877-503-9797 or [irb@emory.edu](mailto:irb@emory.edu).

To tell the IRB about your experience as a research participant, fill out the Research Participant Survey at <https://tinyurl.com/ycewgkke>.

### **Consent**

Do you have any questions about anything I just said? Were there any parts that seemed unclear?

Do you agree to take part in the study?

Participant agrees to participate:      Yes                      No



Do you consent to having your identifiable information in public documents? If you choose *no*, you will be de-identified in any documents written for public consumption by a pseudonym, and identifying details will be changed. Data and identifiers will be secured in a document on a password-encrypted account in Emory OneDrive and deleted after the completion of the study.

Participant agrees to having identifiable information in public documents:      Yes                  No

If participant agrees to participate in the study:

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Signature of Person Conducting Informed Consent Discussion

\_\_\_\_\_  
Date                  Time

\_\_\_\_\_  
Name of Person Conducting Informed Consent Discussion

## *Interview Guide*

My introduction:

- Introduce myself
- Describe the project and its structure
- Purpose of this interview:
  - understand how the pandemic impacted [organization name's] community action
  - As well as understanding your subjective, personal experience as a community organizer during the pandemic

[Read the consent form]

### **Introductory questions**

1. Tell me a little bit about yourself.
2. How did you initially get involved in \_\_\_\_?
  - a. When?
  - b. Why?
  - c. Level of involvement/specific positions?
  - d. What initiatives have you been involved in?
  - e. What are your responsibilities?
  - f. What makes you the most excited about your involvement in \_\_\_\_?

### **Pandemic Over Time**

#### **Pre-Pandemic**

- What were you involved in before?
- What were typical challenges you (or your organization) faced before the pandemic? How were they addressed?
- What methods did [your organization] use before the pandemic to mobilize communities or make an impact?
- How did you view your personal identity in the public health sphere before the pandemic? What drew you to this type of work?

#### **During the Pandemic**

- What was your motivation to take action during the pandemic?
- How did your sense of identity change during the pandemic?
- Tell me about some of the impact that you were able to make during this time period
  
- How did the pandemic affect the operations of your organization during the first few months?
  - Specific to Atlanta?
  - What capabilities were hurt?
  - What new capabilities arose?
  - How did your own responsibilities change?



- What were the largest challenges that \_\_\_ faced?
  - What were some creative solutions?
- What methods or strategies were the most effective?
  - Least effective?
- Did your organization use any online platforms to help with bringing people together/organization/operations?
  - If yes, which ones?
  - How were they used?
  - In your opinion, what were the greatest advantages of these platforms? What were the disadvantages?
- What lessons did you and \_\_\_ learn about community organizing during this time period?

### **After the Pandemic**

- What do current operations for \_\_\_ look like now?
  - Did any new additions from the pandemic remain?
  - Did any additions disappear?
- From your perspective, what is the greatest legacy that COVID left on community organizing and mobilization?

### **Closing**

1. Are there any other thoughts you'd like to share that we didn't touch on?
2. Do you have any questions for me or about this study?

**Read:** Thank you so much for your participation in this interview! I really appreciate your time and thoughts throughout this conversation. For any future questions, or if you would like to fully or partially withdraw your responses, please email me at [emily.silver@emory.edu](mailto:emily.silver@emory.edu).

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