

9-2015

# Getting Out of the Ghetto: Harm Reduction, Drug User Health, and the Transformation of Social Policy in New York

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GETTING OUT OF THE GHETTO: HARM REDUCTION, DRUG USER HEALTH, AND  
THE TRANSFORMATION OF SOCIAL POLICY IN NEW YORK

by

RACHEL FAULKNER-GURSTEIN

A dissertation submitted to the Graduate Faculty in Political Science in partial fulfillment  
of the requirements for the degree of Doctor of Philosophy, The City University of New York

2015

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This manuscript has been read and accepted for the Graduate Faculty in Political Science to satisfy the dissertation requirement for the degree of Doctor of Philosophy.

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## **Abstract**

### **GETTING OUT OF THE GHETTO: HARM REDUCTION, DRUG USER HEALTH AND THE TRANSFORMATION OF SOCIAL POLICY IN NEW YORK**

by

Rachel Faulkner-Gurstein

Adviser: Prof. John Mollenkopf

This dissertation is a qualitative study of the emergence and evolution of harm reduction drug policies in New York City. It examines harm reduction as a case of the institutionalization of a public health policy movement. Harm reduction seeks to treat the medical and social consequences of drug use without requiring abstinence. The dissertation examines the process by which harm reduction has managed, in the words of one informant, to “get out of the ghetto” and become increasingly integrated into New York’s public health establishment. Harm reduction has undergone three stages of institutionalization. It began as an activist policy movement. This was followed by a period of partial institutionalization, characterized by grant funding, organizational autonomy and limited state support. Finally, with harm reduction’s integration into Medicaid as well as the widespread adoption of naloxone overdose prevention strategies, it has assumed a mainstream position within the health system. This dissertation argues that institutionalization has changed harm reduction at the grassroots level and also contributed to wider changes in the design and delivery of public health in New York State. While some activists remain skeptical of what they see as harm reduction’s co-optation, the process has created new relationships between marginalized communities and the state,

and led to new forms of social and political inclusion for drug users. This research demonstrates the effectiveness of social movements as policy actors and provides a case study of progressive policy change during a period marked by the privatization and restructuring of social welfare provision. The harm reduction approach, pioneered by drug users and public health activists, is now being applied to the health system more broadly.

## Acknowledgements

This dissertation would not have been completed without the help and support of a great many people. First, I'd like to extend my profound thanks to the dedicated and knowledgeable service providers, users activists and public health officials who generously took the time to teach me about harm reduction in New York. I first entered the field as a naïve Canadian, keen to learn but not always the most tactful. The people I met throughout the city at syringe exchanges, government offices, protest rallies, and everywhere in between showed me bottomless patience and a real willingness to help and support my research. Confidentiality prevents me from identifying individuals by name, but I have been and will remain deeply impressed with the great efforts so many have made to bring about change in the way drug users are treated in New York. It is my hope that my research reflects their experience faithfully.

I am grateful also to my excellent committee and the many professors who have provided me with guidance on this project. Thanks especially to my advisor John Mollenkopf whose knowledge of New York politics is as incisive as it is vast, and Joe Rollins whose thoughtful comments have pushed me to be a more careful and strategic scholar. Their confidence in me has been a source of encouragement when I couldn't see my way forward. Thanks also to Nicole Marwell who provided me with comments and support during the proposal phase, and to Janet Gornick for stepping in and helping me get over the finish line.

My time at the Graduate Center would have been miserable indeed without the solidarity and friendship of excellent friends and colleagues. I'd especially like to thank Joyce Rivera whose unshakable political commitment, great intellect, and deep empathy showed me that

there is no contradiction between being an activist, an academic, and a caretaker. Thanks also to Kate McLean for being a knowledgeable sounding board for my half-baked theories, Alex Zamalin for his political science department camaraderie, and the many others who made the journey though graduate school as rewarding as the destination. Kristin Hole, Daniel Cohen, David Wachsmuth, Esmé Webb, Dory Kornfeld Thrasher, Hillary Angelo, Ronna Popkin, Lee Naught and the volunteers at Bluestockings Feminist Bookstore, and others too numerous to name made New York live up to its reputation as a hotbed of lefty intellectuals.

I am also grateful to Greg Falkin and George DeLeon at NDRI for inviting me to be a fellow in NIDA's Behavioral Sciences Training program, and to the Social Sciences and Humanities Research Council of Canada whose financial support made this research possible.

I moved to London, UK in 2012 and have been very fortunate to find a community of scholars and friends in this new land. The NYLON group has been a critical lifeline to a supportive academic network, and I am deeply indebted to Anna Bull, Ruth Sheldon, Katherine Robinson, Liene Ozolina-Fitzgerald, Fran Tonkiss, Vic Sidler, and the many other regular workshop attendees who have been such thoughtful and generous readers over the past three years. Thanks also to the London School of Economics Social Policy Department for giving me an institutional home away from home.

As was true of New York, living in London is made so much richer by an excellent crew of friends. Thanks to Melissa Fernandez, Isaac Marrero-Gillamón, Farah Jamal, Eric Woods, Paula Durán, Austin Zeiderman and Michelle Kelly for easing my entry into British life.



There is nothing that will settle you faster or more thoroughly into a new place than having a child. Which is exactly what we did in January 2014. The people we met in our NCT class have become friends, and we now have the pleasure and privilege of watching our children grow up together. Carrie Friese, Stephanie Miller and their daughter Hazel, Alicia Blum-Ross, Shez Sherrard and twins Penny and Abe, and the other mamas and papas and kiddos that make up our social circle are a vital resource that we rely upon for solidarity and hand-me-downs. Thanks especially to our expat family, Amanda Sheely, Tom Kemeny and their boys Milo and Nicholas for being a constant source of advice and support. Dinners in the park after nursery gave me something to look forward to at the end of a day of writing, and Sundays at the pub kept me sane throughout the long months of dissertating.

No list of thank yous would be complete without an expression of deep and heartfelt gratitude to my crew of best girlfriends. Sheena Purcell, my oldest friend, can always be relied upon for a gossipy Skype session. She welcomed her third son to the world only six months after I gave birth to my daughter, and her wisdom and experience in the ways of parenthood have been invaluable to this newbie. In 2006, Ashley Thorvaldson and I packed our lives into the back of my '85 Nissan pickup truck and drove east from Vancouver to Ontario. Now, nine years later, she will marry her Easterner only four days before I defend this dissertation. Her wit, humor, warmth and charm make her among my favorite people and I am thrilled that this summer will see the culmination of many years of heartache and hard graft, for both of us. When Alison Powell and I first met in 2010, it was immediately clear that we would be friends. Our friendship has been built on a bedrock of shared experiences—we both got married in the same now-defunct Polish catering hall, we both had babies while in graduate school, we both love to talk about our mothers—and our Skype chats have become a heavily relied upon lifeline to this reclusive author. Her

brilliance, hard work, and commitment to family have been an inspiration and I am profoundly grateful to count her among my dearest friends. A lucky twist of fate has brought Sue Pell and I together in the same city again, after years of living on opposite ends of the continent. Sue has been a constant presence in my life since we first met as co-workers in 2004. We have stood by each other through all the ups and downs life has thrown at us. I was honored to have supported Sue at her wedding this summer, and I know I would not be writing these acknowledgements to preface a completed dissertation without her support and encouragement over the years. Sue has helped me to be a more ethical and conscientious person, and the imprint of our friendship can be seen on the pages that follow. My relationships with all my friends, but especially these women, have been and will continue to be hugely important to me and I will be forever grateful for the love, laughter and real talk we have shared.

I am also fortunate to have a loving and supportive family around me. My brother Marc Gurstein and sister-in-law Vicki Meyouhas can always be relied upon for good times and good conversation, and my niece Emily Renaud has consistently impressed me with her quiet strength and generous soul. I couldn't be prouder that she appears poised to follow in the family tradition and become a sociologist for social justice. My brothers and sisters-in-law Mike Madden and Mindy Saraco, and Ben Madden and Jenny Marron have been excellent hosts, travel companions and friends.

As well I am indebted to my grandmother Sylvia Gurstein and late grandfather Emanuel Gurstein. Their years of active political engagement in causes greater than themselves have been an inspiration. Clem and Sandy Alpert have welcomed me warmly into their family and demonstrated how to live long and live well. It is thanks to the collective

generosity of this generation that we have managed to make a comfortable life for ourselves in London. It is not lost on me how lucky I have been to be the recipient of such support, without which this dissertation would almost certainly never have seen the light of day.

I am immensely grateful to my parents-in-law Judy and Brian Madden for their support and generosity over the years. In the last stages of writing they came to London and were an enormous help in getting over the final hurdle. I feel very fortunate indeed to have such loving and reliable people in my corner.

On my bookshelf sits the collected works of Freud, given to me by my mother Fernande Faulkner. Next to it sits the heavily-annotated 1960s edition of Karl Marx's *Capital Volume 1*, given to me by my father Michael Gurstein. The joke goes that from my mother I learned how to worry, and from my father I learned what to worry about. Of the many things my mother taught me, possibly the most important has been how to love people for who they are not who you wish they were. And my father's unyielding commitment to the underdog is something that I also share. They provided me with exposure to the vast spectrum of human experience which has shaped the person I have become. I will always be grateful to them for that.

And my own small family, my husband David Madden and our daughter Emmanuelle. What a privilege to have married someone like David. He constantly amazes me with the depth of his kindness, the range of his intellect, and his impressive musical talent. It is one of the greatest pleasures in my life that he and I share a life of the mind, and a life of love. He has been an invested and hands-on editor, a collaborator, and a coach. It is an understatement to say that I wouldn't be here without him. And of course I must also thank

my smiley, chatty, funny and irrepressible Manu. This dissertation happened because of and despite her appearance in our lives. She helped to focus my priorities and gave me a reason to keep working, even though she was also the chief culprit of a marked downturn in work productivity! Despite the extra time it took to get to this point, I absolutely would not have had it any other way.

This dissertation is dedicated to all of these people who have, in their own ways, helped guide me through this project, and through life.

R.G.

2015

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## Chapter 1

### Introduction: Harm Reduction in Context

#### I. Introduction

The story of harm reduction is fundamentally urban. It tells how some of society's most marginalized, feared and vulnerable members, intravenous drug users, were able to join in a coalition of other actors to develop policies to address the deadly health risks that they face. In so doing, they initiated larger transformations in the way health systems deliver services to risky populations. Harm reduction arose in exactly those corners of the post-industrial city that were described by outside observers as ungovernable wastelands—places that were imagined as the targets of social policies, not their progenitors. What arose in these places constitutes the latest chapter in the long history of local health authorities acting in innovative ways, often at odds with national practices or norms, to address problems exacerbated by their urban settings.

In his study of the historical geographies of public health in Seattle, Michael Brown notes, "For reasons that have not been entirely clear, those who conceptualize 'urban politics' rarely consider public-health departments as an interesting apparatus of the state."<sup>1</sup> To fill this lacuna, Brown urges historians, geographers and others to "frame public health as a

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<sup>1</sup> Michael Brown, "Public Health as Urban Politics, *Urban Geography* 30.1 (2009): 23. See also Jason Corburn, "Reconnecting with Our Roots American Urban Planning and Public Health in the Twenty-first Century." *Urban affairs review* 42.5 (2007): 688-713.; Rachel Slocum, "Commentary on 'Public Health as Urban Politics, *Urban Geography* 30.1 (2009): 30-35; Roger Keil, "Urban Politics and Public Health: What's Urban, What's Politics?" *Urban Geography* 30.1 (2009): 36-39; Tim Brown and Craig Duncan, "Placing Geographies of Public Health," *Area* 33.4 (2002): 361-369.



form of urban politics.”<sup>2</sup> Indeed, scholars have located urban politics in topics ranging from the minutiae of urban housing markets to the placement of street furniture—while the knowledge, practices, and institutions of urban public health are typically regarded as apolitical infrastructure. This is partly due to the institutional separation of public health research from urban planning and urban studies research. And it is partly due to the efforts of public health practitioners themselves. Public health departments work hard to keep themselves out of the rough-and-tumble world of urban political conflict, even when pursuing deeply progressive and contested agendas on behalf of the largely poor and marginalized populations that they serve.

To frame public health as a form of urban politics is to see public health as a central part of struggles over resources, space and belonging in the city. As much as municipal bureaucracies surrounding housing, crime, sanitation, neighborhoods and other spheres of urban governance have been the object and instrument of struggles to shape the modern city, so too have public health authorities been central to forming urban life. And in fact, public health actors have directly and indirectly acted upon issues like housing, crime and sanitation in the interest of population health and safety. Public health actors produce much of the basic knowledge and data—statistics about births, deaths and other crucial actuarial and demographic information—that forms the basis for a host of policy decisions. In a direct way, what we know about the city is derived from information gathered through the public health bureaucracy’s mandate to conduct population surveillance. Because of its unique epistemological, political and medical functions, public health is a privileged site for understanding agency, surveillance, exclusion, community, empowerment, and other central urban political questions.

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<sup>2</sup> Brown, *op. cit.*: 1.

Much is at stake in understanding public health as a domain of urban politics. Whether or not public health should be seen as properly “political” is not merely an abstract question of disciplinary authority. Uncertainties surrounding its politics are part of the very phenomenon of urban public health itself. Throughout American urban history, whenever representatives of public health departments, doctors, medical scientists, activists and others have debated public health measures, they have tried to adjust the boundary between the political—where we use the language of values, ethics and power to debate both process and ultimate ends—and that which is considered “nonpolitical” or “apolitical” and thus treated merely as matters of efficiency in means not the appropriate ends.<sup>3</sup> These tensions—between value rationality and instrumental rationality, between the medical establishment and drug user mutual aid, between pragmatism and radicalism—are at the heart of harm reduction, both as a social movement and shorthand for a whole set of public health policies.

An important strand of contemporary analysis identifies harm reduction as part of the neoliberalization of social policy.<sup>4</sup> Harm reduction, such scholars argue, shifts responsibility

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<sup>3</sup> Nancy Krieger, “The Making of Public Health Data: Paradigms, Politics, and Policy.” *Journal of Public Health Policy* (1992): 412-427.; George Rosen, *A History of Public Health*, Revised Ed. (Baltimore: MD, Johns Hopkins University Press, 2015.); John Duffy, *History of Public Health in New York City, 1625-1866*, (New York, NY: Russell Sage Foundation, 1968.)

<sup>4</sup>See for example Gordon Roe, “Harm Reduction as Paradigm: Is Better than Bad Good Enough? The Origins of Harm Reduction,” *Critical Public Health*, 15.3 (2005): 243-250.; Katherine McLean, “The Biopolitics of Needle Exchange in the United States. *Critical public health*,” 21.1 (2011): 71-79.; Donald Moore, “Governing Street-Based Injecting Drug Users: A Critique of Heroin Overdose Prevention in Australia,” *Social Science & Medicine* 59.7 (2004): 1547-1557.; Philippe Bourgois, “Disciplining Addictions: The Bio-Politics of Methadone and Heroin in the United States,” *Culture, Medicine and Psychiatry*, 24.2 (2000): 165-195.; Benedikt Fischer et al., “Drug Use, Risk and Urban Order: Examining Supervised Injection Sites (SISs) as ‘Governmentality’,” *International Journal of Drug Policy* 15.5 (2004): 357-365; Tim Rhodes, “Risk Environments and Drug Harms: A Social Science for Harm Reduction Approach,” *International Journal of Drug Policy* 20. 3 (2009): 193-201.;

for health and wellbeing from the state to the user, while developing new forms of discipline and surveillance that shape users' subjectivities and bodies. While these critics make valid points, my analysis takes a different tack. As explained in chapter two, the adoption of harm reduction strategies as a central approach to public health also requires the decentralization and the de- and recomposition of policy bureaucracies. But this does not mean that adopting a harm reduction approach is equivalent to deregulation or privatization. Rather, we must analyze the relationships between users, activists, community organizations, medical actors, and different branches of the state to understand harm reduction in a more precise and nuanced way.

This dissertation analyzes the politics of harm reduction in New York City between 1992 and 2012. Harm reduction has its roots in outsider social movements and marginalized spaces, but it became mainstream public health policy in New York. Its techniques have moved from the immediate context of the politics of addiction to the larger landscapes of social policy. This study places harm reduction in the context of a longer transformation of the state. It examines how harm reduction managed, in the words of one of my informants, to "get out of the ghetto" and become central to the city's public health bureaucracy.

The relationships between the city's public health bureaucracy and the activists and service organizations who comprise the harm reduction movement pushed the New York City public health system to transform the way they responded to drug use. The philosophy of harm reduction is everywhere in this new politics of addiction, although it sometimes takes the form of language about risk management or calls for evidence-based policy. Harm

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Peter G. Miller, "A Critical Review of the Harm Minimization Ideology in Australia," *Critical Public Health* 11. 2 (2001): 167-178.

reduction would not have been mainstreamed without the city's well-organized harm reduction movement, but many other parties played a role in the long-term transformations in social policy at the municipal, state and national levels. Despite their new position as the front line of a reconfigured public health state, New York's harm reduction organizations still see themselves as laboring on the margins. They see the challenge as maintaining the liberatory, social justice, user-centered orientation of the early harm reduction movement while expanding their services and becoming an increasingly routine practice of the state. They are a case study in the struggle to implement progressive policies in a neoliberal era.

As chapter two explains, harm reduction may fairly be called a neoliberal development within public health, taking the recent turn sometimes called the "new public health."<sup>5</sup> Along with other neoliberal social policies, it touts a 'common-sense,' cost-efficient approach that calculates risk and emphasizes personal responsibility. It has been adopted as part of what Peck and Tickell call the "roll-out" of new forms of social control and surveillance over users as individuals and populations.<sup>6</sup> It enables the state to discipline, punish, supervise, and manage deviant populations without addressing the underlying structural inequalities that deepen the negative consequences of drug use for already marginalized groups.

But rather than subjecting harm reduction to readymade critique, this study argues that we can use it to detect under-exploited opportunities for progressive change in a largely anti-progressive era. What do pro-poor social policies look like today? What strategies should activists use to pursue politics that support marginalized social groups in an unequal era?

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<sup>5</sup> See, e.g., Alan Petersen and Deborah Lupton, *The New Public Health: Health and Self in an Age of Risk* (Thousand Oaks, CA: Sage, 1996).

<sup>6</sup> Jamie Peck and Adam Tickell, "Neoliberalizing Space," *Antipode* 34.3 (2002): 380-404.

In a time of austerity and privatization, how can we extend public services to excluded groups?

Harm reduction has a deeply transformative potential, stemming from its origins as a mutual aid movement among users. It mobilizes the language of human rights in relation to a marginalized group. Because it looks to users themselves as experts on drug use, it revalues the experience of marginality. It forges new coalitions between medical researchers, law enforcement, public health administrators and drug users activist groups in order to pursue progressive goals. By integrating drug users *as users* into political society, these new networks provide new avenues for participation, solidarity and citizenship. This dissertation will explore these political consequences of harm reduction, and show how they are connected to changing policy paradigms in New York.

## **II. Harm reduction in New York City**

The streets and neighborhoods of New York City mark the battle lines of the war on drugs. Home to the nation's largest concentration of drug users, the city has also been an epicenter of the HIV/AIDS epidemic. Nowhere have the drug war's devastating consequences been more deeply felt. It is thus no surprise that the harm reduction movement for drug policy reform has become firmly established here, despite and because of New York's struggles with rising rates of drug dependency and the myriad problems associated with drug use, like mass incarceration, HIV infection, and overdose deaths.

New York is, of course, the most populous city in the U.S.. It is also among the country's most unequal. These two factors have ensured that New York has a major national profile,

as well as major problems—and they have both contributed to New York’s outsize influence in the arena of urban policy. The nation’s most impoverished congressional district, the South Bronx, sits uncomfortably close to some of the most expensive real estate in the world. Mott Haven, the heart of the South Bronx and the location of my field sites, also has the dubious distinction of being the New York neighborhood with the highest rate of overdose death.<sup>7</sup> Patterns of economic inequality, health inequality and racialized residential segregation combine to make the city a mosaic of vastly different life chances.<sup>8</sup>

The harm caused by drug use is on a different scale in New York than that of any other American city. New York has as many as 200,000 intravenous drugs users, the largest such population in the country.<sup>9</sup> According to recent estimates, the city is home to over 117,000 people living with HIV. Of those, about 16.3% have a history of injection drug use.<sup>10</sup> Though still insufficient to meet demand, New York now boasts the largest syringe exchange network in the nation, annually delivering over three million clean needles to users in all five boroughs.<sup>11</sup> The number of new HIV infections linked to injection declined sharply in recent years, thanks in part to the herculean efforts of syringe exchange programs and other AIDS and harm reduction service providers. New York City nevertheless remains a hotspot for new HIV infection, especially in high poverty neighborhoods in Brooklyn and the Bronx. Other direct consequences of intravenous drug use on the health of drug users

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<sup>7</sup> DOHMH, “Drugs in New York City: Misuse, Morbidity and Mortality Update,” *Epi Data Tables*, (2011).

<sup>8</sup> Merrill Singer, “AIDS and the Health Crisis of the US Urban Poor: The Perspective of Critical Medical Anthropology,” *Social Science & Medicine* 39.7 (1994): 931-948.

<sup>9</sup> DOHMH, “HIV Risk and Prevalence Among New York City Injection Drug Users.” (2009).

<sup>10</sup> DOHMH, “New York City HIV/AIDS Annual Surveillance Statistics 2013,” (2013).

<sup>11</sup> Don C. Des Jarlais, et al., “HIV Incidence Among Injection Drug Users in New York City, 1990 to 2002: Use of Serologic Test Algorithm to Assess Expansion of HIV Prevention Services.” *American Journal of Public Health* 95.8 (2005): 1439-1444.

are overdose (discussed in chapter four), Hepatitis C, abscessed veins, and blood-borne infection to name just a few.

New York has long pioneered in the field of public health, making it well placed to address these challenges. Along with its distinctive approach to public housing, labor relations, and other aspects of municipal policy, the City has an advanced public health system.<sup>12</sup> The historian Paul Starr argues:

New York City was no microcosm of America. In many regions, particularly the South and the West, public health often barely reached the stage of sanitary reform, if it went that far. The underdevelopment of public health was the more characteristic pattern in the United States. The experience in New York is significant precisely because, as an exceptional case, it discloses some of the political constraints limiting public health at its boldest.<sup>13</sup>

Much of the history of American public health has been written in New York.<sup>14</sup> Understanding the limits and possibilities of public health history in this city can therefore teach us about the politics of public health policy more generally.

The New York City Department of Health and Mental Hygiene (DOHMH) was originally founded in 1805 as the Board of Health. The DOHMH “is at once prototypical and unique,” in that it “operates with unusual autonomy from the rest of the state, enforcing a health code that supersedes state regulations in many areas.”<sup>15</sup> From its early efforts at improving sanitation in the slums in order to control outbreaks of cholera<sup>16</sup> to its latter-day campaigns

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<sup>12</sup> Joshua B. Freeman, *Working Class New York: Life and Labor Since World War II* (New York, NY: New Press, 2001).

<sup>13</sup> Paul Starr, *The Social Transformation of American Medicine: The Rise of a Sovereign Profession and the Making of a Vast Industry* (New York, NY: Basic Books, 1982): 185.

<sup>14</sup> See for example John Duffy, *op. cit.*

<sup>15</sup> James Colgrove, *Epidemic City: The Politics of Public Health in New York* (New York, NY: Russell Sage Foundation, 2011): 7.

<sup>16</sup> Charles E. Rosenberg, *The Cholera Years: The United States in 1832, 1849, and 1866* (Chicago, IL: University of Chicago Press, 2009).

against cancer, cardiovascular disease, obesity, and diabetes—“the epidemics of the modern era”<sup>17</sup>—the health department has long been entangled not only with public health policy itself, but with housing, civil rights, municipal statistics and other aspects of urban administration. Public health in the city, as elsewhere, has wrestled with questions about what lies at the discipline’s core, where and how to intervene, and whom to prioritize.

As a rule, public health’s purview, which is far-reaching and progressive, is in many ways ill matched to its powers, which tend to be limited and specific. Many of the health problems the DOHMH has had to deal with over the years—lead poisoning, tuberculosis, HIV to name but a few—have occurred as a consequence of, or been aggravated by, the social and economic status of their sufferers. One of the hallmarks of public health is a focus on population-level interventions aimed at the prevention of disease, not its cure. As such, the DOHMH has had to content itself with targeted programs like syringe exchange, rather than addressing the systemic factors—like poverty and racism—that contribute to drug use and continue to plague the city’s marginalized communities. Many within the health department recognize the limitations of their offerings and wish they could do more.

Sanitation in water and sewage may have been the major object of early public health interventions, but substance use has always been an important target for public health advocates as well. New York has had a reputation as a magnet for drug users dating at least to the early twentieth century. And from well before the AIDS crisis, drug use was already being treated as a public health problem. Struggles taking place nationally over the definition of the problem of drug use—was it an aberrant behavior and thus a crime, or was

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<sup>17</sup> Thomas R. Frieden, et al., "Public Health in New York City, 2002-2007: Confronting Epidemics of the Modern Era," *International Journal of Epidemiology* 37.5 (2008): 966-977.



addiction a disease?—were crystalized in concurrent and seemingly contradictory developments taking place in New York City and State in the 1970s. Community-based methadone programs were first introduced by the DOHMH in 1970. Only three years later, the state introduced mandatory minimum sentencing for drug related offenses. As a drug policy that was created at the metropolitan scale, and one that allowed for users to continue certain forms of drug consumption, methadone can be seen as part of the pre-history of harm reduction. And yet New York State's mandatory minimum sentencing was influenced by and gave credibility to the war on drugs declared by President Richard Nixon in 1971. The medical and the carceral models pioneered in New York would both be taken up and replicated across the country.

New York was not always the first jurisdiction to adopt harm reduction measures. New Haven, Connecticut began syringe exchange a few years before New York, and Chicago, San Francisco and the state of New Mexico were pioneers in naloxone distribution. But New York's size means that harm reduction has been institutionalized here at a uniquely large scale. The size of the population receiving services requires a well-developed infrastructure to be put in place, which has helped to move the services out of the periphery and into the mainstream. And despite often-vocal opposition, New York's liberal political climate has been favorable to harm reduction measures, with activists finding supporters among state and city officials as well as elected members of the city council and the state assembly.

The city's adoption of harm reduction was far from straightforward. In his support for methadone maintenance therapy, Mayor John Lindsay established a pattern which continues to this day, where New York mayors would promote harm reduction policies through seemingly exceptional, irregular means: pilot studies, administrative experiments

and public-private partnerships.<sup>18</sup> Methadone maintenance therapy, which began as a pilot study out of Beth Israel Hospital in 1968, expanded within a few years to be offered at outposts across the city.<sup>19</sup> For Mayor Lindsay, methadone seemed to be an answer for a number of different problems. In an era of urban crisis, rising crime rates and major social conflict, methadone seemed like a way to reduce the criminal behaviors like theft, burglary and assault that were blamed on drug-addicted people. In a period of looming fiscal crisis, methadone was also a way for Mayor Lindsay to use the health department's infrastructure of community-based health centers to tap into federal money connected to President Lyndon Johnson's Great Society.<sup>20</sup>

Harm reduction in New York had its first period of expansion in response to the HIV/AIDS epidemic of the late 1980s and early 1990s, during the Koch and Dinkins administrations. In an effort to get a handle on the worsening AIDS crisis, senior officials at the DOHMH approached Mayor Koch with a proposal for a city-run syringe exchange program in 1985. Though personally in favor of the idea, syringe exchange failed to materialize at this time due to the political climate during the Koch administration.<sup>21</sup> But in the face of the heaviest HIV casualties in the nation, the city's public health establishment persisted in their efforts to implement syringe exchange and in November 1988 the first exchange was opened as a

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<sup>18</sup> Samuel Roberts, "To Enter a Society which Really Doesn't Want Them: The Making of Controversies During New York City's Heroin Crisis, 1955-1975," Paper presented to the New York University American History Workshop (3 April 2009). Arguably the tendency towards operating in a space of exception, policy-wise, is typical of harm reduction globally.

<sup>19</sup> Colgrove, *op. cit.*, 59

<sup>20</sup> *Ibid.*

<sup>21</sup> For a discussion of intricacies of the coalition politics of the Koch administration, see John Hull Mollenkopf, *A Phoenix in the Ashes: The Rise and Fall of the Koch Coalition in New York City Politics* (Princeton, NJ: Princeton University Press, 1994). Specifically on the topic of Mayor Koch and syringe exchange, see Colgrove, *op. cit.*: 107-179.

research pilot out of the Manhattan headquarters of the DOHMH.<sup>22</sup> For several reasons that chapter three will explain, the syringe exchange did not succeed in attracting the large volumes of drug users officials had anticipated. And when Dinkins defeated Koch in the mayoral election of 1989, one of his first acts as mayor was to shut down the exchange after only fourteen months in operation. Dinkins ignored the mounting public health consensus around the effectiveness of syringe exchange at curbing the spread of HIV. Instead, he deferred to the sensitivities of the political coalition that helped to put him in office, which included powerful members of the city's Black establishment who were vocal opponents of syringe exchange.<sup>23</sup>

Following the closure of the health department-run site, syringe exchange went underground. Activists continued to operate unsanctioned exchanges in neighborhoods with high levels of drug use. At the time, over 50% of injection drug users were HIV positive<sup>24</sup> and drug users had by this point in the epidemic overtaken gay men as the group with the most new HIV infections.<sup>25</sup> For public health workers, this was a time of deep frustration with the political process. Many got involved in activism and civil disobedience alongside drug users and other allies, finding ways to support syringe exchange despite its illegal status. The situation came to a head with a test case brought by activists, which ended with a declaration that HIV constituted a public health emergency. In 1992 Mayor Dinkins

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<sup>22</sup> G. Alan Marlatt, et al., eds. *Harm Reduction: Pragmatic Strategies for Managing High-Risk Behaviors* (New York, NY: Guilford Press, 2011): 224.

<sup>23</sup> Prominent members of New York City's Black community came out forcefully in opposition of syringe exchange, with some linking its then pilot status to a longer history of medical experimentation on African American communities. Syringe exchange was widely condemned in the language of genocide. See Cathy J. Cohen, *The Boundaries of Blackness: AIDS and the Breakdown of Black Politics* (Chicago, IL: University of Chicago Press, 1999).

<sup>24</sup> Don C. Des Jarlais, et al., "HIV Incidence Among Injection Drug Users in New York City, 1992-1997: Evidence for a Declining Epidemic," *American Journal of Public Health* 90.3 (2000): 352.

<sup>25</sup> See DOHMH, "AIDS in New York City, 1981 – 2007," (2008).

reversed his position on syringe exchange, overstepping state paraphernalia laws and finally legalizing syringe distribution within the city. While he removed this legal obstacle to syringe access, Dinkins did not go so far as to authorize city funding for it. Meanwhile, the New York State Department of Health (NYSDOH) responded by initiating a process whereby groups that had been conducting underground syringe exchange could apply for a waiver from state paraphernalia laws.<sup>26</sup>

A pattern was thus established. Syringe exchange was legalized as a response to a public health emergency. But due to its highly controversial nature, it remained in a policy space of exception. This led to the establishment of a handful of harm reduction agencies that operated independently from the city. These organizations relied on grant funding from the New York State AIDS Institute, American Foundation for AIDS Research (AmFAR), MAC AIDS and a small handful of other private donors. The consequences of this ad hoc, partly private and partly public arrangement, can still be seen today.

While the AIDS crisis persisted into the mid-1990s, syringe exchange remained in place. Mayor Rudolph Giuliani, while no personal supporter of the harm reduction ethos nevertheless refrained from interfering with it. Not reliant upon or even eligible for city funding, agencies hobbled along and did the best they could within their limited budgets. But the exceptional nature of funding for syringe exchange also meant that agencies enjoyed some degree of autonomy. Unlike fully funded public clinics subject to uniform requirements, syringe exchange sites were able to develop specialized organizational identities.

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<sup>26</sup> W. Henry Lambright and Mark J. O'Gorman, "New York State's Response to AIDS: Evolution of an Advocacy Agency," *Journal of Public Administration Research and Theory* 2.2 (1992): 175-198.

The second major expansion of harm reduction in New York came during the mayoralty of Michael Bloomberg. In general, Bloomberg made public health a major priority and signaled his seriousness on the matter by appointing Thomas Frieden, “an innovative and sharp-elbowed health commissioner.”<sup>27</sup> To deal with the continued risk of HIV infection among intravenous drug users, the administration promoted harm reduction policies directly through a vast expansion of the city’s syringe exchange program. The Bloomberg administration lobbied for a change in New York State law that legalized the sale of up to ten syringes at a time to customers through pharmacies and other authorized vendors such as medical professionals without a prescription, which facilitated syringe distribution by doctors in partnership with groups like Positive Health Project and the Lower East Side Harm Reduction.<sup>28</sup> The administration also supported other harm reduction programs like the overdose reversal drug naloxone, discussed in chapter four. And it provided funds for Intravenous Drug User Health Alliance (IDUHA) and other user-activist groups.

As alien as user-activist politics were to the persistently business-oriented Bloomberg brand,<sup>29</sup> some aspects of harm reduction politics resonated strongly with the Bloomberg ethos.<sup>30</sup> One of the Bloomberg administration’s central conceits was its commitment to pragmatic, data-driven policy. In press releases, campaign literature, and statements by the mayor, the administration advertised its self-conception as being “above politics,”

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<sup>27</sup> Colgrove, *op. cit.*: 15.

<sup>28</sup> See New York State Department of Health’s website for information on the expanded syringe exchange demonstration project, available online at [http://www.health.state.ny.us/diseases/aids/harm\\_reduction/needles\\_syringes/esap/update.htm](http://www.health.state.ny.us/diseases/aids/harm_reduction/needles_syringes/esap/update.htm)

<sup>29</sup> On Bloomberg’s business-centric agenda, see Julian Brash, *Bloomberg’s New York: Class and Governance in the Luxury City* (Athens, GA: University of Georgia Press, 2011).

<sup>30</sup> See Lawrence O. Gostin, “Bloomberg’s Health Legacy: Urban Innovator or Meddling Nanny?” *Hastings Center Report* 43 (2013): 19-25.

dedicated to finding solutions in a practical manner “beyond ideology.” Whether or not such an assertion can be validated, the ambition towards policy beyond politics clearly shaped Bloomberg’s preference for technocratic, evidence-based government. In education policy, administration decisions emphasized testing and accountability. In environmental policy, the administration signaled its dedication to practical measures through the promotion of weatherization, tree planting, and the creation of open space and bike lanes. In health policy, the administration implemented initiatives like the indoor smoking ban, calorie counts on restaurant menus, and a ban on trans fats which were seen as small-step solutions to some of the city’s obesity and general health problems. These measures were simultaneously activist, paternalistic, progressive, elitist, and pragmatic—exemplary, in other words, of the contradictions of urban social policy today. Although it is cast as the ideological opposite of all things Bloomberg, in public health policy, the de Blasio administration has so far declined to repudiate the strategies of its predecessor.

As subsequent chapters demonstrate, numerous actors and interests shape harm reduction in New York. These actors are organized into complex networks and hierarchies. There is a dimension to harm reduction that is top-down and initiated by the mayor, the governor, and public health bureaucracies at the city and state level; a meso-level of organizations that use harm reduction to preserve their position within the ecology of New York grant- and city-funded service providers; and a bottom-up dimension where harm reduction resembles a social movement. Harm reduction in New York simultaneously exists at each of these three levels.

The mayoral administrations mentioned above pursued harm reduction for a range of ideological, fiscal, administrative and strategic reasons. Through appointments, official and

unofficial policy changes, public discourse and other mechanisms, mayors and their staff have been able to promote, or if they prefer, to obstruct harm reduction policies. But the city's massive public health bureaucracy has an inertial force of its own that often outlasts mayoral changes. DOHMH and other agencies are sensitive to political context and are subject to executive authority. But they tend to be guided by logics that are more aligned with public health imperatives than with the calculations of electoral coalition building. Individuals within the public health bureaucracy have even at times pursued harm reduction strategies in ways that are at odds with official positions.

What can be seen as the middle-level—where service providers connect upward to higher layers of bureaucratic power as well as downward to grassroots efforts—has been an important element of New York harm reduction as well. The city is home to many active community-based organizations (CBOs) that compete and cooperate for access to resources and influence.<sup>31</sup> CBOs and elected representatives create long-term partnerships that shape particular fields of policy. By lobbying the city for more and particular kinds of harm reduction measures, organizing participants for pilot studies and other avenues for research and policy innovation, and most importantly, implementing the policies themselves, CBOs play a crucial role in the story of harm reduction in the city. These CBOs can be seen as the professionalized offshoots of 1980s- and 1990s-era social movements.<sup>32</sup> They have a permanence that social movement actors tend to lack. And they serve to link

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<sup>31</sup> See Nicole P. Marwell, *Bargaining for Brooklyn: Community Organizations in the Entrepreneurial City* (Chicago, IL: University of Chicago Press, 2009).

<sup>32</sup> See Elisabeth S. Clemens and Debra C. Minkoff, "Beyond the Iron Law: Rethinking the Place of Organizations in Social Movement Research," *The Blackwell Companion to Social Movements* (2004): 155-170; Margaret S. Kelley, et al., "Doing Syringe Exchange: Organizational Transformation and Volunteer Commitment." *Nonprofit and Voluntary Sector Quarterly* 34.3 (2005): 362-386.

grassroots efforts to urban regime politics.<sup>33</sup> In the case of harm reduction, IDUHA, created in 2004, is a coalition of local syringe exchanges that compete with one another but also join forces to lobby City Council for increased overall funding.

Finally, a grassroots-level of activist groups have supported harm reduction. Some, like Voices of Community Advocates and Leaders (VOCAL), are explicitly user-activist organizations. Others, like the Drug Policy Alliance (DPA) or the Harm Reduction Coalition (HRC) are oriented primarily or entirely towards drug policy. But other social movements have also animated harm reduction. This dimension was especially important in the early years, when harm reduction drew strength from a variety of movements, including local representatives of national gay rights and AIDS-oriented groups like the AIDS Coalition to Unleash Power (ACT UP).<sup>34</sup> As harm reduction in New York became institutionalized, it has lost some of its early activist zeal. Many of the original activists became professionalized and identify as advocates or health service providers. Others moved out of the scene altogether. But there are still plenty of members of the public health bureaucracy and social services organizations who see themselves as activists as well as professionals.

As the following chapters explain, the field of harm reduction in New York has undergone a process of institutionalization that has brought changes to the organizational forms, the sources of funding and support, and the political ambit of harm reduction as a social movement. Institutionalization, is the process by which harm reduction became a

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<sup>33</sup> Mollenkopf *op. cit.*; William Sites, "The Limits of Urban Regime Theory New York City Under Koch, Dinkins, and Giuliani," *Urban Affairs Review* 32.4 (1997): 536-557; Clarence Nathan Stone, *Regime Politics: Governing Atlanta, 1946-1988* (Lawrence, Kansas: Kansas University Press, 1989).

<sup>34</sup> Howard Lune, *Urban Action Networks: HIV/AIDS and Community Organizing in New York City* (Lanham, Maryland: Rowman & Littlefield, 2007); Howard Lune and Hillary Oberstein, "Embedded Systems: The Case of HIV/AIDS Nonprofit Organizations in New York City," *Voluntas: International Journal of Voluntary and Nonprofit Organizations* 12.1 (2001): 17-33.



formalized, routinized, and generally accepted response to drug use.<sup>35</sup> Table 1 details the stages that harm reduction has undergone in New York since its earliest days before it was legalized.

**Table 1. The institutionalization of harm reduction in New York**

<b>Degree of institutionalization</b>	<b>Funding sources</b>	<b>Scope of action</b>	<b>Organizational form</b>	<b>Political orientation</b>
<b>Low: activist organizing (before 1992)</b>	-Donations -Small grants	-Syringe distribution -Community organizing -Direct-action protest	-Protest movement	-Demanding government response to AIDS crisis -Empower drug users
<b>Medium: partial institutionalization (1992 - 2014)</b>	-New York City and State grants -Private grants	-Syringe access -HIV prevention and care services -Ancillary social services -Overdose reversal	-Community-based organization	-Treatment of marginalized people -Promoting professionalized harm reduction
<b>High: integration into Medicaid (2014 and after)</b>	-Share of resources budgeted for Medicaid -New York City and State grants -Private grants	-Syringe access -HIV management -Overdose reversal -Drug user health	-Participant organization in managed care network	-Mainstreaming harm reduction -Broader policy change

This table is a simplification of a complicated and uneven process. But it highlights the trajectory of harm reduction as a political movement and policy domain in New York. As it developed, harm reduction moved through the three stages of institutionalization described in the table. The bottom row describes harm reduction’s current, emerging state.

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<sup>35</sup> Ronald Weitzer, “The Social Construction of Sex Trafficking: Ideology and Institutionalization of a Moral Crusade,” *Politics & Society* 35.3 (2007): 458; William Gamson, *The Strategy of Social Protest* (Homewood, IL: Dorsey, 1975).

New York's turn to harm reduction has produced measurable successes. In the twenty years since the peak of the AIDS epidemic in the mid-1990s, the city saw HIV infection rates drop, due in part to the expansion of needle exchange programs, now numbering 17 across the five boroughs, and the dedication of harm reduction outreach workers throughout the city. But despite the decline in new infections in recent years, HIV is still spreading in New York City at three times the national rate,<sup>36</sup> disproportionately affecting residents of poor neighborhoods in Brooklyn and the Bronx. The concern over the concentration of new HIV cases and AIDS-related deaths within the South Bronx was enough to push the DOHMH into introducing a new large-scale program that would see every Bronx resident tested for HIV, the most comprehensive testing program in the nation.<sup>37</sup>

Syringe exchange represented, and continues to represent, the most visible success for the harm reduction movement in New York City. And it exemplifies the contradictions and paradoxes at the heart of the movement. Harm reduction has been a vehicle for user activism and a way to incorporate users *as users* into the city's public health bureaucracy. But it has also been promoted by mayoral administrations that were more closely aligned with the business establishment or broken-windows-inspired policing agendas than community-based social movements.<sup>38</sup> This tension within the movement can be the source of political opportunities: as the Rockefeller drug laws are being dismantled, harm

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<sup>36</sup> Sewell Chan, "H.I.V. is Spreading at Three Times the National Rate," *New York Times*, 27 August 2008.

<sup>37</sup> Anemona Hartocollis, "Push in Bronx for H.I.V. Test for All," *New York Times*, 26 June 2008.

<sup>38</sup> For the Bloomberg administration there was no contradiction between promoting stop and frisk in policing and harm reduction in public health. In contrast, many activists see *opposition* to stop and frisk as naturally aligned with the harm reduction ethos. But for Bloomberg and similar politicians like Rahm Emanuel, there is no contradiction—they see both policies as non-political responses to evidence that is imagined as sovereign.

reductionists have the chance to promote their projects in the name of cost-cutting. The efficiencies exhibited by harm reduction, especially as a technique for reaching high-risk, high-cost populations, has attracted attention from New York State's Medicaid Redesign Team, as I explain in chapter five. The question is whether harm reduction in the long run will empower the technocratic wing of the movement or its diverse community-based elements.

### **III. Case and methods**

This study positions itself in line with the growing field of qualitative and ethnographic policy research. It examines the ways the movement to adopt harm reduction has transformed the public health policy of New York City and State. As such, harm reduction is a shorthand for the entirety of the non-abstinence-oriented approach to managing the consequences of drug use—not only the policies that embody this approach, but also the organizations, movements, networks, and larger culture that continue to promote and administer them. This definition suggests the political and ideological urgency of this task that motivates those within the organizations that pursue the harm reductionist policy agenda.

The analysis of harm reduction presented here focuses on two areas. First, it provides an in-depth examination of the dynamics of the harm reduction policy domain. Much of what has been written about harm reduction in the U.S. context has focused only on its flagship intervention, syringe exchange, from a number of specific perspectives. They have tended either to be public health studies that narrowly evaluate syringe exchange as an intervention or broad histories of how syringe exchange came about in the context of

HIV/AIDS activism. Several histories chronicle the fractious time during which syringe exchange was born, amid the HIV/AIDS crisis of the late 1980s and early 1990s.<sup>39</sup> These studies frequently narrate the voices of participants within these organizations. Many of them have also placed gay rights activism in the center of the story, seeing harm reduction as an offshoot of that movement. My goal is not to object to these literatures, but to fill a gap within them. Relatively few social science analyses have examined harm reduction as a political project or as a policy domain with its own trajectory that is relatively distinct from AIDS and gay rights activism. Hence this study examines the political movements and organizational forms that made and continue to make harm reduction in New York.

Second, this study analyzes how the harm reduction movement, defined as both policy and politics, has helped to reshape larger fields of health care delivery in New York City and State. Harm reduction directly changed a number of social policies. But its logic has also echoed throughout social policy more generally. It is a microcosm of the recent history of policy change and also as a stimulant for further policy changes.

It is important to stress that this dissertation is a study of some of the professionals, activists, organizations, and practices that play a part in drug policy, not a study of drug users and their worlds. Since the 1950s, ethnographic research has explored many aspects of the 'drug scene.'<sup>40</sup> Intrepid researchers fanned out across the 'ghettos' of America's major

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<sup>39</sup> Randy Shilts, *And the Band Played On: Politics, People, and the AIDS Epidemic* (New York, NY: St. Martin's Press, 1987); Charles Perrow and Mauro F. Guillen, *The AIDS Disaster: The Failure of Organizations in New York and the Nation* (New Haven, Connecticut: Yale University Press, 1990).

<sup>40</sup> Howard S. Becker, "Becoming a Marihuana User," *American Journal of Sociology* 59.3 (1953): 235-242; Harold Finestone, "Cats, Kicks, and Color," *Social Problems* 5.1 (1957): 3-13; Alfred Ray Lindesmit, *Addiction and Opiates* (Oxford, UK: Aldine, 1968); Edward Preble and John J. Casey, "Taking Care of Business: The Heroin User's Life on the Street," *Substance Use & Misuse* 4.1 (1969): 1-24; Alan G. Sutter, "The World of the Righteous Dope Fiend," *Issues in Criminology* 2.2 (1966):

metropolitan centers to report back about the habits and practices of the drug using masses. This has produced a number of important works, some of which influenced policy. But the focus has almost entirely been on the distinctive subcultures of drug users or the unintended consequences of drug prohibition. In contrast, this study is more in line with ethnographies of the policy process that examine policymaking itself from an ethnographic perspective.<sup>41</sup>

New York is the most appropriate case for this study not because it is representative of the rest of the country, but because it has always lead the country in designing and implementing new public health policies. It continues to serve as a model to the rest of the country. Because it has the largest network of syringe exchanges anywhere in the country and the highest concentration of injection drug users, the experiences of New York shed light on the possibilities and limitations of harm reduction. It is one of the most important centers of harm reduction innovation, and it demonstrates the need for continued harm reduction programs. Additionally, the DOHMH created the country's first director of harm reduction within its Bureau of Alcohol and Drug Use Prevention, Care, and Treatment. So

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177-222; Bingham Dai, *Opium Addiction in Chicago* (Glen Ridge, NJ: Patterson Smith, 1970); Dan Waldorf, *Careers in Dope* (Upper Saddle River, NJ: 1973); Michael Agar, *Ripping and Running: A Formal Ethnography of Urban Heroin Addicts* (New York, NY: Academic Press, 1973); Don H. Zimmerman and D. Lawrence Wieder, "You Cant Help But Get Stoned: Notes on the Social Organization of Marijuana Smoking," *Social Problems* 25.2 (1977): 198-207; Bill Hanson, et al., *Life With Heroin: Voices from the Inner City* (Lexington, MA: Lexington Books, 1985); James P. Spradley, *You Owe Yourself a Drunk: An Ethnography of Urban Nomads* (Lanham, MD: University Press of America, 1988); Philippe Bourgeois, *In Search of Respect: Selling Crack in El Barrio* (Cambridge, UK: Cambridge University Press, 1995); Howard S. Becker, *Outsiders: Studies in the Sociology of Deviance* (New York, NY: Free Press, 1997).

<sup>41</sup> Mara S. Sidney, *Unfair Housing: How National Policy Shapes Community Action* (Lawrence, KS: University Prress of Kansas, 2003); Alex Stevens, "Telling Policy Stories: An Ethnographic Study of the Use of Evidence in Policy-Making in the UK," *Journal of Social Policy* 40.2 (2011): 237-255; Dominique P. Béhague and Katerini T. Storeng, "Pragmatic Politics and Epistemological Diversity: The Contested and Authoritative Uses of Historical Evidence in the Safe Motherhood Initiative," *Evidence and Policy* 9.1 (2013): 65-85.

harm reduction has been institutionalized here in a way that assures its continued existence and facilitates its further evolution.

Harm reduction is now in its third decade in the city and many of the most contentious debates over harm reduction policy have been waged and won. Unlike most of the rest of the country, harm reduction measures like syringe exchange have become firmly embedded in the landscape of public health provision in the city and the state. New York is thus an ideal vantage point from which to observe harm reduction's onward trajectory.

Data for this study were gathered over a two-year period from January 2011 to December 2012, using multiple qualitative methods. It is informed by participant observation and open-ended qualitative interviews. Participant observation took place at three syringe exchange agencies in the Bronx neighborhood of Mott Haven. The majority of my hours in the field were spent at an organization here named as South Bronx Harm Reduction (SoBroHR) where I volunteered once or twice a week for one year. I also spent several months volunteering at agencies called Harm Reduction Revolution (HRev) and the Harm Reduction Partnership (HRP) here. In accordance with Institutional Review Board protocol, names of the organizations have been changed to protect the agencies that shared sensitive operational information with me, as well as individual informants at these agencies who did not wish to be identified. Public figures are identified by name where appropriate and where permission has been given.

Semi-structured, open-ended interviews were conducted with 37 agency staff and peer volunteers, employees of the DOHMH Bureau of Alcohol and Drug Use, Prevention, Care and Treatment, the NYSDOH AIDS Institute, and harm reduction advocates working at

three additional New York City-based harm reduction and drug policy advocacy organizations. In total, 40 interviews took place (3 people were interviewed twice). Interviews lasted between 30 minutes and 2 hours, with most lasting one hour. All but two interviews were recorded and the interviews were transcribed and coded before being analyzed. Interviewees were selected based on my emerging analysis of the harm reduction field. I sought to interview key figures at each organization, as well as other important actors identified by reputation and using well-established snowball sampling methods.

In addition to the participant observation conducted at harm reduction agencies, my fieldwork included the larger harm reduction scene. This involved attending several meetings of the Intravenous Drug Users Health Alliance; attending a conference hosted by the AIDS Institute to commemorate twenty years of harm reduction; joining a daylong meeting also hosted by the AIDS Institute to inform harm reduction organizations about the upcoming changes to Medicaid; and participating in a direct action in Washington DC organized by several harm reduction agencies in protest of the re-imposition of the federal funding ban on syringe exchange. My fieldwork also included attending numerous overdose prevention training sessions as well as a observing training offered by the AIDS Institute for employees and volunteers at syringe exchanges. It was my intention, with these varied and various venues, to develop a sense of the harm reduction world in New York. As such, my ethnographic interest was not so much in micro-practices at the sub-agency level, but rather in the dynamics of interaction between differently situated actors.

This study has a number of methodological limitations. One of them concerns the pace of change in the harm reduction scene. Describing a world as complex and fast moving as harm reduction in New York is exceedingly challenging. Over the course of my fieldwork I

watched agencies metamorphose from run-down syringe exchanges to gleaming full-service medical centers. Long-time allies and institution builders retired, taking with them their irretrievable, unreplicable experience and organizational memories. Some major figures died from drug overdose. And the federal ban on syringe exchange funding was reinstated only two years after it was first repealed. Meanwhile, a growing opioid overdose crisis that was first emerging shortly before my fieldwork began has now gripped the nation in what has been characterized as a full-blown epidemic.<sup>42</sup> Any study of harm reduction policy would necessarily be a snapshot of a moment in time, and that is certainly true of this one.

Another challenge is the breadth of the harm reduction field. It encompasses health commissioners and bureaucrats from the City and the State; elected officials and their staffs; directors of harm reduction agencies and their cadres of employees, volunteers and peers; academic public health researchers; policy entrepreneurs; non-governmental advocacy organization employees; activists, some of whom are affiliated with formal organizations, some of whom are not, operating at the local and national levels; and users with an interest in health and policy, as well as their families and friends. It obviously would not have been practical to speak with everyone. For the purposes of this study, my data gathering focused on the three groups mentioned above—DOHMH and NYSDOH bureaucrats, staff at harm reduction organizations, and members of advocacy groups. This corner of the field provided information about harm reduction as a whole. But inevitably my data includes more material from some parts of this field than others.

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<sup>42</sup> The Centers for Disease Control has reported an increase in heroin and prescription opiate as well as a four-fold increase in opiate deaths between 2002 and 2013. It has characterized this recent trend as an “epidemic.” Significantly, drug use has gone up across all age and income levels, meaning that opiate addiction is not a problem confined to the inner city. The broadening demographic of both prescription and illegal opiates is one of the reasons the peer administration of the overdose reversal drug naloxone has been relatively uncontroversial. This is discussed in more detail in chapter four. See CDC, “Today’s Heroin Epidemic: More People at Risk, Multiple Drugs Abused,” *Vital Signs*.



Due to the fast-changing and vast nature of harm reduction, my sample of informants is not a representative cross-section of actors. However, multiple qualitative methods enabled me to check the validity of my data to a high standard of confidence. Where possible, data gathered through fieldwork was crosschecked with published materials. As with all qualitative studies, the interpretation is my own, but I have done my best to make my assumptions clear and my interpretive reasoning transparent.

#### **IV. Chapter outline**

This chapter has introduced the major arguments and ideas and provided historical and political background to the present study. Chapter two examines harm reduction in the context of changing policy paradigms. Harm reduction is often associated with neoliberal forms of social policy. The chapter critically engages with this literature and argues that invoking neoliberalism can obscure the ways activists and policymakers work to influence and implement policy change.

Chapter three examines the development of syringe exchange in New York. It analyzes the relationships between harm reduction activists and the public health bureaucracy, arguing that the way in which syringe exchange was authorized through a waiver of state paraphernalia laws caused harm reduction to become partially institutionalized. Partial institutionalization was beneficial to harm reduction agencies as it allowed them to maintain autonomy while also influencing policy. But it also contributed to a close tie to HIV/AIDS and a precarious situation where harm reduction agencies were reliant on grant funding.

Chapter four analyzes the city's use of the overdose reversal drug naloxone, a major emerging harm reduction strategy. It provides the first social-scientific analysis of naloxone, arguing that the success of overdose prevention programs depends not only on the chemical properties of naloxone, but on the social strategies launched by users, clinical personnel, public health workers, and others in the harm reduction movement. Naloxone's diffusion throughout the public health system required the adoption of peer administration and lay training. It creates new alliances between drug users and medical professionals, as expertise and authority are extended into the worlds of users themselves. The social networks of the users become new kinds of targets for public health interventions. In a fashion typical of harm reduction, all of this occurs in a legal space of exception, with regulations and laws being rewritten after the fact to take into account new practices. Naloxone is an example of harm reduction's evolution into new areas of health practice, reaching new populations not historically connected to syringe exchange or the harm reduction movement.

Chapter five analyzes harm reduction's incorporation into Medicaid. At the time of my research, harm reduction services were poised to become reimbursable through Medicaid. At the same time, the harm reduction model of service delivery had been flagged by the Medicaid Redesign Team involved in a wider process of Medicaid reform as a strategy to emulate throughout the system. Harm reduction has thus become a mainstream practice, and a mainstream policy ideology. While some activists are skeptical of this process, many in the harm reduction field embrace the opportunity presented by Medicaid. The example of harm reduction's incorporation into Medicaid and managed care demonstrates the complexities of social policy in an era of privatization.

The dissertation concludes with chapter six. It recaps the major findings and arguments of the dissertation. And it shows how the case of harm reduction in New York can help us understand the politics of new public health policies and the unforeseen political opportunities in the era of neoliberal, evidence-based, increasingly technocratic policy.

## Chapter 2.

### Contesting Harm Reduction

#### I. Introduction

This chapter examines the meanings of “harm reduction” and “neoliberalism,” and explains the connection between the two. Many scholars have connected the emergence of harm reduction to the neoliberalization of social policy and constructed a critique upon that basis. My argument dissents from the perspective. While the emergence of harm reduction drug policies is indeed inseparable from those social policy trends that others have characterized as neoliberal, the diffusion of harm reduction demonstrates the potential for progressive policy change in the contemporary era. It is not inherently problematic, as the neoliberal label might suggest. The restructuring of the welfare state has paradoxically created an opportunity for expanding services to drug users, a category of citizen that in previous eras was largely excluded from receiving state benefits.

There are clearly many reasons to be skeptical of the concept of neoliberalism. Certainly, analysts of social policy should avoid reifying it as a causal force. But if used to describe specific trends within policymaking rather than as an epithet, the term can still hold analytic meaning. Furthermore, ignoring the concept altogether would mean ignoring much of the literature on the political developments that constitute the context of the growth of harm reduction. And it would mean ignoring some major debates within the harm reduction movement itself. The challenge for analysts of harm reduction, then, is to develop a position regarding its relationship with the neoliberalism debate that captures their essential connections without creating a caricature of either.

Harm reduction programs fundamentally place the responsibility for health and welfare on service recipients, rather than on the state. Such programs assume the existence of individualized citizens committed to self-improvement. They mobilize decentralized, distributed social networks as policy tools. And their promoters present harm reduction policies as apolitical measures rooted in evidence and data rather than ideology. In short, harm reduction is a prime example of what we talk about when we talk about neoliberalism.

But that is not the end of the story. Harm reduction in fact illustrates the complexity of contemporary social policy, in that it is simultaneously neoliberal and progressive. Wherever it has been adopted, harm reduction was promoted by social movements that knew how to effectively position themselves within states and municipalities undergoing budget cuts, privatization, and ideological reconfiguration. But it also reflects these changes and depends upon them. Harm reduction should therefore cause us to reexamine many of our assumptions about the political possibilities in the contemporary era.

## **II. Defining harm reduction**

The concept of harm reduction refers, in the first instance, to policies and programs that do not expect drug users to abstain.<sup>1</sup> Rather than attempting to eliminate their drug use, it seeks to reduce the individual and collective harms that drug use can cause. However,

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<sup>1</sup> G. Alan Marlatt, et al., eds. *Harm Reduction: Pragmatic Strategies for Managing High-Risk Behaviors* (New York, NY: Guilford Press, 2011); Don C. Des Jarlais, "Harm Reduction: A Framework for Incorporating Science into Drug Policy," *American Journal of Public Health* 85.1 (1995): 10-12

harm reduction has never been focused on the personal freedom to use drugs. Rather, it has been about transforming the ways in which contemporary social, legal and political systems treat drug users, seeing them as “deserving of caring and life rather than punishment and death.”<sup>2</sup> Harm reduction is both a public health strategy and a dimension of drug policy, though drug policy is a multifaceted phenomenon that includes regulation, enforcement, treatment, and prevention. Far from being a static and prescriptive program, harm reduction is fluid, reactive and evolving. It emerged by molding itself to the contours of the social, legal and political institutions and practices that continue to sustain the war on drugs, offering targeted interventions to lessen some of the more harmful effects of this still-ongoing “war.”

Harm reduction exists alongside and is shaped by this other approach to drug policy but includes distinct goals and strategies. It should not be seen as a replacement for enforcement, but rather as an addition and corrective to it. And harm reduction does not entail decriminalization. Although many harm reduction advocates do support decriminalization and legalization, they are distinct actions with different rationales, strategies, and bases for support. Simply put, decriminalization focuses on legal responses, while harm reduction is a public health measure to reduce the negative side-effects of taking drugs. Harm reduction strategies thus exist alongside the criminalized status quo, responding to its consequences by ameliorating its outcomes.

Typically, front-line workers such as nurses, doctors, and other public health service providers develop harm reduction strategies. For them, drug use is a practical problem.

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<sup>2</sup> Dan Small et al., “The Establishment of North America’s First State Sanctioned Supervised Injection Facility: A Case Study in Culture Change,” *International Journal of Drug Policy* 17 (2006): 74.

They encourage and promote input from members of the target population<sup>3</sup>, with the idea that interventions are most likely to succeed when they are demanded by and created in partnership with the people affected.

While many political approaches to drug use have attempted to reduce harmful consequences, activists in the Netherlands first explicitly used the language of “harm reduction” in the 1980s in response to the escalating HIV/AIDS crisis among intravenous drug users. They departed sharply from the punitive model of drug policy, which at that point was still nearly universal. Dutch harm reductionists formulated a core set of principles that are still central to harm reduction today. They saw themselves as pursuing a “pragmatic philosophy and embrace[d] a public health view of drug problems”<sup>4</sup> that was rooted in a “common sense” approach to social policy. Harm reduction supporters argued that they were “willing to meet the individual on his or her own terms—to ‘meet you where you are’ rather than ‘where you should be.’”<sup>5</sup> They felt that “reducing the stigma associated with problems of addiction” would lessen the barriers for social and political participation, thus minimizing “anti-social” behavior and allowing for greater ease of access to potentially life-saving services.<sup>6</sup>

The idea that public health interventions should target drug users to not only curb the spread of disease but also improve the condition of users’ lives subsequently gained popularity throughout Western Europe, Australia, Canada and in some limited capacities,

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<sup>3</sup> Anne Schneider and Helen Ingram, "Social Construction of Target Populations: Implications for Politics and Policy," *American Political Science Review* 87.02 (1993): 334-347.

<sup>4</sup> G. Alan Marlatt, “Harm Reduction Around the World,” *Harm Reduction: Pragmatic Strategies for Managing High-Risk Behaviours*, G. Alan Marlatt, ed. (New York: Guilford Press, 1998): 31

<sup>5</sup> *Ibid.*: 55.

<sup>6</sup> *Ibid.*

the United States. In the U.S., the first organized syringe exchange program began operations in Tacoma, Washington in 1988, though the informal practice of distributing sterile injection equipment to drug users is older.<sup>7</sup> New York State authorized syringe exchange in 1992, the Harm Reduction Coalition—a national service and advocacy organization—was founded in 1993, and by the late 1990 select health departments and AIDS service organizations across the country were offering syringe exchange. As detailed in chapter three, the expansion and diffusion of harm reduction, specifically syringe exchange, tracked the onset of the HIV/AIDS epidemic in the late 1980s and 1990s, solidifying its association with the struggles and upheavals that HIV brought to the world of medicine and public health.<sup>8</sup>

Harm reduction is not only a public health project. It is also a “health-based social movement,” pursued by activists.<sup>9</sup> Health-based social movements draw on the contentious tactics and rhetoric of social movements in order to shape public health policy and wider debates about health and social justice. As a social movement, it reflects a broader critique of centralized, bureaucratic urban social policy, also represented by the movement for community control of schools, housing and other institutions.<sup>10</sup>

The health social movement side of harm reduction seeks to act upon the place of drug users within the health system in a broader way than just changing policy. Activists have

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<sup>7</sup> James A. Inciardi and Lana D. Harrison, eds., *Harm Reduction: National and International Perspectives* (New York, NY: Sage Publications, 1999).

<sup>8</sup> Ronald Bayer and Gerald M. Oppenheimer, *AIDS Doctors: Voices from the Epidemic: An Oral History* (Oxford, UK: Oxford University Press, 2002); Ronald Bayer, "Public Health Policy and the AIDS Epidemic: An End to HIV Exceptionalism?" *New England Journal of Medicine* 324.21 (1991): 1500-1504; Steven Epstein, *Impure Science: AIDS, Activism, and the Politics of Knowledge* (Oakland, CA: University of California Press, 1996).

<sup>9</sup> Robert H. Keefe et al., "From the Bottom Up: Tracing the Impact of Four Health-Based Social Movements on Health and Social Policies," *Journal of Health & Social Policy* 21.3 (2006): 55-69.

<sup>10</sup> James DeFilippis, *Unmaking Goliath: Community Control in the Face of Global Capital* (New York: Routledge, 2004).



sought to change the relationship between drug users and the state, to make drug users more active producers, and less stigmatized consumers, of health services. As Henman et al. put it, due to harm reduction efforts, “it will be difficult in the future to treat IDUs simply as the passive objects of state intervention.”<sup>11</sup> In most contexts, activists have explicitly sought to move drug users beyond this politically passive condition.

Harm reduction, especially in its early years, was promoted by drug user unions, like the *Junkiebond* in the Netherlands and the Vancouver Area Network of Drug Users (VANDU) in Vancouver, Canada, which practice harm reduction as a form of mutual aid.<sup>12</sup> Drug user unions also pushed state agencies to incorporate users as legitimate political participants, rather than as feared, stigmatized outcasts. They exemplify the bottom-up side of harm reduction, which has often been in tension with the movement’s more top-down practitioners in public health and medical institutions.

In many cities, harm reductionists formed coalitions composed of reformers, user activists, health care providers and local politicians. The strategies they promoted—syringe exchange, supervised injection, distribution of overdose reversal drugs, and prescription heroin for hardcore users, among others—had rapid and dramatic effects. Studies of harm reduction interventions conducted over the past twenty years in an array of venues have demonstrated a substantial decrease in HIV transmission rates,<sup>13</sup> a decrease in overdose

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<sup>11</sup> Anthony R. Henman et al. "Injection Drug Users as Social Actors: A Stigmatized Community's Participation in the Syringe Exchange Programmes of New York City," *Aids Care* 10.4 (1998): 397.

<sup>12</sup> Kerr et al., “Harm Reduction by a ‘User-Run’ Organization: A Case Study of the Vancouver Area Network of Drug Users (VANDU),” *International Journal of Drug Policy* 17.2 (2006): 61-69.

<sup>13</sup> There has been a wealth of medical and epidemiological literature produced that has established the by now global consensus that harm reduction strategies like syringe exchange contribute to reducing HIV transmission rates among intravenous drug users. A few examples are Don C. Des Jarlais, et al., “HIV Incidence Among Injecting Drug Users in New York City Syringe-Exchange

deaths,<sup>14</sup> and a decrease in public drug use,<sup>15</sup> with no evidence that these “permissive” policies have led to increases in drug use, or “drug tourism,” as was feared.

Harm reduction is both a set of programs, and a philosophy that guides the development of ever-evolving responses to the harmful consequences of the war on drugs. As a philosophy, it is relatively consistent across space and time. But harm reduction strategies are, by design, constantly evolving to meet the needs of specific populations. These needs will vary depending on health care regimes (private insurance vs. single-payer),<sup>16</sup> law enforcement strategies (mandatory sentencing vs. treatment-oriented diversion programs),<sup>17</sup> drug preferences and availability,<sup>18</sup> the particular contexts of racialized oppression (medical experimentation on African American communities in the United States:<sup>19</sup> the marginalization and dispossession of Aboriginal people in Canada<sup>20</sup>), gendered behaviors

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Programmes,” *The Lancet* 348.9033 (1996): 987-991; Susan F. Hurley, et al., “Effectiveness of Needle-Exchange Programmes for Prevention of HIV Infection,” *The Lancet* 349.9068 (1997): 1797-1800; Don C. Des Jarlais, et al., “HIV Incidence Among Injection Drug Users in New York City, 1990 to 2002: Use of Serologic Test Algorithm to Assess Expansion of HIV Prevention Services,” *American Journal of Public Health* 95.8 (2005): 1439-1444.

<sup>14</sup> Sandro Galea, et al., “Provision of Naloxone to Injection Drug Users as an Overdose Prevention Strategy: Early Evidence from a Pilot Study in New York City,” *Addictive Behaviors* 31.5 (2006): 907-912; Sarz Maxwell, et al., “Prescribing Naloxone to Actively Injecting Heroin Users: A Program to Reduce Heroin Overdose Deaths,” *Journal of Addictive Diseases* 25.3 (2006): 89-96; Thomas Kerr, et al., “Drug-Related Overdoses within a Medically Supervised Safer Injection Facility,” *International Journal of Drug Policy* 17.5 (2006): 436-441.

<sup>15</sup> Evan Wood, et al., “Changes in Public Order After the Opening of a Medically Supervised Safer Injecting Facility for Illicit Injection Drug Users,” *Canadian Medical Association Journal* 171.7 (2004): 731-734.

<sup>16</sup> Ellen Benoit, “Not Just a Matter of Criminal Justice: States, Institutions, and North American Drug Policy,” *Sociological Forum* 18.2 (2003): 269 – 294.

<sup>17</sup> Jonathan Cohen and Joanne Csete, “As Strong as the Weakest Pillar: Harm Reduction, Law Enforcement and Human Rights,” *International Journal of Drug Policy* 17.2 (2006): 101-103.

<sup>18</sup> Don Weatherburn et al., “Supply Control and Harm Reduction: Lessons from the Australian Heroin ‘Drought’,” *Addiction* 98.1 (2003): 83-91.

<sup>19</sup> James H. Jones, *Bad Blood* (New York, NY: Simon and Schuster, 1993).

<sup>20</sup> Victoria Smye et al., “Harm Reduction, Methadone Maintenance Treatment and the Root Causes of Health and Social Inequities: An Intersectional Lens in the Canadian Context,” *Harm Reduction Journal* 8.1 (2011): 17.

(for example, women are more likely than men to be injected by someone else<sup>21</sup>), and so on. For all these reasons, harm reduction is not one unified set of practices, but should be seen as an ideological orientation that seeks out strategies that will intervene at the level of the user in ways that will produce improved health outcomes for users, and by extension, the wider community.

Despite the many locations, applications, and potentials of harm reduction, in many settings it came to be synonymous with syringe exchange. And indeed, syringe exchange is undoubtedly the most common and well-known harm reduction intervention. As chapter three will discuss in more detail, early efforts to introduce syringe exchange into hard-hit urban areas like New York City, an epicenter of the HIV/AIDS epidemic in the United States, served as a lightning rod for protest, focusing both the activists and the public health bureaucracy's energy and attention on convincing a skeptical public and political establishment of its necessity. Syringe exchange was prototypical, although as chapter four will explain, newer innovations like overdose reversal programs are continuing this work and bringing it new populations.

Programs like syringe exchange have modest, measurable goals. But those promoting harm reduction always sought bigger ends than simply a targeted HIV prevention strategy. In contrast to mainstream American policy's focus on punishment and abstinence, they wanted to promote an alternative politics of addiction. They are a political movement, appealing to notions of rights and social justice, every bit as much as a policy movement advocating pragmatism and incremental, achievable change. Much debate within the world

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<sup>21</sup> Lucy Platt et al., "Impact of Gender and Sex Work on Sexual and Injecting Risk Behaviors and their Association with HIV Positivity Among Injecting Drug Users in an HIV Epidemic in Togliatti City, Russian Federation," *Sexually Transmitted Diseases* 32.10 (2005): 605-612.

of harm reduction has centered on this internal tension in goals. Some commentators lament that harm reduction has strayed from its origins as a grassroots users' movement, claiming that a narrow focus on the outcomes of specific interventions like syringe exchange distract from the larger mission of social, political and economic justice for drug users.<sup>22</sup> Others point to the fact that harm reduction has always emphasized a value-neutral pragmatism that can be seen as a deeply political stance in a world where drug use and drug users are subjected to heavy moral condemnation.<sup>23</sup> Helen Keane argues that:

In a context where drugs are predominantly identified as bad (or even evil) and drug use as pathological, a view that drug use is neither right nor wrong is not neutral, but is itself a committed and critical standpoint.<sup>24</sup>

At issue is the existence and placement of a boundary between the political and the medical. Some harm reduction supporters believe the medical *is* the political.

These debates have not been confined to academic circles. During my fieldwork, countless harm reduction service providers and members of the public health bureaucracy articulated versions of these positions. Whether or not syringe exchange was “political” became an enduring source of controversy in public discourse—and the accusation of “being political” has become a way to contest harm reduction itself. Edward Jurith, acting director of the Office of National Drug Control policy, wrote to the *New York Times* on October 9<sup>th</sup>, 2001:

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<sup>22</sup> Katherine McLean, "Needle Exchange and the Geography of Survival in the South Bronx," *International Journal of Drug Policy* 23.4 (2012): 295-302.; Andrew D. Hathaway, "Shortcomings of Harm Reduction: Toward a Morally Invested Drug Reform Strategy," *International Journal of Drug Policy* 12.2 (2001): 125-137.; Nadine Ezard, "Public Health, Human Rights and the Harm Reduction Paradigm: From Risk Reduction to Vulnerability Reduction," *International Journal of Drug Policy* 12.3 (2001): 207-219.; Christopher B. R. Smith, "Harm Reduction as Anarchist Practice: A User's Guide to Capitalism and Addiction in North America," *Critical Public Health* 22.2 (2012): 209-221.

<sup>23</sup> John Strang, "Drug Use and Harm Reduction: Responding to the Challenge," pp 3-20 in Nick Heather, et al., eds., *Psychoactive Drugs and Harm Reduction: From Faith to Science* (New York: Rutledge, 1993).

<sup>24</sup> Helen Keane, "Critiques of Harm Reduction, Morality and the Promise of Human Rights," *International Journal of Drug Policy* 14.3 (2003): 228.

‘Harm reduction’ is a political movement, not sound policy based on science. Far from reducing harm, its advocates promote policies that lead to increased usage rates and a false sense of security.... At best, harm reduction is an approach that concedes drug abuse prevention is impossible.<sup>25</sup>

In response, Robert Sharpe, program officer for the Lindesmith Center Drug Policy Foundation, wrote:

Edward H. Jurith... mischaracterizes harm reduction as a political movement. Harm reduction is a public-health alternative to the highly politicized drug war that acknowledges that both drug use and drug enforcement have the potential to cause harm.... Harm-reduction proponents tend to be medical professionals who put public health ahead of political correctness.... The ‘zero tolerance’ approach favored by drug war profiteers is simply not cost-effective.<sup>26</sup>

Jurith and Sharpe here both seem to be saying that ‘good’ policy should not be political, and they imply that we should dismiss policies based on ‘politics.’ But when policy becomes evidence-based, evidence becomes politicized. Whether harm reduction is purely a pragmatic, evidence-based practice or a self-consciously activist political movement remains an enduring question both for practitioners and analysts of harm reduction. While this divide has particular resonance within harm reduction, it characterizes policymaking in the present time. It is impossible to divorce policy from politics either in theory or practice.<sup>27</sup> Many questions that are essentially contested are nonetheless being removed from the political fray and debated in the supposedly apolitical, technocratic language of evidence.<sup>28</sup>

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<sup>25</sup> Edward H. Jurith, “‘Harm Reduction’ Is Deceptive,” Letter to the Editor, *New York Times*, 9 October 2001.

<sup>26</sup> Robert Sharpe, “Harm Reduction as Alternative,” Letter to the Editor, *New York Times*, 16 October 2001.

<sup>27</sup> See Deborah A. Stone, *Policy Paradox: The Art of Political Decision Making* (New York, NY: Norton, 1997).

<sup>28</sup> See W. B. Gallie, “Essentially Contested Concepts,” pp 167-198 in *Proceedings of the Aristotelian Society* (Harrison & Sons: 1955). Gallie’s notion of essential contestedness refers to a degree of inescapable difference and indeterminacy that is deeply at odds with the evidence-based policy ideal.

New York's former mayor Michael Bloomberg most exemplifies this process, as a great champion of harm reduction.<sup>29</sup>

Harm reduction policies have met with more resistance in the United States than in either Europe or Canada. The drug policy climate in the U.S. has long been dominated by a zero-tolerance, war on drugs mentality that “establishes an absolute dichotomy between no (zero) use and any use whatsoever.”<sup>30</sup> In effect, this labels all:

drug use as equally criminal (or sick), and fails to distinguish between lighter and heavier drug use or degrees of harmful use.<sup>31</sup>

This perspective justifies harsh mandatory sentencing laws that, for example, send first time offenders sent away for twelve years on charges of selling small amounts of drugs to undercover officers.<sup>32</sup>

To a large extent, drug policy reform has been hobbled in the U.S. by a moralistic discourse which, on the one hand, constructs drug use as a personal failing, and on the other hand, sees it as the result of predatory supply-side of producers and dealers. This dominant narrative is translated into policies that seek either to “cure” the addict by requiring abstinence-based treatment or, failing that, to punish petty dealers with excessive prison sentences. In either case, American drug policy and law maintains as its objective a

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<sup>29</sup> In response to a flap about pamphlets published by the health department that critics claimed gave instructions on how to inject and thus normalized drug use, Mayor Bloomberg said “I would certainly not recommend to anyone that they use hard drugs or soft drugs. But our health department does have an interest in if you're going to do certain things to get you to do it as healthily as you possibly can.” Quoted in Trish LaMonte, “New York City Mayor Michael Bloomberg Defends Pamphlet for Heroin Users.” *Syracuse.com*, 6 January 2010.

<sup>30</sup> Marlatt, *op. cit.*, 51.

<sup>31</sup> *Ibid.*

<sup>32</sup> See, for example, the story of Louis Carasquillo in Jake Mooney, “A Retrieved Reformation for an Addict,” *New York Times*, 27 February 2009.

completely drug-free society.<sup>33</sup> In this sense, American drug policy is oriented towards a future aspirational condition, one that diverges greatly from actual social practices today. This orientation is sharply at odds with harm reduction's more modest goals and more realistic temporality, where the goal is to reduce harm in the present so that users can live to seek treatment in the future. These totalistic, zero-tolerance and abstinence-oriented policies have had dramatic consequences, and not in the ways intended: most notably, they contribute to sky-rocketing incarceration rates which have linked up with more pervasive projects for the control and criminalization of large segments of American urban life,<sup>34</sup> without delivering sought-after reductions in drug use and addiction.<sup>35</sup> This has led many commentators to characterize the war on drugs as an abject failure.<sup>36</sup>

In addition to moralistic policy regimes, drug policy reformers in the U.S. have also had to contend with a fractious political system that unevenly distributes authority between cities, states and the federal government in the realm of criminal drug laws and health policy. This uneven policy landscape complicates the availability of harm reductionist measures like syringe exchange and the legal purchasing of sterile injection equipment in

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<sup>33</sup> Unless, of course, those drug are legally prescribed. The American appetite for prescription narcotics is insatiable. See Boji Huang, et al., "Prevalence, Correlates, and Comorbidity of Nonmedical Prescription Drug Use and Drug Use Disorders in the United States: Results of the National Epidemiologic Survey on Alcohol and Related Conditions," *Journal of Clinical Psychiatry* 67.7 (2006): 1062-1073.; Wilson M. Compton and Nora D. Volkow, "Abuse of Prescription Drugs and the Risk of Addiction," *Drug and Alcohol Dependence* 83 (2006): S4-S7.

<sup>34</sup> See Loïc Wacquant, *Prisons of Poverty* (Minneapolis, MN: University of Minnesota Press, 2009); Ruth Wilson Gilmore, *Golden Gulag: Prisons, Surplus, Crisis, and Opposition in Globalizing California*, (Oakland, CA: University of California Press, 2006).

<sup>35</sup> See also the ONDCP Policy Fact Sheet on Drug Trends, available online at <http://www.whitehousedrugpolicy.gov/publications/factsht/druguse/drugusetrends.pdf>. The percentage of persons 12 and over reporting illicit drug use in the past year declined from 17.5% in 1979 to 10.6% in 1998, but has since been on the rise, inching back up to 12.6% in 2001. The data suggest that while there has been some fluctuation over the past 30 years, drug use patterns have been more or less stable at around 12% of the population. This estimate is conservative; other accounts put the figure at closer to 20%.

<sup>36</sup> See Jimmy Carter, "Call Off the Global Drug War," *New York Times*, 16 June 2011.

pharmacies. National drug policy has traditionally been shaped by abstract, moralistic debates, leading to federal drug laws and punitive prohibition.<sup>37</sup> Actual drug users have a more visible presence in political debates at smaller scales. Federal policymakers represent users as abstract threats—prison inmates, predators, addicts. At the municipal scale, users are constituents, neighbors, patients, and consumers of social services.<sup>38</sup> More pragmatic policies and innovations have tended to emerge at the municipal level. It is not that local politicians are immune to the temptation towards moral grandstanding. It is that there is a scalar asymmetry with social problems like drug use, with the legislation being national and the impacts being local. Thus even a mayor as dedicated to “tough on crime” rhetoric like Rudolph Giuliani grudgingly allowed needle exchange programs to expand in response to the HIV/AIDS crisis in New York City, which peaked at the beginning of his first term in office.<sup>39</sup>

Harm reduction emerged as a reaction and corrective to the war on drugs. Whether in its politicized or institutionalized forms, it has come to represent a “paradigm shift”<sup>40</sup> in dealing with the problems associated with drug use. Social policies, however, do not evolve in isolation from larger political developments. Public health’s embrace of harm reduction principles coincides with a more general retooling of social policy. The question is whether harm reduction swims with or against the tide of this new era in policymaking.

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<sup>37</sup> Matthew B. Robinson and Renee G. Scherlen, *Lies, Damned Lies, and Drug War Statistics: A Critical Analysis of Claims Made by the Office of National Drug Control Policy* (Albany, NY: SUNY Press, 2014).

<sup>38</sup> Alex Wodak, "All Drug Politics is Local," *International Journal of Drug Policy* 17.2 (2006): 83-84.

<sup>39</sup> Daliah Heller and Denise Paone, "Access to Sterile Syringes for Injecting Drug Users in New York City: Politics and Perception (1984-2010)," *Substance Use & Misuse* 46.2-3 (2011): 140-149.

<sup>40</sup> Patt Denning and Jeannie Little, *Practicing Harm Reduction Psychotherapy: An Alternative Approach to Addictions* (New York, NY: Guilford Press, 2011).



### III. Debating neoliberalism

Numerous scholars associate harm reduction with a broad tendency in politics and policy known as neoliberalism. The concept of neoliberalism has been at the center of recent scholarly debates. For some, it is the key term for understanding the shape of contemporary state actions in general. For others, it is a phantom, too expansive to be meaningful and lacking explanatory power. Neoliberalism is used here as a term to describe an era in the history of the state and policy, with the understanding that the neoliberal era is far less monolithic and far more complex—functionally, politically and normatively—than it is sometimes imagined to be.

There are definitely limitations to the usage of this term, and critics of the neoliberalism frame have important arguments to make. However, the idea of neoliberalism still usefully highlight changing state forms and policy paradigms. When neoliberalism is understood not as a monolithic movement or causal force but instead as a period in a longer history of state formation, the term can help scholars and activists point to salient features of contemporary politics and policymaking. But as I shall explain, this requires a more nuanced perspective, one that recognizes the conflicting currents and progressive potentials within the wide field of struggle that characterizes neoliberal policy practices.

There are two basic approaches to theorizing neoliberalism: one focused on political economy, and one focused on biopolitics. The political-economic perspective can be found in the work of theorists like David Harvey, who writes that

neoliberalism is in the first instance a theory of political economic practices that proposes that human well-being can best be advanced by liberating individual entrepreneurial freedoms and skills within an

institutional framework characterised by strong private property rights, free markets and free trade. The role of the state is to create and preserve an institutional framework appropriate to such practices.<sup>41</sup>

Neoliberalism here is in essence a form of market fundamentalism. A similar perspective can be found in some work by Pierre Bourdieu, who stresses the view of neoliberalism as fundamentally the pursuit of a “utopia of a pure and perfect market” which thus foregrounds a “programme of the methodical destruction of collectives.”<sup>42</sup> In this view, neoliberalism is rooted in the thought of Friedrich Hayek and other orthodox neoclassical economists and pursued paradigmatically by Margaret Thatcher and Ronald Reagan. It is seen as a fundamentally subtractive project involving the removal of the state from an ever-larger set of policy domains, and as a set of policy prescriptions that inevitably privilege competition over social protection, individualism over social bonds, and market actors over state capacity. The paradigmatic neoliberal social policy in this view is privatization, combined with a strong penal component aimed at punishing, surveilling and controlling actors that are thought to be hostile to market logic or troubling for their smooth operation.<sup>43</sup>

While the historic link between neoliberal policy actors, Austrian economics and Thatcherite/Reaganite politics is well established, a more convincing account of neoliberalism stresses its complex, contradictory nature. Peck and Tickell, for example, argue that there is not one “neoliberal” doctrine but rather a process of state restructuring that they call *neoliberalization*. They argue, “The process of neoliberalization...is neither

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<sup>41</sup> David Harvey, *A Brief History of Neoliberalism* (New York, NY: Oxford University Press, 2005): 3-4.

<sup>42</sup> Pierre Bourdieu, “The Essence of Neoliberalism,” *Le Monde Diplomatique*, March 1998: 3.

<sup>43</sup> Loïc Wacquant, *Punishing the Poor: The Neoliberal Government of Social Insecurity* (Durham, NC: Duke University Press, 1996).

monolithic in form nor universal in effect.”<sup>44</sup> The 1980s era of Reagan and Thatcher was only one moment in a history of neoliberal state transformation—what Peck and Tickell call “roll-back” neoliberalism characterized by the dismantling (or roll-back) of the welfare state. Whereas the 1990s saw the rise of something much more relevant for the current study: “roll-out” neoliberalism, where new forms of “proactive statecraft” engender new forms of regulation, control and service provision.<sup>45</sup> Rather than aiming to destroy society, neoliberal policies often assume the existence of strong social bonds and try to build upon them.

Perhaps the most succinct definition of neoliberalism was supplied by Loïc Wacquant in a recent debate. Citing Jamie Peck’s argument that “neoliberalism has always been an open-ended, plural and adaptable project,” Wacquant argues that

it nonetheless has an *institutional core* that makes it distinct and recognizable. This core consists of *an articulation of state, market, and citizenship* that harnesses the first to impose the stamp of the second onto the third. So all three of these institutions must be brought into our analytic ambit.<sup>46</sup>

It is not that neoliberalism must mean subtracting the state and letting the market take its place. Rather, it means the reformation of these institutions in ways that are less state-centric compared to the Fordist-Keynesian state, but not overdetermined by any particular market actor.

Neoliberalism, for theorists like Peck, Tickell, Wacquant, Brenner and Jessop, is an internally contradictory moment in policy-making that includes the formation of new

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<sup>44</sup> Jamie Peck and Adam Tickell, “Neoliberalizing Space,” *Antipode* 34.3 (2002): 384.

<sup>45</sup> *Ibid.* See also Neil Brenner and Nik Theodore, eds., *Space of Neoliberalism: Urban Restructuring in North America and Western Europe* (Oxford, UK: Wiley-Blackwell, 2002).

<sup>46</sup> Loïc Wacquant, “Three Steps to a Historical Anthropology of Neoliberalism,” *Social Anthropology* 20.1 (2012): 71.

political subjects and new policy paradigms. Other scholars, writing from post-structuralist or Foucault-influenced perspectives, have taken this argument even further. Building on Foucauldian conceptions of biopolitics and governmentality that has been central to many critical studies of public health and harm reduction, Rose argues that “advanced liberalism” entails a “politics of life itself”: “Since the 18<sup>th</sup> century, political power has no longer been exercised through the stark choice of allowing life or giving death... Politics now addresses the vital processes of human existence: the size and quality of the population... health and disease; birth and death.”<sup>47</sup> The state, so this argument goes, increasingly involves itself with the maintenance and regulation of life.

This might sound somewhat detached from the political-economic conception of neoliberalism, and it is indeed distinct in its concern. The link between the two is the concept of the individualized and individualistic subject. Rose and Miller also associate neoliberalism with the process that they call “responsibilization,” where risk, responsibility and rights are shifted from collective to individual actors.<sup>48</sup> Other scholars have identified responsibilization with the rise of a more general “individual responsibility framework.”<sup>49</sup> Larner argues that neoliberalism involves “a particular politics of self in which we are all encouraged to ‘work on ourselves’ in a range of domains.”<sup>50</sup> This emphasis on individualized political subjects has come full circle, and now neoliberalism embraces social norm

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<sup>47</sup> Nikolas Rose, “The Politics of Life Itself,” *Theory, Culture and Society* 18.6 (2001): 1.

<sup>48</sup> See Nikolas Rose and Peter Miller, “Political Power Beyond the State: Problematics of Government,” *British Journal of Sociology* 43.2 (1992): 172-205.

<sup>49</sup> Garry C. Gray, “The Responsibilization Strategy of Health and Safety: Neo-Liberalism and the Reconfiguration of Individual Responsibility for Risk,” *British Journal of Criminology* 49 (2009): 328.

<sup>50</sup> Wendy Larner, “Neo-Liberalism: Policy, Ideology, Governmentality,” *Studies in Political Economy* 63 (2000): 13.

formation, social network theory and a whole range of techniques that are premised on utilizing, rather than destroying, social bonds.<sup>51</sup>

There have long been voices claiming that neoliberalism is a chaotic concept. Some, like Clive Barnett, are skeptical of the usefulness of the concept at all, questioning “whether neo-liberalism is a coherent, ambitious programme of rule; and whether it does aim to extend itself by bringing into existence fully-formed neo-liberal subjects.”<sup>52</sup> Other scholars also ask whether there is any essential characteristic that unites all “neoliberal” policies in general.<sup>53</sup> This stance also questions what these authors see as the simplistic normative politics of the critical literature:

Theories of ‘neoliberalism’ are unable to recognize the emergence of new and innovative forms of individualized collective action because their critical imagination turns on a simple evaluative opposition between individualism and collectivism, the private and the public.<sup>54</sup>

While these skeptics make a number of important points about the dangers of positing neoliberalism as a causal force, there is no reason why all accounts of neoliberalism—as a field of struggle or era in the history of state formation and policymaking—must take the monolithic form these authors are criticizing.

What is most interesting in these skeptical authors is their argument about the unforeseen progressive potential that could emerge from some actors in the neoliberal field. James

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<sup>51</sup> See Rhys Jones, et al., “The Geographies of Soft Paternalism in the UK: The Rise of the Avuncular State and Changing Behavior After Neoliberalism,” *Geography Compass* 5.1 (2011): 50-62.

<sup>52</sup> Clive Barnett, et al., “The Elusive Subjects of Neo-Liberalism,” *Cultural Studies* 22.5 (2008): 626.

<sup>53</sup> E.g. Stephen J. Collier, “Neoliberalism as big Leviathan, or...? A Response to Wacquant and Hilgers,” *Social Anthropology* 20.2 (2012): 186-195.

<sup>54</sup> Clive Barnett, “The Consolations of ‘Neoliberalism,’” *Geoforum* 36 (2005): 11.

Ferguson, for example, has noted “the surprising affinity of some aspects of what we call ‘neoliberalism’ with certain forms of progressive politics.”<sup>55</sup> Ferguson argues:

to say that certain political initiatives and programs borrow from the neoliberal bag of tricks doesn’t mean that these political projects are in league with the ideological project of neoliberalism...only that they appropriate certain characteristic neoliberal ‘moves.’ These moves are recognizable enough to look ‘neoliberal,’ but they can, I suggest, be used for quite different purposes than that term usually implies.<sup>56</sup>

He sees a proposal for universal basic income in South Africa as one example of a policy that uses neoliberal “moves” for ends that are—unquestionably, though not simplistically—“pro-poor.”

If neoliberal social policies are in fact not monolithic but instead subject to the same contestations and contradictions of all forms of policymaking, then the possibility of neoliberal policy tools being used for progressive ends is always present. Ferguson notes that for a variety of reasons, these policies are likely to prominently feature “those hard-to-categorize urban improvisers who have for so long been relegated to the margins both of society, and of social analysis.”<sup>57</sup> Harm reduction, in my views, is one of these policies that, through the work of dedicated urban activists and public health professionals, has much to teach about the progressive possibilities and complexities of policy in a neoliberal era.

#### **IV. Harm reduction and the limits of critique**

Public health in the neoliberal era tends to have a number of characteristics. It emphasizes individual responsibility over collective provision. It uses the tools and language of markets,

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<sup>55</sup> James Ferguson, “The Uses of Neoliberalism,” *Antipode* 41.S1 (2009): 170.

<sup>56</sup> *Ibid.*: 174.

<sup>57</sup> *Ibid.*: 168.

seeing patients as clients and understanding health care as a service. It emphasizes choice and consumer sovereignty rather than centralized authority. While it typically means the reduction of public responsibility, it does not conceive of individuals as free-floating atoms. Instead, it seeks to leverage the social networks within which contemporary health subjects are embedded in order to achieve objectives and outcomes determined by the state, often in partnership with the targets of these policies.<sup>58</sup>

Public health during the neoliberal era is sometimes called the “new public health.”<sup>59</sup> In this telling, the old public health was focused on “controlling filth, odor and contagion,”<sup>60</sup> on maintaining order and reacting against infectious disease. In contrast, the new public health is focused on *behavior*—on responsibility, lifestyle, self-control. It is proactive, oriented towards managing chronic conditions and syndromes within populations. If the old public health developed fighting cholera, tuberculosis, typhoid and other illnesses of industrial society, the new public health is geared towards combating heart disease, diabetes, obesity, and addiction—the illnesses of late capitalism.

The old public health was shaped by the political currents of the Progressive Era. Social reformers used the tools of the state to pursue a moralistic agenda and ameliorate the conditions of the urban poor. For Progressive Era reformers, moral concerns were fused with concerns about disease and social order. The new public health is similarly a product of its time in its post-ideological, pragmatic approaches to managing health through the

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<sup>58</sup> Vicente Navarro, “What We Mean By Social Determinants of Health,” *International Journal of Health Services* 39.3 (2009): 423-441.

<sup>59</sup> See, e.g., Alan Petersen and Deborah Lupton, *The New Public Health: Health and Self in an Age of Risk* (Thousand Oaks, CA: Sage, 1996).

<sup>60</sup> Kristen Bell et al., “Alcohol, Tobacco, Obesity and the New Public Health,” *Critical Public Health* 21.1 (2011): 1-8.

calculation of risk. It enables the state to discipline, punish, supervise, and manage deviant populations without addressing the underlying structural inequalities which may lead to the harmful outcomes of drug use in the first place. Progressive Era reformers were concerned with transforming the environment to produce healthier, more virtuous citizens. Today's progressive public health workers also seek to produce healthier citizens. But their moral project is less about reforming the character of the poor and more about affirming their individualism, autonomy and responsibility.

Bruce Alexander has described addiction as one of the major health problems of contemporary global capitalism.<sup>61</sup> It is not surprising, then, that many social scientific analyses of the contemporary growth of harm reduction have identified it with the new public health, and neoliberal policy more generally.<sup>62</sup> And when neoliberalism is invoked in these analyses, it is usually to say that harm reduction has been colonized, coopted or even “gentrified.”<sup>63</sup> According to Gordon Roe, harm reduction's institutionalization is a betrayal of its original intention to disrupt the social and political marginalization of drug users. Instead, harm reduction has been captured by public health technocrats committed to applying the tools and tactics of neoliberalism to better manage a hard to reach and “risky” population. He argues, “what began as a ‘bottom-up’ movement became ‘top-down’ policy.”<sup>64</sup>

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<sup>61</sup> Bruce Alexander, “The Roots of Addiction in Free Market Society,” pp 107-126 in Robert Granfield and Craig Reinarman, eds., *Expanding Addiction: Critical Essays* (New York, NY: Routledge, 2015).

<sup>62</sup> Katherine McLean, “The Biopolitics of Needle Exchange in the United States,” *Critical Public Health* 21.1 (2011): 71-79; Gordon Roe, “Harm Reduction as Paradigm: Is Better than Bad Good Enough? The Origins of Harm Reduction,” *Critical Public Health* 15.3 (2005): 243-250; Philippe Bourgeois, “Disciplining Addictions: The Bio-Politics of Methadone and Heroin in the United States,” *Culture, Medicine and Psychiatry* 24 (2000): 165-195.

<sup>63</sup> Christopher B. R. Smith, “Harm Reduction Hipsters: Socio-Spatial-Political Displacement and the Gentrification of Public Health,” pp 1-28 in Zack Marshall and Christopher B. R. Smith, eds., *Critical Approaches to Harm Reduction Policy, Practice and Philosophy: Conflict, Institutionalization, (De-) Politicization, and Direct Action* (Hauppauge, NY: forthcoming).

<sup>64</sup> Roe, *op. cit.*: 245.



Roe's position is perhaps among the most strident in its critique of what he sees as a "newly mainstreamed" and "medicalized" harm reduction.<sup>65</sup> In his characterization of the adoption of harm reduction by public health authorities he draws on theorists heavily influenced by Foucault, like Mitchell Dean, Nickolas Rose, Colin Gordon and others, to underline the various ways in which the institutionalized harm reduction project is compatible with neoliberal trends. Quoting Mitchell Dean, he writes:

Harm reduction is an excellent illustration of a technology of agency, through which 'populations that manifest high risk or are composed of individuals deemed at risk' become the target of programmes 'to transform their status, to make them active citizens capable, as individuals and communities, of managing their own risk.'<sup>66</sup>

In a similar vein, Peter Miller characterizes harm reduction as "a safety net, not a strategy, representing a convergence of economic rationalism and social policy."<sup>67</sup>

Scholars working in the Foucauldian theoretical tradition tend to see harm reduction as a biopolitical project. Philippe Bourgois, for example, sees some forms of harm reduction as a bio-medicalized way of disciplining and punishing the bodies of heroin users by disabling the experience of pleasure they might derive from the use of illicit substances.<sup>68</sup> Other scholars, like Katherine McLean and Benedikt Fischer, associate harm reduction with the disciplining and punishing of contemporary subjects.<sup>69</sup> Under neoliberalism, health becomes the subject's own individual responsibility, rather than that of the state. Drug users are

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<sup>65</sup> *Ibid.*: 243.

<sup>66</sup> *Ibid.*: 246.

<sup>67</sup> Peter G. Miller, "A Critical Review of the Harm Minimization Ideology in Australia," *Critical Public Health* 11.1 (2001): 177.

<sup>68</sup> Bourgois, *op. cit.*: 167.

<sup>69</sup> Katharine McLean, "Reducing Risk, Producing Order: The Surprisingly Disciplinary World of Needle Exchange," *Contemporary Drug Problems* 40.3 (2013): 415-430; Benedikt Fischer, et al., "Drug Use, Risk and Urban Order: Examining Supervised Injection Sites (SISs) as 'Governmentality,'" *International Journal of Drug Policy* 15.5 (2004): 357-365.

compelled to use the techniques of self-surveillance and self-control towards the end of masking social conflict in post-welfarist spaces.

As influential as the Foucauldian critique of harm reduction has been, it may have outlived its usefulness. Foucault's political theory does not lend itself very well to formulating a positive politics, so the element of mutual aid within harm reduction is bound to register as an example of neoliberal "care of the self." But labeling it as such limits any deeper consideration of the full empirical and normative significance of harm reduction as policy. Foucault's inability to understand autonomy and self-help as anything other than the effects of controlling, external power limit the usefulness of Foucauldian thought for understanding harm reduction. When applied to harm reduction, concepts such as governmentality and discipline will always yield the same negative conclusions, thus limiting our engagement with harm reduction rather than broadening it.

Most critics of harm reduction's neoliberal program are quick to affirm the positive benefits that harm reduction policies have brought to the lives of drug users. But for some, those benefits are dismissed either as a result of compromises to true harm reduction or as no real benefit at all. Roe writes "by ameliorating their worst effects, harm reduction simply relieves the institutions of prohibition and abstinence-based treatment of responsibility for those harms."<sup>70</sup> By reducing harm but not changing the conditions that enable it, Roe argues, harm reduction in its institutionalized form actually enables an unjust situation to persist.

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<sup>70</sup> *Roe, op. cit.*: 247.

But the nostalgia for a pure, radical, user-activist led harm reduction movement ignores the fact that the movement has always sought to change public health policy. It has always sought to become integrated into the state. Harm reduction activists have had many connections to other movements and projects, but it has fundamentally been a movement about public health. It may have begun as an act of protest, relying on classic social movement strategies like direct action, civil disobedience, and community organizing. But wherever harm reduction has emerged it has always linked up with health departments, medical researchers and social service organizations. The goal has always been to push the state to expand at a time of contraction, to include drug users within the reach of state services. In this, harm reduction has been remarkably successful.

The literature on cooptation describes how social movements lose their radical edge as the state incorporates their demands into policy.<sup>71</sup> Roe makes a similar argument about harm reduction. For him, as it institutionalized, it became content with making the system more efficient rather than overturning it. But harm reduction activists who were distributing needles in the streets always sought state support for their action. They always wanted the state to assume responsibility for the wellbeing of citizens that were excluded. It is not that an earlier anti-statist movement became coopted. Rather, cooperating with the state was always one of its goals. As chapter three discusses, harm reduction organizations in New York managed to achieve a level of cooperation with the state that allowed them to maintain their organizational autonomy while influencing policy at higher and higher scales.

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<sup>71</sup> See, e.g., Patrick G. Coy and Timothy Hedeem, "A Stage Model of Social Movement Co-optation: Community Mediation in the United States," *The Sociological Quarterly* 46.3 (2005): 405-435; Sandra Morgen, "The Dynamics of Cooptation in a Feminist Health Clinic," *Social Science & Medicine* 23.2 (1986): 201-210.

It is true that in many ways harm reduction is prototypically neoliberal. But for a number of reasons, this should not justify dismissing it. For one, harm reduction is a movement that seeks the inclusion of a group—drug users—that was actively excluded from the welfare state in its classic postwar form.<sup>72</sup> Drug users, for example, were often barred from public housing, and classed among the “undeserving poor” that were not included in the state’s social net. As well, harm reduction clearly clashes with other policies—especially the profit-led expansion of the carceral state—that are also identified with the neoliberal moment. Rather than seeing this as cause to dismiss harm reduction, it should cause scholars to pay more attention to the conflicts and contradictions *within* putatively neoliberal social policy.

## V. Conclusion

Harm reduction is a contested, internally inconsistent and evolving public health movement. In its concern with ameliorating the conditions of life of drug users, it resembles earlier efforts to address social problems through health interventions. And like earlier movements, it is inextricably and inescapably a product of its time.

Harm reduction’s time is the neoliberal era. Many critics of harm reduction have focused on this point, rather than on the success or failure of harm reducing policies achieving their objectives. Indeed, there is near unanimous consensus on the dramatic decline of HIV due to syringe exchange. Other harm reduction strategies have been similarly successful. Harm

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<sup>72</sup> Walter I. Trattner, *From Poor Law to Welfare State: A History of Social Welfare in America* (New York: Free Press, 1999).

reduction's poststructuralist critics miss the fact that it represents a major form of progress in drug policy, one that faces challenges but which continues to make strides.

There is thus a strange disconnect between debates in the social science literature about harm reduction and popular debates about it. The left wing social science literature is focused on the extent to which harm reduction represents new modes of discipline and governmentality. But harm reduction's real opponents in the public domain are conservatives who think it presents a moral hazard. In fact, in their anti-welfarist stances, there is arguably more overlap between the Foucauldian critique and the conservative position than the former would generally admit. In general, the overall normative and political ends of the Foucauldian position are unclear, as they are in the specific case of harm reduction.<sup>73</sup>

It is not that scholars are wrong to associate harm reduction with neoliberalism. Rather, they are wrong to leave the argument there. The challenge is to use the concept of neoliberalism to historicize changing drug policies—and to use the case of harm reduction to bring the complexities of contemporary policy into sharper relief. Critical policy scholars obviously are under no obligation to support contemporary trends in policymaking, and it is not my intention to do so here. But we should do justice to those movements which are successfully achieving policy change. This does not mean affirming neoliberal policies. It means developing a critical stance that can recognize the opportunities for change that do exist in the contemporary era.

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<sup>73</sup> On the issue of Foucault's ambiguous politics, see Neil Brenner, "Foucault's New Functionalism," *Theory and Society* 23.5 (1994): 679-709; Nancy Fraser, "Michel Foucault: A 'Young Conservative'?" *Ethics* 96.1 (1985): 165-184.

## Chapter 3.

### The Institutional Evolution of Syringe Exchange

#### I. Introduction

This chapter examines the evolution of the syringe exchange program (SEP) in New York City. Syringe exchange is arguably the iconic example of the harm reduction movement—for many people, harm reduction is synonymous with syringe exchange. And indeed, most of today's multiservice, professionalized harm reduction organizations started life offering a single, illegal service, with volunteers exchanging dirty needles for clean ones out of backpacks on street corners, in shooting galleries or SROs. Informal organizations that were disconnected from the official public health system became integrated within it, in the process transforming both the harm reduction project in New York as well as the approach to drug user health. How and why this transformation happened, and the policy transformation that accompanied it, is the subject of this chapter.

Syringe exchange has come a long way since it became legal in New York State twenty-three years ago. Many of the originally clandestine groups have grown and matured, expanding the range of services they offer. These informal, improvisatory organizations became much more bureaucratic, in the process replacing an ethos of direct action with formal accounting. Folding tables in church basements have evolved into multi-story health hubs. Staffs have professionalized and budgets have ballooned. At the same time, syringe access has expanded as regulations have loosened and new mainstream venues have been added to extend the reach of activist-founded SEPs.

Not only have SEPs undergone organizational change; the relationship between syringe exchange and the state has also radically shifted. City and State public health departments have embraced syringe exchange and harm reduction more generally, finding ways to develop and expand harm reduction programs in the face of a hostile political climate. Harm reduction organizations that began as illegal syringe exchanges in the late 1980s have a presence today in the institutional landscape of New York City social service provision that is unlikely to fade away.

And yet the institutionalization of syringe exchange, and the incorporation of harm reduction into the state, has so far only been partial. The ban on federal funding for syringe exchange still stands. And both New York City and State to this day allow the operation of syringe exchange through temporary, exceptional measures. If SEPs today are part of the contemporary public health state, they are also marginalized within it. Understanding this ambiguous insider-outsider status is crucial for understanding why SEPs operate as they do today and their hopes for the future.

That future is likely to see an acceleration of the historic trend towards greater integration with the state. At the time of my fieldwork, SEPs were at a crossroads. Since their inception, they have traditionally relied upon funding sources tied to HIV prevention and care. But these sources are drying up, reflecting the diminishing urgency of HIV as a public health emergency—thanks in no small part to the consistent successes of syringe exchange. These organizations, which began as outsider activists confronting the state for their failure to value the lives of drug users, now find themselves in close partnerships with the state. They are likely to continue becoming closer still, altering the services they offer and becoming more integrated with mainstream social service provision.

But this not simply a story of cooptation. My point is not to critique harm reduction for straying from its roots. Rather, my goal is to to understand the causes and consequences of the process of institutionalization and bureaucratization that is shaping all of the syringe exchange programs in New York. Some people in the harm reduction field do see the increasing formalization of harm reduction as a problem. But many if not most others see a move towards the state and the transformation into bigger and more formal organizations as the only viable way forward for harm reduction—even as they remain concerned about maintaining harm reduction’s social justice orientation. My goal is to understand how these tensions are worked out within these organizations themselves and within the larger field of which they are a part.

This is a point that is not well represented in the social science literature on harm reduction. Some scholars, as chapter two explained, have criticized the medicalization and neoliberalization of the harm reduction movement. But this does not adequately capture the fears of people working in the field. Most of my informants welcome the stability that formalization and bureaucratization have brought. They see the restructuring of public health as potentially opening some important opportunities for harm reduction organizations. They do not want to avoid medicalization or incorporation into the neoliberal health system. Rather, they are unsure about how to maintain some of the characteristics—low threshold, anonymity, a community-based character, the peer-to-peer structure, etc.—that were central to harm reduction’s success while also becoming more integrated into the state. The future of harm reduction depends upon how these organizations respond to the new public health context.



## II. Syringe exchange as outsider organizations

A number of developments in the 1980s decisively shaped the field of harm reduction in New York City in ways that are still felt today. The mainstream response to the HIV/AIDS crisis placed drug user activists outside of the main policy circuits, which at the grassroots level were dominated by the relatively less marginalized gay community. This was the “pre-waiver” era, before the state issued a waiver to exempt SEPs from drug paraphernalia laws. Syringe exchanges were underground, illegal operations. They were largely informal organizations that were not integrated into the official public health system and operated at very small scales. But their exclusion from the city bureaucracy led to the flowering of an organizational multiculture<sup>1</sup> where activists formulated a social-justice-oriented identity that still shapes expectations and norms for actors in the field today.

In this era, harm reduction referenced a political sensibility much broader than today’s version. In an atmosphere where drug users were severely stigmatized outcasts, conducting sound public health in a highly politically charged climate was itself an act of political resistance. As the product of poorly funded and loosely organized groups, harm reduction had a self-consciously radical perspective. Some activists are openly nostalgic for these more explicitly politicized days. But this was a consequence of the exclusion of drug users and their advocates from the public health establishment—just as the subsequent medicalization of harm reduction, and the bureaucratization of harm reduction organizations, was a consequence of their integration into the public health system.

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<sup>1</sup> Cf. the idea of “monoculture” or “monocropping” in organizational studies: Michael McQuarrie, “Community Organizations in the Foreclosure Crisis: The Failure of Neoliberal Civil Society,” *Politics and Society* 41.1 (2013): 73-101; Peter Evans, “Development as Institutional Change: The Pitfalls of Monocropping and the Potentials of Deliberation,” *Studies in Comparative International Development* 38.4 (2004): 30-52.

The Centers for Disease Control (CDC) announced the first official case of AIDS in the USA in 1981. Chroniclers of the disease use this date as the starting point of the epidemic, though cases were known to have occurred both among gay men and injection drug users (IDUs) before this time.<sup>2</sup> One retrospective study estimates that by 1980, 50% of injecting drug users were likely already infected with the virus,<sup>3</sup> and IDUs composed more than a quarter of diagnosed AIDS cases in New York City by 1982.<sup>4</sup> Despite drug users being among the first cohort of patients diagnosed with the disease, prevention activities among this population were slow to mobilize. This is notable especially in comparison to the early grassroots organizing within the gay community that produced the Gay Men's Health Crisis (GMHC) in 1981 during the early days of the epidemic. Colgrove notes that

the public image of AIDS as a 'gay disease' would persist for years, cemented by the initial MMWR [Morbidity and Mortality Weekly] reports and the early mobilization by gay rights activists, but this perception was always illusory.<sup>5</sup>

As a consequence of the rapid and effective mobilization within the gay community, organizations oriented towards the needs of gay men led both the advocacy and social service responses to the HIV/AIDS epidemic. All levels of government came under fire for not acting fast enough to address the growing crisis in New York City and elsewhere.<sup>6</sup> Governor Mario Cuomo responded to pressure from a well-organized, well-resourced and politically well-connected gay community by authorizing the founding of the AIDS Institute

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<sup>2</sup> Charles Perrow and Mauro F. Guillén, *The AIDS Disaster: The Failure of Organizations in New York and the Nation* (New Haven: Yale University Press, 1990).

<sup>3</sup> Don C. Des Jarlais, et al., "HIV-1 Infection Among Intravenous Drug Users in Manhattan, New York City, From 1977 Through 1987." *Journal of the American Medical Association* 261.7 (1989): 1008-1012.

<sup>4</sup> Bruce F. Berg, *Healing Gotham: New York City's Public Health Policies for the Twenty-First Century* (Baltimore, MD: Johns Hopkins University Press, 2015).

<sup>5</sup> James Colgrove, *Epidemic City: The Politics of Public Health in New York* (New York, NY: Russell Sage, 2011): 160.

<sup>6</sup> Randy Shilts, *And the Band Played On: Politics, People, and the AIDS Epidemic* (New York, NY: St. Martin's Press, 1987); Perrow and Guillén, op. cit.

within the New York State Department of Health in 1983. The first director of the AIDS Institute, Mel Rosen, had previously been the chief administrator of the GMHC, and the early years of the Institute can be characterized as focused almost exclusively on HIV/AIDS among gay men. “Many of those who joined the institute were gay men in the health field for whom the mission of the agency was literally a matter of life or death. [...] It is fair to say that in the early life of the institute the staff consisted of a group of zealots.”<sup>7</sup> VC, the founding director of Harm Reduction Partnership (HRP), herself an early activist and pioneer of syringe exchange in New York City, told me that “the infrastructure was being built for gay men and gay men's health.” This meant that emerging strategies like syringe exchange that mainly concerned IDUs—who were disproportionately poor people of color—lacked vocal champions in the rush to produce a policy response to a new disease that had no cure.

The failure to get in front of the crisis during the first wave of HIV/AIDS prevention work was soon to have devastating consequences. While in absolute terms gay men outnumbered IDUs, proportionate to their population, users of injection drugs were becoming far more likely to contract HIV. 1984 saw the development of the HIV antibody test which confirmed that the numbers of HIV positive IDUs in New York City had been drastically underestimated. According to the CDC, there were less than 1,500 AIDS cases among IDUs in the USA in 1984. But a study conducted among injection drug users in New York found that up to 60% of New York City's injecting drug users were HIV positive, representing over

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<sup>7</sup> W. Henry Lambright and Mark J. O'Gorman, “New York State's Response to AIDS: Evolution of an Advocacy Agency” *Journal of Public Administration Research and Theory: J-PART 2.2* (1992): 175-198; 184.

100,000 people.<sup>8</sup> By 1985, the CDC was reporting a 500% increase in HIV infection rates among IDUs nationwide. And New York City, with the highest concentration of HIV-positive IDUs in the country, was the epicenter of the epidemic.<sup>9</sup> Prevention messages were rapidly diffusing through the well-organized networks of gay men in cities like New York and San Francisco, and broad public awareness campaigns emphasizing the importance of safe sex were targeted at the wider public. Despite the growing awareness of the severity of HIV/AIDS prevalence among IDUs, no equivalent messaging highlighting the dangers of needle sharing was produced for this population at the time. Piecemeal attempts at prevention emphasizing bleach distribution lacked official support, and the health and safety of this particular intervention was uncertain.

Drug users were not only left out of prevention and treatment efforts, they were also increasingly criminalized and socially ostracized. At this time, the “War on Drugs” was ramping up. The Comprehensive Crime Control Act was passed by Congress in 1984, when Reagan extended and doubled down on Nixon’s tough-on-crime policies. The act reinforced the view of drug use as a criminal pathology, rather than an illness. The law created longer sentences for drug-related offenses and deep cuts to drug treatment, education and prevention. In New York State, drug users continued to face the harsh sentencing regime introduced by Governor Nelson Rockefeller in 1973. Added to this, New York State was one of nine states that prohibited the sale of syringes in pharmacies or the possession of hypodermic needles without a prescription. And it was one of 44 states with paraphernalia

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<sup>8</sup> Don C. Des Jarlais, et al., "Continuity and Change Within an HIV Epidemic: Injecting Drug Users in New York City, 1984 Through 1992." *Journal of the American Medical Association* 271.2 (1994): 121-127.

<sup>9</sup> Ann M. Hardy, et al., "The Incidence Rate of Acquired Immunodeficiency Syndrome in Selected Populations," *Journal of the American Medical Association* 253.2 (1985): 215-220.

laws that imposed criminal penalties on the possession or distribution of needles.<sup>10</sup> All of this occurred against the backdrop of New York City's continued fiscal crisis, which had decimated the city's once robust public health department, hobbling their ability to mount an effective response to the growing number of health concerns among New York City's most vulnerable residents.<sup>11</sup>

Drug users did not initially form advocacy groups around syringe exchange or other harm reduction measures in part because of their extremely marginal social status. Though gay men suffered from the prejudice and moral approbation of politicians and the wider public, being gay was not illegal but in fact supplied a positive identity that helped to consolidate a highly effective social movement.<sup>12</sup> Many drug users, on the other hand, came from poor communities facing racism, discrimination and other injustices. And they were frequently viewed with suspicion and hatred within these communities; a sign appearing in Harlem at this time asked, "When will all the junkies die so the rest of us can go on living?"<sup>13</sup> The illegal nature of drug use in an increasingly militaristic anti-drug climate meant that they were pushed even further to the margins, hidden from sight, ignored by government and private charities. As one analyst put it, "efforts to implement syringe exchange forced us to

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<sup>10</sup> Daliah Heller and Denise Paone. "Access to Sterile Syringes for Injecting Drug Users in New York City: Politics and Perception (1984-2010)." *Substance Use & Misuse* 46.2-3 (2011): 140-149.

<sup>11</sup> In addition to the HIV/AIDS epidemic, tuberculosis was experiencing a comeback in the mid-1980s, especially among New York City's homeless population. The link between tuberculosis, homelessness and HIV is discussed in Karen Brudney and Jay Dobkin, "Resurgent Tuberculosis in New York City: Human Immunodeficiency Virus, Homelessness, and the Decline of Tuberculosis Control Programs." *American Review of Respiratory Disease* 144.4 (1991): 745-749.

<sup>12</sup> Steven Epstein. *Impure Science: AIDS, Activism, and the Politics of Knowledge* (Berkeley, CA: University of California Press, 1996).

<sup>13</sup> Warwick Anderson, "The New York Needle Trial: The Politics of Public Health in the Age of AIDS," *American Journal of Public Health* 81.11 (1991): 1506 – 1517; 1512.

confront our commitment to the welfare of a subpopulation defined principally by their association with a criminal activity.”<sup>14</sup>

The Health Omnibus Program Extension (HOPE) Act, passed by Congress in 1988, cemented the marginalization of IDUs from the federal response to the HIV/AIDS crisis. The purpose of the HOPE Act was to provide federal funds for HIV research, prevention, testing and education. The law is remarkable in that it set the stage for major federal investment in combating HIV/AIDS, a disease still at this time associated with stigmatized populations. But it also explicitly prohibited any of the funds to “provide individuals with hypodermic needles or syringes so that such individuals may use illegal drugs, unless the Surgeon General of the Public Health Service determines that a demonstration needle exchange program would be effective in reducing drug abuse and the risk that the public will become infected with the etiologic agent for acquired immune deficiency syndrome.”<sup>15</sup> This language enshrined into law one of the major obstacles to expansion of harm reduction to this very day: the federal ban on funding for syringe exchange.<sup>16</sup>

Two years later, Congress passed the more extensive Ryan White Comprehensive AIDS Resources Emergency Act, which greatly increased the level of federal investment in HIV research, prevention and care. The Ryan White Act forms the bedrock of all HIV/AIDS programs in the country. The law’s original formula distributed most of the funds directly to cities, as urban centers were the hardest hit. The Ryan White Act also included a provision aimed specifically at giving states the option of providing Medicaid for people

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<sup>14</sup> Howard Lune, *Urban Action Networks: HIV/AIDS and Community Organizing in New York City* (New York, NY: Rowman & Littlefield, 2007): 84.

<sup>15</sup> HOPE Act, 1988.

<sup>16</sup> The ban was lifted briefly in 2009 only to be reinstated in 2011.

with HIV. But it included no measures intended specifically to prevent infection from injection, despite the mounting international and domestic evidence that syringe exchange was effective at stemming the spread of HIV among IDUs.

This major AIDS infrastructure that was erected in the early 1990s came to represent public expenditure at the federal, state and city level in the tens of billions of dollars. But IDUs, who by the time these laws were passed were the most vulnerable to new infection, were left out almost entirely. The federal ban prohibited any federal funds being spent on syringe exchange. Indeed, consequences of this early institution building are evident today.

GN, an employee of the DOHMH whom I interviewed, told me:

*GN: The Bureau of HIV has huge muscle, compared to our bureau. The Bureau of HIV is huge and really well funded, they have over 200 staff. And it's like so disproportionate to the number of people living with HIV in the city. Compared to the Bureau of Alcohol and Drug use where we have 20, 25 people. And if you put that in proportion to the number of people who are problematic drug users in this city, it's so disproportionate. And that's because of a lot of different reasons, because of historical advocacy, drug users don't have as good advocates.*

This is the legacy of an administrative and strategic separation between the city's response to HIV and its strategy for dealing with the health of drug users.

This is not to belittle the herculean efforts undertaken by committed gay men and their allies, who struggled against an often hostile and ignorant public. Without their activism, the toll of the AIDS crisis would have been far higher, and subsequent organizing drew on the groundwork laid by these activists. But syringe exchange activists did feel left out of the initial governmental responses to the crisis, which, they argued, were created exclusively with the epidemic's most visible victims in mind. This sense of exclusion was significant in shaping the culture of syringe exchange. It heightened their self-conception as outsiders

who needed to engage in direct action in response to a government complacent in the face of an emergency. The slowness of the city's response heightened this sense as well. While the government did eventually mobilize around HIV/AIDS prevention and care, an IDU specific intervention, syringe exchange, was first authorized fully eleven years after the first cases of HIV/AIDS were diagnosed among drug users.

Syringe exchange was not only absent from the state response to the AIDS crisis. Even within activist circles, syringe exchange was a contentious and divisive issue, laying bare the disparate demographics of the disease. GL, an interviewee who had participated in the early days of syringe exchange, was a member of the well-known group AIDS Coalition to Unleash Power, widely known as ACT UP.

*GL: What I would say was true of ACT UP was it was speaking for a queer body, a white queer body. And my very first meetings, the issues of race were right out on the table. People of color were speaking up. Women were speaking up. All the people who weren't included in this image were speaking up and the white men were continually going, "Why are you always making an issue out of this? We're not marginalizing anything. I'M DYING!!!! And YOU'RE NOT DYING!!!! So shut up!"*

Here GL describes an organization whose attention grabbing, direct action political tactics were underwritten by a sense of do-or-die desperation that members felt at the time. Though drug users were present in ACT UP, their voices tended to be marginalized.

*GL: There were drugs users in ACT UP. There were active drugs users in ACT UP. But by and large, the identity of needle exchange was a recovery identity. But that was very, very present in ACT UP. That was the heart that could be worn on one's sleeve in the face of all this, "I am dying," and sort of have equal standing, in terms of all of this sort of like repentance: "Oh, I know, because I'm an addict" ... But needle exchange was voted down three times before it was accepted. Three times. But eventually it did gain the momentum that it needed and that's when the needle exchange eight were arrested and all this stuff happened. It was done in a very constructive way, but at that point, the only legitimate dialogue that could occur on the floor of ACT UP was one in which it was framed as, for instance, dead addicts don't recover.*



The struggle to translate common health risk into concrete political projects is a challenge faced by many “health social movements.”<sup>17</sup> As GL explains in the interview excerpt above, ACT-UP was divided between different identities and interests of gay men and drug users. What, after all, did they have in common other than a shared vulnerability to a deadly disease?

Drug user exclusion from mainstream responses to the epidemic was not a given. Outside the U.S., drug user groups had been successful in developing state-supported strategies to address the growing HIV/AIDS crisis. The earliest instances of harm reduction brought together drug user unions like the *Junkiebond* in the Netherlands and the Vancouver Area Network of Drug Users (VANDU) in Canada with their respective local and national health systems to develop and implement syringe exchange programs that helped these places, and indeed most of Europe, avoid the scale of the HIV/AIDS crisis that New York faced. In these places, drug users enjoyed some semblance of citizenship rights. Their specific needs were acknowledged by the health system, to which they had a right to inclusion as citizens. In the largely private and increasingly anti-drug U.S. context, drug users had no such expectations.

People within New York City’s Department of Health were paying attention to the successes of syringe exchange in Canada, Europe and Australia, including the Commissioner of Health David Sencer. In 1985 he approached mayor Koch with a proposal to initiate a network of syringe exchanges in the city. According to Colgrove, the mayor initially rejected the idea but quickly changed his mind. In an interview, Sencer told

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<sup>17</sup> Phil Brown, et al., “Embodied Health Movements: New Approaches to Social Movements in Health,” *Sociology of Health & Illness* 26.1 (2004): 50 – 80.

Colgrove that “although the mayor was still doubtful about the efficacy of the approach and its political feasibility, he was open to floating a trial balloon.”<sup>18</sup> Sencer drafted a proposal which Koch circulated to officials and journalists to gauge public sentiment and political reaction to the plan. Opposition came from all quarters and within a month, Koch had dropped the idea of a city-run syringe exchange as a “political nonstarter.”

Meanwhile, awareness was spreading among the IDU population about the risks of needle sharing. Opponents of syringe exchange claimed that not only would giving drug users clean needles encourage them to use more, but that users were in any event fixated on their addiction and unwilling or unable to change their destructive behavior. Special Assistant District Attorney for Narcotics Sterling Johnson “scoffed at the notion that ‘slaves of addiction’ in a ‘narcotic-induced stupor’ cared about using clean syringes or could be taught to do so.”<sup>19</sup> A widely cited study conducted by Des Jarlais, Friedman and Hopkins conclusively discredited this view and demonstrated that in fact drug users had already started changing their behavior to protect themselves from infection. They found demand for sterile injecting equipment among users, the sale of “resealed” syringes, and drug dealers peddling clean syringes by telling their customers to “get the good needles, don’t get the bad AIDS.”<sup>20</sup> Their study also suggested that a major hurdle to using clean syringes was their lack of availability, constrained by the broader legal environment.

While the prevention efforts were beginning to bear fruit among gay men who had seen the number of new infections level off, the same could not be said for drug users and by 1988,

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<sup>18</sup> Colgrove, *op. cit.*: 163.

<sup>19</sup> Colgrove, *op. cit.*: 164.

<sup>20</sup> Don C. Des Jarlais, et al., "Risk Reduction for the Acquired Immunodeficiency Syndrome Among Intravenous Drug Users," *Annals of Internal Medicine* 103.5 (1985): 755-759.

“newly diagnosed cases of the disease among drug users in New York City outnumbered those among gay men for the first time.”<sup>21</sup> As Heller and Paone point out, “IDUs had no existing organizational structures and few advocates for the cause.”<sup>22</sup> The most visible group at the time advocating on behalf of drug users was the Association for Drug Abuse Prevention and Treatment (ADAPT). Founded in 1980 to provide counseling to drug users, ADAPT had “a history of working within the system and institutional ties to city government.”<sup>23</sup> ADAPT received limited city funds to provide education and safer injecting supplies like bleach kits and “cookers” to drug users, though crucially these supplies did not include sterile syringes.<sup>24</sup>

Groups like ADAPT increasingly pressured the city to establish a syringe exchange. And many in the Health Department, including then-Commissioner Dr. Stephen Joseph, were openly supportive of the idea. With Mayor Koch’s approval, Commissioner Joseph tried again to begin syringe exchange in New York City. By this time SEPs had been tried in other cities around the U.S., including Tacoma, Washington and New Haven, Connecticut. But the New York State Health Commissioner David Axelrod, whose agreement was necessary, was seen to be stalling, claiming that more evidence was needed to substantiate the effectiveness of the intervention. Axelrod eventually agreed to allow the program to proceed on the condition that it be conducted as a research study.<sup>25</sup> “In New York City a pilot needle exchange scheme, in order to have even a remote chance of acceptance, was packaged from the start as a controlled clinical trial, as a scientific experiment.”<sup>26</sup> This

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<sup>21</sup> Colgrove, *op. cit.*: 160.

<sup>22</sup> Heller and Paone, *op. cit.*: 142.

<sup>23</sup> *Ibid.*

<sup>24</sup> Colgrove, *op. cit.*: 195.

<sup>25</sup> Anderson, *op. cit.*

<sup>26</sup> Anderson, *op. cit.*: 1507.

would not be the last time that a harm reduction strategy was introduced under the legal status of a pilot study.

Progress on setting up the research study was slow and syringe exchange advocates wanted to push the city to move faster. ADAPT announced their intention to begin syringe distribution, in direct contravention to paraphernalia laws. As Yolanda Serrano, ADAPT's director, said, "Something has to be done now. Someone has to take the initiative to challenge the state in the name of public health."<sup>27</sup> This seems to have spurred the government to action as the syringe exchange trial was finally approved six weeks later. The plan originally called for four community-based exchanges in district health centers spread across the city in high-need neighborhoods. But due to strong opposition from a broad alliance that included community board members, City Councilors, state legislators, U.S. Congress members, the NYPD, and representatives of various neighborhoods and ethnic communities, the plan was drastically scaled back to only one site.

The syringe exchange was finally opened in 1988 in the downtown headquarters of the New York City Department of Health. Only drug users on waiting lists for a place in a treatment program were eligible to participate. Additionally, users were required to carry an ID card with a photo and a fingerprint, and subject themselves to regular blood tests and medical screenings. The syringe exchange faced other barriers owing to its hours of operation and to its location, far away from areas drug users typically frequented, and around the corner from the headquarters of the NYPD. One of my informants, YH, a New York State AIDS Institute employee, describes visiting the site at the time.

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<sup>27</sup> Quoted in Anderson, *op. cit.*: 1509.

*YH: I came to visit the New York City syringe exchange when they were giving out one syringe to a drug user in a canister and the syringe exchange was located in the lobby of the same building where the police station was. What amazed me was they had two clients who came and got this little tin with the one syringe in it. And it was clearly absurd, but you get your foot in the door in any way you can.*

In the end, despite great anticipation, the program limped along for 14 months and only served a paltry 294 drug users<sup>28</sup> before being shuttered in 1990, after the election of David Dinkins.<sup>29</sup> Drug users were again left to their own devices to prevent HIV infection.

The closing of the syringe exchange trial precipitated a surge in activist activity. Linking up with ACT UP, syringe exchange activists began distributing clean needles illegally, concentrating efforts in the Bronx, Harlem and the Lower East Side.<sup>30</sup> These groups would eventually become waived syringe exchange programs. Many activists at this time were active or former drug users or the friends or loved ones of users. Many had personally experienced the tragic consequences of the epidemic, having seen family members and friends die after contracting HIV through intravenous drug use. Harm reduction combined personal, pragmatic and political motives. Other activists were committed public health workers and researchers who felt they could not sit idly by while AIDS ran unchecked through communities that were already facing many other social and economic struggles.

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<sup>28</sup> Lee M. Kochems, et al., "The Transition from Underground to Legal Syringe Exchange: The New York City Experience." *AIDS Education and Prevention* 8.6 (1996): 471 – 489.

<sup>29</sup> Exemplifying the complicated racial politics of the time, opposition was particularly strong in city's African-American establishment. David Dinkins selected Woodrow Myers to be the city's first African American Commissioner of Health. Like Dinkins, Myers was opposed to syringe exchange saying that he "favoured expanding drug treatment but was 'ideologically opposed' to needle exchange and could not imagine any empirical evidence that would change his mind. Myers considered needle exchange 'shortsighted and wrong. It absolved the government of the bigger problem, which was figuring out what to do about drug abuse." See Colgrove, *op. cit.*: 195

<sup>30</sup> Kochems et al., *op. cit.*: 473

After many years of sidelining the plight of drug users, the AIDS activist community decided to take on the cause of syringe exchange. In 1991 ACT UP staged the arrest of eight activists in order to force a test case on the legal necessity of syringe exchange. The activists were successful and the judge ruled in favor, concluding that the AIDS epidemic among injection drug users constituted a public health emergency. The judge in the case explained her verdict by offering:

The distinction, in broadest terms, during this age of the AIDS crisis, is death by using dirty needles versus drug addiction by using clean needles. The defendants' actions sought to avoid the greater harm.<sup>31</sup>

In essence, the judge echoed the rationale of harm reduction in her decision, clearing the way for policy change.

Syringe exchange supporters at the time tended to base their claims on appeals to social justice. This was the period that saw the creation of harm reduction principles such as the revalorization of user experiences, respect for users' lives, non-judgment and 'meeting people where they are.' RN, former ACT-UP activist and founder of a major New York syringe exchange, said describing syringe exchange activism of the time:

*RN: Harm reduction from that point of view is a revolutionary thing. You actually want to turn society upside down because society is unequal and unjust. But that's a really big thing. So what's the next best thing you can do? Hand out needles to someone because that could change their lives right there and then. But ultimately, that's what we want to go for, is a complete reordering of society. But we do it through different means, I guess.*

At the same time, many early syringe exchange activists in New York recognized that their efforts needed to be scaled up in order to be effective.

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<sup>31</sup> Ronald Sullivan, "Needle-Exchangers had Right to Break Law, Judge Rules." *New York Times*. 26 June 1991.

*EL: Harm reduction in this sense, needle exchange is a fucking band-aid, and we were providing services the state was not. And the state should have been providing these services and someone had to step up to the plate, and that's what we did.*

For RN, EL and others, the distribution of sterile syringes to prevent HIV transmission was both a pragmatic matter and an important ethical commitment. When some activists criticize what they see as the overly medicalized harm reduction of today, it is this pre-waiver-era conception of harm reduction as a social justice movement that they use as a benchmark.

The essential characteristic of syringe exchange in the 1980s was that it emerged outside of both the state bureaucracy and the mainstream activist response to the AIDS crisis. The syringe access infrastructure was late in developing in the history of the AIDS epidemic and was not initially embraced either by the government or by activists. As a result of this marginalized position, SEPs were relatively amateurish, but also relatively radical. All of this was set to change.

Why did they not stay that way? Why would activists, some of them ardent critics of the public health establishment, seek to become integrated with the state in the first place? RN explains the issue was one of scale:

*RN: One of the arguments I used to have is when we were underground, we had limitations, we had limits on what we could afford to do and what we couldn't afford to do. When we first started we only gave out twelve syringes per person, because we didn't have anymore. Then we got funding, you could give out more. And so the complaint was, well I liked it better when I knew everyone. Well, you know what, you weren't having a public health impact when you knew everyone. When you could know every single person you saw by first name and their families, then you weren't having a public health impact. So by becoming institutionalized to a degree, you then have an actual real public health impact as opposed to just an impact on individual's lives. And that's what you need to do if you are going to reverse a problem. And we did. In New York City we did reverse the epidemic.*

Syringe exchange during the underground days was limited in terms of impact. To jump scale, SEPs needed to become institutionalized. This was difficult if not impossible, given laws against distribution of drug paraphernalia. Either official policy had to change, or some other legal maneuver needed to be found.

### **III. The partial institutionalization of syringe exchange: waivering**

The modern history of syringe exchange in New York began with the legal mechanism known as ‘the waiver.’ In 1992, the New York State Department of Health authorized the conduct of syringe exchange statewide. Rather than changing the law, the state declared a public health emergency and introduced a system whereby SEPs, hitherto operating illegally, could apply for a waiver exempting themselves and their participants from laws governing the possession of drug paraphernalia. Initially brought in as a one-year emergency measure following the 1991 court decision, the waiver system was later extended and made permanent.

The waiver system, along with the grant funding structure that accompanies it, typifies the ‘partial institutionalization’ of syringe exchange. This is the process by which SEPs have become institutionalized as part of the state bureaucracy, and as such become formal, legally-sanctioned organizations, rather than the loose, legally questionable groups that they had been in the past. But this process has only proceeded up to a point. Because of the political unpopularity of harm reduction measures, syringe exchange still exists in a state of exception.



Partial institutionalization, in this sense, can be seen as typical of harm reduction policies more generally.<sup>32</sup> In the New York context, it has been the defining feature of SEPs. It initiated and formalized the relationship between the activists, now running syringe exchange programs, and the state, in the form of the New York State Department of Health's AIDS Institute. It is the precondition of the ambivalent inside-outsider status that has come to define syringe exchange in New York. It has allowed them to become sources of policy innovation while still maintaining some of the legitimacy and stability that legalization and institutionalization provides. But it has also forced SEPs to abandon some of their activist identity and the social justice-orientation of their outsider days. And according to some, it has restricted their organizational autonomy.

The waiver allowed syringe exchange agencies in New York City to exist in a hostile political environment. Both the Dinkins and Giuliani administrations registered their opposition to syringe exchange, and neither mayor allocated them any city resources. While not technically blocking their ability to operate, neither mayor did anything to promote or facilitate syringe exchange in the city. For the first ten years of syringe exchange, the DOHMH had no direct relationship with SEPs, preferring instead to let the state handle the funding and overseeing of these politically unpopular organizations.

Members of the New York State Department of Health AIDS Institute took the lead in drafting the regulations for syringe exchange. AL, a long time employee of the New York State Department of Health, remembers how this came about:

*AL: So we had to figure out how to do it, cause we were not going to get legislative action to authorized these programs. It just wasn't going to*

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<sup>32</sup> A similar situation, for example, holds regarding InSite in Vancouver, which began operations in a waived state of exception. It remains the only safer injection site in Canada.

*happen. So what we had to do was search through public health law to find the authority to respond to the public health epidemic. And respond to the science. And use that basic authority in public health law to adopt emergency rules and regulations.*

Bypassing “legislative action,” the AIDS Institute instead found the authority to initiate syringe exchange through its ability to use public health law to adopt emergency measures to address the HIV crisis among IDUs. This had the desired effect of creating the legal context for syringe exchange without needing to rely of the lengthy and uncertain legislative process.

Though waivering did legitimize syringe exchange, some activists were critical of the way it took place. GL, a former ACT UP activist involved in syringe exchange, commented:

*GL: So the way needle exchange is legal in New York State—technically it's a crime for syringes to exist, and it's a crime for people to have them. Unless the public health law, Section 3381 of the public health law, designates you as a class of people who may lawfully possess syringes. The public health law doesn't say what constitutes unlawful possession. It says what constitutes lawful possession and all other possession is de facto, unlawful. Who can possess syringes includes doctors and nurses and pharmacists and people with prescriptions and as of 1992, the health commissioner, according to the public health law, according to his or her wisdom, may also designate other classes of people who may lawfully possess syringes. And that is what happened in 1992... The law was not rewritten to say, "Now all syringe possession is lawful." The law was written to say, "The health commissioner has exercised her authority to designate people who operate syringe exchange programs and people who receive syringes from syringe exchange programs as lawfully entitled to possess their syringes." But syringe exchange, itself, is still very locked in around the idea that in order to receive authorization you have to demonstrate certain things. And one of those things that you have to demonstrate, although it doesn't actually say it in writing, the state's still very, very clear that for some reason you can't just give syringes to people who don't have them.*

As GL explains, syringe exchange was never legalized in any straightforward way. The waiver system did not fundamentally bring about a change in the status quo.

*GL: We have, to this day, the fact that needle exchange is this elaborate capitulation to the authority of the war on drugs. In virtually every aspect of*

*its configuration, the war on drugs still has the upper hand, in terms of how to define public health in the presence of drug use.*

The declaration of a public health emergency around HIV/AIDS among injectors did not translate into a wider reevaluation of the social and legal structures that contributed to the creation of this emergency. Public health bureaucrats within both the City and State public health departments saw the waiver as a victory. It was a practical, expedient way to circumvent the political system and allow for the implementation of a desperately needed public health intervention. But activists were never fully satisfied with the way syringe exchange under the waiver was rolled out. As RN put it:

*RN: It's a political tool, that's all it is. Needle exchange itself is a strategy. It was an expedient phrase to quell the nervousness of politicians to say exchange. The theory being you take one in and you give one out. That's not even good public health.*

For RN and GL, syringe exchange is a compromise. By not pursuing a change in the criminal law, the underlying problem of the criminalization of drug users with all the deleterious consequences this entails remained unchanged. That syringe exchange depends upon a waiver, rather than a change in official policy, only underscores its unfinished nature.

Internally, the process of formalization presented many challenges. Almost overnight, syringe exchange was transformed from an act of civil disobedience to a regularized and regulated public health service. Activists who had been motivated to act by a sense of outrage and desperation found themselves needing to redirect their energies to more mundane tasks such as bookkeeping and contract deliverables reporting. As Heller and Paone note,

many activists who had played central roles in the underground programs had to re-orient themselves to an altered environment, from clandestine operations where they were sometimes harassed by authorities yet otherwise

autonomous in their operations, to programs sanctioned and funded, and thus regulated, by the government.<sup>33</sup>

Before the waiver

SEPs operated as what a few long-term SEP volunteers referred to as ‘self-regulating’ organizations. Their ability to distribute syringes was dependent of available supply. Organizational issues were decided among SEP activists by consensus when possible and majority rule when necessary.<sup>34</sup>

After the waiver, more hierarchical management structures were put in place to satisfy the requirements laid out by the State’s regulatory framework. As VC, founding director of HRP told me, “Once you start negotiating with the state, you find yourself getting pacified, coopted.” Underground groups were now trying to build organizations around syringe exchange, attempting on the one hand to keep the oppositional spirit of harm reduction while simultaneously instituting systems that would make them transparent and accountable to the state.

The waiver creates the context for a particular relationship between activists and the state. Despite the legacy of the underground era, the relationship between activists and the state is not typically oppositional or always confrontational. Lambright and O’Gorman describe the AIDS Institute as a “bureaucratic advocacy organization” which places “the bureaucratic organization at the center of policymaking, rather than at its periphery.”<sup>35</sup> Employees of the AIDS Institute, as well as employees of the DOHMH, identify with the message of the harm reduction movement and many of them identified as activists working within the state to bring about change. There is of course a long history of public health workers being more progressive and radical than the prevailing political temperament of

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<sup>33</sup> Heller and Paone, *op. cit.*: 143

<sup>34</sup> Kochems et al, *op. cit.*: 475

<sup>35</sup> Lambright and O’Gorman, *op. cit.*: 176

their times.<sup>36</sup> Harm reduction is an example of this—people in the bureaucracy moving government policy in a direction in which politicians are not yet prepared to go.

Though some state employees told me they personally identify with the harm reduction movement, the state public health apparatus is also subject to political and legal imperatives that structure its action in the harm reduction field. AIDS Institute contract managers oversee the programs and enforce adherence to regulations. The regulations which govern syringe exchange were written with political palatability in mind. AL, a long-time employee of the AIDS Institute, explains:

*AL: It was in 1991 when we issued the emergency regulations. And I think the regulations have not changed; they are the same today. And there are certain things there that might need revision at some point. But one of the things that the regulations did, although there are strict things, like there have to be a number of syringes provided, syringes had to be returned. But the way that they are written it's more like, well there have to be policies and procedures for it. Policies and procedures for this, policy and procedures for the intake, policies and procedures do not have to go through a regulatory process, per se. So you could make changes in policies and procedures. So that is a document that we have, policies and procedures, that we provide to the agencies.*

On the one hand, AL acknowledges that there are some “strict things” like the number of syringes SEPs are able to provide their participants, and that syringes “had to be returned”, requirements which come directly from the wider political concern that SEPs would flood the streets with needles and that the increased availability of needles would lead to more drug use. On the other hand she says that the way to get around these strict regulations is by the manipulation of policies and procedures that do not have to go through the regulatory process.

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<sup>36</sup> George Rosen, *A History of Public Health*, revised ed. (Johns Hopkins University Press, 2015): 106-168.

This strategy—exploiting the space between the politically determined regulations and the more malleable policies and procedures meant to operationalize these regulations—has been at the core of the relationship between the state and the SEPs and has formed the basis of the field of harm reduction in New York.

*AL: It gave flexibility to the programs, because programs didn't have to look alike. Many of them do, others don't. It gives programs flexibility. We revised policies and procedures about three years ago, to open up in certain areas that programs were asking us, well: If we only provide let's say 50 syringes to this person, but this person is injecting four or five times a day, and if this person can only come to the exchange once a month, we are not providing for this person. So that was open. Programs can now provide more syringes at every transaction than ever before.*

The “flexibility” afforded the agencies meant that they “didn’t have to look alike.” For some, incomplete institutionalization meant an extension of the organizational and political autonomy that accompanied syringe exchange’s underground years. RN, an activist involved in underground exchange who then went on to serve as director of one of the first waived programs described the early post-waiver period as a “golden era where you had some funding, but limited funding.” According to RN, the limited funding of the immediate post-waiver period allowed the agencies to regularize their core service while continuing to operate with the inclusive ethos of the underground days.

*RN: And because no one knew really what harm reduction was, we made it up, we invented it, to a degree. We invented what we were supposed to do. So the programs were much more inclined to be social in aspect at times, we had poetry readings and stuff like that and we created community. The approach was much more inclusive in some ways of the participants of the programs, the drug users were integrated into programs as people providing services.*

They did not have the same degree of organizational autonomy as they did during the pre-waiver era. But agencies could maintain their own personalities and what some

interviewees referred to as “brands” of harm reduction service delivery in keeping with their activist roots.<sup>37</sup>

As well, this space for negotiation created a channel through which agencies were able to affect policy change. The AIDS Institute is in some ways a “captive regulator” in the sense that its employees do not act as a watchdog for the politically determined public interest, which they understand for the most part to be unenlightened and counterproductive. NN, an employee with the New York City Public Health department who had been active during syringe exchange’s early days articulates this sentiment:

*NN: We have bent the law—never broken it! But I’m a person that knows that there are laws that need to be broken sometimes. And we in public health can’t be timid about breaking laws that need to be broken. We have to be forceful in our convictions, and do the right thing, regardless of who works against us. Because we know what we are obliged to do is to save lives. We don’t have to be politicians, we’re not running for office, we’re not running popularity contests.*

Public health workers are obliged to “do the right thing,” even if this requires bending the law to achieve the desired public health goal. Not beholden to the vagaries of public opinion, they try as much as possible to facilitate the legitimation of SEP practices that sometimes push the envelope or run afoul of the official rules. YH, a contract manager at the AIDS Institute, reflects on this relationship:

*YH: If you just have people who are rule followers, and I mean we in government are rule followers, but you also have to understand that things are so dynamic here and the programs are dealing with people on the street and changing forces on the street, and they are recognizing and getting it first hand. We go out and see the programs and monitor the programs and see what’s going on, but it’s not the same as that day-to-day interaction with people where you really start to see things changing on the ground. And so we get informed by that, and we try to be responsive to that, and not just say, “Oh, here’s the rule and we have to follow it to the T, no matter what.”*

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<sup>37</sup> This individuation would become one of the most often cited objections to harm reduction’s incorporation into Medicaid, as discussed in chapter five.

The state provides the boundaries of what is doable within the limits of the legal and political framework. But in many ways, the allegiances of state employees are to the programs, and to a larger feeling of connection to a public health mission. While the waiver represents the failure of the state to fully endorse and legalize syringe exchange, the strategy's incomplete institutionalization also provides an avenue for policy innovation.

An early and oft-cited example of the willingness of the state to work around the preferences of the agencies is the repeal of the initial requirement that all syringes distributed by programs be tagged, in order to track return rates. Programs balked at the onerous, labor-intensive practice and the state acquiesced by removing the requirement.<sup>38</sup> Over the years, there have been other instances when programs have directly challenged state regulations, and the AIDS Institute has generally responded by adjusting the policies and procedures to reflect the practices and preferences of the programs. Even the “strict” requirements limiting the number of syringes given to participants was circumvented by the introduction of “contingency contracting” which GL describes as:

*GL: The state's magnificent capitulation to the stupidity of one for one. They said, “Here, we'll come up with reasons and ways you can beat one for one, but one for one is still technically the principle.”*

Just as the waiver allowed syringe exchange to take place without a change in the law, the regulation stipulating one for one exchange remained unchanged but a work-around was found.

The flexibility that resulted from the incomplete institutionalization of syringe exchange enabled a number of important innovations. The most interesting is the transformation of the illegal practice of secondary exchange into the formalized—and celebrated—

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<sup>38</sup> Heller and Paone *op. cit.* discuss this example, as did several of my informants.



intervention of Peer Delivered Syringe Exchange (PDSE). The regulations governing syringe exchange do not allow for secondary distribution, as the waiver stipulates that only those drug users officially registered with a syringe exchange program may legally possess syringes. But it was widely known, if not directly acknowledged, that registered syringe exchange participants would provide needles to friends and family who were not enrolled at an SEP, and this was in fact a desirable practice from a public health perspective. According to GL, the state knew for years that secondary exchange was happening.

*GL: Then I'm supposed to assume that this guy or woman gets off 1,000 times a day, because clearly they don't. Secondary exchange was against the rules back then, completely. The state very blandly chose not to look very hard at the numbers.*

A handful of SEP participants were responsible for extremely large volumes of exchange. As long as the syringes going out were accounted for, the state chose to ignore it. I asked AL about this:

*R: Did PDSE formalize secondary exchange?*

*AL: We don't use that word.*

*R: Why?*

*AL: Because it's not secondary exchange. Secondary exchange is against the law. The law interprets secondary exchange as the sale—and regulations do not allow you as the participant of the program, to sell. And even if you are furnishing it is considered a sale. So for us it's not secondary distribution. For us, it's—these are peer-to-peer individuals that are part of a program. [...] We had thought about peer delivery a long time ago. But at the beginning we had to write this concept in a way that didn't bring questioning. So it took us a couple of years to be able to get there, plus we did a pilot first.*

Allowing drug users to directly “furnish” syringes to their peers is a practice as old as syringe exchange itself. But official sanction is more recent and comes directly from the demands made by SEPs for the formalization of this model of syringe access. As AL points out, secondary exchange was and remains illegal. But the PDSE model was allowed to

develop by deputizing certain users as employees of the syringe exchanges, thereby getting around the regulations.

PDSE could have only arisen in an organizational field marked by partial integration with the state. SEPs could act as laboratories for new public health strategies because there was a space for negotiation between the representatives of the official bureaucracy and the “street-level bureaucrats”<sup>39</sup> who directly oversaw syringe exchange and became policy entrepreneurs in their own right.

*GL: But I would say, you know, PDSE is very, very benign. Contingency contracting was very, very benign. And these were the attempts of the state to respond to what we, as activists, were saying on the ground. I'm not going to gainsay that they were attempting to respond, but that was the dynamic. We would denounce and they would try and rearrange.*

In their willingness to include the demands of the activists, the state effectively incorporated active drug users into the policymaking process in a way not done before.

In this way, the harm reduction philosophy has become increasingly important to public health practices without any official change in stated policy. New York State, which had been a pioneer in punitive drug control measures, was now, in the form of the AIDS Institute, supporting policy aimed at ‘meeting the user where they are’ and including users in the design of services to encourage their feelings of ownership, responsibility and self-sufficiency. The specific relationship between the AIDS Institute and the SEPs allowed for this innovation. It is not only a shift in terms of the philosophy underlying social policy but also a change in the way policy is made.

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<sup>39</sup> Michael Lipsky, *Street-Level Bureaucracy: Dilemmas of the Individual in Public Service*, 2<sup>nd</sup> ed. (New York, NY: Russell Sage, 2010 [1980]).

Syringe exchanges see it as part of their mission to “let the participant’s voice be heard,” and for some, the informal policy change process represented by PDSE is a more effective way for this to happen than the formal arrangements for it. One of the requirements under the waiver for SEPs is that they have a participant advisory board (PAB) composed of users who participate in syringe exchange.<sup>40</sup> As user autonomy is part of the philosophy of harm reduction, most agencies take this requirement very seriously.<sup>41</sup> PABs allow agencies to monitor the uptake of various services and solicit the opinions and suggestions of service users. These then get transmitted to the AIDS Institute in a variety of ways, leading to shifts in policy to better reflect the “things changing on the ground,” as YH explains above. But some SEP participants and employees see the PABs as paying “lip service” to the idea of participant decision-making. In contrast, the informal process of quietly adjusting policy to align it with actual practices, as with PDSE, is a direct way in which user experience translates into policy change.

#### **IV. The partial institutionalization of syringe exchange: grant funding**

The other component of syringe exchange’s partial institutionalization was its uncertain and ad hoc funding structure. Rather than funding syringe exchange through standard budget allocation, SEPs are funded through a system of special grants. This has had several consequences for SEPs. The first is that organizations have adjusted their goals in line with those of grantees. In most cases this has meant moving ever closer to AIDS service provision rather than an ability to focus on drug user health more broadly. And this has,

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<sup>40</sup> NYSDOH AIDS Institute, “Policies and Procedures: Syringe Exchange Programs,” (2009): 24.

<sup>41</sup> Anthony R. Henman, et al. “Injection Drug Users as Social Actors: A Stigmatized Community’s Participation in the Syringe Exchange Programmes of New York City.” *Aids Care* 10.4 (1998): 397-408.

according to some SEP supporters, restricted their autonomy. The other consequence is that organizations have had to compete for the limited funding available, which has prevented deeper cooperation among SEPs at the political level.

Most of the grants supporting syringe exchange originate with the federal government, though SEPs are also reliant on private donors, such as the American Foundation for AIDS Research (AmFAR), which pays for syringes as well as program evaluation. The system by which syringe exchange is supported and funded is immensely complicated and varies greatly across the country.<sup>42</sup> The federal Ryan White and CDC money awarded to New York City for HIV/AIDS prevention was passed through to the State government via the AIDS Institute, which oversaw the dispersal of funds to the agencies. Because the ban on using federal funds for syringe exchange remains in place, SEPs use federal dollars to pay for what are called “wrap around” services like risk reduction counseling, case management and other programs tied almost exclusively to HIV prevention. As MI explains:

*MI: And if you look at the federal funding closely, there's a lot of federal dollars that go into overall HIV prevention—HIV testing and case management and all that stuff that provides that kind of integrated service model for people who inject drugs. Even if the federal dollars isn't being used on syringe exchange, all that other stuff can sort of support and wrap around that.*

These contracts include a certain percentage of funds that can be spent on organization overhead, which allow SEPs to cobble together enough funds to be able to provide services not directly covered by their contracts. Dahlia Heller, former director of an important New York SEP, describes how the agency grew from a small, barely legal operation with no physical space to an established organization with a swelling budget, expanding physical footprint, and growing roster of services to offer program participants.

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<sup>42</sup> Don C. Des Jarlais, et al., "Public Funding of US Syringe Exchange Programs," *Journal of Urban Health* 81.1 (2004): 118-121.

*DH: We got mental health money, but it was Ryan White money so we could only serve HIV positive people. I knew that of course, but we needed any mental health money cause we needed the money to be able to do mental health services. So then I went and hustled a private foundation that was interested in doing mental health services and got them to match it, or partially match it, so I was able to creatively share time across contracts and be able to see HIV negative people, and so we weren't stuck.*

These wrap around services required the agencies have the appropriate staff to deliver the services, which in most cases meant employing social workers or other staff with professional degrees. It is widely known that CDC would like to directly support SEPs but are blocked from doing so by the federal ban, which would take an act of Congress to overturn.

While it can be a source of freedom and facilitate some forms of policy innovation, grant funding comes with its own challenges. Being grant funded is always, as Heller put it, a hustle. Many of my interviewees saw the grant funding system itself as both precarious and burdensome.

*RN: Up until fairly recently, it's been harder. You struggle to keep the doors open. There was never, not that this has necessarily affected the programs, but there was never a budget line in the State Department of Health budget for syringe exchange. It was always left over money each year. So theoretically it could have all crashed and crumbled at any time. It didn't, and the Health Department has been really amazingly supportive. They always had to be really amazingly creative as people—we've been really lucky with the health department, that we had the same staff there as twenty years ago, because they looked out for the programs.*

Organizations must cobble together a series of small contracts to keep their doors open, continually reapply for funding, and rely on the willing cooperation of employees at the Health Department to ensure their continued operation. This in itself presents organizational challenges. An employee of the DOHMH observed:

*GN: It's ridiculous. The way that a lot of these agencies survive is by piecing together like twenty different tiny little contracts and each of those has their*

*own reporting systems and reporting schedules and data management requirements. So it's a nightmare, it's a total nightmare.*

Relying on grants from multiple sources has exacerbated the administrative burden on small agencies, requiring them to devote ever-larger shares of their resources to professional staffing, which has pulled agencies away from the early days of user involvement.

For other informants, the grant funding system functions to restrict the autonomy of SEPs. They are forced, as one informant told me, to “follow the money.” Most of the funding available to harm reduction organizations for the first twenty years of their post-waiver existence was tied to HIV prevention. This led to the drift in the direction of being an AIDS service organization, rather than emphasizing either medical or political concerns specific to drug users. NL, a researcher, social worker, board member of HRev and drug user activist who was active in the early post-waiver syringe exchange movement, told me:

*NL: My initial ideas about harm reduction, I didn't say the word HIV. And I didn't say the word needle exchange. It was a much, much broader idea about how to approach drug use and people who use drugs. The quote-unquote harm reduction movement was completely driven by the HIV epidemic. If there was no HIV, there would be no harm reduction. It was a fucking crisis. It was a serious, serious health crisis among the most disadvantaged and oppressed and the response which was an underground, political, activist response was right on. But, what has happened is that it was impossible to extricate harm reduction from HIV in those days because harm reduction was all about HIV prevention and it was funded entirely by HIV prevention funds. It's more nuanced than that, obviously but HIV prevention and HIV incidents and HIV prevalence were the gold standard outcomes that would justify taking this approach to drug use, which more or less meant needle exchange in the United States, in New York City.*

For NL, the structure of grant funding strongly shaped syringe exchange as a strategy and the harm reduction movement in New York.

This was a particular problem in the early days of the waiver, when HIV/AIDS—and not issues specific to drug users—dominated the available funding. PR, director of HRev, a Bronx SEP, expresses frustration with the HIV focus of syringe exchanges and harm reduction. HRev was among the first three waived programs in New York City, a direct offshoot of ACT UP activism, which explicitly had HIV/AIDS at the heart of their activism.

*PR: The HIV epidemic is what allowed syringe exchange and a harm reduction approach to kind of take hold. That was the doorway and that's where the money was. And so I think harm reduction in New York—it's interesting because you've got a very supportive state government, a very supportive city government. You've got money behind it. So you take this very grassroots, very activist led, very user-led movement, I guess for lack of a better word. And you institutionalize it, because now there is all this money, now there is all these structures, now there is all this compliance and administration and you become part of the machine. The money that's out there is HIV, so the programming is going to be coming out of these pots. Now that doesn't mean that the organizations are only doing HIV work. They are spinning whatever they are spinning, so that they can get this money to do this work that they are doing. That being said, to a certain extent, HIV kind of becomes the predominant force there....*

*PR: And so I think what happens slowly over time is that if you are thinking about the heart of these organizations, the heart of the organization moves from being about drug users and drug user health overall and then it pivots so the heart of the organization becomes HIV. Because people are putting their programming together around the money instead of going after the money and having the programs lead.*

Over time, she claims, organizations “pivot” towards the money, which has all been tied to HIV prevention, and away from the original “heart” of the organization, which was drug user health.

For other informants, concerns about being forced to pivot away from original organizational goals dovetail with fears of co-optation and the enforcement of an official line. The state, they argue, has at times acted in ways that the programs have perceived as punitive and arbitrary. SEP employees have complained about the imposition of rules like one-for-one exchange and of audits, for example. State employees explain this as needing to

respond to, and in some instances preempt, the hostile political climate, thus protecting the programs from wider scrutiny. But as one SEP program director told me:

*VC: I like AL [the long-time employee of the AIDS Institute]. I've known her for years. But if she is told to do something against our agency, she might do it with a tear in her eye, but she'll do it. She doesn't work for us, she's The Man.*

For VC, while those who work for state agencies are colleagues and possibly comrades, they also represent “The Man,” the establishment, which has never fully and openly endorsed harm reduction. RN voices similar concerns:

*RN: But then you had this period where that expansion that took place from 1989 through 1995 petered out. What you began to see then is this slowing down of new programs, but a gradual taking over, not taking over, but health departments began to look at this as a thing to do. So you begin to develop those programs developed by health departments or overseen by health departments, regulated by health departments. So then you begin to see a regular funding stream that comes in and you have the regulations which define what you do and how you do it. But you also have the funding stream that begins to define what actual services you are going to deliver. And that began to eat away at some of the creative elements that were there at the beginning. And they changed the nature of it to a degree, it became another service.*

The dependable funding stream is welcome, but it “begins to define” the SEPs and to determine their direction. For NL, when SEPs became grant-funded by the AIDS Institute, they become “arms of the state,” and thus subject to the limitations of state- and federal-level drug policy:

*NL: My experience is that these agencies tend...I mean it's complicated but, broad over-generalization, tend to function more as arms of the state. And have a very difficult time thinking out of the box the state's agenda imposes on them. And that social justice, like really investing in this idea of social justice, even within the world of harm reduction and job opportunities and employability, investing in participants, designing programs and systems to build participant skills and knowledge and functioning and employability and those sorts of things—have really been unfortunately absent. So it's sort of turned into this Band-Aid. Harm reduction has done a terrible job of addressing the structural, and it's so outside of a lot of agencies' radar. Partly because the structural is incredibly difficult to impact, but I don't even think that the majority of agencies conceptualize things in that way. Some of these services are designed to be Band-Aid solutions. The services come from the*



*funding, the funding comes from the state level to the federal level. And nobody's interested in social change. Nobody's interested in taking on the issue of the criminalization of drug use, none of the funders are.*

For VC, NL and others, grant funding prevents SEPs from being able to address the user-specific issues that they would like to address. In this way, the move away from drug-user-oriented social movement towards bureaucratic social service provider was encouraged by the grant funding system.

Grant funding also structures the larger field of interaction between different syringe exchange agencies. Under the competitive dynamic that took hold with grant funding, organizations found themselves competing with one another for the limited grant dollars available, militating against the formation of a broader sense of solidarity among various syringe exchanges. As RN puts it, "There is collaboration but there is also competition." Over the years, SEPs in New York have made various attempts at organizing collectively to advocate for syringe exchange in the city. The most recent attempt has been the Intravenous Drug Use Health Alliance (IDUHA).

*DH: In the late '90s there was HRCNY—Harm Reduction Care Network of New York. Prior to HRCNY there was NYNEN—the New York Needle Exchange Network. The programs have always tried to organize themselves in this city. IDUHA is just the latest form, and the longest standing.*

But many informants expressed skepticism that IDUHA would overcome the competitive dynamic between SEPs. Agencies operate independently one from the other. There is not a high degree of transparency or cooperation. Their relationships with each other, mediated by IDUHA, is characterized by competition for scarce resources. IDUHA is often described in disparaging terms as a "trade organization," not a true political coalition. EO, the executive director of SoBroHR, does not have any interest in partnering with other agencies. He says:

*EO: IDUHA is not a coalition, IDUHA is a trade group. Any time that you form in order to protect funding, that's a trade group, not a coalition.*

Through IDUHA and other measures, SEPs support each other in some capacities, but EO says that he would never disclose or share financial information.

*EO: Let's say we work together and VC tells me she's going to move so in those days you are going to see an influx. We are working together, partnering. Like I consider VC a true partner, but we have zero business relationship. And I don't know if we need one. I don't think VC knows if we need one.*

They are, in this sense, classic CBOs struggling to maintain their existence in a difficult funding environment, concerned centrally with their own survival.

*GN: It's like high school, in a lot of ways. These programs have been around for a long time and there are personalities. But I think at the heart of it is just they are competing for scarce resources. None of them are funded to the degree that they should be compared to other types of HIV prevention. Because of the federal ban, because of the climate in which we live, all of these programs need more money and so they are forced to compete. And it's a sucky situation.*

As GN notes, “competing for scarce resources” undermines solidarity between SEPs, and is exacerbated by the federal ban and hence reliance on discretionary grant funding from New York City and State and a handful of other smaller private sources. Many wish that IDUHA could do more, could be a more effective lobby group, but it has so far failed to materialize.

*NL: So essentially IDUHA is a coalition of agencies that do some sort or form of syringe distribution that advocate... for a couple million dollars every year.*

*R: Which is distributed evenly among the agencies?*

*NL: No, and that's been a huge... there was especially in the beginning an element of secrecy among IDUHA, around who could be allowed in the room.*

*R: Why do you think that is?*

*NL: Because it was all about the money. And they wanted that money, and they didn't want anybody else. The more people in the room, the less money their organizations got. So it was very sort of secretive, and very... not open.*

*It's just interesting to me that they're called the Injection Drug Users Health Alliance and there was nobody at the table who is an injection drug user. There was no community. They were the community, and it was all executive directors, who defined themselves as the community.*

This experience suggests that competition between SEPs can have the effect of subordinating the user-centricity of harm reduction to the goal of organizational maintenance.

Partial institutionalization has thus been a mixed blessing for SEPs. It has provided legitimacy, funding and legal sanction. But it has also forced SEPs to alter their mission and compete with one another, with the effect of preventing the emergence of collaboration across the syringe exchange field.

## **V. The urban politics of syringe exchange**

Despite being in the city and of the city, for ten years SEPs were not supported by the City. That is not to say that employees of the DOHMH didn't quietly work in the interest of harm reduction, but rather that the New York City government could not and did not openly endorse syringe exchange. This meant that for the first ten years of the waiver system, SEPs pursued changes in policy at the State level, pushing against the boundaries of the regulations and taking advantage of the flexibility afforded by the pro-harm reduction employees at the AIDS Institute. All this was to change, however, with the election of Mayor Michael Bloomberg in 2001. He took up the challenge of tackling public health in the city as no mayor in recent history had. Though a contested and polarizing figure for many self-identified progressives, Bloomberg's brand of technocratic, data-driven city management undoubtedly offered unprecedented opportunities for harm reduction

advocates, many of whom had felt that despite their many successes, they were still laboring in the margins.

Syringe exchange during the Dinkins and Giuliani years took place despite the City. Giuliani especially was a dedicated practitioner of a deeply moralizing, conservative politics of addiction, centered on concerns about moral hazard and the need to stigmatize drug use. Heller and Paone characterize this period as “oppositional,” pointing out that the “difficulties inherent in mediating a relationship between those engaged in ‘illegal’ behavior and the government authorities were further compounded by a law enforcement policy actively challenging the activities of syringe exchange programs.”<sup>43</sup> Giuliani, a conservative, Republican mayor, became known for his particularly harsh brand of ‘tough on crime’ politics and broken windows policing.<sup>44</sup> This translated into increased crackdowns on syringe exchange participants and the targeting of SEPs for law enforcement actions. NL, an employee of SoBroHR during the Giuliani years recalled:

*NL: So if you had the card you were allowed to have syringes on you, and if you didn't have the card then you weren't legally allowed to possess them. But what was happening is that people were getting arrested. People with cards were getting arrested and charged with possession of a controlled substance in the 7<sup>th</sup> degree. But it was people who had used syringes and were getting charged—and were legitimate exchangers—were getting charged with possession of a controlled substance because of the residue in the barrel of the syringe. So there was this conflict. And I think the conflict still exists between the public health law and the criminal law. That was leading people who were on the one hand doing things that were funded by the state and then on the other hand the state was arresting them for what the state said was ok. So it was just this ridiculous situation where two different institutions within the state bureaucracy were completely contradicting each other.*

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<sup>43</sup> Heller and Paone *op. cit.*: 144

<sup>44</sup> Alex S. Vitale, *City of Disorder: How Quality of Life Campaigns Transformed New York Politics* (New York, NY: New York University Press, 2008); Neil Smith, “Giuliani Time: The Revanchist 1990s,” *Social Text* 57.16.4 (1998): 1-20.

This point was echoed by Daliah Heller, the former assistant commissioner for the Bureau of Alcohol and Drug Use Prevention, Care and Treatment, who told me:

*DH: In the same city, we'll have with the one hand the health department supporting an initiative, and with another hand, the police department interfering with it or screwing it up because they're confiscating syringes, or the homeless shelter being like, you can't come in here with those.*

While syringe exchange was made legal by the State, the City still found ways to make life harder for SEP participants.

The partial institutionalization and uneven adoption of harm reduction led to a certain element of policy incoherence, in that what was supported by one branch of the government was undermined by others. This is typical of harm reduction policies generally. As Philippe Bourgois notes, discussing the Canadian context, “The left arm of the state attempts to soften the repression of the right arm via inconsistently administered high-tech health and social services.”<sup>45</sup> In this context, the divide between City and State exacerbated this incoherence. The New York State Department of Health was working with and listening to drug users, coaxing them into actively participating in the state project of disease reduction through their use of sterile needles. The New York City Police Department, for their part, was continuing to stop, frisk and arrest users for these same behaviors. This policy incoherence hampered the operation of SEPs and prevented the expansion of other harm reduction policies and programs. This had public health consequences, as “police stops were associated with a decreased likelihood of consistent SEP use.”<sup>46</sup>

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<sup>45</sup> Philippe Bourgois, “Crack and the Political Economy of Social Suffering,” *Addiction Research and Theory* 11.1 (2003): 31-37. The metaphor of the left hand and right hand of the state is associated with Pierre Bourdieu.

<sup>46</sup> Leo Beletsky, et al., “Syringe Access, Syringe Sharing, and Police Encounters Among People who Inject Drugs in New York City: A Community-Level Perspective,” *International Journal of Drug Policy* 25:1 (2014): 105-111.

After so many years on the defensive, harm reduction advocates in New York City were hopeful when Bloomberg was elected. As Heller remembers:

*DH: So Bloomberg was elected, and it became pretty clear early on that his administration was willing to talk to the community. Which was a completely different experience from Giuliani.*

As a consequence of Bloomberg's election, two significant events changed the prospects of SEPs in the city. The first is that in 2001, New York City Council decided for the first time to fund syringe exchange. The second is the appointment of Tom Frieden as Health Commissioner. The early 2000s were heady days for harm reduction activists, when city government finally opened its doors to them. Activists welcomed the prospect of further institutionalization and integration into health and social service provision, which they hoped would consolidate SEPs' position as the vanguard of a new wave of pragmatic, non-ideological public health action in the city.

Because of the opposition to syringe exchange by Mayor Dinkins and then Mayor Giuliani, the DOHMH did not have any direct involvement with SEPs in the city until 2001 when the City Council first allocated discretionary funds to support syringe exchange. According to Heller:

*DH: There was no City Council money, ever. So the City Council money was the first City money to ever go to needle exchange.*

As noted, most of the money that was available to SEPs has been tied to HIV prevention, treatment and care. When the City began funding SEPs, it was also under the auspices of HIV prevention.

*DH: There was a group that was formed called NYCOCHAC—New York City Communities of Color HIV AIDS coalition—and a staff member from [one SEP] and a staff member from [another nearby SEP] were going to the meetings regularly to represent syringe exchange, with the goal of representing the issue there. The idea of NYCOCHAC was, we need City Council discretionary money to address in a more effective way, HIV*

*prevention in communities of color in New York City... We were basically able to rally up all this support and we did council visits, us and [the other SEP] along with NYCOCHAC, and we got money for needle exchange. We were trying to get all the other programs to come to this meeting, and they were like ppft, you're crazy, we're never going to get city council money for needle exchange. And then it happened! And it was very clear, it was on the slate. So we got the money and it went to all the programs. So the next year the other programs were like, oh we're going to get involved in this and NYCOCHAC was like ok, wait a minute. At that time there were like 10 programs or something, and they were like we can't suddenly have this bum rush of the needle exchanges dominating these meetings. We were like, well we haven't done this before, we've been like the political bastard step-children of everything, we don't know how to go talk to politicians who are supportive of us, we can't even imagine that this is happening!*

In joining forces with NYCOCHAC, syringe exchange activists were able to link their campaign to a larger politics of racialized health inequality. Although HIV rates in the city overall had been declining, poor communities of color still suffered from the highest incidence of new infections in the city. The SEPs were able to secure funding by linking harm reduction to this issue. Doing so also allowed them to participate in the city's politics in new ways.

City council funding brought SEPs into direct relationship with the health department. One of Bloomberg's first and arguably most important appointments was Tom Frieden as Health Commissioner. Frieden, a strong proponent of evidence-based approaches to public health problems, was widely credited with effectively managing the tuberculosis outbreak in New York during the 1990s while he was an employee of the health department.<sup>47</sup> During this time he worked with members of the harm reduction community, as TB treatment adherence among homeless drug users was especially difficult to monitor and enforce. This contact created a familiarity and mutual respect between Frieden and harm

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<sup>47</sup> Colgrove *op. cit.*

reduction activists. Dahlia Heller, then the executive director of a major Bronx SEP, recalls approaching Frieden for his support for city funding for syringe exchange:

*DH: We went and started harassing Tom Frieden, in a nice way, we went and met with him, and he was like you know, I really agree, needle exchange makes perfect sense. And we were like, wow! Ok great! So then we went and made up a mock budget and we were like this is how much it would cost, so why don't you just fund us all! The city could fund us! And basically what happened was the deal was that he would, I mean he wanted to make sure that the city had actively done something before they just gave out money to all the existing programs, so then they worked and started the Queens program.*

Harm reduction activists found in Frieden an ally and an advocate who, crucially, had the ear and the trust of the Mayor. This direct access to political influence was a new experience for these activists who had previously been, in Heller's words, the "political bastard step-children of everything." For the first time since the waiver, harm reduction practitioners would not need to rely on influencing obliging bureaucrats into molding the application of state-determine regulations. They would now have a hand in crafting policy directly.

Early in his tenure as Health Commissioner, Frieden oversaw a major restructuring of the Health Department. Until 2001, there was a separate Department of Mental Hygiene, Mental Retardation and Alcoholism that was merged with the Department of Health as a ballot initiative in the same election that brought Bloomberg into office. With this merger, the Department of Alcoholism, which oversaw drug treatment contracts, was brought into a unified New York City Department of Health and Mental Hygiene. This reorganization also saw the creation of the Harm Reduction Unit, to which Dahlia Heller was recruited as director.

*DH: But harm reduction was in the HIV bureau, they created the structure of the harm reduction job over in the HIV bureau, and the syringe exchange money was running through the HIV bureau. Frieden reorganized [the*



*Health Department] and created this Bureau of Alcohol and Drugs, then appointed somebody from there assistant commissioner and that guy called me up and said look I'm going to be assistant commissioner of this bureau and I want you to come over and run all the initiatives. Program and policy initiatives. And I said ok, but I'll only do it if I can bring harm reduction with me, cause harm reduction belongs with drugs stuff, not with HIV stuff.*

When Heller came to the department from her role as executive director of a SEP, she insisted on moving the harm reduction unit out of HIV, where it had been housed, to the newly created Bureau of Alcohol and Drug use. She brought an activist sensibility to her job and set about transforming the way health services were conceived of and delivered to drug users.

With Bloomberg's reorganization and the appointment of Heller, syringe exchange in New York City was finally supported by an agency with the specific mission of addressing drug user health. GN, who works for the DOHMH, was very clear about this:

*GN: [The New York City Department of Health is] totally, totally in agreement [with harm reduction]. I mean, that's why syringe exchange in the health department is not housed in the Bureau of HIV. It's housed in the Bureau of Alcohol and Drug Use, because we see it as not just the needle preventing a case of HIV, it's part of a broader set of services that address the health needs of people who use drugs, and that includes a whole bunch of stuff. That's one of the big selling points of syringe exchange, when they go to city council every year to ask for money is, we're not just giving out syringes, we're providing health education, we're connecting people to care. I mean, the whole referrals and linkages to treatment for chronic diseases, to suppressing viral load is huge in terms of the epidemic and that means getting people to their doctor and getting them to keep taking their medications and that means getting people stable in their housing situations and that means getting people out of violent households and there's all this kind of stuff.*

Syringe exchange had begun life as an underground movement, and subsequently developed on the margins of HIV prevention. With Bloomberg, syringe exchange was finally embraced by the city's public health system. Harm reduction's assimilation into official City public health policy has been hugely important for its further institutionalization. One of

the key consequences has been the expansion of harm reduction from its niche within HIV prevention towards reshaping services focused on drug user health. Heller told me:

*DH: Everybody knew why it was in HIV. It was because advocacy for needle exchange grew out of the HIV epidemic. But Frieden was very clear that syringe exchange was about a lot more than giving people needles. It was about engagement, it was a gateway to treatment, and blah, blah, blah. He understood all of that. It was natural. It was a continuum of services for people who use drugs, it made a lot of sense. In a world where you're operating more on public health principles, it's the way you would think to organize things. Instead of on history and politics.*

The “history and politics” Heller alludes to is the story of how and why harm reduction came to be so closely associated with HIV. Without the HIV epidemic, there would be no syringe exchange, and there would be no harm reduction. While the epidemic has been brought under control, drug users continue to face serious barriers to their health and wellness. These new problems, exacerbated by socioeconomic inequalities, cannot be solved by the distribution of clean needles. This is the new turn in harm reduction services in New York.

As a result of this shift away from an exclusive focus on HIV, the influence of the State-level AIDS Institute is waning as City-level agencies are becoming more important. This has happened as the City has begun taking back the Ryan White and CDC contracts it had once ‘passed through’ to the State. The City now had direct relationships with SEPs and began taking on the management role that the State has until recently preformed. The transfer of contracts was more than a bureaucratic transaction. It was the process by which syringe exchange was expanded into a fuller harm reduction project.

*GN: Another pot of money came from the CDC, was awarded to New York City, and New York City chose to use it to fund syringe exchange programs, this prevention money. And this was at the very beginning of syringe exchange, and at that time New York City Department of Health had no existing contracts with syringe exchange programs in New York City and no relationships whatsoever. The State, however, was funding syringe*

*exchange programs. So what the City did at that time when they won the money from the CDC and decided that they wanted the money to go to SEPs, administratively they decided to pass that money over to the State Department of Health, to just add it to what they were already doing to fund the syringe exchange programs, just to make it administratively easier. So that's been going on for the last many, many years, even though in the last few years we've started now doing our own contracting with syringe exchange programs. So this has been talked about for a while, ever since we started doing that we were like well it doesn't really make sense to be passing that money over to the state anymore. Now that we have all of the processes in place, we don't need to keep passing it over to them, we can keep it ourselves. ... And we are taking back many of those contracts with the idea of like, by holding those contracts, we can have the power to infuse the philosophy that we want in them and that is a harm reduction philosophy.*

The process of New York City “taking back” contracts was as an opportunity to “infuse the... harm reduction philosophy” into policy and promote a broader definition of drug user health.

*GN: One way that you could show that we at the health department support syringe exchange as something broader than HIV prevention, is the way we structured their contracts. So all of the syringe exchange programs hold contracts with us and they are all deliverable-based contracts. And only one of the five deliverables is handing out syringes. One of them is prescribing naxolone, one of them is all about hepatitis, so prevention, education, getting people into care and that sort of thing. One is about broader health care access issues, escorting people to their medical appointments, getting them primary care physicians, et cetera. And then the last one is just education on a number of different topics related to drug user health.*

The DOHMH is pushing harm reduction away from being a specialized program for HIV prevention towards a broader incorporation of other services focusing on drug user health such as Hepatitis C, overdose prevention using naloxone, as well as using harm reduction as a model of engagement to get high risk people into primary care.

In the process, they are trying to pull harm reduction out of its isolated position in HIV prevention and related to other already existing services for drug users, including traditional drug treatment, which historically has not supported harm reduction measures.

*GN: Part of what we're trying to do in this bureau is take harm reduction out of this ghetto. So far it's been—here's harm reduction and then here's the rest of the medical world and the drug treatment world. We're trying to really infuse a harm reduction philosophy into all things drug related. So it kind of normalizes harm reduction and takes off some of the hard core advocacy aggressive edge that I think we think about it as.*

To be sure, some activists mourn the loss of syringe exchange's "hard core advocacy aggressive edge." For some, having the health department define and dictate the content and meaning of the "harm reduction philosophy" is proof of harm reduction's medicalization and its disconnection from its activist roots. But for GN and other harm reduction supporters within the New York City government, the process of taking back syringe exchange from the State is a fulfilment of the process of institutionalizing harm reduction, of getting it "out of the ghetto" and into mainstream public health policy. For them, this is social justice in action.

The irony was not lost on activists that it took Bloomberg—whom 1980s-era harm reduction agitators would have reviled—to push the city to embrace syringe exchange. For AE, a harm reduction activist involved with the user advocacy organization UserUnion, Bloomberg was still the enemy. But Bloomberg's support for evidence-based policy opened the door for the City to embrace syringe exchange:

*AE: We are one of Bloomberg's and Cuomo's number one critics, and that's not an exaggeration. At the same time, there are some areas, when it doesn't cost him any money, he tries to be evidence-based. So he's been a big proponent of syringe exchange. So I don't want to be too critical of Bloomberg in the sense that he doesn't give a shit about harm reduction—I mean, I don't think he doesn't give a shit about harm reduction, but he's not hostile to it, he's going to let the health people support harm reduction.*

Although some syringe exchange activists see themselves as the ideological and cultural opposites of Bloomberg's technocratic approach to governance, it was only during his administration that the City government began directly supporting syringe exchange, and

the broader harm reduction project. AE and others see Bloomberg's interest in "evidence-based" governance as an advantage when it comes to harm reduction and drug policy more generally.

The Bloomberg-era embrace of syringe exchange represented a further step in the institutionalization of harm reduction. Some elements of policy incoherence remained. Bloomberg of course never fully demobilized Giuliani-era policing strategies. Under his leadership, the City continued to punish poor communities with one hand while reducing the harm of drug use within them with the other. But by taking back contracts that had been administered through New York State and through key public health appointees, syringe exchange became more mainstream than ever before. And SEPs continued their evolution from outsider social movement to CBOs providing social services as part of a broadly neoliberal public health agenda.<sup>48</sup>

## VI. Conclusion

In the past three decades, syringe exchange, which in the U.S. has been the paradigmatic harm reduction strategy, has undergone a far-reaching transformation. In the initial stages, it confronted the state as an outsider movement, promoted by groups that saw themselves as a social movement responding to a public health crisis ravaging an abandoned population. After the concerted effort of activists from a variety of backgrounds—poor communities, movements pushing for a stronger response to the

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<sup>48</sup> On CBOs as providers of social services in the context of privatization, see Nicole P. Marwell, "Privatizing the Welfare State: Nonprofit Community-Based Organizations as Political Actors," *American Sociological Review* 69 (2004): 265-291; Steven Rathgeb Smith and Michael Lipsky, *Nonprofits For Hire: The Welfare State in the Age of Contracting*, (Boston: MA, Harvard University Press, 2009.)

HIV/AIDS crisis, public health professionals—syringe exchange became partially institutionalized and adopted by various levels of government. The space of exception that syringe exchange came to inhabit was due to the unwillingness of elected officials to publicly embrace a controversial strategy. But the result was that syringe exchange occupied an insider-outsider status at the edge of the state that allowed for further innovations to emerge. Finally, the government of New York City adopted syringe exchange and harm reduction in a more significant way.

In short, as GN, one of my interviewees in the New York City government put it, syringe exchange has gotten out of the ghetto. We can understand this in a number of ways. A strategy born in the city's poorest communities has become adopted more widely. Syringe exchange is no longer a separate and marginalized practice for a stigmatized population. It has been reorganized and rebranded as another form of health care. SEPs have increasingly come to resemble CBOs delivering routine social services in partnership with the state<sup>49</sup>, operating on a scale that was previously unthinkable.

Two developments made the mainstreaming of syringe exchange possible. The first is the crisis of public health and social service provision during the heyday of government cutbacks. Syringe exchange could not have been adopted had the policies of punishing drug users and ignoring AIDS sufferers been successful. And the government of New York City did not embrace syringe exchange until there was an administration that allowed practical measures of success to override the moralizing symbolic politics of addiction. The second precondition was the concerted efforts over decades of activists who were canny enough to

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<sup>49</sup> Rathgeb and Lipsky, *op. cit.*

realize that the changing approach to public health created strategic opportunities for syringe exchange to jump scale from a series of uncoordinated local efforts to a city- and statewide venture.

My informants have stressed that this is not a uniformly positive process. Important parts of the culture of harm reduction as an outsider movement have been eroded. These include not only the more politicized atmosphere of the social movement era, but also the more intimate environment when most people involved in syringe exchange were familiar with one another, creating a sense of warmth and belonging that was tied to the harm reduction philosophy. The process of institutionalization has also reduced organizational autonomy, subjecting SEPs to some extent to the programs of their funders.

And although syringe exchange has been partially institutionalized at different governmental levels, it is still far from the dominant approach to public health, much less drug user public health. Abstinence continues to be the prioritized in political discourse and social service. There has never been a widely publicized announcement that harm reduction will be official policy. Syringe exchange still relies on the legal mechanism of waiving. And many communities are still facing drug war tactics in place of or alongside harm reduction.

Although harm reduction has not yet been fully embraced by the City or State government, it seems clear based on the data presented here that syringe exchanges have evolved into more widely accessible community-based health and social service providers. And with Medicaid reform on the horizon (discussed in chapter five) SEPs are well on their way towards becoming fully mainstream. The harm reduction project also continues to evolve,

as evinced by fast-growing strategies like peer-delivered syringe exchange and peer-administered naloxone, which is detailed in the next chapter.



## Chapter 4.

### Naloxone and the New Public Health

#### I. Introduction

Harm reduction in New York is evolving in two directions. It is moving towards new scales, impacting policy at higher levels and larger political units. And it is also developing new interventions, which use new methods and involve new populations. This chapter examines naloxone, an overdose prevention program, as an example of the latter. Naloxone signifies a departure from harm reduction's close association with syringe exchange and HIV prevention. With naloxone, harm reduction methods are branching out into areas that target a population that is broader than those who use syringe exchange programs. Naloxone's use as a harm reduction strategy began as a limited pilot program in a handful of syringe exchanges, but it has now become a widely accepted public health policy, with a sufficiently high profile that Congress is now considering a bill establishing naloxone-based overdose prevention programs nationwide. It represents the combination of user advocacy and cutting edge thinking in public health policy. A closer look at the inner workings of naloxone is instructive in order to understand what harm reduction policy looks like today.

The success of overdose prevention programs arguably depends not only on the chemical properties of naloxone itself, but on a number of social strategies developed by users, clinical personnel, public health workers, and others in the harm reduction movement. Naloxone demands a reorganizing of relationships within the public health system and what can be seen as the deputizing of users as agents of the public health state. Naloxone's diffusion throughout the public health system required the adoption of peer administration

and lay training. It has benefits from positive identification from users themselves, many of whom enthusiastically participate in naloxone overdose reversal strategies as a way to be ‘good citizens’ among users. It creates new alliances between drug users and medical professionals, as they extend expertise and authority into the worlds of the users themselves. The social networks of the users become a new target of public health intervention. All of this occurs in a legal space of exception, with regulations and laws being rewritten after the fact to take into account new practices.

Community-based naloxone distribution is an example of a public health strategy that only became possible with the emergence of the “new public health.”<sup>1</sup> Like syringe exchange, and like the New York version of harm reduction in general, naloxone is unquestionably an example of what scholars have in mind when they analyze neoliberal social policy—but it unsettles the usual critique. Overdose reversal might be the ultimate harm reduction practice, in that it embodies the idea that users are “deserving of caring and life”<sup>2</sup> rather than death by overdose. Naloxone suggests that the forms of decentralization and responsabilization that typify neoliberal public health regimes are compatible with projects for collective dignity, autonomy and mutual aid. It is an example of what Ferguson sees as a progressive policy that uses typical “neoliberal moves.”<sup>3</sup>

The roll out of naloxone and of peer-administered harm reduction exemplifies the process of policy transformation whereby harm reduction, itself moving away from a narrow focus on

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<sup>1</sup> See Alan Petersen and Deborah Lupton, *The New Public Health: Health and Self in an Age of Risk* (Thousand Oaks, CA: Sage, 1996) and chapter two.

<sup>2</sup> Dan Small et al., “The Establishment of North America’s First State Sanctioned Supervised Injection Facility: A Case Study in Culture Change,” *International Journal of Drug Policy* 17 (2006): 74.

<sup>3</sup> James Ferguson, “The Uses of Neoliberalism,” *Antipode* 41.S1 (2009): 174.

HIV prevention into a larger program of drug user health promotion, is also influencing and to some extent promoting the reconfiguration of broader public health bureaucracies, while at the same time being shaped by them. Aided as well by the changing demographics of overdose, naloxone is becoming an important part of New York City and State's public health system. As its use becomes more widespread and more entrenched within the fields of health and medicine, the development of peer-delivered naloxone enables deeper structural changes in public health policy. As a strategy, it formalizes a new relationship between drug users and the state. Whereas older drug policy paradigms relegated users to the role of passive recipients, increasingly public health strategies include them as active participants.

## **II. Overdose death and its reversal**

In the United States, more injection drug users die each year from opiate overdoses than from any other cause, including AIDS, hepatitis, or homicide.<sup>4</sup> Drug overdose is a grim reality for many drug users, with approximately half of all illicit drug users reporting at least one nonfatal overdose during their lifetime.<sup>5</sup> And it has been a perennial problem for New York City, which has long had high levels of drug use in some quarters. Overdose is the third leading cause of accidental death among New Yorkers aged 25 to 34, with opioids being involved in 77% of cases.<sup>6</sup> These overdose deaths are not only claiming the lives of heroin users. In line with national trends, the New York City Department of Health and

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<sup>4</sup> Karen H. Seal, et al., "Naloxone Distribution and Cardiopulmonary Resuscitation Training for Injection Drug Users to Prevent Heroin Overdose Death: A Pilot Intervention Study," *Journal of Urban Health: Bulletin of the New York Academy of Medicine* 82:2 (2005): 303

<sup>5</sup> Sandro Galea, et al., "Provision of Naloxone to Injection Drug Users as an Overdose Prevention Strategy: Early Evidence from a Pilot Study in New York City," *Addictive Behaviors* 31.5 (2006): 908

<sup>6</sup> DOHMH, "Unintentional Drug Poisoning (Overdose) Deaths Involving Opioids in New York City, 2000 - 2013," *Epi Data Brief* 50 (August 2014): 2.

Mental Hygiene (DOHMH) reports that the rate of overdose deaths involving opioid analgesics (otherwise known as painkillers) increased by 256% from 2000 to 2013, with 215 reported deaths in 2013.<sup>7</sup> And the rate of overdose deaths involving heroin increased for three consecutive years from 209 deaths in 2010 to 420 deaths in 2013.

Before the development of overdose reversal programs, drug users had engaged in various do-it-yourself forms of overdose reversal, drawing on folk remedies and improvisation. One study of San Francisco drug users reported that:

91% of respondents had tried various measures to revive their peers, the most common involving painful stimuli (physical striking; ice on genitals; injection of concentrated saline), but only half reported summoning emergency help for fear of reprisal from authorities responding to the emergency call.<sup>8</sup>

These techniques were ineffective and dangerous. But in the ways in which they instigated drug users to act in a quasi-medical capacity as a form of mutual aid, they presaged more organized programs for overdose reversal.

Naloxone hydrochloride, sometimes known as Narcan (one of the brand names under which it is sold), is an opiate-blocking drug that reverses the effects of overdose. It is effective on all types of opioid overdoses—from street heroin to prescription pharmaceuticals—by counteracting the depression of the central nervous system and respiratory system that can lead to death. It has an unscheduled regulatory classification, meaning that it has no addictive or psychoactive properties and thus no potential for abuse, and serious adverse affects are rare.<sup>9</sup> It is however a prescription medication, which means that physicians and

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<sup>7</sup> Ibid.: 3

<sup>8</sup> Sarz Maxwell, et al., "Prescribing Naloxone to Actively Injecting Heroin Users: A Program to Reduce Heroin Overdose Deaths," *Journal of Addictive Diseases* 25.3 (2006): 89 – 90.

<sup>9</sup> Seal et al., *op. cit.*: 304

others with prescribing authorities currently control access to naloxone. Administration of naloxone can lead to acute withdrawal symptoms in opiate-dependent persons but will have no effect on non-opiate users. Likewise, it will have no effect on someone overdosing on a non-opioid drug.

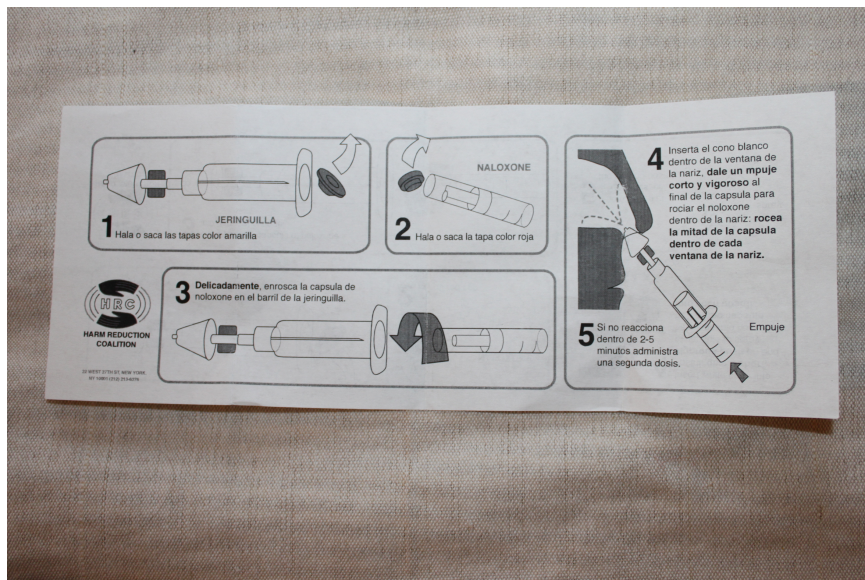
Naloxone is administered via intramuscular injection or intranasally via an atomizer (See Figures 1 – 3). Typically, the drug takes a few minutes to take effect and can last about thirty minutes to two hours, depending on the dose administered and the amount of opiates present in the body. There is a risk of the individual returning to an overdosed state if they still have large amounts of opiates in their system as the naloxone wears off. Those who administer naloxone are thus instructed to contact emergency services and encourage the overdoser to go to the hospital to seek medical attention.



**Figure 1. Intramuscular naloxone kit.** Contains two syringes; two vials of naloxone; gloves; alcohol swabs; a face shield for rescue breathing; a prescription written in my name; and an instructions pamphlet.



**Figure 2. Intranasal naloxone kit.** Contains two atomizers, two vials of naloxone, gloves, a face shield for rescue breathing, a certificate of completion certifying that I have been trained in opioid overdose prevention and citing New York State Public Health Law, a prescription in my name; an instructions pamphlet and a graphic instructions diagram, shown in detail in Figure 3.



**Figure 3. Intranasal naloxone instruction sheet.**

After a short training session led by peer trainers at harm reduction drop-in centers, interested participants are given a naloxone kit which contains a vial of the drug and either two syringes or an atomizer, first aid equipment, and written instructions (see figures 1 and 2). These training sessions provide more than just instructions on how to deploy naloxone on an overdosing body; they are also occasions for formalizing a new relationship between the drug user and the state.

Currently there are over 80 overdose prevention outlets in New York State, with the majority located in New York City.<sup>10</sup> Other than syringe exchanges and harm reduction agencies, naloxone is also available at certain methadone programs, drug treatment centers and homeless shelters. Both the State and City health department provide naloxone kits to community-based overdose prevention programs, with the state supplying intravenous naloxone kits and the City supplying intranasal. The Centers for Disease Control and Prevention (CDC) reported in 2012 that “since the first opioid overdose prevention program began distributing naloxone in 1996, the respondent programs reported training and distributing naloxone to 53,032 persons and receiving reports of 10,171 overdose reversals.”<sup>11</sup> One evaluation of the New York City program indicates that 82.2% of participants said they feel comfort or very comfortable using naloxone and 86.2% indicated they would want naloxone administered if they were overdosing.<sup>12</sup> The eagerness with which naloxone has been met signals the ready willingness of drug users to take up the mantle of naloxone.

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<sup>10</sup> NYSDOH, “Opioid Overdose Prevention Programs Directory.”

<sup>11</sup> CDC, “Community-Based Opioid Overdose Prevention Programs Providing Naloxone — United States, 2010” *Morbidity and Mortality Weekly Report* 61:6 (February 17, 2012): 101.

<sup>12</sup> Tinka Markham Piper, et al., “Evaluation of a Naloxone Distribution and Administration Program in New York City.” *Substance Use & Misuse* 43 (2008): 858–870.

First developed in the 1960s, naloxone was initially studied as a possible replacement for methadone.<sup>13</sup> It quickly became an important drug in the treatment of accidental opiate overdose within clinical settings. Hospitals are required to have naloxone on-hand whenever an opioid is administered. Naloxone has been actively used as an opiate reversal drug since the 1960s and has been a familiar and routine presence in emergency rooms, operating theaters, and ambulances since that time. But its adoption by the harm reduction movement and the development of a harm reduction strategy based around it—which facilitated the drug’s migration out of the clinic and onto the street, and out of the hands of doctors and emergency medics into the hands of drug users themselves—is considerably more recent.

### **III. Bringing naloxone to New York**

Naloxone’s trajectory from clinic to street began in Chicago in 1996. Doctors working with the Chicago Recovery Alliance (CRA)—a harm reduction agency that had begun conducting syringe exchange in 1991—began prescribing and dispensing naloxone directly to select CRA participants. Motivated by the overdose death of one of the founders, and seeing a wider need among their program participants, the doctors undertook the task of transforming naloxone from an unwelcome intervention imposed by unsympathetic emergency medical personnel, to the symbol of drug user self help and mutual aid that it would eventually become. Dan Bigg, one of the founders of CRA, describes the first naloxone program:

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<sup>13</sup> Arthur Zaks, et al., “Naloxone in the Treatment of Opiate Dependence: A Progress Report,” *Committee on Problems of Drug Dependence, Bulletin, Problems of Drug Dependence: Report of the thirty-first meeting* (1969): 6263.



For those who had heard about naloxone, it was generally as kindly as garlic might be to a vampire as most experiences were abuses of the drug at the hand of an emergency medical provider who shot 2mg IV into a person who overdoses, then fought with them as they exploded out of the emergency room or ambulance in withdrawal. Following H[arm] R[eduction] practice we sought out medical help which valued and respected life and human rights. Shawn DeLater, an emergency room physician and Sarz Maxwell, an addictionologist, were our first medical care providers ready and willing to put a healthy, lifesaving touch to reversing opiate-related overdose with effective and humane intervention.<sup>14</sup>

As Bigg makes clear, naloxone's reputation was as a drug often administered callously by first responders who did not understand the lived reality of both overdose and withdrawal for drug users. As practiced by paramedics, intravenous administration of a high dose (2mg) of naloxone rapidly strips the body of opioids, which is the functional equivalent of sudden and violent opiate withdrawal, causing dependent users severe pain and discomfort. In refashioning naloxone as a tool that "valued and respected life and human rights," harm reduction practitioners modified not only the setting in which the drug is administered, but the nature of the medical intervention itself by introducing lower dose (0.4mg or 0.8mg) intramuscular or intranasal application which has a much gentler effect on the body.

As with syringe exchange, naloxone's use in peer administered overdose reversal took the tools of medical practice and applied an off label use. And also like syringe exchange, naloxone's evolution as a harm reduction tool was borne of the relationships that developed between politically-committed medical practitioners and user-activists within syringe exchange sites. Naloxone had previously not been used in this capacity, and the peer-administration model pushed against established medical norms. The development of peer-administered naloxone thus had something of the character of direct action. It was not precisely illegal, but it pushed the boundaries of legality.

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<sup>14</sup> HRC, "Chicago Recovery Alliance: Case study."

In the years following the initial small-scale beginnings of naloxone distribution in Chicago, public health departments in a handful of other cities and states began developing pilot programs, including San Francisco, New Mexico and New York. In many instances, once underground or quasi-legal programs that had already been involved in syringe exchange with injection drug users began circulating naloxone through their already established networks.<sup>15</sup> Naloxone was also becoming more prominent within harm reduction circles, and in 2000 the Drug Policy Alliance (DPA) held the first Opiate Overdose conference in Seattle, attracting international attention. At the time, heroin overdose was the main focus of harm reduction activism and opioid analgesics were not the subject of any paper given at the conference. Harm reduction activists' attention was focused on the high rates of overdose among intravenous drug users, a population now being accessed and served through the syringe exchange programs (SEPs) expanding across the country.<sup>16</sup>

Utilizing the infrastructure of SEPs, community-based naloxone distribution programs expanded in New York City in the early 2000s. The Harm Reduction Coalition (HRC), a national drug user advocacy and service organization, initiated this program, drawing on the experience of Chicago. In 2004, a pilot overdose prevention program at two New York syringe exchanges trained approximately one hundred drug users on overdose prevention, including the use of naloxone. And in 2005 the HRC started the Skills and Knowledge on Overdose Prevention Project (SKOOP). According to the HRC, SKOOP had three main goals:

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<sup>15</sup> Maxwell et al., *op. cit.*

<sup>16</sup> "Preventing Heroin Overdose: Pragmatic Approaches," Conference program available at <http://adaa.washington.edu/training/conf/agenda.htm>.

(i) to reduce overdose-related deaths through the distribution of naloxone hydrochloride to injection drug users in NYC; (ii) to build evidence for the effectiveness of take-home naloxone in harm reduction settings, and (iii) to create wider support for the inclusion of naloxone in harm reduction, methadone, and other public health programs.<sup>17</sup>

From the beginning, naloxone's supporters in New York used the rhetoric of evidence-based health policy, which was encouraged by the Michael Bloomberg mayoral administration.<sup>18</sup>

The data collection dimension of SKOOP provided the Harm Reduction Coalition with an evidence base and lobbying tool when pushing for laws to change and naloxone distribution to be expanded.

Nationally, naloxone's adoption by harm reduction programs preceded legal and policy changes to formalize its widespread use. This was also the case in New York. There are no legal barriers to prescribing naloxone to individuals at risk of overdose, but legislation was necessary to legalize third party administration by peers. New Mexico was the first state to act. In 2001, the legislature authorized naloxone distribution programs using lay savers and provided exemption from civil liability to doctors and laypersons who administer naloxone to others. New York followed in 2005 with legislation authorizing opioid antagonist administration programs.<sup>19</sup>

In April 2006, a New York State law regarding opioid overdose prevention authorized the state health commissioner to establish standards for overdose prevention programs and the

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<sup>17</sup> Tinka Markham Piper, et al., "Overdose Prevention for Injection Drug Users: Lessons Learned from Naloxone Training and Distribution Programs in New York City," *Harm Reduction Journal* 4.3 (2007): 292.

<sup>18</sup> See Ted Alcorn, "Redefining Public Health in New York City," *The Lancet* 379.9831 (2012): 2037-2038; Lawrence O. Gostin, "Bloomberg's Health Legacy: Urban Innovator or Meddling Nanny?" *Hastings Center Report* 43.5 (2013): 19-25.

<sup>19</sup> Leo Beletsky, et al., "Closing Death's Door: Action Steps to Facilitate Emergency Opioid Drug Overdose Reversal in the United States," *Conference Report from The Center for Health Law, Politics and Policy, Temple University*, (2009).

use of naloxone by non-medical staff in the case of an overdose. All naloxone programs are licensed by the NYSDOH and abide by the regulatory framework set out by the law. This bill was unanimously passed in the House and Senate and signed into law by the Republican Governor George Pataki. The conservative Medical Society of the State of New York also supported it.<sup>20</sup> The bipartisan acceptance of overdose prevention and naloxone distribution represents a remarkable political outcome for advocates of harm reduction, considering how controversial syringe exchange had been when it had been first attempted in the mid 1980s. Unlike syringe exchange, access to naloxone did not take the form of a waiver or similar temporary, exceptional measure. Against the backdrop of a worsening opiate epidemic, activists, public health workers and politicians alike applauded naloxone's authorization.<sup>21</sup>

Both syringe exchange and community-based naloxone distribution are public health interventions that fall under the broad umbrella of harm reduction, but naloxone has tracked a different political trajectory. As FR, a prescribing physician and early naloxone supporter, noted:

*FR: This is a whole different cup of tea than needle exchange. We kind of equate them as movements in harm reduction, but my experience nationally and internationally is that overdose is much easier to get people behind than syringe exchange.*

Overdose prevention programs have proven to be much more popular than harm reduction policies like syringe exchange, as evidenced by the uncontroversial passage of the 2006 bill in New York. Part of the reason for this is that it had the public support of the DOHMH who began collecting data on drug overdose in 2005. And the HRC and the NYSDOH used data from New York's naloxone trials, including SKOOP, to pave the way with groups like

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<sup>20</sup> Markham Piper et al., *op. cit.*: 294

<sup>21</sup> Maia Szalavitz, "The Shot That Saves," *New York Times*, 21 August, 2005.

law enforcement and traditional drug treatment providers normally resistant to any change perceived as enabling drug use. FR, a physician and harm reduction activist, described to me the work done by the DOHMH and NYSDOH:

*FR: So we had been to all these different agencies. So the bill passes unanimously, the governor starts calling these places saying, "Should we sign this bill?" So it really wasn't very hard once whatever had happened behind the scenes happened. Once it was passed, as I say, it was unanimous in the house and the assembly.*

*FR: The Department of Health does not necessarily work with any agency to push anything through, on paper. But yeah, they were, especially under the Pataki Administration. There were cooperative things going on. But it's kind of like the [New York State] Department of Health truly saw it was time to do it, I think. And I think that's a lot of what happened to change the legislation to something doable—and then we had a few problems with it. But given prescription regulations, I think it's about as good as it could have been then.*

Given the apparent risks and the break with established policy, the unanimous passage of the bill allowing for naloxone in New York was an impressive victory.

Though widely celebrated, the bill's unanimous passage did not necessarily represent the success of grassroots harm reduction at influencing state law. Daliah Heller, who had been the executive director of Citiwide Harm Reduction before becoming an assistant commissioner at the DOHMH was instrumental in launching New York City's naloxone distribution program. She reflected on the way in which change in the law came about:

*DH: It wasn't a program. It's the law that changed... Nobody told us in the city that that law was happening. So what happened is San Francisco started doing it, a staff member from Citiwide, a staff member from Lower East Side [Harm Reduction] and the guy John who runs Streetwork Project wanted to try to get it going in New York, as a demonstration. So they developed everything and we put in for a little Tides grant, I got [DOHMH Commissioner Tom] Frieden to give us a letter of support, and we got it, we got the money... Little did we know, the state drafted up a bill, made something up... So the bill passed, but it was kind of without us, any input from the ground of what would meaningfully work and what could be done. Anyway, the bill passed in '06... Then I found out that Frieden had done a*

*huge legal analysis like two years before I got there with the DOH lawyers, trying to figure out how could we do this...*

According to Heller, the shape the law ultimately took reflected the priorities of bureaucrats and program officers, without “input from the ground.” Public health agencies pursued a version of the law that was possible to achieve, if not seen by everyone as the version most desirable.

Nevertheless, naloxone’s widespread support reflects the extent to which the public health bureaucracy had been successful in presenting the intervention as an apolitical first-aid measure. The connections to syringe exchange and the language of harm reduction were downplayed in favor of narratives about family tragedy and medical evidence.<sup>22</sup> And some supporters, like DOHMH employee ON, believe that naloxone’s ready acceptance also reflects the changing demographics of overdose.

*ON: I think the whole naloxone shift has to do with because it's opiate analgesics, and that's a different population. And so it's the middle class white population that's affected by it now, and it's not injecting drug users. They are considered people of color, the junkies, and so I think that that's part of what's motivating this. But so what? You use that. You know, it's all sad. But if it's going to move things forward, everyone is going to benefit from it. And that's how I look at it, but I'm aware that that's why - if we were talking about this in the context of only heroin, this wouldn't move forward.*

Unlike syringe exchange, which is still to a large extent a marginal public health intervention targeting a marginalized population, naloxone has moved into the mainstream. It is a harm reduction intervention for the white, rural, and suburban masses.<sup>23</sup>

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<sup>22</sup> Stories like “Mom’s Last Resort: Opiate Antidote Saves Addicts’ Lives” which appeared on NBC News on 15 March 2012 humanized the overdose epidemic by focusing on the loved ones of addicts.

<sup>23</sup> David Goodman and Michael Wilson, “Heroin’s New Hometown: On Staten Island, Rising Tide of Heroin Takes Hold,” *New York Times*, 4 May, 2014.

Even after the NYSDOH cleared the way, other legal changes were necessary to encourage users to adopt naloxone. It is important that emergency medical services be called after administering the drug to someone experiencing an overdose, as the overdoser is still at risk of lapsing back into overdose, or may experience other symptoms associated with opiate withdrawal. Many drug users as well as their friends and family fear dialing 911 as summoning emergency responders can mean police involvement, which could lead to the arrest of the overdoser or the bystanders on drugs charges.<sup>24</sup> The Good Samaritan law was passed in 2011 to address this. “The law encourages people to call 911 immediately during an overdose situation by offering a limited shield from charge and prosecution of drug and alcohol possession for a victim or witness who seeks medical help during a drug or alcohol overdose.”<sup>25</sup> As one naloxone prescriber told me,

*FR: What to tell people who are in New York State who are afraid to call 911 cause they might have a warrant out for their arrest. You know, fear of police arrest—we know that’s the biggest barrier to effectively responding to overdose.*

The Good Samaritan law was designed to complement the existing public health statute authorizing naloxone distribution as it was observed that many for whom naloxone could potentially be a life saver were still nevertheless ambivalent about receiving the training and carrying the kit.

Emergency call immunity laws can be a political challenge. Immunizing the possession of drugs, even the small quantities usually in question in a Good Samaritan situation, derogates from a “zero-tolerance” approach to drug control.<sup>26</sup> New York State had maintained an official policy reinforcing abstinence throughout the HIV/AIDS crisis of the

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<sup>24</sup> On the fear of outstanding warrants, see Alice Goffman, *On the Run: Fugitive Life in an American City* (Chicago, IL: Chicago University Press, 2014).

<sup>25</sup> DPA, “Implementing New York’s 911 Good Samaritan Law.”

<sup>26</sup> Beletsky et al., *op. cit.*: 12

1980s and 1990s. This was reflected in its tough-on-crime mandatory sentencing laws which locked away increasing numbers of people on drug-related charges<sup>27</sup> and through the Office of Alcohol and Substance Abuse Services (OASAS), the state agency responsible for drug treatment and methadone programs. OASAS had been critical of syringe exchange and generally resistant to adopting the language and philosophy of harm reduction. As a result syringe exchange did not become a regularized part of drug treatment in the state. But unlike its cool reception of syringe exchange, OASAS supported the Good Samaritan Law, and has been favorable to overdose prevention measures more generally.

In January 2012 the Drug Policy Alliance hosted a meeting on the implementation of the Good Samaritan Law. During the meeting, a DPA representative reported that they had received very positive feedback on the law from OASAS. As reported in my fieldnotes:

*GE reporting to the group on his meeting with OASAS about the Good Samaritan Law. He describes OASAS as more “traditional,” but that in their last meeting there was some recognition that harm reduction should be part of the spectrum of treatment. GE says that DPA was encouraged to hear this, and that OASAS even referenced VOCAL’s methadone report in their meeting. GE says that OASAS are ready to work with groups to implement the law and are looking for direction from stakeholders. GE described OASAS as “very gung ho” and supportive of the Good Samaritan Law. “We have buy-in from OASAS, even though they haven’t historically been part of harm reduction.” He continued by saying that he has never seen such an open dialogue with OASAS. They even sent out a letter to all their treatment and methadone programs encouraging them to become naloxone providers.*

OASAS’s ready acceptance of naloxone represents the extent to which naloxone has come to be seen as an important tool in the treatment of drug users. It also signals a broader shift within this “traditional” agency, long a stalwart of treatment programs that prioritize abstinence. OASAS’ embrace of naloxone is evidence of acceptance that people in

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<sup>27</sup> Ernest Drucker, "Population Impact of Mass Incarceration Under New York's Rockefeller Drug Laws: An Analysis of Years of Life Lost," *Journal of Urban Health Bulletin of the New York Academy of Medicine* 79.3 (2002): 434-435.



traditional, abstinence-based treatment programs and methadone programs often continue to use illicit drugs, and that continuing to deny this reality puts the lives of the people it purports to serve at risk. The hope of many in the harm reduction world is that the dialogue made possible by overdose prevention will lead to the further development of strategies that decenter the necessity of abstinence in favor of addressing broader issues of drug user health.

#### **IV. Naloxone and medical authority**

Naloxone depends upon and requires a new relationship between drug users and medical authorities. The peer-to-peer administration model decenters the primacy of the physician in the provision of life-saving care. Physicians, reluctant to get involved with naloxone distribution because of anti-user bias as well as concerns over liability, were largely uninvolved with naloxone distribution, at least initially. This meant that public health departments and community organizations took the lead, shaping the program to avoid contact with a medical provider as much as possible. New ways of managing liability, responsibility and prescriptive authority had to be developed—and are still evolving.

The prescription of regulated drugs is structured by a particular set of social and institutional relationships. Empowered by the state and their own professional organizations, physicians act as the gatekeeper and prescribing authority for their patients. Typically, to issue a prescription, physicians must abide by the ordinary standard of care. In general, this requires being in the same place at the same time as their patient. The physician will conduct an examination, collect a medical history, and make a determination of necessity and suitability based on his or her clinical knowledge and training. In return

for their monopoly on medical authority, physicians are liable for wrongful prescriptions or misdiagnosis and must be insured against these outcomes. The structure of legal and ethical authority here is relatively settled and straightforward.

The innovation is that naloxone sidesteps the medical authority of the physician. The intention is that the overdose reversal drug be administered within a peer-to-peer context, outside of a clinical environment. And it is not intended to be used on the person for whom the prescription is written. Instead, naloxone is to be administered by the prescription-holder on a third party whose identity has not been pre-determined by the prescribing authority and about whom no prior knowledge is available. The prescription-holder might have a longstanding relationship with the person to whom they administer naloxone, where medical history, risk and consent could conceivably have been discussed—or they might be complete strangers where none of these issues have been addressed. Questions of risk, consent and responsibility are unsettled. And because an element of anonymity is central to naloxone as a strategy, these questions might have to remain unsettled.

The peer-to-peer deployment of naloxone—as opposed to its usage in emergency medical contexts—requires a wholesale, in some ways radical reordering of medical authority. This presented a problem to New York’s first naloxone programs. Daliah Heller explained:

*DH: The problem was we couldn't get, I mean Streetworks and Lower East Side found a psychiatrist who was willing to prescribe, actually a doctor who happened to be a psychiatrist. We couldn't get a doctor to come to the South Bronx in the evenings. That doctor wouldn't and we couldn't get anyone, we just couldn't get any doctors to come and prescribe. And that was a problem cause it was sort of like taking a chance on your license cause you were prescribing something, you know, you were prescribing something to use on somebody else so it was a third party administration.*

For those working to bring naloxone to New York, the need to prescribe a drug to an anonymous user was a major obstacle that raised questions about liability and licensing.

According to analysts of naloxone's legal feasibility:

In strict legal terms, a prescription is only appropriate if it is issued to a patient for the patient's own medical need. A lay savior who is not a drug user but is trained to help others at risk of overdose, strictly speaking, has no personal medical need for the drug. Moreover, providing naloxone under those terms would amount to deputizing the lay person as a medical practitioner, which contravenes the basic idea of licensure and criminal laws that prohibit the unlicensed practice of medicine.<sup>28</sup>

Deputizing lay persons as medical practitioners is no simple matter. It requires the development of new legal and regulatory doctrines, and creates potential conflicts with those who have a stake in maintaining the status of medical licensure.

The forward deployment of medical authority is not completely unknown. Established medical protocols set some precedents for non-medical personnel to administer drugs to bystanders. According to addiction researchers:

Prescription of antidotes for peer administration in emergency situations has become routine medical practice in certain situations. Diabetic patients are prescribed glucagon and instructed to educate their family and friends regarding its use in reversing insulin shock. Persons hypersensitive to insect stings are prescribed equipment for emergency administration of epinephrine in case of anaphylaxis. Both of these examples involve medications that have far greater potential for adverse reactions than does naloxone.<sup>29</sup>

But epinephrine or glucagon are prescribed to their ultimate recipients, even if they may be administered by a third party. In the case of naloxone, the drug is prescribed to the intended administrator while the ultimate recipient remains unknown to the prescribing authority.

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<sup>28</sup> Beletsky et al., *op. cit.*: 17 – 18.

<sup>29</sup> Maxwell et al., *op. cit.*: 90.

The closest analogue to this distribution model is the Expedited Partner Therapy (EPT) used to treat chlamydia or gonorrhea. Medication is given to the partners of those who test positive for the diseases, even though they have not been examined by a doctor.<sup>30</sup> Like naloxone, this is a relatively new practice, first proposed by the CDC in 2005, and is not uniformly available across the country. Also like naloxone, EPT has been expanding rapidly despite uncertainties among medical providers about its legal status. Where EPT and naloxone differ, however, is that unlike EPT which simply requires one partner to give oral antibiotics to another, naloxone requires specialized equipment and complicated administration in stressful, potentially deadly situations.

Different pilot studies used different approaches to satisfy legal requirements about the prescription and administration of drugs. For example, researchers who conducted studies in Chicago took this approach:

A physician may prescribe medication only within the confines of a physician/patient relationship. Establishment of a legal physician/patient relationship is accomplished in our program by meeting three requirements: (1) formation of a clinical chart for each participant; (2) documentation within the chart that the participant has been informed of the risks, benefits, alternatives, and proper use of the treatment; and (3) evidence of the physician's good faith.<sup>31</sup>

In this case, the researchers still assumed some sort of stability in relationships between medical personnel and drug users. Other studies, including that of Seal et al., did not make that assumption: "Most of the overdose interventions occurred in non-study participants, confirming that IDUs are willing to intervene to resuscitate a peer in the event of overdose.

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<sup>30</sup> Ryan Cramer, et al., "The Legal Aspects of Expedited Partner Therapy Practice: Do State Laws and Policies Really Matter?" *Sexually Transmitted Diseases* 40.8 (2013): 657.

<sup>31</sup> Maxwell et al., *op. cit.*: 92 – 93.

These results suggest that limiting naloxone training and distribution to IDUs with stable injection partners may not be necessary.”<sup>32</sup>

By disconnecting the administration of a drug from the medical establishment’s traditional monopoly over prescribing authority, naloxone almost inevitably created a conflict between its supporters and doctors. Many harm reduction advocates see doctors as some of the biggest obstacles to wider usage of overdose reversal drugs. As naloxone trainer NK explained to me:

*NK: One of the big barriers is I think, one of the reasons I've been really into doing it is because it sort of breaks the professional barriers, and I think that's why in some ways a lot of the resistance is coming from MDs, because you are usurping their power. They like being the gatekeepers for control of this stuff.*

Part of what is at stake in the question of naloxone is a struggle over authority and control.

*NK: Which is a part of why doctors are like, the stigma against drug users by doctors is really bad because that's their prerogative to give people drugs and if you are doing that yourself, it's like you are usurping their power.*

The flipside to doctor’s control was that undercutting their authority could be seen as expanding the autonomy of their would-be patients. RN, a long time harm reduction activist, put it this way:

*RN: It [naloxone programs] is recognizing that you need to put tools in the hands of drug users so they can have autonomy over their drug use.*

This conflict over the gatekeeping function of medical decision-making is part of the broader politics of harm reduction. But because of questions surrounding prescribing authority specifically, it is particularly acute regarding naloxone.

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<sup>32</sup> Seal et al., *op. cit.*: 309.

The administration of naloxone can occur in any number of organizational contexts. As a harm reduction strategy, it is accompanied by a new bureaucratic and practical distance between the prescribing medical authority and the drug's ultimate recipient. Naloxone's advocates in New York and elsewhere moved towards the deployment of "standing orders" to work around the medical monopoly on legitimate drug distribution. There is still in principle a line of authority connecting legally empowered doctors with those who receive naloxone. But rather than a traditional prescription, it more resembles a blank check.

*FR: The last two years the change in law allows for standing orders. There are non-person-specific orders, and you can designate a lay person to train and distribute naloxone.*

These designates can be anyone: a non-medically-trained social agency staff member, a drug user, a community member. They are given the authority to distribute naloxone to people within their communities.

*FR: Okay, so standing orders is this idea that a doctor or somebody with prescribing privileges could deputize... my understanding of it is it somehow deputizes people who are under the supervision of a doctor or a nurse practitioner, somebody with prescribing abilities, to administer or prescribe the medication when they are not there.*

Standing orders maintain the basic status quo regarding the legal power to prescribe drugs, while allowing, practically speaking, for the redistribution of that power. In practice, once designated to train and distribute naloxone, laypersons freely circulate naloxone kits and the knowledge about their proper use. The standing orders ultimately become meaningless in terms of regulating the distribution and use of the drug. Naloxone programs in this sense do indeed engage in a form of deputizing, but rather than sharing the monopoly over access to regulated drugs with carefully selected laypersons, it dispenses with this monopoly altogether and allows anyone to decide on the naloxone's appropriateness according to need.

The prerogatives to decide when and where to prescribe drugs are not the only dimensions of medical authority and responsibility that are unsettled by naloxone prescription programs. Uncertainty surrounding liability and the ever-present possibility of lawsuits was also a major obstacle to getting physicians involved. Since the early twentieth century's hysteria over "dope doctors," physicians have been wary of accepting active drug users as patients.<sup>33</sup> This wariness was even stronger in the case of a relatively non-lucrative, experimental program where established norms surrounding responsibility did not apply.

In order to address this wariness, New York State and other jurisdictions passed laws to exempt naloxone prescribers from medical liability. Researchers noted, "Medical liability is another concern voiced by some physicians"<sup>34</sup> in relation to their involvement in wider naloxone distribution. FR, a physician who was involved in the development of naloxone told me:

*FR: The law holds the person administering naloxone harmless. And it holds the programs harmless. It doesn't hold the prescribers harmless, they tried to make them harmless but they didn't make it through the code committee on the state level. So liability and malpractice is still somewhat of a disincentive to physicians who want to get involved in prescribing naloxone. So liability is not decided. Malpractice companies haven't looked closely at the naloxone program. There hasn't been a test case.*

The lack of clarity regarding liability reflects larger questions about naloxone's legality. Naloxone was at the time of its introduction in what numerous informants described as a legal "gray area." One public health worker I spoke with told me that she asked the DOHMH legal team about the legality of naloxone at the department.

*GN: And legal said, 'Well, it's not entirely legal, but it's not entirely illegal.' So it was kind of this vague answer that we got back.*

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<sup>33</sup> David F. Musto, *The American Disease: Origins of Narcotic Control (Expanded Edition)* (New York, NY: Oxford University Press, 1987).

<sup>34</sup> Maxwell et al., *op. cit.*: 93.

The uncertain legality of peer administered naloxone distribution was and continues to be the most important barrier to wider participation by physicians, even though legislation has been passed shielding them as much as is possible from liability.

My respondents involved in naloxone distribution were unanimous in asserting that the risk of injury or harmful side effects of naloxone were minimal, possibly even non-existent. Yet many doctors remain worried. “Because health professionals have to be involved, these programs must deal with practitioner concerns about malpractice liability, which can be powerful even when not well-founded in fact.”<sup>35</sup> As researchers note, “Anxiety can be minimized by the extremely low risk/benefit ratio for naloxone, as well as by recognizing the low potential for litigation in this patient population.”<sup>36</sup> But the experimental, pilot nature of naloxone programs so far means that this has not been firmly established.

Tellingly, the unresolved questions about liability, which can be decisive for other medical treatments, have not been insurmountable obstacles for naloxone. The question of liability has been absorbed into the logic of emergency. The assumption is that anyone who needs naloxone would otherwise die; hence, to a greater extent than in most other areas of medicine, anything goes. As FR said, “The only thing that could go horribly wrong is that the person dies anyway.”

As will be explained below, the idea of emergency structures the politics of naloxone more generally. Here it means that issues surrounding liability have been reduced or relocated—a stance that is almost unprecedented in American medical policy. It enables the naloxone

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<sup>35</sup> Beletskly et al., *op. cit.*: 17 – 18.

<sup>36</sup> Maxwell et al., *op. cit.*: 93.



programs to proceed, but the issue cuts both ways. On the one hand, naloxone programs would likely not exist without laws removing medical liability from doctors, program staffers and those who administer naloxone on others. On the other hand, the lack of liability leaves the person on whom naloxone has been administered without any legal recourse. No one is held liable, but at the same time, no one—with the possible exception of the overdosing user him- or herself—is held responsible for the outcome.

A redeployment of medical authority, liability and risk is an inherent part of naloxone programs. While pharmaceutical companies, harm reduction clinics and prescribing doctors are necessary for any naloxone program, in their traditional form they are not sufficient. New lines of authority had to be established. This is the emerging edge of public health practice: the redeployment of expertise and the transformation of medical risk and peer-to-peer drug delivery. In line with the undercutting of the traditional structure of medical authority, naloxone strategies operate with a distinctly decentralized social logic.

## **V. The social logic of naloxone**

As a harm reduction strategy, what can be called the social logic of naloxone is as important as its chemical properties. As the history detailed above indicates, naloxone was in production for decades before it came to be used as a harm reduction tool. Its deployment by drug users, as opposed to medics, makes use of a decentralized, peer-to-peer logic which can be seen both in the drug's patterns of distribution and use as well as in the trainings and tacit knowledge upon which this use depends.

The notion of a peer-based, networked harm reduction strategy emerged from addiction researchers' analysis of the structure of drug use itself. It had long been known that people use narcotics within a social matrix.<sup>37</sup> Overdose, too, follows a social pattern. It is an issue that affects drug users collectively but unevenly. As addiction researchers studying a naloxone distribution program in Pittsburgh noted:

Our finding that 3.4% of program participants returned for refills 10 to 24 times provides a glimpse into the social structure that is important to overdose prevention and health among the study population. This might point to the existence of 'hubs' or 'nodes' of experience and knowledge within drug-using communities which appear to be recognized by users and their peers.<sup>38</sup>

The idea that there are “hubs of experience and knowledge” became central to naloxone as a strategy. Its proponents recognized that the people who occupy these nodal points in user social networks could serve as what they term “lay health care educators” and “indigenous public health workers” who could “help reach a larger number of users who may not be seen by mainstream and community-based services.”<sup>39</sup> The idea of indigenous public health workers exemplifies the forward deployment of neoliberal strategies in health policy. They extend the reach of the public health system into previously impenetrable social domains. In doing so, they amplify the effectiveness of state policy but also obscure its presence. The hope was that “[o]nce naloxone rescue kits are distributed into the community to people trained in overdose prevention, they are further disseminated through social networks to

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<sup>37</sup> This point is made by an entire body of literature stemming from Howard Becker's “Becoming a Marihuana User.” See Howard S. Becker, “Becoming a Marihuana User,” *American Journal of Sociology* (1953): 235-242; Jock Young, *The Drugtakers: The Social Meaning of Drug Use* (London, UK: MacGibbon and Kee, 1971); Carl Latkin, et al., “Using Social Network Analysis to Study Patterns of Drug Use Among Urban Drug Users at High Risk for HIV/AIDS,” *Drug and Alcohol Dependence* 38.1 (1995): 1-9.

<sup>38</sup> Alex S. Bennett, et al., “Characteristics of an Overdose Prevention, Response, and Naloxone Distribution Program in Pittsburgh and Allegheny County, Pennsylvania,” *Journal of Urban Health: Bulletin of New York Academy of Medicine* 88.6 (2011): 1020 – 1030.

<sup>39</sup> *Ibid.*

people who were not trained directly by the distribution programs.<sup>40</sup> The very structure of user networks, which has historically been seen as an impediment to abstinence-oriented drug treatment, might become a tool to amplify the effectiveness of public health interventions.

The notion of using these networks for the purposes of reducing harm represents a pragmatic departure from traditional politics of addiction by recognizing that sociability is an important dimension of drug use. From the “drug farms” of the early twentieth century<sup>41</sup> to the residential treatment facilities of today that cut off all contact with the outside world, drug treatment has relied on the need for dependent users to sever ties with the social world of their drug use. Naloxone distribution, rooted in the harm reduction philosophy, follows a different social logic. It sees the inherently social nature of drug use not as a hindrance to treatment but as a means to it. Speaking to a seminar room full of staff members from New York area social service providers and drug treatment programs, a naloxone trainer and prescriber described a situation with which many present were very familiar:

*HB: It's a terrible irony that people go to detox to get clean, and they vow and are certain that they're going to stay away from people, places and things. And as so many of you here know, they get out and what, after all, is there for them on the day they get out or the day after except those old things. And so relapse rates are 50% - 80% or so of these people. And they are at tremendous risk of overdose during that period.*

New York's naloxone program designers decided that, rather than requiring users to vow to stay away from familiar people, places, and things, they should use these social contexts as

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<sup>40</sup> Maya Doe-Simkins, et al., “Overdose Rescues by Trained and Untrained Participants and Change in Opioid Use Among Substance-Using Participants in Overdose Education and Naloxone Distribution Programs: A Retrospective Cohort Study,” *BMC Public Health* 14 (2014): 297.

<sup>41</sup> Caroline Jean Acker, “The Early Years of the PHS Narcotic Hospital at Lexington, Kentucky,” *Public Health Reports* 112.3 (1997): 245 – 247.

a vehicle for providing care. Naloxone distribution is thus a policy innovation that deals with the actual practices and habits of drug users as they are, not as they should be.

The question for naloxone supporters was precisely *how* to incorporate the social structure of drug use into overdose prevention. In 2001 the San Francisco Department of Public Health sponsored a pilot research study that included opiate education and naloxone prescription, using as a model the Chicago program.<sup>42</sup> Anticipating political opposition, the pilot study initially involved pairs of drug users who were given four interactive training sessions of two hours each.<sup>43</sup> The intention was that trained pairs would each receive a prescription and administer naloxone on one another, should the need arise. But it soon became evident that reality did not conform to this expectation, as pairs split up or used drugs with other people not trained in overdose reversal, and for whom naloxone had neither been prescribed nor administration consented to prior to overdose.

Eventually, the pilot programs were taken by the researchers to have demonstrated that naloxone would not remain within the confines of consistent, long-term relationships between physicians, prescription-holders and those to whom naloxone is administered. In place of matched pairs, program designers moved to a more anonymous and decentralized model. FR described to me how even before the law was changed allowing third party administration, prescribing practices reflected the fact that it was impossible to keep naloxone within pre-determined pairs of users.

*FR: We started prescribing sort of very make believe in pairs. I didn't actually figure out who the pairs were. I mean, I may have in the first day or two, but after that it was just sort of make believe. So it was no secret that*

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<sup>42</sup> Karl A. Sporer and Alex H. Kral, "Prescription Naloxone: A Novel Approach to Heroin Overdose Prevention," *Annals of Emergency Medicine* 49.2 (2007): 175.

<sup>43</sup> Seal et al., *op. cit.*: 304.

*we were doing it. I may have sort of said that I was doing it in pairs, I don't remember, but we really weren't. So fortunately - so in March we started doing that, and the overdose bill passed in August of that year, and took effect April 1st, 2006.*

Eventually, those involved with naloxone prescription determined that the pair model was impractical. Drug use and overdose occur in far more complex social networks. In place of pairs, it was acknowledged that users would bring the tools and the knowledge of overdose reversal into their wider spaces and domains, and use it on anyone they witnessed experiencing an overdose. This became a central tenet of naloxone strategies: naloxone would spread along the vectors of overdose risk, freely circulating within user social networks, which were now seen as structures to be exploited rather than barriers to be overcome. And as with syringe exchange, the law was changed post-hoc to reflect already existing practice.

Along with the naloxone kit, knowledge of naloxone's proper application had to be distributed along peer networks as well. The training session is central to naloxone as a harm reduction strategy. Training sessions are a way to create the group of "indigenous public health workers" that are to carry out overdose prevention. It is only by training users to administer naloxone to one another that its decentralized logic is possible, as it allows overdose prevention to take place detached from medical settings and personnel.

Training sessions take many different forms and have evolved over time to reflect not only pedagogical requirements but also the needs and experiences of those being trained. Early training sessions had a quality of direct action. At times they even occurred out in the street, in an unstructured, improvisatory manner. EL, a board member at HRev, described one such early training session:

*EL: Me and Peter, through HRev, I wasn't on the board yet, Roberta and some other people, we went to 125<sup>th</sup> and Lexington. Middle of the street. We had people there before hand, making announcements. We had about 65 fucking drug users form a big circle around me and Roberta. And I did the overdose training. I yelled out real loud, Roberta translated into Spanish, Peter just sat there and wrote 'scripts. We did 65 prescriptions in less than an hour and a half.*

As naloxone and harm reduction in general became more institutionalized in New York, training tended to become more regularized. Training sessions are a legal requirement under the law, which lays out specifications for certain material that must be covered. And though programs vary from one location to another, a core curriculum has been developed with the input of the HRC and includes:

- Basic opioid neurophysiology
- Pharmacodynamics and pharmacokinetics of commonly used opiates
- Pharmacology and pharmacokinetics of naloxone and other opiate antagonists
- Risk factors and prevention techniques for opiate overdose
- Signs and symptoms for the early recognition of opiate overdose
- Prevention of choking and aspiration in the unconscious patient
- Techniques of rescue breathing
- Routes of administration and dosing guidelines for naloxone
- Protocols for follow-up care.<sup>44</sup>

Learning to participate in the naloxone strategy requires mastering a broad amount of information. Properly administering naloxone requires knowledge about how to recognize that an overdose is occurring; how to manoeuver an unresponsive body into the recovery position in order reduce the risk of choking and to optimize airflow; how to perform rescue breathing; whether or not naloxone is even appropriate given the specific narcotics that have been ingested, a determination that requires knowledge about drug interactions and the social dynamics of drug using situations; how to correctly use syringes and other medical paraphernalia in a highly time-sensitive, life-and-death situation; and how to respond to possibly violent people experiencing drug withdrawal symptoms. Few public

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<sup>44</sup> Maxwell et al., *op. cit.*: 90.

health initiatives place this level of responsibility in the hands of non-specialists, and especially non-specialists who are as stigmatized and untrusted as intravenous drug users. But far from treating users as passive objects of policy intervention, naloxone draws on the relatively high degree of medical knowledge that exists, in its own distinct forms, within the cultures of drug user networks. As NK, a clinical staffer told me, “I mean there's a cultural thing. I think there's like, people who have experience with needles are fine with it.”

One of the most important innovations of naloxone programs is that they came to build upon the specific forms of expertise that many users develop on their own. It was found that not only were drug users able to learn the skills necessary to properly administer naloxone,<sup>45</sup> but that “people trained in overdose recognition and naloxone administration were comparable to medical experts in identifying situations in which an opioid overdose was occurring and when naloxone should be administered.”<sup>46</sup> Naloxone strategies not only draw on forms of ‘street-level’ expertise; they also merge this with more formal medical knowledge to create a progressively better informed cadre of indigenous public health workers.

Though the training curriculum listed above may seem intimidating to the uninitiated, once translated out of medical jargon, the content actually covers topics about which drug users

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<sup>45</sup> Karin E. Tobin, et al., “Evaluation of the Staying Alive Programme: Training Injection Drug Users to Properly Administer Naloxone and Save Lives,” *International Journal of Drug Policy* 20.2 (2009) 131–136.

<sup>46</sup> Traci C. Green, et al., “Distinguishing Signs of Opioid Overdose and Indication for Naloxone: An Evaluation of Six Overdose Training and Naloxone Distribution Programs in the United States,” *Addiction* 103.6 (2008): 984.

tend to have significant practical knowledge. An excerpt from my fieldnotes describes a typical meeting of an overdose prevention training group at SoBroHR.

*The overdose prevention training took place on a Saturday afternoon in April. It was led by NK, a physician's assistant under the employ of UserUnion who was able to prescribe naloxone kits under Dr. FR's license. Every other Saturday, NK would make the trip up to the Bronx to run this training and write scripts for any who wanted.*

*The group began shortly after 2pm, and was held in the windowless ground floor group room. In the minutes leading up to the start, participants milled around the room before taking their seats around the table. There were 15 participants in attendance, 12 men and 3 women. Many of the participants I had seen before and knew to be agency 'regulars'.*

*NK began the training by asking people to call out the names of different types of opiates. What followed was a long and detailed list of the many forms opioids can take, including an alphabet soup of pharmaceutical brand names, and their street appellations.*

*NK: So what are the different kinds of opiates?*

*Crowd calls out long list of different forms of opiates, including heroin, methadone, oxycodone, hydrocodone, morphine, codeine, Vicodin, Percocet, and lesser known variants such as Xolox, Dilaudid, Fentanyl, Demerol, among others.*

*Male Participant: Opioids is made to work on the same receptors as the opiates.*

*NK: Right, right. Besides opiates, there's completely synthetic medicines, like Fentanyl is one, methadone is one, those are all made in the laboratory.*

*MP: Suboxone is an opioid.*

*NK: Right, right. Opioids are opiates, so they're both natural opiates, from the opium poppy, and synthetic ones.*

*Female Participant: Mmmhm.*

*MP: I know medicine, man, I know medicine.*

*NK: So again, those are the drugs that Naloxone works on. It doesn't work on, in particular, the benzos, the benzodiazepines. So what are some of those?*

*Group: Xanax, Klonopin, Librium, Ativan...*



*FP: What about Catapres?*

*NK: No, Catapres is not a benzo, but it also doesn't work with this. It's something that you could potentially overdose on.*

*MP: It's not a benzo, but it works like one, boy. You take a Catapres with some dope or whatever...*

*MP: It's for high blood pressure.*

This excerpt demonstrates how training sessions build upon users' experiential knowledge. The attendees have quite a deep level of knowledge about opiates already—they know the difference between opiates and opioids, they can identify benzodiazepines, and they have a basic understanding of the biochemical differences between different classes of drugs and their effects on the body.<sup>47</sup> The trainer does not emphasize any status difference between himself and the attendees. Nor is he patronizing or condescending towards them. The training session has an overall atmosphere of peer education. The goal is to draw upon the knowledge that these assembled users have acquired in the course of their lives and to channel it towards harm reducing ends.

Leveraging users' experiential knowledge is important as a starting point from which to discuss the action of actually administering naloxone. The fieldnote excerpt below is reproduced at length to give the reader a sense of not only the tone of naloxone training, but also the technical nature of the task indigenous public health workers are asked to perform.

*NK, the trainer: So if you're going to give them an intramuscular dose, you've got two bottles like this, and two syringes. One syringe for each bottle. You only have to use the syringe once. You know, you never want to use a syringe more than once, if you can avoid it. And if you do, you should clean them out. But you've got two here, just so you don't have to worry about that.*

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<sup>47</sup> Green et al., *op. cit.*: 985.

*Male Participant: You can use that to...? [crowd laughs]*

*NK: Um, you could, it's a big needle. This is a pretty big gauge needle.*

*MP: That's because it's big like that so it could go through clothes, and stuff like that.*

*NK: This is, you're not looking for a vein. It's intramuscular.*

*MP: Yeah, it's intramuscular but it's made to be able to go through clothes.*

*NK: You don't even have to do that. You can go through clothes, but just before, like when you open up the needle, the points come off so make sure it's on tightly.*

*MP: You can hit the leg or no?*

*NK: You can hit the leg. The next step... these are single dose vials, so use the whole bottle, you don't have to worry about measuring. Use the whole bottle. And there's not very much in here. It's 1 CC, so the bottle looks like it's almost empty, don't be alarmed. You just want to get everything that's in bottle into the syringe. And to help you do that, it helps to put some air into the bottle first. So open up your syringe, get a CC of air into there. And then, the bottles when they're new, they have a little orange top on them. Pull the top off, and then there's a little rubber stopper. Just put the needle right through the stopper, just so you can see the point sticking out at the top. Then we can push the air in, the pressure will start to push it out by itself. If the needle's too high, you'll start to get air, so if you're getting air and there's still liquid left in the bottle, push the air back out, pull the needle down so it's under the surface, just so you can see the tip sticking out, and then pull the rest in. Just get as much in as you can, every drop. And then any air left in the needle, push it out. And then you're ready to go. So there should be about this much liquid. If there's a couple bubbles in that it doesn't matter cause again, we're not going for veins. Intramuscular injection. So you want to go in the [MP: shoulder] shoulder, or in [MP: the thighs] right, the thighs. It's better to go too deep than too shallow. Cause it's a big needle and you want to get it into the muscle.*

*MP: What about the butt cheek?*

*NK: Not the butt cheek. Don't go in the butt. One, that's where the most fat is.*

*MP: Oh yeah, that's right.*

*NK: And you want to go under the fat, into the muscle. So you got a guy with a lot of body fat, don't be afraid to go deep. Cause you want to get underneath the fat. The muscle has all the circulation.*

*MP: What happens if the person is thin?*

*NK: Thin? It's not going to go that far, if you go too far you're going to hit bone. Can't go further than bone. You want to go straight in. Straight in. Cause that'll get you to the muscle the quickest. If they're skinny, it's not going to go all the way. You can actually kind of feel cause your muscles are surrounded by kind of a thick membrane, so you might as you go in, you might feel it resist a little bit and then pop through. Then you know you're in the muscle. You want to go in straight, don't be afraid to go deep, like a dart. Stick it in, push all the medicine in, and then, when you're done.*

*MP: Get ready to run!*

*NK: Well, be careful, there may be a little blood leaking out. But that's good, cause that means you got into the muscle where there's circulation. But you don't want to come into contact with the blood. And the needles have a little flap that you pop up and lock over the point. That way, no one can stick themselves. If you need to use a second dose, just use another needle. So give them a dose, and again you don't want to go in the butt, aside from being the place with the most fat, there's also a large nerve that you might damage. So these two spots [points to the thigh and the shoulder] there's nothing you can really damage, permanently. So. We called 9-1-1, we gave him some breaths, we gave him a dose, and you want to give it a couple minutes to work, cause sometimes it can take a little bit. So as soon as you give him a dose, go back to giving him breaths. Every 5 seconds. Now if you've given him 20 or 30 breaths and nothing happened, then you can go ahead and give him a second dose. But give the first one a chance to work cause the more of it you give them the sicker they are likely to be when they wake up. So. We've gone back, we've given some breath, we've been doing this for a while and nothing's happened so we're going to give him a second dose. If you have the intranasal kit, how that works, you're going to have 2 boxes like this. Each box has, again, a single dose. Inside is going to have 2 pieces like this [points to disassembled atomizer] Sometimes this piece might actually be separate, so in that case it'll be...*

*MP: And you got two liquid things in the nasal one, cause two of them equals on needle shot.*

*NK: Well there's only one vial. There's one vial that has liquid in it. And then, if the nose piece comes separately, in a separate bag outside of the box, then it'll look like this. So if that's true, just take off the big cap and open up the little bag and it just screws right on. But the ones that we have here, we already did that part and taped the boxes back up, so you don't have to do that stuff. But what you will have to do is, there's two caps, actually this one disappeared, but there's a purple or pink cap on the vial that has the naloxone, so you pop that off. And there's a little yellow cap on the end here. Pop that off, and then the holes match, they slide together. And as soon as you feel that it won't go anymore, give it a couple twists. This is important.*

*You don't want to push it, you want to twist it just till it gets tight. And then it works just like a syringe. You point it up their nose and put half in each nostril. So there's 2 ccs, you got twice as much liquid in here, so you push half in one side, and half on the other. You want them to be on their back, or have their head tilted back or it'll drip back out. It's absorbed by the mucus membrane on the inside. Same way as you know when you sniff coke or heroin, it works the same way. So you squirt that up both sides, and then again you go back to giving him breaths to give it a chance to get absorbed in. It might take a little bit longer to work. Don't be alarmed, just keep giving him breaths. But again, give him like 20 to 30 breaths and if nothing happens, give him a second dose.*

The excerpt illustrates the complexity and difficulty involved with overdose reversal. Administering naloxone is a medical procedure that requires a particular level of competence. Simply possessing a familiarity with injection is not sufficient to successfully administer naloxone. Users must know where and how to inject, how to load 1 CC of medication into a syringe or an atomizer, and crucially, how to perform rescue breathing. Although naloxone supporters insist to the contrary, this training suggests that there are real risks involved—risks to both the person receiving and the person giving the dose of naloxone. This highlights some of the challenges of rolling out a public health initiative of this type.

The high success rate of naloxone is real, but training sessions clearly present challenges as well. One challenge for naloxone program designers is how to deliver the training, the content of which can be quite technical, to a group of people whose ability to retain information is far from certain. One evaluation of the New York City naloxone program admits that:

Some of the highest risk users may not have more than 10 minutes to spend in a training as they are trying to sustain a heroin habit or may not have a long attention span because they are under the influence of several drugs.<sup>48</sup>

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<sup>48</sup> Piper et al., *op. cit.*: 296.

Ten minutes is a far cry from the intensive eight hours of training spaced over four sessions that early participants in the San Francisco pilot were given. And indeed, skeptics of naloxone distribution questioned whether drug users would be able to retain any training and perform such critical tasks under pressure. Another staff member at a harm reduction agency told me that “One peer reports that there are people out in the streets of East Harlem that really don’t know what to do with the kits,” suggesting that once out of the training room, not all people are able to use the tools they have been given.

The training session transcribed above was conducted by a physician’s assistant. With the most recent evolution in the law in August 2014, lay people may be designated as naloxone trainers and providers. This means a further step towards decentralization and devolution of medical authority. The concern held by some is that if access to naloxone is completely separated from formal medical oversight, naloxone might be given to people who do not know how to properly wield it. One prescribing physician told me she was in favor of making naloxone even more decentralized by having peers conduct trainings and do distribution, but that in order for this to happen “we need to figure out how to keep accurate and appropriate records, and keep the level of training high—even though the training around naloxone has been streamlined, so it now takes fifteen minutes and it used to take four sessions.” One of the DOHMH harm reduction staffers told me:

*GN: I'm all about getting more naloxone into the hands of more people. I mean I think that's the ultimate goal. The problem with naloxone is as it stands right now, it's coupled with education. And that education piece is really important. So how do you talk to people about like the risks of an overdose and how you actually use the naloxone, and if you can just buy it off the shelf at a pharmacy, it's not clear that somebody's going to A, use it in the right circumstance, B, use it in the right way, C, still call 911, which is crucial and that's like the biggest thing that we educate people about: Call 911, then give the naloxone. Like whatever you do, you still have to call 911 because it could be other stuff. They could go back into an overdose after the*

*naloxone wears away. There's a lot of reasons why. We could put in on an insert maybe.*

The worry is that if naloxone were to be decoupled from the trainings and broader social strategy, it would lose its harm reduction efficacy.

The social logic of naloxone means that the strategy socializes both benefits and risks. Recipients risk possible nerve damage from a misplaced injection, among other possible injuries or worse. Administrators risk exposure to blood and other potentially biohazardous bodily fluids, and people who “wake up swinging.” But participants—and not only those revived by naloxone—derive a host of benefits as well. Putting on its head the assumption about users as essentially anti-social, naloxone strategies expect and encourage drug users to act towards one another in a deeply social way. As researchers have determined,

Many participants involved in an overdose reversal, both as victim and as rescuer, report that the education about and availability of naloxone has opened new avenues of thought regarding safety and personal health.<sup>49</sup>

In fact, one naloxone prescriber told me, “Actually, my personal view of it, which is based on no data whatsoever, is that the person doing it, the person reviving the other person may be the person most likely to go into treatment.”

Some trainees come to strongly identify themselves with the naloxone project. My fieldnotes describe one such training session participant:

*Ricardo is a tall Latino man in his mid-thirties. He has short black hair and a rigid posture. He strides through SoBroHR and HRP with an air of familiarity and authority. He is a regular at several of the local harm reduction agencies and is known to staff and many of the participants. He attends all of the naloxone training sessions, often volunteering to act out the role of overdozer. He wears a naloxone kit around his waist, the blue pouch dangling from his belt like a janitor's key ring.*

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<sup>49</sup> Maxwell et al., *op. cit.*: 92.

Not all training session attendees adopt these sorts of proudly pro-naloxone subjectivities, but Ricardo is not alone in doing so. And many participants see becoming trained in naloxone administration and carrying naloxone kits as opportunities to give back. This is a powerful and deeply social dimension of the naloxone strategy, one which researchers have determined may carry its own benefit:

The finding that perceived competency (i.e. self-efficacy) in recognizing opioid overdose was associated independently with greater knowledge of overdose recognition suggests that mechanisms to improve confidence in one's abilities such as attending trainings and practicing newly acquired skills exert an influence on knowledge, a key mediator of behavior change.... For drug users, there may be a sense of empowerment and other important psychosocial benefits gained through receipt of overdose recognition and naloxone training.<sup>50</sup>

Reversing an overdose is a significant experience. Merely being a part of it may have knock-on effects on the long-term health prospects of participants.

Interestingly, many participants involved in an overdose reversal, both as victim and as rescuer, report that the education about and availability of naloxone has opened new avenues of thought regarding safety and personal health. Some participants, after being dispensed naloxone, have returned to be tested for HIV and HCV, telling us that they are now feeling a greater sense of hope that they may live to see a long-term future.<sup>51</sup>

By adjusting one's sense of self as an informed, concerned, active moral agent, merely attending overdose prevention training sessions, even if one never attempts to reverse an overdose event, might have positive effects on users. This is not an accidental side effect but a consequence of the inherently social logic of naloxone strategies.

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<sup>50</sup> Green et al., *op. cit.*: 985.

<sup>51</sup> Maxwell et al., *op. cit.*: 92.

## VI. Conclusion

Peer-administered overdose reversal was pioneered by users in a syringe exchange, but it is now widespread and being used as a model for other public health strategies. Overdose prevention is still evolving. But in a relatively short period of time, and going against the grain of traditional medical authority and official prescription practices, naloxone in New York has been legalized and is on its way to being fully incorporated into mainstream public health.

In its goal of ameliorating some of the terrible consequences of drug use without asking for abstinence, its historical origins in user self-help networks, and its appeal to medical and social-scientific evidence, naloxone is a prototypical harm reduction policy. It is also unthinkable without the changes in the structure of the state and the policy process that some have identified with neoliberalism. Naloxone would arguably have been impossible in the Fordist-Keynesian era, which tended to pursue policies that were hierarchical, centralized, clinical and paternalistic. And in attempting to save drug users' lives without regard to their behavioral changes, naloxone is the antithesis of the war on drugs. Only in a larger policy environment that encourages decentralization and the exploitation of social networks, where normal procedures can be suspended in the institution of the pilot study and where seemingly apolitical appeals to medical science can be sufficient justifications could naloxone have become established policy.

In many ways, naloxone is a good example of a neoliberalism policy. Its introduction into user networks is a "responsibilization strategy." Predicated on the existence of an



individualized, responsible subject,<sup>52</sup> naloxone deputizes the user him- or herself to act as a public health agent, moving the techniques of overdose reversal out of the clinic and into the spaces and streets of the city. By giving users the tools for their own survival, the state is responding to the needs of users who, for various reasons, are unable or unwilling to access health services in conventional ways (such as presenting themselves in emergency rooms) and is thus fulfilling its obligation to promote life for all citizens. But it accomplishes this by drastically extending its reach into the practices and habits of drug users, while simultaneously obscuring its presence, turning the object of its medicalized gaze into its primary acting agent.

But the standard critique of neoliberal policy almost completely misses the mark when it comes to naloxone. In part, this is because the relationships between marginalized groups, experts and the state are far more unsettled than this literature tends to acknowledge. These unsettled relationships suggest unsettled questions about risk, expertise, and responsibility: the responsibility to administer naloxone if and when it is needed, the responsibility to learn about its risks, and the larger issue of responsibility within new public health paradigms.

More fundamentally, naloxone highlights how the new state formation that marks the neoliberal era can harbor some progressive policy potentials. Naloxone's goals and peer-to-peer administration establishes that users have a claim on a right to life and access to those tools—including overdose reversal drugs—that will enable them to continue living. In this

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<sup>52</sup> The production of the responsible subject is ongoing, though to a certain extent the legwork has already been done by already existing programs like needle exchange and methadone. For a discussion of the biopolitics of needle exchange, see Katherine McLean, "The Biopolitics of Needle Exchange in the United States," *Critical public health* 21.1 (2011): 71-79.

sense it is not adequately captured by the idea of either the “roll back” of social protections or the “roll out” of new forms of social governance.<sup>53</sup> Rather, it points to the ways in which new collective claims can emerge in a post-welfare context. Enabled by quantifiable forms of evidence, justified in both ethical and fiscal terms, and empowered by legal exceptionalism, activists managed to establish state support for the avoidance of user-specific forms of death.

As discussed in chapter two, Foucault saw responsabilization as one of the central characteristics of neoliberal governmentality. As subjects become increasingly responsible for their own wellbeing, that move absolves the state from the duty to protect the wellbeing of all. There is undoubtedly much about naloxone, as with harm reduction generally, that confirms Foucault’s perspective. But what he missed, and what the standard critique of neoliberalism tends to miss, was the possibility that newly responsible subjects, far from being the individualistic atoms of neoliberal rhetoric, might be able to enact forms of social care in ways in which the pastoral state was unable or unwilling to manifest. They might learn to effectively exercise this responsibility to aid each other. With naloxone programs, users are becoming subjects responsible for their own fate in new ways—but along with allies in the public health and medical establishments, they use these new capacities to occasionally bring one another back from the brink of death.

Naloxone, represents one of the new directions in which harm reduction is currently moving. It is a highly technical yet highly social innovation that circulates in locations far from the syringe exchange. It is one way in which harm reduction is becoming more

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<sup>53</sup> See Jamie Peck and Adam Tickell, “Neoliberalizing Space,” *Antipode* 34.3 (2002): 380-404; see also chapter 2.

mainstream. But it is not the only way. As the next chapter explains, syringe exchanges themselves are becoming integrated into the public health system.

## Chapter 5.

### Harm Reduction, Medicaid and the Future of Policy

#### I. Introduction

Towards the end of my fieldwork, two events took place that captured the state of the harm reduction field in New York at that moment in time. The first was a celebration, hosted by the AIDS Institute, marking twenty years of syringe exchange in New York State. Held on the top floor of a Midtown office building, the room was bright and festive. Tables were spread throughout the room and attendees milled around, moving from table to table, chatting and catching up with friends and colleagues. Representatives from all of New York States SEPs were present, and the day was filled with testimonials of struggle and triumph, call-outs of appreciation to activists and AIDS Institute employees, remembrances of the fallen, and exhortations to continue to fight for an end to the war on drugs. This was a gathering to recognize the accomplishments of a movement, with attendees linking the plight of drug users to larger struggles for social and economic justice.

The second event, also hosted by the AIDS Institute, was a meeting on Medicaid reform and the future of harm reduction in the state. The same people now sat quietly around a large conference table in the New York State Department of Health's downtown offices, watching PowerPoint presentations on budget restructuring and Medicaid payment delivery system reform. Ostensibly held to keep "stakeholders" in the loop about the changes underway, the meeting was also an opportunity for front-line harm reduction providers to voice their concerns about the highly complex, state-driven process that would inexorably affect their organizations in profound ways.

Taking place within a month of each other, these events brought home the internal contradictions of harm reduction in New York. While the anniversary celebration looked back on the history of struggle and all that harm reduction activists had achieved, the Medicaid meeting looked forward to the future of healthcare delivery and spoke to SEPs as service providers in the language of bureaucracy. The future, it was becoming increasingly apparent, would include greater levels of integration into state healthcare provision through SEPs' absorption into Health Homes and Medicaid managed care networks. Regularized state support of harm reduction services seems poised to be the ultimate conclusion to the institutionalization process that had begun with the waiver twenty years previous. But what will become of harm reduction as a philosophy of drug user health and empowerment, and as a political movement oriented towards social change, after it goes fully mainstream?

This chapter looks at the way harm reduction accessed mainstream channels of health care provision in New York State through the state's Medicaid redesign process. This process began in 2011 and was ongoing at the time my fieldwork concluded. It was, and continues to be, a profound change in the funding, political standing and ultimately the culture of harm reduction—and it also shows evidence that harm reduction is beginning to shape the structure and culture of Medicaid. Not only have specific harm reduction interventions been recognized as legitimate for Medicaid reimbursement; in fact, the harm reduction philosophy has helped to shape larger scales of reform by providing a new model of health care delivery. Within the larger project of health system reform, the harm reduction philosophy has been accepted by and integrated into other state behavioral health and substance abuse services.

Chapter three argued that the partial institutionalization of harm reduction through the grant funding system left space for organizational autonomy. With Medicaid, this space may be closed. Medicaid integration therefore may prove to be a paradoxical process for harm reduction. The distinctiveness of harm reduction services offered by syringe exchange programs (SEP) could potentially be eroded. And yet the larger health system is being influenced by the ethos and techniques of harm reduction.

## **II. Medicaid reform in New York State**

Harm reduction has entered a new period of expansion and institutionalization at precisely the moment when New York's health system is being significantly transformed. Due to the restructuring of the state's public health bureaucracy and changes in the financing of health care, the grant-funded infrastructure that supported harm reduction's expansion in New York is changing. A new set of organizational and political opportunities is arising for harm reduction, most significantly though not exclusively in the overhaul of Medicaid. Becoming integrated into Medicaid represents the direct inclusion of SEPs and their participants into the mainstream health system. From their origins as activist organizations engaged in protest and clandestine activity to being grant funded agencies on the margins of the public health state, harm reduction organizations are now becoming an exemplary model of success for other areas of health service delivery in New York State. Harm reduction organizations have come a long way.

In 2011, New York State initiated Medicaid reform. The state faced sky-high levels of spending on Medicaid and the prospect of vastly increased enrolment with the upcoming

roll-out of the Affordable Care Act. It also offered mediocre quality of service, which contributed to major health disparities.<sup>1</sup> In an effort to control costs and address quality issues, Governor Cuomo created the New York Medicaid Redesign Team (MRT), which set about proposing sweeping changes to the state's Medicaid program. The extent of reform has been broad and complex. Among the most significant changes proposed by the MRT is "ending the state's Medicaid fee-for-service system and replacing it with a comprehensive, high-quality and integrated care management system."<sup>2</sup> And it has focused particular attention on a population subgroup identified as high need and high cost. Drug users, with their multiple physical, behavioral and substance abuse problems, fall into this category.

Managed care is a form of devolution. Rather than the state providing direct reimbursement for individual services to specialists and hospitals, it outsources administration, patient care and reimbursement of providers to private, mostly for-profit managed care organizations (MCOs), which are paid a set per capita rate. In theory, the capitated payment structure incentivizes MCOs to seek efficiencies above that of which government is thought to be capable, as any savings can be appropriated by the MCOs themselves as profit. In this, the move towards managed care is undeniably a form of privatization. And in a classic example of the redistribution of risk, MCOs are freighted with the responsibility to economize, a risk that had previously been borne by the state.

Some observers of this process are deeply skeptical of these claims. Maskovsky, for example, argues that managed care "has transformed the question of the state's willingness

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<sup>1</sup> Kevin Fiscella, et al., "Inequality In Quality: Addressing Socioeconomic, Racial, and Ethnic Disparities in Health Care," *Journal of the American Medical Association* 283.19 (2000): 2579-2584.; Ichiro Kawachi, et al., "Health Disparities By Race and Class: Why Both Matter," *Health Affairs* 24.2 (2005): 343-352.

<sup>2</sup> NYSDOH, "Medicaid Redesign Team Health Disparities Work Group Final Recommendations," 20 October, 2011: 5. (Hereafter MRT) Emphasis in original.

to provide public health services into a question of the state's willingness to enable or inhibit the profitability of commercial insurers.”<sup>3</sup> For Rylko-Bauer and Farmer, managed care represents “an incrementalist market-based strategy that champions cost-effectiveness and profits rather than equity and compassion, while shifting responsibilities for cost-containment onto the individual ‘consumers’ of health care ‘products.’”<sup>4</sup>

Yet for many committed progressive public health reformers, managed care represents an opportunity to improve a fatally flawed system. EU, an employee of the DOHMH and a member of the MRT admits that MCOs are “mercenary...profiteering... They’re not interested in wellbeing.” Despite this, however, EU supports the transition to managed care and sees in it an opportunity:

*EU: So we have this huge opportunity to expand the services now, because a managed care company doesn't give a shit whether it happens in a clinic or not. The government shouldn't give a shit, but it does give a shit because it's worried about being audited and it's worried about pushing the envelope too far open. A managed care company isn't worried about those things in the same way. It just wants to see low cost services delivering high yield outcomes.*

For EU, a private, profit-driven MCO is more likely than government to “push the envelope” and expand services. They are not beholden to a voting public and can therefore promote services, like harm reduction, which may not be politically popular but are low cost and produce “high yield outcomes.”

*EU: If [MCOs] can be real smart about what kind of care is most cost effective, theoretically, that produces profits for them, because they have a contract that allows them to play with a certain amount of money, and there's something called a medical loss ratio that we determine in the contract that sets a threshold for how much of their contract has to go towards paying for services, and how much of it can go towards administrative expenses. And*

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<sup>3</sup> Jeff Maskovsky, ““Managing” the Poor: Neoliberalism, Medicaid HMOs and the Triumph of Consumerism Among the Poor,” *Medical Anthropology* 19.2 (2000): 132.

<sup>4</sup> Barab Rylko-Bauer and Paul Farmer, “Managed Care or Managed Inequality? A Call for Critiques of Market-Based Medicine,” *Medical Anthropology Quarterly* 16.4 (2002): 477.



*the better they are at supporting services that are cost effective, the more profitable the whole venture is for them. What contributes to cost effective services? Cheaper services, better outcomes, theoretically. So theoretically, it's a system—in Newt Gingrich's wildest wet dream—that should produce much better health care.*

Despite describing the emerging managed care system as “Newt Gingrich’s wildest wet dream,” EU supports the replacement of fee-for-service in favor of managed care and is helping to design and implement it in New York State. EU is not a general or ideological supporter of market solutions. Rather, like many harm reduction supporters, he sees in this change an opportunity to work the ethos and techniques of harm reduction into the medical system at a new scale.

An important aspect of the MRT’s plan for managed care in New York is the roll out of Health Homes. Health Homes are an Affordable Care Act initiative whose purpose is to create better coordination and communication between different service providers and to bring down costs and improve outcomes. Health Homes are an integration of medical and behavioral care, to break down the silos in the care system that have existed. According to the NYSDOH:

A Health Home is a care management service model whereby all of an individual's caregivers communicate with one another so that all of a patient's needs are addressed in a comprehensive manner. This is done primarily through a "care manager" who oversees and provides access to all of the services an individual needs to assure that they receive everything necessary to stay healthy, out of the emergency room and out of the hospital.<sup>5</sup>

The MRT identified the lack of coordination between different health care providers regarding high-need patients as one of the causes of high costs in the fee for service model. They argue that “for far too many people, care is not effectively managed.”<sup>6</sup> Instead of offering consumers more “choice,” the mantra of earlier iterations of the transition to

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<sup>5</sup> NYSDOH, “Medicaid Health Homes.”

<sup>6</sup> MRT, *op. cit.*: 6, emphasis in original.

managed care, Health Homes are decidedly more paternalistic. They seek the “active management” of care through case management and care coordination for high need, high risk, high cost populations. Rather than conceiving of the Medicaid enrollee as an autonomous consumer of self-selected services, Health Homes introduce a “care manager” whose job it is to guide the person towards the care they need in order to stay “out of the emergency room.”

Health Homes are where and how SEPs connect to Medicaid. The MRT is explicit in the requirement for Health Homes to involve “community-based organizations” in the management and delivery of care for enrollees with complex health issues. In EU’s comment above, he alluded to the devolution of healthcare delivery, saying that “a managed care company doesn’t give a shit whether it happens in a clinic or not.” This comment reflects a broad shift within the thinking of those planning New York’s healthcare delivery system. There is recognition and acknowledgement of the important role community based organizations play in promoting health, supported by the growing prominence of the ‘social determinants of health’ in public health scholarship.<sup>7</sup> According to the MRT:

New York’s vision for health homes relies on a wide array of current providers forming new partnerships and stretching their list of services in ways that ensure recipients with complex health issues are effectively managed. ... Health home networks will always include community-based organizations because they are uniquely positioned to meet the social needs

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<sup>7</sup> Health system reform is not unique to New York State or even the United States. Similar processes are taking place across the developed world, driven by the new priorities in health care imposed by aging populations and the need to mitigate the ever increasing cost of managing chronic conditions. There is growing consensus that health systems must incorporate an understanding of the social determinants of health—that is, socio-economic factors that shape the conditions of people’s lives—in order to do a better job designing impactful and cost-effective interventions. This is a departure from health systems, like the U.S.’s, which has hitherto focused on finding cures for diseases, rather than on their prevention. See WHO, “Closing the Gap: Policy into Practice on Social Determinants of Health: Discussion Paper,” (2011); Michael Marmot and Richard Wilkinson, eds. *Social determinants of health*. Oxford University Press, 2005. And for a critical perspective, see Vicente Navarro, “What We Mean by Social Determinants of Health,” *International Journal of Health Services* 39.3 (2009): 423-441.

of patients that often transcend health care needs.<sup>8</sup>

By emphasizing the need for current providers to stretch their list of services and to partner with community-based organizations, the MRT is signaling the way forward for harm reduction organizations. The logic of healthcare delivery is changing focus—from treating disease in the hospital, to engaging with people in their communities, to address the “social needs of patients” in order to prevent disease. According to the New York Academy of Medicine:

Addressing basic needs through providing pantry bags of food and meals, a warm place to spend the day; and maintaining a connection and communication to the world, including the healthcare system, through access to computers and a place to receive mail, are critical to facilitating appropriate healthcare utilization for many people. It’s not necessarily the role of the healthcare system to create these places, but it becomes incumbent upon the healthcare system to partner with such places and work to ensure that they can operate.<sup>9</sup>

The MRT plan laid out a blueprint for major changes in the way healthcare would be designed and delivered in New York State. It also explicitly signaled the intention of the state to incorporate SEPs and harm reduction services into Medicaid. The MRT report recommends:

Actions should be taken to promote and address health care needs of persons with chemical dependency including allowing medical providers to prescribe syringes to prevent disease transmission; and by authorizing NYS DOH AIDS Institute Syringe Exchange providers to be reimbursed by Medicaid for harm reduction/syringe exchange program services provided to Medicaid eligible individuals.<sup>10</sup>

The inclusion of SEPs in the MRT’s report was highly significant. Drug users were no longer an exceptional, essentialized population. The reality is that the “vast majority of harm reduction participants are Medicaid beneficiaries and many have multiple chronic

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<sup>8</sup> MRT, *op. cit.*: 13

<sup>9</sup> Peter Schafer and Michele Calvo, “The Integration of Harm Reduction and Health Care: Implications and Lessons for Healthcare Reform,” *New York Academy of Medicine*: 2015.: 33. (Hereafter NYAM)

<sup>10</sup> MRT, *op. cit.*: 24.

conditions and are high utilizers of emergency department and inpatient services”<sup>11</sup> which makes them “relevant to the larger New York State Medicaid reform initiatives underway, and whose experiences can inform the implementation of those initiatives by healthcare systems in New York.”<sup>12</sup>

Though still thought of as a fringe or outsider movement, harm reduction has become official health policy in New York. This led to much excitement and uncertainty among harm reduction providers and advocates. Medicaid integration is altering the funding structure, the organizational autonomy and the general mission of harm reduction in New York.

### **III. Opportunities and threats of Medicaid integration**

Medicaid integration requires that harm reduction organizations adapt to the requirements of a new system. As one of informants told me of the Medicaid Redesign Team’s harm reduction proposal, “I think a lot of us saw it as equal measures opportunity and threat.” As Chapter 3 argued, the grant funding system only facilitated partial institutionalization. Medicaid integration represents a fuller form of institutionalization. In that sense, it is a solution to the challenges of grant funding. Not only does it promise a steady flow of resources and a new level of legitimacy in the eyes of the public—it also allows for the full development of harm reduction as an approach to drug user health broadly defined, rather than an adjunct to HIV prevention. But the relative autonomy of SEPs from the AIDS Institute allowed for flexibility. It allowed harm reduction activists to maintain an oppositional, outsider identity which gave them legitimacy in the eyes of their program

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<sup>11</sup> NYAM, *op. cit.*: 23.

<sup>12</sup> NYAM, *op. cit.*: 9.

participants. SEPs fear that integration into for-profit, highly bureaucratic MCOs will mean a loss of autonomy and the eclipsing of the political dimension that brought many activists to harm reduction in the first place.

The idea that SEPs should take advantage of the changing funding landscape—or risk their ability to continue functioning—was reinforced during both the twentieth anniversary of syringe exchange celebration and the Medicaid redesign meeting. At the former, CB, a manager at the AIDS Institute, urged agencies to “evolve” to stay alive.

*CB: As grants change, as funding becomes less available for a discreet area, there has to be a mechanism in the organizations, and in your thinking, to evolve. To take advantage of your expertise, your knowledge and your experience so you can take advantage of the opportunities so that you can survive, so that you can continue to provide the services to the population that you want, but at the same time, be able to survive as an entity.*

Organizational survival was the main topic of discussion and concern at the Medicaid redesign meeting. Agencies had been told about the opportunities presented by Medicaid reform but were unsure how, in their current form, they would be able to take advantage of them.

In their integration into managed care networks, SEPs are able to untether themselves from most of the grant-funding infrastructure. This means a move away from the close connection between SEPs and HIV prevention, the source of the majority of their funding up to this point. MI, an employee of a harm reduction advocacy organization, explained the funding landscape SEPs were facing:

*MI: We cannot count on HIV being the rationale for supporting our programs anymore. ... To the extent that we're successful, people forget that there was a reason to support us in the first place, in the context of the HIV epidemic. Overall, HIV is de-prioritized in public opinion and in the political sphere.*

The importance and public profile of HIV has waned, thanks in part to the success harm reduction organizations have had in reducing new infections among drug users. For SEPs relying on grant funding tied to HIV, the looming prospect of this source of funding drying up means that SEPs must look elsewhere for support. MI shared with me the calculations that many SEPs are making:

*MI: A lot of the money for HIV case management and linkage to care is coming from the Ryan White Care Act, which is about 2 billion dollars. Now, the Ryan White Care Act was created over 20 years ago as a payer of last resort. Now, this is in a pre-Affordable Care Act environment. In theory, the Affordable Care Act will expand coverage. What's the role of Ryan White after 2014? After Medicaid expansion, after the establishment of insurance exchanges and subsidies and all that stuff—do we still need this special program? And the fear is that it will essentially wither on the vine. So, if you are an HIV organization that was getting Ryan White funding, and you were looking ahead, you would have to be very scared ... And if you're not currently able to bill Medicaid, or you're not currently partnering and have a formal relationship with an institute that can do Medicaid billing, then you could be left out in the cold.*

MI looks ahead at the uncertain funding landscape facing SEPs as “HIV organizations.” He concludes that without a formal relationship tying agencies to some sort of Medicaid reimbursement mechanism, agencies, like the Ryan White program to which they are fiscally tied, risk “withering on the vine.” MI’s speculation and calculation was representative of an overall uncertainty in the harm reduction field.

In order to benefit from Medicaid, agencies must play by the rules laid out by the MRT. That includes demonstrating their ability to cater to more than just HIV, something that many of the SEPs are keen to do anyway. But the way in which they must go about it is by marketing themselves and their service models to MCOs, using the language and the metrics of profit. JH, a NYSDOH employee and member of the MRT, exhorts the assembled group of SEP directors at the Medicaid Redesign meeting to show themselves in the most attractive light:

*JH: I really think this is an opportunity to sell yourselves, and the fact that you have boots on the ground. There's going to be a certain amount of marketing yourselves. We have these services to work with this client population that is traditionally not in care.*

Agencies are compelled to sell themselves, to market themselves on the basis of having “boots on the ground.” They must leverage their experience ministering to high need, high cost, hard to reach populations in order to win the approval of the MCOs who, because of the capitated payment structure, see new enrollments as an opportunity to increase revenue.

Throughout this process, harm reduction supporters recognize that the state is not necessarily investing in drug user health out of a benevolent concern for their wellbeing.

*MI: If we say we're not just a syringe exchange agency, we're not just the HIV prevention people, we're the drug user health people. Who is the audience for solutions to drug users health problems? Who is invested in having healthy drug users?*

After all, drug use is still illegal, and numerous other “right hand of the state” functions are still dedicated to punishing drug users.

The fact of the matter is that drug users are an expensive population. An IDUHA survey shows that 75.4% of SEP participants have at least one non-substance abuse related chronic health condition and 41.9% have two (asthma, hypertension and liver disease are the three most common).<sup>13</sup>

*MI: People who have addictions and mental health issues, are high utilizers of very expensive health care. Emergency room care. If they're on Medicaid, or if they are dually eligible for Medicaid and Medicare, these are what are being seen in the accounting, actuarial terms as the cost centers, the cost to be driven down. And there are two ways to drag these costs down. Refusing care, or improving care. I think we're on the side of improving care. But we need to prove that we have a way to do that. And we will have opportunities*

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<sup>13</sup> NYAM, *op. cit.*: 8.

*to do that, but I think that we'll have to be very nimble and we'll have to be very fast in order to take advantage of that.*

Harm reduction supporters are well aware that the Medicaid embrace of their organizations is driven by economic calculations. According to MI, SEPs are the most appropriate agencies for targeting these “cost centers.”

In order to become part of an MCO network, SEPs also must have particular levels of organizational capacity. Medicaid imposes huge responsibilities for billing and recordkeeping. SEP directors and employees worry that as small organizations, they will not be able to cope with the technical requirements of the Medicaid billing and record sharing systems. As NYSDOH employee YH explained to me:

*YH: These are small agencies that are going to have to either link with someone who can bill for Medicaid or develop that ability themselves. Well that is a huge bureaucratic hurdle, to bill for Medicaid. I don't understand anything about it, really, except that I know it is very intensive. The billing itself and the administrative infrastructure that you need to do that is significant. The application process itself is significant. Yeah, huge hospitals, gigantic organizations like Housing Works or Gay Men's Health Crisis, they can hire a consultant or hire someone to do these applications.*

Larger, more established organizations like Housing Works or Gay Men’s Health Crisis would be able to handle this challenge. But smaller, community-based SEPs will struggle to meet Medicaid’s onerous administrative burden. IH, the executive director a major New York harm reduction organization and long time activist put it this way:

*IH: You're going to have to be able to bill Medicaid. Probably it's an improvement over a cost reimbursement contract, but particularly smaller organizations realize that right now they don't have the technical capacity to do that. They are going to have to learn how to do that. If they don't do it well they are going to lose money.*

The fear is that organizations must learn to operate by Medicaid’s rules or face the disappearance of their funding.



This same process also raises the threat that SEPs will lose the organizational autonomy that has always been so important to them. As LD, the executive director of a SEP explained, it may cause some syringe exchanges to partner with large organizations, which will overwhelm them:

*LD: Syringe exchange programs can very quickly be submerged in the tsunami of much, much larger agencies. And I think there has to be a recognition of the transformation that needs to happen, or the maturation if you will, that the syringe exchange programs can in fact be capacitated to bill Medicaid. Unless there is a mechanism that really allows the agencies to understand the full requirements and the path that will enable us to become licensed either as a 31 under mental health services or a 32 relative to drug treatment that we are not going to ultimately be able to stand independently. There will be the continuous need for us to lean on another entity that will then have control of the purse strings. We want to look at the fullest breadth of harm reduction services that can address our constituents, and not limit it only to syringe exchange.*

LD's concern is that in their current form, many SEPs lack the capacity to bill Medicaid. This means that in order to benefit from Medicaid funding, agencies would need to "lean on another entity" and risk being "submerged in the tsunami" of much larger organizations. The loss of "control of the purse strings" would signal the end of SEPs as autonomous organizations.

SEPs are also concerned that the eligibility requirements for reimbursement will be incompatible with harm reduction strategies. SEPs developed a low-threshold model of health service provision, with low barriers to access: no identification was required, no referrals. Patients could remain anonymous. Low threshold services were compatible with the arms-length management of the grant funding system. Could the low-threshold model survive the stiffer requirements of Medicaid? GN, a DOHMH employee, reflects:

*GN: Syringe exchange is one of the last services around that's still completely anonymous. I mean, people have member ID codes, but it's not like John Doe has a case file at a syringe exchange program that has all of his health records and all of his everything. It doesn't work that way.*

Having a low-threshold for access is not an incidental part of the SEP model—it stems from the core of the harm reduction approach. UserUnion organizer AE is concerned that moving towards Medicaid integration could mean compromising harm reduction’s ability to “reach people.”

*AE: We also want to be low threshold enough to reach people who aren't going to interact with the health care system anywhere else. And if you just support syringe access, in particular solely through Medicaid, you are going to lose a lot of drug users.*

Yet for EU, these concerns are overblown.

*EU: Most of the people who go in there are enrolled in Medicaid and so are already part of systems of surveillance that these agencies, as they represent themselves, would find totally draconian, but that their consumers may not have problems with it. And so that's also kind of where you see this funny disconnect between harm reduction idealized, the way it actually works, and the way people actually get the services. A lot of people who run these agencies are like "Fuck this, fuck Medicaid." I mean, they will say that. But then where would the preponderance of people who come in there be without Medicaid. Most of the people they are serving would not say, "Fuck Medicaid."*

EO, from the perspective of a service provider, echoes this view.

*EO: I don't think there's one participant that's come in and said they don't want to give their name to get on Medicaid to be able to see the doctor.*

There is a residual impulse within the harm reduction world to be wary of the surveillance of drug users. But this often clashes with the reality of contemporary health service provision.

While anonymity may be difficult to maintain, for many SEPs, trust is paramount. As a public health strategy, harm reduction interventions like syringe exchange rely on a close relationship with service users. It is important that drug users identify with and ‘buy into’ the harm reduction project in order for it to work. User involvement in the design and delivery of services has, from the beginning, been a constitutive part of harm reduction both

in theory and in practice. AL, an AIDS Institute employee who has overseen harm reduction programs since the earliest days of the waiver sees the conflict this way:

*AL: Here in New York with the Medicaid redesign, Medicaid reform, there is this opportunity where harm reduction is making this move towards more mainstream. But that's not good now because it may take away—I don't want to say the simplicity of harm reduction, I would say it's more of the easy access to services. There are other people that are thinking, well, let's examine this and let's try to point out what are the models that may work. And I think that the fear of the further we go into mainstream is that people fear the further we'll get away from the people, that means the service.*

MI made a similar point.

*MI: When we talk about user involvement, we become trapped in becoming so successful that we get more government funding and that we lose the legitimation that we needed in the beginning. Where we didn't have so much money so we had to make a lot of friends. And our first friends were people who were injecting drugs who came to us for supplies.*

In their early days, SEPs didn't have a lot of money and so had to rely on their "first friends," people who were injecting drugs. The risk, as MI sees it, is exchanging increased scale and stability for the street-level legitimacy that made them into the models of success they are today.

To a certain extent, concerns around the kinds of services Medicaid would reimburse were a response to the Medicaid system as it was, rather than what it was becoming. SEPs did not believe that Medicaid would reimburse the sort of non-medical, peer-focused practices that constitute harm reduction. Yet some policymakers were intent on importing precisely that aspect of harm reduction into the revamped health system. EU—who was a member of the Medicaid Redesign Team responsible for determining what would be reimbursable, and how—made this quite clear to me:

*EU: Medicaid would reimburse peer support activities that folks are engaged in; Medication distribution; care coordination; recovery management.... If there is a singular emphasis on shifting the purview of reimbursable services*

*within Medicaid, it's on that. It's on low-intensity, sub-clinical, services. With the biggest emphasis being on peer support.*

To be sure, some SEP directors dismiss concerns about the loss of autonomy or goal drift as missing the point. For EO, executive director of SoBroHr, harm reduction has always been about addressing drug user health in the broadest way:

*EO: I think selling out is hanging on to just the syringe transaction and never digging deeper to see what people need and trying like hell to meet those needs. Like hunger, like housing, like treating hepatitis while the liver is rotting away. Or worrying about the syringe exchange transaction and doing harm maintenance, when someone's toes are falling off from diabetes. And so to me, that's the cop-out. Get your shit together and if you can't do it yourself, connect them with somebody who can or get doctors here or whatever.*

SoBroHr has gone farther than many other SEPs in embracing the emerging medical model. It has located a health clinic and pharmacy on site, and is expanding into other areas of social service provision like job training and housing. But for EO, all of this is represents a fulfillment of the harm reduction project, not an evolution away from it.

Ultimately, Medicaid integration raises fundamental questions about what harm reduction is for and whether its original goals can survive its own success. AIDS Institute employee YH reflects on the potential of a standardized harm reduction:

*YH: When things become too standardized, and you can't just be, you know, the thing about harm reduction is it's based upon this idea of meeting the client where they are. I fear that some of this is going to turn into meeting the bureaucracy where it's at.*

Other informants saw this situation in similar terms.

*MI: There is an inherent tension between building up your syringe access component, which really has to be about being nimble, being low threshold, being networked and engaged with the cultures and communities of people who are injecting drugs. And the imperative to address more and more health issues, by professionalization, by institutionalization, by expansive services, by new facilities. There's just an inherent tension there.*

For MI, there is no way to avoid the trade-off between the institutionalization that Medicaid integration brings and the informality that is central to the harm reduction mission. This is another version of the tension between politics and medicine that has been at the heart of harm reduction from the beginning.

*MI: There's a sort of historical, archaeological sense to it that harm reduction entered the lexicon in the States through syringe exchange, which was a response to the HIV epidemic. So that it was around public health, it was around preventing blood-borne virus, and syringes were the tool for that and the philosophy that explained and rationalized it was harm reduction. So, by extension, anything that you could analogize to syringe exchange to prevent HIV could be seen as a harm reduction intervention. But if you talk about operationalizing drug user health as a concept, then you're moving into a maybe more clinical context. You could include psycho-social aspects to that. You could conceive of it broadly. And there's a certain resistance to that, because harm reduction's other route was not just the public health thing but was the more radical challenge to the laws, policies and norms that marginalized, stigmatized and excluded people who use drugs. So there's a certain kind of political element to it that if you use a clinical framework—which is the language you end up finding yourself talking in when you start talking about Medicaid, then you're talking in theory about depoliticizing a movement. So I think it's a tension right now.*

What is interesting about MI is that he recognizes these tensions but is quite sanguine about them. For him, harm reduction is not selling out by scaling up. It has always had a philosophical commitment to practical solutions to health problems, and hence asserted the necessity to operate at greater and greater scales. Similarly, for EO, the director of SoBroHr, there is no contradiction between growing larger and staying true to the original spirit of syringe exchange. Medicaid and the move towards a more holistic approach to drug user health that it represents, is fully compatible with what harm reduction has been all along.

*EO: We serve active drug users. Some are in recovery, but ours is a model of serving drug users that really emphasizes health. That emphasizes improving their social status, meaning destigmatizing homeless people, and drug users, and people with AIDS, and people with Hepatitis, and really building a way that's effective for serving people. The days of just giving out a syringe, for us at least, are over. It's unacceptable just to do that.*

For EO, authentic harm reduction lies in the future, not the past. When SEPs were distributing needles out of backpacks in the street, they weren't practicing an outsider approach to public health. They were stepping in to provide services that they always felt should be provided by the state. As EL put it "*we were providing services the state was not. And the state should have been providing these services and someone had to step up to the plate.*" Now, with full state support and integration into the same health system that serves the wider non-drug-using population, many harm reduction activists have seen the realization of their ambitions.

On entering the field, I expected to find grassroots organizations opposing managed care, because it operates on a for-profit basis and seems anathema to the politics of harm reduction activists. Some SEP rank-and-file do criticize Medicaid integration on these grounds. But my findings on this matter confounded my expectations. Despite their misgivings, most of my informants embraced Medicaid as the future of harm reduction in New York.

#### **IV. Mainstreaming harm reduction**

The mainstreaming of harm reduction has not only meant the transformation of SEPs into Medicaid-eligible service providers. At the same time, Medicaid and other welfare state infrastructures are transforming to reflect the priorities of harm reduction. Mainstreaming does not only mean SEPs linking in to networks of state-funded healthcare. It also means dissolving the distinctiveness of SEPs. This has happened because people like EU, a vocal proponent of harm reduction as the only approach to drug use that, as he put it, "makes any fucking sense," have influential positions within city and state bureaucracy. And it is

happening because of larger social, cultural, and political shifts in the way drug use is understood and dealt with. The consensus is growing that addiction is a chronic relapsing disorder,<sup>14</sup> that the war on drugs has failed,<sup>15</sup> that drug users are not just criminal lowlife types lurking in the ghettos of the inner city.<sup>16</sup> So where does this leave harm reduction as a social and political movement? Have activists succeeded?

Harm reduction is rippling out from the world of drug user treatment and health and into larger state bureaucracies with a broad reach. Specifically, the movement's oft-repeated guiding principle of "meeting people where they are" is beginning to gain acceptance as a sound approach to social service delivery outside the small world of community-based syringe exchange organizations. One of the three aims of Medicaid reform is to offer "person-centered care," which implies a harm-reduction-like emphasis on tailoring services and interventions to the specific realities of individual health consumers, and aiding the whole person, not just addressing the medical condition.

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<sup>14</sup> In recent years, addiction research has focused on the genetic and biological components of dependent drug use. This is a departure from earlier eras of drug use research that emphasized personal deficits and criminal tendencies. See Alan I. Leshner, "Addiction is a Brain Disease, and it Matters." *Science* 278.5335 (1997): 45-47.; Charles O'Brien, "Addiction and Dependence in DSM V." *Addiction* 106, no. 5 (2011): 866-867.

<sup>15</sup> The literature on the failure of the war on drugs is vast (for some scholarly examples see Chapter 1), and not only found among the usual critics of state policy. Even former New York State senator and presidential hopeful Hillary Clinton said recently in a speech on criminal justice reform that she supported a change in the "unjust federal sentencing disparity between crack and powder cocaine crimes" which have contributed to high incarceration rates among minority communities. Clinton seems to be deliberately veering away from the tough on crime language of the war on drugs in favour of an emphasis on treatment. In this she is representative of a bi-partisan shift away from the tough on crime policies that epitomize the war on drugs. See Daniel Strauss, "Read the Full Text of Hillary Clinton's Prison Reform Speech," *Talking Points Memo* 29 April, 2015. See also Saki Knafo, "Senators Take Major Step Toward Ending the Drug War," *Huffington Post* 1 January, 2014.

<sup>16</sup> Drug use in the U.S. is on the rise, and the demographics are changing. Increasingly, it is white youth in suburban or rural areas that are grabbing headlines. See for example Olga Khaza, "The New Heroin Epidemic," *The Atlantic*, 30 October 2014; Nan Marie Astone, et al., "Death Rates for US Women Ages 15 to 54: Some Unexpected Trends," *Urban Institute*, March 2015.

The philosophy of harm reduction accepts that drug users are willing and able to make decisions and take responsibility for their health and care. As explored in detail in chapter four, harm reduction's approach to health decenters the physician or credentialed service provider as ultimate authority in favor of the expertise drug users gain through lived experience. It relies on the power of peers and social networks to amplify the effectiveness of interventions by modeling behavior change within the communities of concern outside of clinical or bureaucratic environments, communicated in the language of the street, and delivered by peers in whom the targets of intervention see themselves reflected. Medicaid reform is embracing, or at least paying lip service, to all of these ideals. This may not sound revolutionary, but in the highly structured, top-down world of health and social service delivery, this blurring of the lines between client and provider is a revelation.

Harm reduction programs provide one of the earliest and clearest examples of devolved, decentralized, individualistic social service provision. EU, the MRT member, made this clear:

*EU: What we have an opportunity to do here is not just help agencies decide whether they want to become medicalized or not, and thereby participate in Medicaid or not. We have an opportunity to reshape what the whole medical, Medicaid model means, in the minds of the people designing this system in the state.*

Other people involved with policymaking made similar points. According to AL, a DOH bureaucrat, SEPs are one of the "shining success stories" of New York State in their ability to tackle a troubling and entrenched health problem within a difficult to engage population, and, she marveled, they did it with "limited resources." According to several people I spoke to at both the city and state public health departments, there is a lot of interest in applying the model pioneered by SEPs to other areas of healthcare reform. CB, a director at the



AIDS Institute, told New York's harm reduction community at the 20<sup>th</sup> anniversary meeting:

*CB: My vision of what syringe exchange programs are, is that you have been a successful partner in bringing together a model that has such a great potential to be helpful in many of the public health activities that entities such as the health department has to offer to people in many different areas.*

And JH, a Medicaid economist with the NYSDOH and member of the MRT told the group at the Medicaid redesign meeting:

*JH: It's somewhat refreshing, over the last two years, in how it's been recognized by the folks in Albany, a lot of the concepts that are being used by the Medicaid program in its entirety, which is essentially care management for all, it's been acknowledged that we have been there, we have done that. And what we have established is not perfect, but it was so far in advance of the general Medicaid program.*

For CB, JH and others, harm reduction services and programs are the vanguard of a new type of public health care. Again, it is important not to flatten the complexity of this change. It represents an approach to care management that is at once paternalistic and individualistic, focused both on guided behavioral change as well as personal responsibility. All these angles are indivisible from the type of health care system taking shape in New York, as elsewhere.

The resonance between the harm reduction sensibility and the new approach to Medicaid can be seen in the language used to promote the program's changes. According to the New York Academy of Medicine, SEP's success comes from "addressing participant's immediate needs and individual desires," creating a "service environment in which "stigmatized participants feel respected and even loved."<sup>17</sup> This creates a "health and social support home in the truest sense" which then sets up the service site as "trusted place" which then opens the door to "successful service delivery because participants want to keep coming

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<sup>17</sup> NYAM, *op. cit.*: 39.

back and they are able to share their needs honestly.” Terms like “love,” “respect,” “trust” and “home” demonstrate the affective scope of the emerging paradigm in Medicaid. They are what EU described to me as “All these sorts of vague soft-touch, behavioral, not even behavioral-therapeutic, but just kind of like human contact interventions.” For EU, instead of “ghettoizing” this approach within harm reduction settings, Medicaid should offer programs along this model for everyone, not only drug users.

*EU: One thing I would like to see more of, that isn't an explicitly harm reduction service, and that again is sort of my bent, to not proliferate quote-unquote harm reduction services but to promote services that reflect the only orientation that makes any fucking sense, so there are recovery centers, that's a model. It's not a clinical setting... They are staffed mostly by peers, and it's a place where maybe there will be some clinical services available but really where it's about feeling connected to your life. There's community shit happening there, there are vocational resources, there are housing resources there, you know, just sort of emotionally supportive resources there. Folks with whom you share a sense of identity. So one thing I've submitted to the folks at the state Department of Health is considering funding that programmatically, so with some kind of flat rate for the program, but then also funding individual services within that.*

This is an explicit articulation of the plan promoted by some Medicaid reformers to fund practices that are not specifically medical—to include “community shit” and affective identification. We can view this cynically, as the evidence of harm reduction as a biopolitical project, which surely it is.<sup>18</sup> And there is no doubt that cutting overall costs is the overriding motivation for embracing this approach. But at the same time, it arguably does harbor significant potential for a more humanistic model of social service provision.

There is another important dimension of the mainstreaming of harm reduction that may have even more profound consequences than the transformation of service models described above. By accepting the harm reduction approach to drug use, and incorporating it into Medicaid the state is signaling a willingness to abandon its insistence on abstinence as a

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<sup>18</sup> See chapter two for a discussion of the biopolitical critique of harm reduction.

pre-condition for the receipt of state benefits. Drug use is no longer a disqualification for social rights. It would be overstating the case to say that harm reduction is solely responsible for the change. It is connected to larger social, cultural, and political shifts, not only a marked liberalization in attitudes towards drug use, but also a renewed emphasis on the individual as change agent that is increasingly coming to eclipse the postwar emphasis on social institutions.<sup>19</sup> But harm reduction activists have definitely played a role in shaping the specific form that this process is taking in New York State.

A separate process has been underway at New York State's Office of Alcohol and Substance Abuse Services (OASAS), the state agency responsible for overseeing drug treatment, including methadone treatment. Historically, the treatment community had been among the most vocal opponents of the harm reduction approach, arguing that interventions like syringe exchange and naloxone distribution enable the continuation of drug use. There are many reasons for OASAS's traditional resistance to harm reduction. The treatment industry in New York, as elsewhere, is based upon the supreme importance of abstinence. Most treatment programs are versions of the 12-step, abstinence-centered model pioneered by Alcoholics Anonymous.

But there is growing acceptance within OASAS that current treatment models are failing to yield the hoped for results. Relapse is a reality for many if not most chronic drug users.<sup>20</sup> Seeing in this an opportunity, savvy policy entrepreneurs working both within government, like EU, and without, like MI and IH, have capitalized on the upheaval brought by

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<sup>19</sup> Pew Research Center, *America's New Drug Policy Landscape* (Washington, DC: Pew Research Center, 2014).

<sup>20</sup> Michael Gossop, et al., "Lapse, Relapse and Survival Among Opiate Addicts After Treatment. A Prospective Follow-Up Study," *The British Journal of Psychiatry* 154.3 (1989): 348-353.

Medicaid reform to push through changes in subsidiary systems like OASAS. For example, IH had a hand in rewriting OASAS's clinical guidance "towards harm reduction outcomes, as opposed to the traditional model." The goal was to change mainstream drug treatment to be more in-line with harm reduction principles. In this case, this simply meant a non-abstinence approach, rather than any specific public health interventions like syringe exchange.

*IH: What makes it different from the other guidance is the outcomes are not abstinence. The outcomes are improved health outcomes, improved activities in daily living, such as a job, reduced use as opposed to eliminating use, and then reduced threat to public safety. All of those are perfectly good harm reduction. This is the official clinical guidelines that all programs have to use to run their program. The guidelines do not mention the word harm reduction once. That phrase is not used at all, but they change the measure from abstinence to this other set of clinical indicators.*

The significance of the change in clinical guidelines for OASAS drug treatment programs is far reaching. Many drug users who end up in treatment have been remanded there by court order, as part of drug court diversion programs. Typically, these programs expect that the drug user will undergo detox and then remain abstinent or be sent back to prison. As IH explains, OASAS's new clinical guidelines mean that drug users can now be mandated to harm reduction programs instead.

*IH: So they get mandated to a licensed OASAS program, but if that program adopted a harm reduction modality, then someone could elect to go to that program as opposed to an abstinence-only program. They are still going to get the urine test because they are going to have to volunteer for it, because if not, whoever is mandating them has sanctions. So but I'm not going to throw them out of my treatment program. Their parole might be revoked, or their probation might be revoked, but I'm not going to throw them out of my treatment program because they didn't do it. It's up to the mandatory to decide how they are going to treat somebody if they refuse the test.*

This is a somewhat paradoxical application of harm reduction. The activists who formulated it did not imagine harm reduction as something to which a user would be "mandated." It was based around a stronger conception of the autonomy and dignity of the

user. OASAS's appropriation suggests that harm reduction can be used as a means that can be applied to a variety of ends.

Harm reduction techniques and terms are being work into other areas of mainstream social service provision. The Human Resources Administration (HRA), which oversees New York City's welfare program, has been exploring harm reduction policies.

*EU: There's been this other conversation that was initiated by the HRA. They approached us and said, 'We have this program called Housing Assistance and Cash Assistance for people who are HIV positive. And we want to make that program as low threshold as possible. We have requirements for people who screen positive for drugs. In order for them to keep getting the full complement of assistance, they need to be enrolled in some kind of drug treatment program. Well, we would like to give them the option of enrolling in harm reduction services.' Which is great! But then that immediately raises all these questions about, okay, so if they need to comply with treatment in order to continue to get their assistance, what does that mean in the context of a harm reduction service? And is it enough for them just to enroll? I mean, how does that impact the whole question of anonymity and personal directiveness? That's a really important aspect of harm reduction, that people determine their own course through it. What if what they determine their want or need is, and for whatever reason, it doesn't satisfy the caseworkers of HRA, then how do we resolve that issue? Do we need maybe to institute a means of measuring progress for people in harm reduction settings that HRA would find acceptable and that the harm reduction service providers would also be invested in, like the quality of life indexes. ... We will do a presentation in collaboration with HRA on sort of these issues to a community of harm reduction providers and say, "So this is kind of what's at stake, these are the issues that we need to hash out. Who wants to be a part of this? Who wants to be an agency to which HRA will refer people? It's likely that HRA would consider at some point making this option available for all of their clients.*

At the time of my research, this meeting had not yet taken place. But crucially, according to EU, ideas about how to move away from a strict requirement of abstinence were beginning to circulate in spheres of social service provision that are not directly connected to HIV, health care or even drug users. What would it mean for the thousands of people who had their social services cut off, or were sent back to jail, for failing a drug test? At the same time, EU points to several issues that highlight the uneasy incorporation of harm reduction

into systems of governance. The importance of self-directiveness is invoked by the state. But ultimately, these are huge bureaucracies that may not be, in their current forms, structurally capable of the type of flexibility required by harm reduction.

Many of my informants noted that as the harm reduction approach filters through institutions that do not have a history or a pre-existing ideological affinity with its philosophy, the risk is that it becomes just another label without also importing the substance. When various elements are cherry picked to serve the interest of the importing institution, harm reduction risks being reduced to a buzzword. PR, executive director of HRev, is skeptical of the motives behind large institutions like hospitals adopting harm reduction programs:

*PR: The harm reduction label is now something that people are talking about. But what that means is you've got hospitals with harm reduction programming—it's not fucking harm reduction programming, are you kidding me!?! So in a weird way, it's almost like the concept is being co-opted by entities that are better positioned to grab this money, so that they can grab the money. And you know, I don't doubt that there are tons of people at the city health department and state health department who buy into it, and who think it's important, but it's the health department.*

For PR, hospitals and other larger institutional players are motivated to adopt the language of harm reduction because there is now money behind it, provided by the incentive created by Medicaid reform. Interestingly, she acknowledges that people in the city and state health departments “buy into” harm reduction, but feels that they will ultimately not be successful in transforming the for-profit healthcare world. This thought was echoed by YH, a NYSDOH employee:

*YH: I think the people that are now drawn to harm reduction are people that have characters open to working with difference in some way or another. And what happens when you go to a place where the policy is harm reduction but the person who is providing the service may just think you're a piece of shit? I'm nervous because now you have people that are drawn to it, but then it's*

*going to be functionally and operationally realized perhaps with people that have no philosophical commitment to harm reduction.*

YH, a long time harm reduction advocate and AIDS Institute employee, worries about the consequences of importing a harm reduction policy without also ensuring the people providing the services have a “philosophical commitment to harm reduction.”

In order to ensure that as harm reduction takes its philosophy with it as it becomes mainstream, people like IH want to see it become its own accredited field. He would like it to become a discipline:

*IH: Any new innovation, whether it's in medicine or anywhere else, if you want an innovation to become part of the norm, you've got to move it into the mainstream. It's very important to me that we have the right kind of credentialing for harm reduction psychotherapist, drug counselors, etcetera. Why? Because I want Hunter [College] to be teaching it. And I want Hunter to be issuing a credential to people. Why? Because once Hunter starts teaching it, and having that certification can get you a job at a licensed facility, it becomes the norm. And people start offering it and innovating off of it, because there's money to be made, there's jobs to be had. And if it starts becoming the norm, and we start showing that this new norm is producing better outcomes than the old norm, it will take over. And it will become the treatment ideology, which is what I want to see happen. These are all tactics, but at the end of the day, what I want for harm reduction is, I want to be able to prove that it is more successful than the traditional in a big enough way to where the traditional that is an absolute failure dies away, and harm reduction takes it's place.*

IH's ambitions for harm reduction is that it not only becomes mainstream but that it supplants the “traditional” so that the traditional “dies away and harm reduction takes its place.” And the way he sees this happening is by turning harm reduction into a credentialed professional discipline.

That harm reduction, based upon a critique of expertise, might transform into a credentialized discipline suggests that the integration of harm reduction into the medical system heightens some of the contradictions within it. As argued in chapter two, there have

always been many different version of harm reduction, and many contradictions within any one formulation of it. What version of harm reduction is being incorporated into Medicaid?

New York State is taking up the more practical, cost-cutting side of harm reduction while deemphasizing or flatly contradicting its project to expand the rights and dignity of drug users. Harm reduction is being more fully institutionalized than before. But its formalization still only represents the partial enfranchisement of drug users. If New York State were to fully embrace harm reduction, it would require not only ending the war on drugs, but a revalorizing of the lives of drug users and their communities.

Most of the leaders of harm reduction organizations acknowledge this conflict—but most still think that institutionalization is a worthy goal. As IH, the executive director of a major AIDS services agency, told me:

*IH: Look, the ban needs to be lifted, the war on drugs needs to change radically, we need to look at decriminalization, all of those things are very, very important political issues that we need to fight out. But at the end of the day, for harm reduction to become a successful treatment modality, it has got to move into the mainstream.*

IH, like many of my informants, feels that the true goal is becoming a widespread treatment modality; emphasizing less practical goals is almost a kind of indulgence. RN made a similar point:

*RN: I would personally say more and more services based upon a harm reduction model that provides access in health care and everything else for drug users is the way to go. Keeping it scrappy and authentic is ultimately going to betray the people you want to serve.*

For IH, RN, and other informants, institutionalization is the entire point of harm reduction.

For them, harm reduction has always been a project to transform the health of drug users:

*IH: So the question is, do you see harm reduction as this low-threshold maintenance program, or do you genuinely view it as a successful treatment*



*modality to deal with addiction? And I happen to believe that it's the best treatment modality we have to deal with addiction. And so absolutely, if somebody wants anonymous exchange and low-threshold services and that's all they want, then I should provide them with that. But if I'm doing my job right, I'm inviting them into higher and higher levels of engagement, a higher level of services, so that they can start getting the treatment that they need and start beginning to take control of their addiction. So to me, at the end of the day, that's the end-game. Needle exchange started out as a public health measure. It was about prevention of disease transmission. That's not the full sum of harm reduction. Harm reduction is giving people their lives back.*

The threshold question here is a matter of tactics. Harm reduction, in this telling, has nothing to do with the political and social standing of drug users. It is only about finding ways to reduce the personal harm of addiction.

Others, however, still see harm reduction as a project to uphold the dignity of the user. VC, executive director of Harm Reduction Partnership offered an alternate reading of harm reduction's past and its future to the 20<sup>th</sup> anniversary of harm reduction meeting:

*VC: This is really like a family gathering. ... Looking back at our work, and how we demonstrated that a behavior did not amount to an identity. People who use illicit drugs have multiple identities. Mothers, colleagues, bankers, bosses, politicians. In our work, we affirm the social facts of those lives, and their intrinsic necessity to community. Sorting people by behavior and then later denying them access to life saving resources, requires sustained institutional effort and a process of dehumanization that diminishes us all. We knew from our work with drug users that they were competent and cared for their health and those of their loved ones. [Applause] We sought to demonstrate that competency as we constructed syringe exchange. Hence, we first had to have an exchange, the one for one, to realize the necessity of wider access. And safe injection facilities are the next logical step.*

VC emphasizes the social dimensions of harm reduction work, not the health dimension. And she alludes to harm reduction's oppositional orientation when she talks about the "sustained institutional effort" that has created the "dehumanization" of drug users. In her telling, harm reduction's core is accepting and demonstrating the "competency" of drug users. And for her the way forward, the "next logical step" isn't deeper integration into the state but taking on the hot button issue of safe injection facilities—of which there are

currently none in the United States. Needless to say, introducing one does not figure into the MRT's recommendations.

As harm reduction becomes more mainstream, there are still those who want to hold on to an oppositional, activist identity and counter-hegemonic political orientation. The role of politics within harm reduction has always been a bit tricky to define. As a movement, many of their claims to legitimacy hedged on not being about politics but about policy,<sup>21</sup> claiming that theirs was a pragmatic, non-ideological approach to solving a pressing health crisis. There are plenty of participants within the harm reduction field who want to maintain this political element within harm reduction, shifting their focus from HIV to social justice for drug users, which they claim has always been the underlying philosophical orientation for the public health interventions. This part of the movement has not been embraced or even acknowledged by the powerful institutions that are now interested in harm reduction measures.

Despite harm reduction's seeming acceptance by the state, there are those like ON, a long time DOHMH employee and harm reduction researcher, who see harm reduction as irreducibly political.

*ON: I think that with harm reduction, syringe exchange, there still has to be some activism that goes on. People that fight for things, that don't just do it as a job.*

For these representatives of the more politicized tradition within harm reduction, institutionalization is betrayal. EL, a board member of HRev, is pessimistic:

*EL: I think what we're getting at here is again this threshold, and the arms of the state entering into people's lives. And I think that's what's happening.*

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<sup>21</sup> See Liz Evans, "Counterpoint: Drug Addicts Can't Recover if they're Already Dead," *National Post*, 20 April 2011.

*It's a ploy. It's a mechanism for them to have more and more control over people's bodies. These are not things I like to engage, man. It really makes me sick. I'm really more direct service, the small, grassroots type thing. So it's really new to me.*

Others within harm reduction's political wing see themselves as "soldiers in a just war," as

NN told the 20<sup>th</sup> anniversary celebration:

*NN: So while we commemorate 20 years, we should also be celebrating this time that you have all been soldiers in this very unpopular but just war. As soldiers you are in a war unlike most others. A just war against prejudice, against preconceptions, and against a war that pits one group of people against another and calls one unworthy. Because we are all worthy.*

This is a claim about harm reduction's past, but also a position that needs to be understood in the context of the movement's contemporary field.

Yet this same trope is turned around dismissively against those who see themselves as "harm reduction warriors." EU was particularly pointed on this topic.

*EU: I was at that [Harm Reduction Coalition] conference in 2008. Ethan Nadelman [of the Drug Policy Alliance] gave a talk. It's like the coziest, funnest conference imaginable because there is this sense of common persecution and marginalization. And it's a conference that's sort of about academic work that's been done on this issue, but all of it motivated by and cloaked in this sense of persecution.*

*EU: I think if you talk to harm reduction folks, they're much more inclined to want to be adversarial and to want to make it more about a sustained pitch battle between these opposing ideological camps, which I think is still part of the whole harm reduction ethos... I mean it feels sort of like a revolutionary gathering without a clear cause. Where there's tons of energy to fight somebody about something, god damn it, because it's bullshit what's happening, and what has happened, but, um, um, um, uh, where do we take our fight, exactly, right now. What's the efficacy of taking this fight anywhere.*

*EU: Allan Clear who heads the HRC uses phrases like, "We are foot soldiers in the Revolution." And so right, we're foot soldiers in the Revolution, who the fuck are we fighting at this point?*

For EU, what he sees as harm reduction's obsession with its own marginality can only hold it back. IH also sees the dispute as one of misguided idealism versus practicality, and comes down on the latter.

*IH: And I think there are people who fear that because we have our own little marginalized space, and in fact, some people have even articulated this. We've been fighting in the trenches doing this for the last twenty years, and what if this becomes profitable and Samaritan Village decides they are going to compete against us? Well hallelujah, that's great. Are you worried about your little organization and your job? Or are you trying to further a larger cause?*

IH decouples the "little organization", present day harm reduction's direct link to its activist past, from the ability to "further a larger cause." That harm reduction did in fact develop in what can only be called a marginalized space seems beside the point. This is a dispute about harm reduction's future and its goals in this moment of official incorporation.

Institutionalization, then, represents the selective uptake of the harm reduction's medical side—the aspect of harm reduction most helpful for cost-cutting purposes, and the side that does not challenge the broader political context of the continuation of the war on drugs. This process does not resolve any of harm reduction's inner conflicts, on the contrary, it intensifies them.

## **V. Conclusion**

After twenty years of struggle and incremental victories, harm reduction is poised to take its biggest leap yet, into Medicaid and fully into the mainstream of health and social care in New York State. This presents harm reduction service providers with many opportunities. As an approach to public health, harm reduction has always sought the widest possible audience. Becoming part of Medicaid managed care networks allows them to tap into a

regular source of funding, thus ensuring their organizational survival, and the continued availability of syringe exchange and other harm reduction services as HIV grant funding dries up. Harm reduction's absorption into Medicaid is also happening on a deeper level, with the service delivery model pioneered by SEPs being used as an example for other high-risk, high-cost populations. Most harm reduction service providers I spoke to were eager to embrace the challenge on becoming Medicaid reimbursable. There was a palpable feeling of vindication among some who had fought hard for this kind of acceptance.

And yet, as harm reduction merges ever closer with mainstream systems of health and social service delivery, it also risks losing that which has made it so successful. The flexibility inherent in grant funding allowed SEPs, in a sense, to write their own rules, with the complicity and encouragement of AIDS Institute employees who identify as activists within the harm reduction movement. Being insider-outsiders enabled SEPs to link in to just enough of the state project to gain legitimacy and keep their doors open but not be overrun with the requirements of administering a highly centralized, bureaucratic institution like Medicaid. Some in the field are worried that as harm reduction gets further and further away from its origins as a grassroots, user-led movement, it is compromising not only its political convictions but its ability to succeed.

The classic theory of social movement institutionalization, derived from Weber and Michels, and subsequently codified and criticized in the modern social movements literature, sees institutionalization as a process of goal displacement.<sup>22</sup> When the founding generation of

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<sup>22</sup> Some works discussing institutionalization of social movements include Sidney Tarrow, *Power in Movement: Social Movements and Contentious Politics*, 3<sup>rd</sup> ed. (New York, NY: Cambridge University Press, 2011); Mary Fainsod Katzenstein, "Stepsisters: Feminist Movement Activism in Different Institutional Spaces," pp 195-216 in David S. Meyer and Sidney Tarrow, eds., *The Social*

charismatic leadership is reduced to bureaucratic routinization, the original social and political objectives are replaced by the overriding goal of organizational maintenance. Social movements become interest groups, political parties, membership organizations or other routinized political organizations.

Interestingly, both sides in this debate see the other as coopted. In the standard story about cooptation, institutionalization represents the triumph of organizational maintenance over purity. Yet in this case, both the opponents and the supporters of institutionalization make that charge. Those who want to keep harm reduction “scrappy and authentic” are accused of wanting to maintain their small-scale, intimate organizations—just as those who want full integration with Medicaid are accused of betraying the original oppositional ethos in exchange for more funding. This speaks to the multiple, irreducible and clashing ideals within harm reduction as a movement.

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*Movement Society: Contentious Politics for a New Century* (Lanham, MD: Rowman & Littlefield, 1996); Charles Tilly, *From Mobilization to Revolution* (New York: McGraw-Hill, 1978); Mayer N. Zald and Roberta Ash, “Social Movement Organizations: Growth, Decay and Change,” *Social Forces* 44.3 (1966): 327-341.

## Chapter 6

### Conclusion: The Transformation of Social Policy

#### I. Introduction

The present work is a case study of the institutionalization of a social movement as it seeks to alter dramatically the conduct of public health policy. It uses an analysis of harm reduction in New York City as the basis for understanding progressive movements for policy change in the contemporary era. Harm reduction has indeed become mainstream public health policy and practice in New York. It also investigates the new directions in which harm reduction is now evolving, such as the use of naloxone, and the new scales in which harm reduction is becoming more widely embraced, via Medicaid and beyond. It examines the process by which harm reduction has managed to “get out of the ghetto” and become increasingly integrated into New York’s public health establishment.

Harm reduction has undergone three stages of institutionalization. It began as an outsider movement, a wave of activist mobilization in favor of syringe exchange as a response to the HIV/AIDS crisis of the early 1990s. At the time, this practice was illegal and drug use not sanctioned. This phase was followed by a long period of partial institutionalization, characterized by grant funding, organizational autonomy, and limited state support. Finally, with harm reduction’s integration

into Medicaid, the groups spawned by the movement have assumed a mainstream position within the health system.

Institutionalization is the process by which outsiders become insiders – and insiders themselves take on the values and orientations of the outsiders. Harm reduction at the grassroots level has contributed to wider changes in the design and delivery of public health in New York State. Through institutionalization, the harm reduction movement was able to realize the goals that it articulated in the outsider days of the 1980s: making the state responsive to the health needs of drug users. While some activists remain skeptical of what they see as the harm reduction movement's having been coopted as the policy establishment adopted their practices, the process has created new relationships between marginalized communities and the state, and led to new forms of social and political inclusion for drug users. The harm reduction approach, pioneered by drug users and public health activists, is now being applied to the health system more broadly.

This final chapter draws some conclusions from this case study. It first outlines the development of this project from its starting assumptions to its empirical findings. Second, it describes how this contributes to the political science literature on social movement institutionalization. Finally, it details a number of future research questions stemming from this project and offer some concluding observations.



## II. Project summary and findings

This research drew on forty in-depth interviews and eighteen months of participant-observation in the harm reduction field in New York City. The project sought to understand how harm reduction had developed from a marginal outsider position into mainstream health policy and practice in New York. The more general goal was to understand if and to what extent and how marginalized groups can succeed in shaping social policy in contemporary political conditions.

As detailed in chapter two, many scholars and activists see the contemporary era as one in which neoliberalism has narrowed the set of political possibilities. The specialist literature on harm reduction is strongly inflected with the narrative that neoliberalism and privatization obstruct progressive policymaking. Especially for harm reduction's Foucault-influenced critics, social policy in general and harm reduction in particular have been reshaped by an efficiency-seeking, market-based state regime that defangs any positive or progressive potential. In this story, most contemporary policies either fail to benefit the poor and the marginalized or actively harm them.

And yet harm reduction in New York is a definite case of progressive policy in action. Against what seems to be the main thrust of contemporary social welfare policy, it has involved the expansion of the state, the improvement of health

outcomes in a vulnerable group, and the introduction of measures that run counter to the context of the war on drugs and American inequality.

The original mystery, then, was how this pro-poor policy grew and became institutionalized during an era that also saw cutbacks in social housing; aggressive policing practices like stop-and-frisk; the growth of homelessness; neighborhood development policies that promoted gentrification in many central areas; skyrocketing levels of economic inequality; and other developments and policies that can be considered harmful to the interests of poor and working-class New Yorkers.

The project began with a number of assumptions. It assumed that harm reduction in New York would provide a classic example of protest movements confronting the state, in the manner of AIDS activism or other oppositional, contentious public health movements. It therefore assumed that activists and service providers, on the one hand, would have a tense relationship with the state, on the other—why else would it have taken eleven years from the start of the HIV/AIDS epidemic and harm reduction mobilization to establish the waiver system for syringe exchange?

Stemming from this first assumption, this project also assumed that harm reduction organizations would display high levels of solidarity and cooperation . It

assumed that they would cooperate for unified policy change, using alliances like the Intravenous Drug User Health Alliance (IDUHA) to pursue movement goals.

This project also assumed that New York's harm reduction movement and policy would be similar to harm reduction activism in Vancouver, Amsterdam, Zurich, Berlin, and elsewhere. In these places, the movement relies on close ties between users and public health researchers and is strongly focused on promoting and expanding safer injection sites (SIFs). As New York does not yet have a SIF, this project assumed that SIFs would also be the ultimate goal of harm reduction in New York.

But my findings countered a number of these assumptions. There are two major causal stories here. On the one hand, drug policy has changed in response to levels of mobilization of the harm reduction movement; the connections between activists and the state; and the ability of activists inside and outside the state to capitalize upon the current political opportunity structure. On the other hand, changing forms of drug policy themselves cause changes in the relationships between users and the state; broader changes in social policy; and drug user health itself, which has become an objective of government policy in new ways, and has markedly improved, as seen for example in lower levels of overdose death and decreased rates of HIV transmission.

This study finds that harm reduction has largely succeeded in achieving its stated goals. The overall goals of harm reduction in New York have been, first, to get the public health system to adopt practices that reduce the harm of drug use. Second, it has sought to influence social policy in a more general way, to diffuse the idea behind harm reduction. My data suggest that harm reduction in New York is in the process of accomplishing both of these goals.

These goals also differ from those of harm reduction movements in other cities, where the movement has also not undergone the same institutionalization sequence. While at least one SEP did build a model SIF in New York City, that is not the movement's main direction. Instead, it has sought to integrate harm reduction services as a basic approach to the broader delivery of health services. Today, leaders of New York's harm reduction field are less focused on opening safer injection sites than on finding their places within Medicaid reform. Many harm reduction activists in New York see this as a triumph, not a capitulation.

Peer-delivered naloxone is a typical New York harm reduction strategy. Activists both inside and outside the state championed the introduction of naloxone, which received bipartisan political support, unlike syringe exchange. Peer-delivered naloxone relies on the social networks cultivated by syringe exchange organizations during the period of partial institutionalization. Public health officials and activists

have utilized these networks to develop the naloxone program, expanding the reach of the state ever deeper into the social lives and bodily practices of drug users.

Harm reduction is becoming mainstream in New York City. The harm reduction philosophy is shaping mainstream health strategies, even when they do not directly involve drug users. The claim that harm reduction is, in the words of one informant, “getting out of the ghetto,” has a number of meanings. It means that harm reduction is no longer found only in marginalized neighborhoods. It means that harm reduction services like syringe access and peer-delivered naloxone are now available in more venues and to more populations. It means statewide health and social service agencies have picked up harm reduction’s low threshold model of service delivery. And it means that harm reduction’s non-abstinence philosophy has found its way into the mainstream of a reconfigured health infrastructure. In all these ways, harm reduction’s trajectory illustrates how politics becomes policy, and what happens to a disruptive political project and policy paradigm when it migrates from the margin to the center.

This study finds that the institutionalization of harm reduction has not meant that it has been coopted in the sense of the movement’s conservative side triumphing over its radical side. In this case, institutionalization coexists with, and even strengthens, identification with the social movement. It is not that harm reduction is *not* becoming less radical in its rhetoric and its tactics. In many ways, it is. But

from the beginning, harm reduction in New York sought to shape the state and become integrated into it, to get the state to cater to a population that it was ignoring, and to become part of the health system. It has succeeded in all these goals.

The dominant theme is neither cooptation via goal substitution nor a continuation of contentious politics, but rather partial and fuller forms of institutionalization. The public health bureaucracy and harm reduction activists had much deeper and longer-standing ties than first appeared. Activists shifted fluidly between social service organizations and the state. People working within and outside the state shared the “activist” identity. Often, people who work in state agencies saw themselves as activists, while people working in syringe exchanges saw themselves as social service providers, not movement activists. There were certainly moments of tension between harm reduction activists and public officials, but for the most part, they saw themselves as working together towards the same goals.

As with many social movements, the harm reduction movement experienced a tension between value rationality and instrumental rationality. Harm reduction was promoted *both* as an ethical project to promote the dignity and autonomy of drug users and as a practical, cost- and life-saving policy innovation. For every “harm reduction warrior” appealing to rights, a bureaucrat points to cost savings.

This case study shows that the movement succeeded in New York not because advocates or bureaucrats prevailed, but because they continue to work together in tension with each other. The value-rational, politicized dimension of harm reduction motivated both activists within marginalized communities and public health professionals. And its instrumental-rational, practical side is undoubtedly one of the reasons that reformist public health bureaucrats adopted it. This duality has left some activists frustrated and community-based harm reduction organizations experiencing tension with city and state governments. But the fact that harm reduction has managed to maintain both of these dimensions has evidently been important for its success.

By recognizing that we cannot reduce harm reduction either to its radical or practical goals, we can see how it unsettles the standard neoliberal critique of social policy. Such critics have accuse harm reduction of favoring the marketization of drug users both in the political-economic and biopolitical senses of the term. Harm reduction does “roll-out” new forms of social control, in the sense that the state now sanctions syringe exchange. Naloxone undoubtedly simultaneously extends and obscures the reach of the state. Like syringe exchange, it relies on a willing and responsible health care consumer, prepared to assume responsibility for their self care.

But none of this means that the primary function of harm reduction is to increase or transform social control, nor that we should evaluate it on this dimension to the exclusion of all others. As this study has shown, harm reduction activists struggled to transform social policy for more than thirty years. Rather than saying this struggle was compromised because it used some neoliberal tools to succeed, we should treat it instead as an instance where a policy reform movement cannily exploited the stresses and strains within changing welfare and health systems. James Ferguson was right that “to say that certain political initiatives and programs borrow from the neoliberal bag of tricks doesn’t mean that these political projects are in league with the ideological project of neoliberalism.”<sup>1</sup>

Harm reduction is not in league with the ideological project of the “Bloomberg way”<sup>2</sup> or some other shorthand for the forces of neoliberalism in New York. Harm reduction has succeeded not despite “neoliberal” policy trends, but by exploiting them, including pushes toward decentralization, responsabilization, evidence-basedness, policy exceptionalism, and the instrumentalization of social networks. Ultimately, this capacity to exploit the “political opportunity structure”<sup>3</sup> of neoliberalism explains the mystery of this successful pro-poor policy in an era of welfare state retrenchment and other anti-poor developments. Rather than

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<sup>1</sup> James Ferguson, “The Uses of Neoliberalism,” *Antipode* 41.S1 (2009): 174.

<sup>2</sup> Julian Brash, *Bloomberg’s New York: Class and Governance in the Luxury City* (Athens, GA: University of Georgia Press, 2011).

<sup>3</sup> Sidney Tarrow, *Power in Movement: Social Movements and Contentious Politics*, 3<sup>rd</sup> ed. (New York, NY: Cambridge University Press, 2011); David S. Meyer and Debra Minkoff, “Conceptualizing Political Opportunity,” *Social Forces* 82.4 (2004): 1457-1492.



dismissing it for these reasons, we should recognize that a social movement successfully democratized one area of policy.

### III. Contemporary dynamics of institutionalization and policy change

The dynamics uncovered in this study suggest ways in which we can improve the political science literature on social movement institutionalization. To oversimplify the matter, social movements can change policy via institutionalization. This study details the nuances of the process by which this took place in New York . It demonstrates, *contra* the dominant critique of the neoliberalization of social policy, that the institutionalization of social movement insurgencies can yield substantively important policy changes today.

Following from the work of Charles Tilly and others, social movement scholars, especially those drawing on resource mobilization theory, had traditionally defined social movements as outside of the state.<sup>4</sup> From this perspective, the specter of cooptation looms over the integration of movements into the state. Piven and Cloward, for example, argue that the state brings movement elites within its structures in order to neutralize the challenging demand they are placing on the system.<sup>5</sup>

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<sup>4</sup> See Charles Tilly, *From Mobilization to Revolution* (Reading, MA: McGraw Hill, 1978); Sidney Tarrow, *op. cit.*

<sup>5</sup> Francis Piven and Richard Cloward, *Poor People's Movements: How They Succeed and Why They Fail* (New York: Random House, 1977).

Subsequent scholars, however, argued that the distinction between movements and the state is not so simple. Smith and Lipsky described how the state contracts out various functions to non-profit groups.<sup>6</sup> Santoro and McGuire develop the idea of “institutional activists,” arguing that activists inside the state are crucial for policy change.<sup>7</sup> Lambright and O’Gorman’s concept of the “advocacy agency” makes a similar point.<sup>8</sup> Meyer and his coauthors define institutionalization as “the ways in which movement actors are... included in the policy process as legitimate actors.”<sup>9</sup> Another recent articulation of this relationship comes from social movement scholar Lee Ann Banaszak, who describes how social movements operate both “inside and outside the state.”<sup>10</sup> She defines what she calls the “state-movement intersection” as those “self-identified members of the movement who hold recognizable positions within the state.”<sup>11</sup> Banaszak argues that this intersection presents a crucial opportunity for movement actors to influence public policy, and that it can be seen

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<sup>6</sup> Steven Rathgeb Smith and Michael Lipsky, *Nonprofits for Hire: The Welfare State in the Age of Contracting* (Boston, MA: Harvard University Press, 2009 [1993]).

<sup>7</sup> Wayne A. Santoro and Gail M. McGuire, “Social Movement Insiders: The Impact of Institutional Activists on Affirmative Action and Comparable Worth Policies,” *Social Problems* 44.1 (1997): 503-519.

<sup>8</sup> W. Henry Lambright and Mark J. O’Gorman, “New York State’s Response to AIDS: Evolution of an Advocacy Agency,” *Journal of Public Administration Research and Theory* 2.2 (1992): 175-198.

<sup>9</sup> David S. Meyer, “Social Movements and Public Policy: Eggs, Chicken, and Theory,” pp xi-xxxvi in David S. Meyer, Valerie Jenness and Helen Ingram, eds., *Routing the Opposition: Social Movements, Public Policy, and Democracy* (Minneapolis, MN: University of Minnesota Press, 2005): xx. See also David S. Meyer and Sidney Tarrow, eds., *The Social Movement Society: Contentious Politics for a New Century* (Lanham, MD: Rowman & Littlefield, 1998); Traci M. Sawyers and David S. Meyer, “Missed Opportunities: Social Movement Abeyance and Public Policy,” *Social Problems* 46.2 (1999): 187-206.

<sup>10</sup> Lee Ann Banaszak, *The Women’s Movement Inside and Outside the State* (New York: Cambridge University Press, 2010).

<sup>11</sup> Lee Ann Banaszak, “Inside and Outside the State: Movement Insider Status, Tactics, and Public Policy Achievements,” pp 121-148 in David S. Meyer, Valerie Jenness and Helen Ingram, eds., *Routing the Opposition: Social Movements, Public Policy, and Democracy* (Minneapolis, MN: University of Minnesota Press, 2005): 126.

to vary along a continuum, from complete legal exclusion, to being outside government but not excluded, to being inside government but marginalized, to more complete inclusion.<sup>12</sup>

The present study contributes three new points to this literature. First, it develops a model of institutionalization —summarized in the table in chapter one—that adds significant depth to this picture of institutionalization. Using Banaszak’s terms, the harm reduction movement has moved from nearly complete legal exclusion to something more like complete inclusion. But this move required and in turn promoted a deep transformation in the funding sources, scope of action, organizational form and political orientation of harm reduction organizations. This study demonstrates that the state-movement intersection is a dynamic strategic location that changes social movement organizations themselves as well as the state.

Secondly, this study illustrates the political efficacy of “partial institutionalization.” As is detailed in chapter three, providing harm reduction services like syringe exchange to drug users during the height of hysteria of the HIV/AIDS crisis was challenging for groups trying to change policy. Giving needles to drug users in order that they might continue using drugs was unpopular and foreign. Nevertheless, the failure of the city’s initial responses to the AIDS crisis led them to become openly supportive of syringe exchange.

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<sup>12</sup> Banaszak, “Inside and Outside the State,” *ibid.*: 128.

They succeeded in this move through a form of partial institutionalization, the granting of waivers from the rules preventing syringe exchange. Significantly, this allowed syringe exchange to take place without changing the larger legal framework. The state could support harm reduction while under political cover. The CBOs provided a public service through private, but informally state-sanctioned means, allowing the state to foster something that was highly effective but politically unpopular. The partial institutionalization gave activists the time and space to consolidate their programs, build an evidence base to support their policy change efforts, and yet maintain the outsider, oppositional identity that was crucial to their legitimacy within the communities they served.

Partial institutionalization allowed the harm reduction movement to bide its time while it developed a politically viable program. It was not an incomplete form of full institutionalization, but rather a specific and dynamic strategy in its own right. It was politically and substantively functional both for harm reduction activists and for the state. Partial institutionalization allowed innovation to happen by encouraging organizational autonomy for syringe exchanges and political cover for embattled government agencies. Grassroots demanded change and the bureaucracy responded in a way that only partial institutionalization made possible.

Finally, this dissertation connects the larger study of how social movements seeking policy reform contribute to the changing nature of the state. The literature on institutionalization should be brought into sharper dialogue with the literature on neoliberalism precisely on this point. The institutionalization of policy reform movements will differ depending on the specific political opportunity structure of a given aspect of the state. The overgeneralized model of institutionalization developed by Meyer, Banaszak' and others wrongly shifts our focus away from concrete changes in state form. It assumes that social movements institutionalize into a basically static state. But we need to build the changing nature of specific, concrete parts of the state into this theory. Since the 1970s, states have indeed undergone the process of neoliberal market restructuring detailed in chapter two. The literature on neoliberalism sees this almost universally as restricting the field of possibility for progressive policy change. But this case study makes it abundantly clear that this transformation also opens up new moments of progressive institutional change.

#### **IV. Directions for future research**

This study raises important questions for future research and affirms the value of qualitative and ethnographic studies of the policy process.

One major question concerns the future of harm reduction itself. My field research ended just as harm reduction organizations were being integrated into Medicaid. Further study needs to track the continuation of this reform process. How will harm reduction change as it becomes part of the larger logic of the new public health system and less specifically connected to drug use? How will it combine with the other changes in social welfare and drug punishment policies in New York State? Can it help to make drug policy less punitive, or will it merge with punitive techniques in ways that some of its most radical critics fear? Will the state sanction other longstanding harm reduction goals such as the opening of a safer injection facility, or will further bureaucratization marginalize the harm reduction movement? And now that harm reduction is diffusing on the state level, will it jump another scale to the national level?

Secondly, we need to compare the New York case in international perspective. Vancouver, Canada remains the iconic example of North American harm reduction. But it has taken a very different form in New York, seen most clearly in its connection to a privatized health system. Does the New York Model of harm reduction differ from other models in the United States, such those in Chicago or San Francisco? And if so, what role does the New York and U.S. experience play in transnational policy circuits? A close examination of the specificities of harm reduction in New York would also shed light on the ways national and

transnational policy movements tailor their approach to policy change in different settings.

Above all, this study suggests that harm reduction has been institutionalized but not coopted in New York. Future research could develop this contrast between cooptation and institutionalization in greater depth and in other policy venues, because the negative connotations associated with cooptation might prevent movements for policy change from finding creative ways to engage in becoming embraced by official programs. Cooptation may fundamentally be a strategy by which bureaucratic opponents neutralize movements for policy change. This study demonstrates, however, that it can also be a strategy by which movements achieve their goals. The harm reduction example suggests that movements can retain their movement identity while public policy practices embrace their desired changes. Research into other movements should test this hypothesis.

## **V. Conclusion**

The ultimate significance of harm reduction in New York, and more broadly in the U.S., is that a group of people who have been categorically excluded from political society form new, more positive relations with the state. The addiction researcher Gabor Maté argues that prior trauma is invariably at the core of addiction.<sup>13</sup> In an

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<sup>13</sup> Gabor Maté, *In the Realm of Hungry Ghosts: Close Encounters with Addiction* (Toronto, ON: Alfred A. Knopf, 2008).

unequal society, trauma is distributed unequally, as are the habits and harms of addiction. And for the past one hundred years, American drug policy has been geared towards further punishing the traumatized.

Twenty-three years after local public health authorities authorized syringe exchange as an emergency response to the HIV/AIDS crisis, we have made incredible strides in our efforts at prevention and treatment, such that people living with AIDS today can enjoy fuller, healthier lives. But the consequences of the larger pattern of addictions are as harmful as ever. We now face unprecedented levels of drug use, both of the prescribed and illegal varieties. This high level of addiction has enormous consequences for the lives of individuals from all communities which are becoming increasingly difficult to ignore and deny. Harm reduction policies offer us a saner, more just, more humane way of helping people with their struggles.

The harm reduction project is fundamentally humane in providing a way for a disenfranchised group to make claims for the state resources and services they need to continue living. And it creates an avenue for them to become active participants in the policy process. This political inclusion in turn allows them to develop a new view of their relation to the state. As one drug user told researchers, through participating in harm reduction, “you begin to get a different feeling about yourself.



To become part of something for who I am and not for who I am not.”<sup>14</sup> Scholars, activists and policymakers alike need to recognize this sentiment as politically and ethically valuable. Harm reduction, then, is proof that a more just and inclusive world is possible.

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<sup>14</sup> Thomas Kerr et al., “Harm Reduction by a ‘User-Run’ Organization: A Case Study of the Vancouver Area Network of Drug Users (VANDU),” *International Journal of Drug Policy* 17.2 (2006): 67.

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