

# BEYOND METHADONE

IMPROVING HEALTH AND EMPOWERING PATIENTS IN OPIOID TREATMENT PROGRAMS

*Hepatitis C, Overdose Prevention, Syringe Exchange, Buprenorphine  
& Other Opportunities to Make Programs Work For Patients*



## ABOUT THE AUTHORS



**VOCAL-NY** builds power among low-income people affected by drug use, HIV/AIDS and mass incarceration to create healthy and just communities. Through base building, leadership development, participatory research, civic engagement and direct action, we ensure that those who are directly affected by these issues have a say in programs and policies that affect their lives. The VOCAL-NY Users Union specifically organizes low-income people who use drugs (including former users) around ensuring a human rights and health-based approach to drug use.

*Research Partner:*



**Community Development Project of the Urban Justice Center (CDP)** strengthens the impact of grassroots organizations in New York City's low-income and other excluded communities. CDP partners with community organizations to win legal cases, publish community-driven research reports, assist with the formation of new organizations and cooperatives, and provide technical and transactional assistance in support of their work towards social justice.

## ACKNOWLEDGEMENTS

Thank you to the VOCAL-NY members who developed the surveys, interviewed participants and reviewed the report, including George Bethos, Hiawatha Collins, Gwen Collins, Jorge Cotto, Carmen England, Jessica Harris, Rose Lindenmayer, Louis Jones, Arnold McDonald, Jessica Melendez, Vernel Moorner, Pam Neely, Jill Reeves, and Pam Williams. Fred Wright, Erik Haberlen, Alfredo Carrasquillo and Jeremy Saunders provided critical staff support for this project through every stage.

We are grateful to the many methadone patients who participated in this survey by sharing their personal experiences in an opioid treatment system that many characterized as controlling, stigmatizing and uninterested in their wellbeing.

Research, writing and editing support was provided by Alexa Kasdan, Phil Marotta and Alison Hamburg from the Community Development Project. They spent many patient hours working with VOCAL members and staff to complete this report and build our capacity to conduct participatory action research.

A group of public health and policy experts also offered valuable feedback during various stages of this report, including Dr. Naomi Braine, Michael Carden, Michael Duncan, Camila Gelpi, Dimitri Muganis, Dr. Robert Newman, Daniel Raymond, and Dr. Sharon Stancliff.

Design and layout by Christopher Chaput: [cchaput@earthlink.net](mailto:cchaput@earthlink.net)

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# EXECUTIVE SUMMARY

## Background

Over the last three decades, the War on Drugs has stripped people of myriad rights, blocked life-saving public health policies and created new social problems, such as housing and job discrimination. The negative consequences of criminalization are not felt equally, as communities of color and low-income people are much more likely to be targeted for drug-related law enforcement.

Increasingly, New York has recognized that drug use is more effectively addressed through a health and safety approach, rather than a criminal-justice approach. One important example is Opioid Treatment Programs (OTPs), which offer methadone and buprenorphine (synthetic opioids) to people who are dependent on heroin and other opioids. Methadone treatment has been shown to be highly effective in reducing the risk of HIV and Hepatitis C Virus (HCV), drug overdose and incarceration while also improving a person's quality of life. In fact, nearly 30,000 New York City residents rely on methadone maintenance treatment to manage their dependence on heroin and other opioids.

Policymakers and public health officials should devote attention to improving OTPs for several reasons. First, serious health issues affecting active and former drug users, such as HCV and overdose, can be mitigated through effective methadone programs. Second, drug-policy reforms have diverted people into treatment programs over prison. Third, growing interest in reducing Medicaid spending has drawn attention to effective treatments for drug use and related harms. Lastly, the New York Office of Alcohol and Substance Abuse (OASAS), the state oversight agency, may soon be consolidated with other state agencies, opening up the possibility for review of its programs.

While methadone can reduce government spending and improve public health, VOCAL New York (VOCAL-NY) has identified a number of concerns related to the provision of care at OTPs in New York City. Accordingly, with the research support of the Community Development Project (CDP) of the Urban Justice Center, VOCAL-NY conducted the current study to gather detailed data from the perspective of OTP patients on the key challenges and opportunities for OTPs in New York City.

## Findings

After conducting over 500 surveys and five focus groups with OTP patients, VOCAL-NY identified five key areas that require urgent attention by both OASAS as well as individual methadone programs.

## Harm Reduction & Other Medical Interventions

► ***The study found that OTPs fail to provide harm reduction and other medical interventions, especially overdose prevention and syringe access, for patients who actively use drugs.***

- One out of ten survey respondents reported experiencing a drug overdose during the past two years and one out of five reported being in the presence of someone who overdosed;
- Seven out of ten survey respondents reported that there was no education to prevent overdose at their OTP;
- Three quarters of survey respondents supported making sterile syringes available at their program to prevent the spread of HIV and HCV.

## Hepatitis C Virus (HCV)

► ***The study found that although HCV is an urgent and severely neglected health issue among OTP patients, most OTPs do not adequately address the virus.***

- More than half of survey respondents who reported testing positive for HCV at their program said they did not receive a viral-load test, and less than 5% reported being referred elsewhere for a viral-load test;
- More than half of survey respondents were not referred by their OTP to a medical professional for HCV care;
- One quarter of survey respondents reported not receiving any services for HCV at their program.

## Treatment Interruptions

➤ ***The study found that interruptions in methadone treatment occur because of limited clinic hours, delays in transportation assistance and Medicaid case closures, which undermine program effectiveness and lead to risky behaviors.***

- More than half of survey respondents reported missing a methadone dose due to limited clinic hours;
- About one-third of survey respondents reported missing a methadone dose due to a delay in transportation assistance;
- Nearly one in ten survey respondents reported missing a methadone dose due to a Medicaid case closure or “cut-off.”

## Patient Rights & Involvement

➤ ***The study found that OTP patients are not properly informed of their rights regarding treatment alternatives, advisory bodies and grievance procedures. Increased patient control can improve treatment adherence, retention and overall well-being for patients.***

- Nearly four in ten survey respondents said they were not aware of a patient bill of rights posted at their program;
- More than one-third of survey respondents did not know how to file a grievance if there was a problem with their counselor, and more than two-thirds reported there was no information posted about how to file a grievance.

## Security and Policing

➤ ***The study found that police and security guards at or near OTPs target methadone patients for arrest and harassment. This creates barriers to treatment, health and safety for patients.***

- Nearly four in ten survey respondents reported being stopped and frisked by police outside their clinic site;
- Seven in ten survey respondents witnessed someone else being frisked or harassed by police while entering or leaving the clinic.

## Recommendations

Opioid treatment is widely recognized as a highly successful and cost-effective treatment for dependence on heroin and other opioids, with numerous benefits for both individual patients and the broader community. However, as findings in this report indicate, the New York State Office of Alcohol and Substance Abuse Services (OASAS) and individual OTPs are failing to meet patients’ needs. Based on the findings in this report and current political and policy developments, **VOCAL-NY** recommends the following to OASAS and New York City OTPs (the complete list of recommendations can be found in full report).

### **1. Promote greater access to Hepatitis C Virus (HCV) prevention, care and treatment.**

- OTPs should provide on-site HCV treatment and care at clinics equipped to provide primary care services. Programs that are unable to offer on-site viral load tests, liver biopsies and/or treatment for HCV should establish a concrete referral system and enter into memoranda of understanding (MOUs) with medical providers for follow-up care for methadone patients with chronic HCV.
- OASAS should track how well OTPs link patients with chronic HCV to care and treatment by monitoring the following indicators at each program on an aggregate basis: prevalence of HCV; availability of diagnostics and on-site treatment; patients receiving treatment on-site; patients enrolled in treatment through the OTP; and participation in HCV support groups.

### **2. Offer harm-reduction services, including syringe access and overdose prevention, for methadone patients who continue using drugs.**

- OTPs should register with the New York State Department of Health (DOH) for the Expanded Syringe Access Program (ESAP) and Safe Sharps Collection Program, which would allow them to make syringes available to patients without a prescription and offer safe disposal.
- OASAS should require OTPs to make naloxone and overdose prevention counseling available to all patients – especially those who are newly enrolled, are being discharged or have positive toxicologies for outside opioid use – and create an Ambulatory Patient Group (APG) reimbursement rate.

### **3. Provide complete and accurate information about treatment options to all patients, including information about buprenorphine as an alternative to methadone maintenance treatment.**

- OASAS should require OTPs to offer all patients the option of receiving buprenorphine as an alternative to methadone during their initial intake, and to modify methadone enrollment consent forms so that they discuss buprenorphine as an alternative to methadone.
- OTPs should make buprenorphine prescriptions available on-site for patients who choose it as an alternative to methadone maintenance treatment and connect patients with a physician for ongoing buprenorphine treatment.

### **4. Improve coordination and delivery of services and programs for OTP patients in order to prevent treatment interruptions.**

- OTPs should require counselors to immediately inform patients when they qualify for additional take-home doses, and document it in their record, in order to promote maximum patient autonomy.
- OASAS should advocate that officials at the federal level enact reforms that will enable patients to qualify for take-home doses sooner with fewer restrictions.

### **5. Increase patients' understanding of their rights, enhance patients' decision-making authority within the program, and take steps to reduce police harassment of patients.**

- OTPs should invest in creating active, meaningful patient advisory committees (PACs) through staff support, funding and training opportunities that empower patients with greater decision-making authority.
- OASAS should educate law enforcement about opioid dependence and the importance of OTPs in order to prevent police harassment of patients.



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# INTRODUCTION

## Background

Over the last three decades, the war on drugs has become a war on *people who use drugs*, stripping them of myriad rights. This criminal justice approach to drug policy has created more problems than it has solved. It has impeded practical health policies, such as syringe exchange to prevent transmission of HIV and viral hepatitis, and created new social problems, such as housing and job discrimination against individuals formerly incarcerated for drug offenses. Moreover, the negative consequences of criminalization are not felt equally, as communities of color and low-income communities are much more likely to be targeted for drug-related law enforcement.

Increasingly, New York has recognized that drug use is better addressed through a health-and-safety approach. This is seen in recent drug policy reforms that emphasize alternatives to incarceration for drug offenses. One important health-based approach is treatment for opioid dependence. Opioid treatment programs (OTPs) offer methadone and buprenorphine (synthetic opioids) to people who are dependent on heroin and other opioids.<sup>1</sup> Opioid treatment has been shown to be highly effective in reducing the risk of HIV and HCV, drug overdose, incarceration and other problems related to illicit opioid use, while also improving a person's quality of life.<sup>2</sup>

People seek out opioid treatment in order to improve their health and gain more stability in the face of problems related not only to physical and mental health, but also concerns such as housing, employment and family status. Patients in OTPs may have different goals for seeking treatment, from abstaining completely from drugs to better managing and reducing their use. Nearly 30,000 New York City residents rely on methadone maintenance treatment to manage their dependence on heroin and other opioids by preventing withdrawal symptoms, suppressing cravings and blocking the effects of street opioids.<sup>3</sup> While methadone can effectively mitigate health concerns associated with opioid use and dependence, **VOCAL New York (VOCAL-NY)** has identified a number of concerns related to the care provided at OTPs in New York City. In order for OTPs to live up to their full potential to improve the health and quality of life of OTP patients, these concerns must be addressed at both the program and state level.

Policymakers and public health officials should devote attention to improving OTPs for several reasons. First, serious health issues affecting active and former drug users, such as HCV and overdose, can be mitigated through effective treatment programs. Second, drug policy reforms have diverted people into treatment programs over prison. Third, growing interest in reducing Medicaid spending has drawn attention to effective treatments for drug use and related harms. Lastly, the New York Office of Alcohol and Substance Abuse (OASAS), the state oversight agency, may soon be consolidated with other state agencies, opening up the possibility for review of its programs.



Photo: Julie Turkewitz

As members of VOCAL New York's Users Union, we advocate an approach to drug use that is rooted in human rights and public health, not criminal law.<sup>4</sup> While we do not argue for one theoretical understanding of drug dependence over another, we do believe that individuals, whether they are actively using drugs or not, should control their treatment and have access to all available harm reduction tools, health care and other social services.

### The current study

VOCAL-NY, with the research support of the Community Development Project of the Urban Justice Center (CDP), conducted the current study to gather detailed data from the perspective of OTP patients on the key challenges and opportunities for OTPs in New York City. As a result of the study, VOCAL-NY has identified five key areas that require urgent attention by both OASAS as well as individual OTPs:

- **Harm Reduction and Other Medical Interventions:** The study examines access to health services, such as overdose prevention, syringe access, and alternative treatments for opioid dependence such as buprenorphine. These services can reduce health risks for methadone patients who continue using drugs or relapse while in treatment.
- **Hepatitis C:** As hepatitis C virus (HCV) is one of the largest unmet health needs among active and former drug injectors, this study explores knowledge of and access to treatment for HCV among methadone patients.
- **Treatment Interruptions:** The study uncovers barriers to consistent methadone treatment that cause patients to miss doses, which can lead to illicit drug use and other high risk behaviors.
- **Patient Rights and Involvement:** Increased patient control can improve treatment adherence, retention and overall well-being.<sup>5,6</sup> The study investigates the ability of patients to participate in their own treatment by having more of a voice in developing the policies of the clinics they frequent.
- **Security and Policing:** The study explores patients' experiences with law enforcement and clinic security guards, particularly examining how negative interactions with law enforcement and security create a barrier to treatment.

### Organization of the report

This report outlines missed opportunities to improve the quality of OTPs and recommends a robust and comprehensive approach to addressing patients' health needs. First the research methodology is described, followed by background information on methadone treatment, methadone patients, and the federal regulation of methadone treatment. The report then presents survey and focus group findings according to each of the five key areas identified by VOCAL-NY. Next, in order to set the stage for possible actions at the policy level, the current political context is discussed. Finally, the report presents a set of recommendations for OASAS and New York City OTPs.



# METHODOLOGY

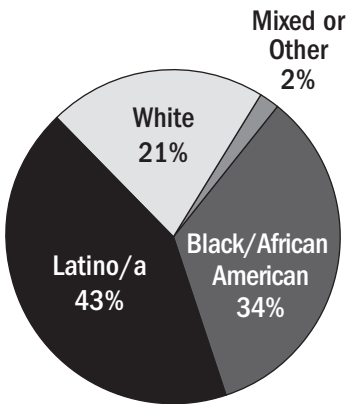
The research findings in this report are based on surveys and focus groups with OTP patients and supplemented with secondary research from public health journals. VOCAL-NY and CDP utilized a participatory action research approach wherein methadone patients were involved in designing, conducting and reviewing the research. Surveys were administered by trained VOCAL staff and members to 502 methadone patients at 29 different OTPs from May to August, 2010. In addition five focus groups with 33 OTP patients were conducted from September to November of 2010. Surveys were primarily conducted through the three largest OTP outpatient agencies in New York City: Beth Israel (41.6% of survey respondents), Narco Freedom (26.5% of survey respondents) and the Addiction Research and Treatment Corporation (ARTC) (22.3% of survey respondents).

**Beth Israel** manages a large network of methadone programs serving approximately 6,000 opioid-dependent patients in 18 clinics throughout New York City. **Narco Freedom** provides 34,000 patients an array of substance use, medical and psychiatric treatment services. The **Addiction Research and Treatment Corporation (ARTC)** serves over 30,000 patients through its drug treatment programs.

## Participant characteristics

A diverse sample of methadone patients completed the survey. The racial/ethnic breakdown of survey respondents was 43% Latino/a, 34% Black, 21% White and 2% other or mixed race (see Figure 1). Females accounted for 41% of respondents, and 10% of respondents identified as LGBTQ. About 31% of respondents had children under 18, and nearly half of these parents did not have custody of their children. Nearly 40% of respondents had been homeless or in a homeless shelter in the past year.

**Figure 1: Race/Ethnicity of Survey Respondents**



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## BACKGROUND

### Methadone Treatment

It is critical to know how methadone works and how it is regulated in order to understand what challenges and opportunities patients face. Methadone is a highly effective and safe treatment for those dependent on heroin, other opioids (e.g., prescription medications) or some combination of the two. According to the National Institutes of Health (NIH), of the treatments available for opioid dependence, methadone maintenance treatment, when combined with attention to medical, psychiatric, and socioeconomic issues, has the highest probability of being effective.<sup>7</sup>

Methadone is a relatively long-lasting opioid, remaining active in the body for 24 to 36 hours. As a continuous treatment that can last for years, it requires daily dosing. While some patients are permitted “take-home” doses if they meet criteria meant to prevent diversion (the illegal distribution and sale of methadone), federal guidelines require most methadone patients to attend clinic appointments three to six days per week. Although these federal regulations limit patient autonomy, the frequent visits currently required by OTPs provide an opportunity for otherwise underserved patients to access health care and social services. In fact, OTPs represent a primary health care site for many patients.<sup>8</sup>

While methadone can be used for time-limited detoxification from opioids, this report focuses on methadone as a *maintenance* therapy over time. Maintenance treatment is recommended over detoxification (typically 30 days or less) for most people who are opioid-dependent and seeking methadone treatment because the benefits of treatment and improvements in quality of life are more sustainable. Maintenance is also considered more cost-effective than detoxification because it is more likely to cut down on overall healthcare spending (including mental health and drug treatment) and illicit opioid use over time.<sup>9, 10, 11, 12</sup>

Methadone treatment reduces illness and death related to opioid use and helps people to better function in everyday life. It is proven to lower illicit opioid use, criminal activity and incarceration; increase employment; and improve familial relationships.<sup>13</sup> Notably, methadone therapy has been found to decrease weekly heroin use by 69% and criminal behavior by 52%, while increasing employment by 27%.<sup>14</sup>

Methadone is a cost-effective public health intervention.<sup>15, 16</sup> National cost-benefit analyses reveal that every \$1 spent on methadone maintenance yields a return of \$4 to \$7 in government savings, and the cost of administering methadone is far less than the cost of incarceration.<sup>17</sup> While some research estimates the annual cost of an individual’s drug dependence to be \$43,000 annually, methadone maintenance treatment costs only \$3,500 annually per patient, according to the Office of National Drug Control Policy.<sup>18</sup>

### Methadone Patients

Approximately 254,000 patients are enrolled in methadone maintenance treatment nationwide.<sup>19</sup> Some methadone patients may continue using opioids while enrolled in treatment because of inadequate dose levels or other factors, including personal choice or dependence on alcohol or other types of drugs unaffected by methadone. Former and current opioid users can have serious, unaddressed health issues beyond drug dependence. They are more likely to experience multiple health problems and wait longer to seek medical care than the average person, meaning more emergency room visits and higher medical costs.<sup>20, 21</sup> They experience disproportionately high rates of HIV, viral hepatitis, bacterial infections, tuberculosis and sexually transmitted infections compared to the general population.<sup>22</sup> Accordingly, OTPs can be an important platform for delivering health care to former and active opioid users, who often face barriers in traditional care settings.

### Regulation of Methadone

Historically, methadone has been tightly regulated at the federal and state levels, producing what many

patients describe as restrictive, hostile programs that fail to meet their basic needs. At the federal level, the Substance Abuse Services and Mental Health Administration's (SAMHSA) Center for Substance Abuse Treatment (CSAT) has primary responsibility for overseeing OTPs. CSAT assumed jurisdiction following criticism of excessive federal regulation of methadone and recommendations for improving quality of care.<sup>23</sup> <sup>24</sup> CSAT now requires OTPs to become accredited by one of four independent organizations responsible for setting standards of care and evaluating performance.<sup>25, 26</sup> In addition, OTPs must comply with regulations outlined in the Drug Enforcement Agency's (DEA) Controlled Substance Act in order to gain federal approval, and the DEA remains responsible for the oversight of diversion.<sup>27</sup>

There is an additional level of regulation at the state level. In New York, the Office of Alcohol and Substance Abuse Services (OASAS) certifies OTPs and primarily finances treatment and care through Medicaid. OASAS recently overhauled the Medicaid reimbursement structure for methadone and other opioid treatment services with the enactment of new rates based on an "Ambulatory Patient Group (APG)" model. The agency also began implementing evidence-based practices to improve the quality of OTPs and other licensed drug treatment programs through its Gold Standard Initiative.<sup>28</sup> As part of this initiative, OASAS will be issuing scorecards evaluating providers' performance. It remains to be seen whether these changes will improve the overall quality of OTPs from the perspective of patients.

Much of the federal regulation of methadone has undermined access to methadone treatment, leading one panel of medical experts in the late 1990s to conclude: "We know of no other area where the Federal Government intrudes so deeply and coercively into the practice of medicine."<sup>29</sup> Although federal regulation has since decreased, methadone remains a highly controlled medication that can lead to burdensome treatment models. It is also notable that buprenorphine, another important medication for treating opioid dependence, is less tightly regulated than methadone, which raises further questions about why access to methadone continues to be so restricted.

There are many unnecessary, counterproductive restrictions on methadone access, such as limited treatment settings (methadone treatment is almost exclusively available through licensed OTPs) and dosing regulations that typically require daily in-person visits to programs. Additionally, general practitioners cannot legally prescribe methadone for maintenance therapy and access to methadone through pharmacies is limited in the United States, although programs outside the country have demonstrated the benefits of these delivery methods for patients.<sup>30</sup>

Because most patients receiving methadone treatment are required to make daily, in-person visits to their program on a long-term basis, their interactions with staff provide important opportunities to improve their overall health and well-being. As such, OTPs can serve as health care homes for patients who may not otherwise access health care services, as OTPs offer integrated addiction, mental health and physical health services. At the same time, methadone patients tend to express frustration about excessive requirements in their programs, such as frequent in-person visits, and which can be attributed to the complex regulations that govern methadone treatment.

Much of the federal regulation of methadone treatment is driven by fear of "diversion," or illegal sale or trade in methadone. This concern is misplaced, given that illegal methadone distribution has been concentrated among people who cannot access methadone treatment, rather than for recreational or casual use.<sup>31</sup> Consequently, the best way to address diversion may be to expand, not constrict, OTP access, encouraging program enrollment and patient retention.

This report focuses on OASAS and individual OTPs, although it is important to remember that many of the policies they follow are designed at the federal level.

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## FINDINGS

This section presents findings on each of the five issues identified by VOCAL-NY: 1) Harm Reduction and Other Medical Interventions; 2) Hepatitis C; 3) Treatment Interruptions; 4) Patient Rights and Involvement; and 5) Security and Policing. Each subsection discusses the importance of the issue in the context of OTPs and highlights key survey and focus group findings.

### ISSUE 1: Harm Reduction & Other Medical Interventions

*“They punish us in a way if we are on methadone, if they see that our urine is still dirty for heroin. Any methadone program where you have drug addicts, you need to have needle exchange to save lives.”*  
– (Focus Group # 1)

Harm reduction is a public health approach that seeks to “meet people where they are” without defining abstinence as the sole goal of treatment.<sup>32</sup> A harm reduction approach acknowledges that some people are unwilling or unable to stop using drugs completely, and that they deserve tools that will enable them to reduce or eliminate potential harms related to drug use. A harm reduction approach also recognizes that drug-related hazards such as disease transmission or overdose can result from broader social factors, including laws and policies that make it difficult to use drugs safely. Methadone maintenance is one harm reduction approach. Additional examples include syringe exchange, overdose prevention training, and counseling on the adverse effects of mixing methadone, drugs and alcohol. The history of harm reduction indicates that people who use drugs are eager to protect themselves, their families and their communities when empowered with the tools to do so.<sup>33</sup>

Methadone effectively and indirectly reduces the use of opioids and other drugs. However, many patients continue using drugs and alcohol or may relapse while enrolled in treatment.<sup>34, 35, 36</sup> This can pose health risks if unacknowledged and unaddressed. OTPs generally have difficulty dealing with continued drug use, in part because they employ treatment approaches meant to eliminate drug use completely. This mindset prevents OTPs from providing harm reduction services such as overdose prevention and syringe exchange to methadone patients who use drugs regularly or relapse. These missed opportunities increase the risk of overdose and communicable disease transmission.

Heroin and other opioids – whether legally prescribed or illicit – are not the only substances that pose a health threat to methadone patients. Drug and alcohol interactions are a serious risk for those who continue using during treatment. Incorporating a harm reduction approach into OTPs means addressing the adverse consequences of drug mixing.

Survey and focus group data indicate that OTPs are missing a critical opportunity to practice harm reduction and other medical interventions that could prevent disease transmission and death. These missed opportunities occur in four areas: overdose prevention, syringe access and disposal, informing patients about treatment alternatives and counseling patients about health risks of poly-substance use.

#### **KEY FINDINGS: OTPs fail to provide harm reduction and other medical interventions, especially overdose prevention and syringe access, for patients who actively use drugs.**

Through this research, VOCAL-NY identified trends that indicate the failure of OTPs to practice harm reduction and prevent disease transmission and death. Moreover, VOCAL-NY found patient support for harm reduction services that can be immediately adopted by OTPs.

**A. Most surveyed methadone patients know other patients who actively use drugs while receiving methadone.**

- Three quarters of respondents (73.5%) said they know someone in their program who mixes legal and illegal substances with their methadone, a finding consistent among all clinics surveyed.

**B. Methadone patients and people in their immediate social networks are at high risk for drug overdose; however, most methadone patients surveyed did not receive any training or education about preventing and responding to an overdose.**

- One out of ten respondents (10.2%) reported experiencing a drug overdose during the past two years, and one out of five (21.1%) reported being with someone when they overdosed.
- Seven out of ten respondents reported that there was either no education (50.2 %) or that they were unaware of any education (21.2 %) to prevent overdose at their program.

Accidental drug overdose is a leading cause of emergency room visits, hospitalizations and premature death statewide, although New York City has recently experienced success with expanded overdose prevention initiatives.<sup>37</sup> Statewide, the Department of Health reported 8,756 emergency room visits related to opioid use and more than 22,000 hospital admissions related to opioids in 2007.<sup>38</sup> Even after a recent reduction in New York City, drug overdose remains the fourth leading cause of premature death for City residents.<sup>39</sup>

Fatal drug overdose from heroin and other opioids could be better prevented if naloxone (sold under the name Narcan) were made available and drug users were trained to use it. Naloxone is a prescription medication that can be administered by non-medical personnel to reverse an opioid-caused overdose. Since federal regulations made naloxone more widely available in 2006, thousands of lives have been saved through programs that train active drug users and people in their networks to administer it.<sup>40</sup> New York City's success in reducing fatal overdose deaths occurred during the same time naloxone became more widely available, and the NYC Department of Health & Mental Hygiene (DOHMH) recommends expanding availability further.<sup>41</sup>

Focus group participants highlighted the need for overdose prevention:

*"I overdosed two years ago. None of my friends knew about Narcan. The time it took them to call the ambulance to get me down from the roof I could have died." – (Focus Group #3)*

*"I have never seen in a methadone program an overdose prevention kit. I have never seen an overdose prevention kit anywhere by staff, by doctors or by the nurse who dispenses the juice. If there is anyone who needs [an overdose prevention kit] it is a methadone program." – (Focus Group # 1)*

Methadone patients are well positioned to respond to drug overdoses if they continue using drugs or otherwise remain in the social networks of users. Moreover, methadone patients who use drugs after a period of abstinence are at elevated risk for overdose because their tolerance level may be lower. Most methadone patients have witnessed someone else overdose at some point in their life, and research has found that as many as 80% of heroin-related overdoses occur in the company of other users.<sup>42</sup> Rarely do people who witness an overdose contact 911 emergency services, in part due to fear of police contact. This further underscores the importance of training and education.<sup>43</sup>

**C. Most methadone patients support syringe exchange services at their program.**

- Three quarters of respondents (73.1%) said they wanted their programs to make available a disposal site for used syringes.
- An equal number of respondents supported making sterile syringes available at their program to prevent the spread of HIV and HCV.



Syringe access and safe disposal programs are highly effective interventions to prevent the spread of blood-borne pathogens such as HIV and HCV, promote proper disposal of used syringes and connect injection drug users to an array of social services.<sup>44</sup>

Unsafe syringe use and disposal is prevalent among methadone patients. While most patients stop using heroin after beginning methadone treatment, some continue injecting heroin, especially during the first months of treatment, or other drugs unaffected by methadone (e.g., cocaine). In a study of patients entering a Bronx methadone program, 69% of injection drug users reported unsafe syringe sources and 80% reported reusing syringes, with syringe sharing also common. Two thirds of patients interviewed for the Bronx study also reported improperly disposing of syringes in the trash.<sup>45</sup> In terms of preventing the spread of HCV, access to sterile syringes and other injection equipment (e.g., cookers and water) is more important than knowledge of HCV status.<sup>46</sup> Given that methadone patients may relapse or continue injecting heroin or other drugs, OTPs are ideal, obvious locations for syringe exchange.

Participants expressed frustration about punitive approaches to drug use in OTPs and the need for syringe access:

*“They punish us in a way if we are on methadone, if they see that our urine is still dirty for heroin. Any methadone program where you have drug addicts you need to have needle exchange to save lives.”*  
– (Focus Group # 1)

*“It is a good idea for people to not use each others’ dirty needles to prevent hepatitis C. I think it is a good idea, I think they should have [syringe exchange] because people do come on a program in the beginning, and they still use because they have to get to a certain level for it to kick in so you don’t have that craving anymore. It took me a month or two.”* – (Focus Group #1)

### **D. Patients are not fully informed of their treatment options by counselors.**

- **About two thirds of respondents (62.5%) did not receive any information about buprenorphine (brand name Suboxone) by their counselor or medical professional.<sup>47</sup>**

Buprenorphine is another medication to treat opioid dependence. It is taken at a low, daily dose to help a person stop using heroin and other opioids by blocking withdrawal symptoms, and can be used either for detoxification or maintenance. It is equally effective as methadone in moderate doses.<sup>48, 49</sup>

Physicians are now allowed to prescribe buprenorphine in office-based settings for both detoxification and maintenance of heroin and other opioids. The medicine is marketed under the brand name Suboxone as a combination of buprenorphine and naloxone (which blocks the effects of opioids if taken) for maintenance treatment, and is available as a tablet or film that dissolves in the mouth. While similar to methadone in that it suppresses cravings for opioids, buprenorphine has certain advantages, including take-home prescription, a lower level of physical dependence, fewer withdrawal symptoms if discontinued, and less risk for overdose if misused.<sup>50, 51</sup>

There are numerous junctures at which an OTP can inform patients about buprenorphine as an alternative treatment option, including at intake and during periodic discussions about treatment. Furthermore, federal CSAT accreditation guidelines recommend that “patients are informed about alternative medications, treatment alternatives, alternative modalities, and scientific advances affecting treatment.”<sup>52</sup> State OASAS regulations require that OTP Medical Directors become certified to prescribe buprenorphine and outline initial dosing requirements for OTP patients who choose buprenorphine, but they do not require that OTPs inform patients about the availability of buprenorphine as an alternative treatment for opioid dependence.

Focus group participants shared their experiences with treatment alternatives at their OTPs.



*“Having [buprenorphine] at a methadone program would be fine, but if they made it so that you would have to come in to get your pill, they look at you in your face at the window, and it got dispensed and you put it on your tongue, and the person that dispensed it would watch you as long as it took for you to dissolve it. If they did it that way, it would be just like getting [methadone]. If they [offered buprenorphine] at a methadone program I would fear that they would institutionalize it.”*

– (Focus Group #5)

*“At [my program], there was a point where they weren’t offering [buprenorphine] to people there already, they were only offering it to newcomers.” – (Focus Group #5)*

### Summary

Many OTPs define abstinence as the primary goal of treatment, and their failure to offer harm reduction services puts patients at risk for disease transmission and fatal drug overdose. The reality is that methadone patients may continue actively using drugs, especially after first enrolling in treatment, and may relapse at some point. Most patients surveyed have not been informed about buprenorphine as an alternative treatment to methadone that would allow greater independence and potentially produce better treatment outcomes. Therefore, OASAS and OTPs should ensure patients have access to overdose prevention training and naloxone, syringe access and disposal, as well as information about buprenorphine.



## ISSUE 2: Hepatitis C Virus (HCV)

*“I think all methadone clinics should have at least one on-site specialist for Hep C because Hep C is an epidemic that affects drug users, particularly injection drug users, and that is who goes to methadone clinics.” – (Focus Group # 2)*

### Background on HCV and OTP Patients

Hepatitis C is an infectious disease caused by the hepatitis C virus (HCV) that attacks the liver. Even though HCV is the most common blood-borne infection in the United States, most of the four to five million Americans living with chronic HCV infection have no symptoms and are unaware of their status.<sup>53</sup> While most will not develop serious liver damage, about one in five will progress to liver scarring (cirrhosis), leading to liver failure, cancer, transplant or death. There are about 12,000 deaths due to HCV nationwide each year.<sup>54</sup>

HCV is prevalent among methadone patients, and ensuing liver disease causes a substantial number of premature deaths in this population.<sup>55</sup> Between 67 to 96% of methadone patients test positive for HCV antibodies.<sup>56, 57</sup> Nationwide, people who inject drugs are at the greatest risk for acquiring HCV, representing more than two thirds of all new cases of infection in the U.S. and about 60% of those who are HCV-infected.<sup>58</sup> Even people who inject drugs for a relatively short period of time are highly vulnerable to HCV infection. Within two years, approximately three quarters of injection drug users will test positive for HCV antibodies, with 94% testing positive after 10 years of injection drug use.<sup>59</sup> There is no vaccine to prevent HCV. Clearly, HCV treatment and prevention are critical issues for OTPs to address.

### HCV Treatment

Unlike with HIV, about half of patients being treated for HCV are able to clear the virus or have it cure through a “sustained virological response,” and this rate will likely improve as new treatments become available. Current standard treatment for HCV involves a weekly injection of Peg-interferon and daily Ribavirin taken orally for a period of 6 to 12 months, with regular monitoring in order to measure whether there is a virological response.<sup>60</sup> Goals for treatment are reaching an undetectable HCV viral load and preventing or delaying further liver damage.

Treatment for HCV recently experienced a major breakthrough.<sup>61</sup> The first drug in a new class of HCV treatment, protease inhibitors, was recently approved by the Food and Drug Administration (FDA) and is expected to both shorten treatment timelines and boost cure rates.<sup>62</sup> The new treatment is expected to improve cure rates among African Americans and Latinos in particular, who have benefited less from the existing standard of care. Unfortunately, the new treatment will still be paired with the Peg-interferon and Ribavirin, meaning that patients may continue to experience the same or even more negative side effects.

Side effects of the HCV treatment regimen may mirror withdrawal symptoms from heroin and other opioids, which can make it difficult for patients to take their medication regularly and can trigger drug use. Counseling and support groups can lessen the impact of side effects and improve treatment adherence, however.

### Barriers to Treatment

Because of systemic barriers, very few people with chronic HCV undergo treatment. Doctors often fail to offer treatment to active drug users, people with a history of psychiatric illness or homeless individuals, despite NIH recommendations that active users or those facing other challenges should not be excluded from treatment.<sup>63</sup> Other factors include poor referral systems and follow-up.<sup>64, 65</sup> Other barriers to treatment include patient factors such as lack of knowledge about HCV, absence of symptoms, and fear of treatment side effects.

Proven approaches to overcoming these treatment barriers exist. For example, methadone patients who receive HCV treatment and diagnostic services on-site at their OTP are much more likely to follow through with treatment than those who are referred outside their clinic.<sup>66</sup>

### OTPs as HCV Treatment & Prevention Opportunity

OTPs provide an exceptional opportunity to offer voluntary HCV testing, education, counseling and linkage to treatment because of the high prevalence of HCV among patients and their frequent contact with the program.<sup>67</sup> OTPs are well positioned to offer on-site “directly observed therapy” of weekly injections and daytime medication doses during the treatment period. Regardless of whether treatment is available on-site or through strong referral agreements, OTPs can support adherence to HCV care and treatment. Despite the availability of promising models for comprehensively addressing HCV among methadone patients, VOCAL-NY’s research finds that most New York City OTPs fail to adequately educate and care for patients with chronic HCV.

Preventing new cases of HCV transmission is another important issue for OTPs. Methadone patients are still at risk for acquiring or transmitting HCV if they continue injecting heroin or other drugs, which is associated with treatment interruptions (where a patient misses one or more methadone doses) or inadequate methadone dose levels.<sup>68</sup>

### **KEY FINDINGS: Although HCV is an urgent and severely neglected health issue among methadone patients, most OTPs do not adequately address the virus.**

*“[The staff at methadone clinic] will tell you not to eat doughnuts, but nothing about hepatitis C.”  
– (Focus Group # 1)*

#### **A. Many patients are unaware of or confused about their HCV status in spite of OASAS requirements that OTPs test patients for viral hepatitis within one week of admission.<sup>69</sup>**

- Only one in three respondents (35.9 %) reported ever having tested HCV-positive at their clinic, even though an estimated 60 to 90% of OTP patients are HCV-positive.
- More than one in four of all respondents (27.9%) reported never having had an HCV test at their clinic.

OTPs are required by OASAS to test patients for viral hepatitis within one week of admission, to train staff in viral hepatitis and other communicable diseases and to have a staff “Health Care Coordinator” responsible for coordinating these services for clients. New York’s OASAS also requires the presence of a Medical Director, nurses and administrator with various responsibilities for supervising medical care and referrals.<sup>70</sup> Federal CSAT guidelines go further and recommend advanced testing for HCV and liver function along with on-site treatment.<sup>71</sup> Based on the findings from the current study, OTPs do not appear to be adhering to these federal and state guidelines.

A series of tests is needed to determine whether a patient has chronic HCV infection, to observe the progression of the virus and its impact on the liver and to gauge eligibility for treatment. Each year, as part of the required annual health screening at OTPs, all methadone patients should be offered tests for HCV antibodies to determine if they were ever infected with HCV. Those who test positive for HCV antibodies must be informed of their test results and offered counseling so they can decide whether to seek additional testing for chronic HCV infection. Participants in the study described their concern about HCV and the lack of support they experienced at their program:

*“I never found out I had Hep C. They [the OTP] never told me. Even when I went to the program, they never told me I had Hep C.” – (Focus Group # 1)*

*“I’m definitely concerned about Hep C. It affects a lot of people. People aren’t even aware they have it and people are likely to transmit it. It’s a terminal disease. It can kill you.” – (Focus Group # 2)*

## B. Methadone patients who initially test positive often do not receive additional tests, services or treatment for HCV at their clinic (see Figure 2).<sup>72</sup>

- More than one half of respondents (58.1%) who reported testing positive for HCV at their program said they did not receive a viral load test.
- Less than 5% reported being referred elsewhere for a viral load test.
- Eight out of ten (81.1%) did not receive an explanation of the role of a liver biopsy in treatment.
- More than half (56.8%) were not referred to a medical professional for HCV care.
- One quarter (23.6%) reported not receiving any services.

**Figure 2: Lack of HCV Services at OTPs**

HCV Service	Percent of Respondents that did NOT receive service at OTP
HCV Testing	58.1%
Referral for Viral Load Test	95.0%
Referral for HCV Care	56.8%
Any HCV Services	23.6%

If a patient tests positive for HCV antibodies, s/he should be offered a second test to measure viral load and determine if s/he has a chronic HCV infection.<sup>73</sup> A viral load test can also help assess whether a person should consider starting treatment. In order to evaluate how much, if any, damage there has been to the liver, a biopsy can also be offered.

If viral load and liver biopsy tests cannot be offered on-site, patients who test positive for HCV antibodies should be linked to care through a strong referral system and a peer advocate who can escort them to appointments. Barriers to treatment such as housing instability, co-occurring mental health issues and provider bias against active drug users should be taken into consideration and *not* prevent further evaluation and treatment. Focus group participants reported the lack of services and referrals from methadone clinics:

*“I was given misinformation. They tell you have nothing to worry about.... Given the disproportionate amount of us who have been injecting drugs, there is an inadequate response.... I went through a whole year when I was waiting for [HCV] treatment.” – (Focus Group #1)*

*“I think all methadone clinics should have at least one on-site specialist for Hep C because Hep C is an epidemic that affects drug users, particularly injection drug users, and that is who goes to methadone clinics.” – (Focus Group # 2)*

Another focus group participant discussed being denied HCV treatment because of mental health issues:

*“I contracted HCV back in the ‘80s. I never really got any treatment because I was in and out of penitentiaries and it was never addressed. Finally I was in a program where they did a biopsy and it turns out I have stage III HCV and I am definitely a candidate for medicine, but they won’t give me the medicine because of a psych history I have. Here I am, I have stage III HCV and they are not giving me treatment for it.” – (Focus Group # 1)*

## C. Regardless of HCV status, most patients surveyed were unaware of critical HCV services at their OTPs. Awareness of HCV services among patients who tested positive for HCV is no better than among those who reported testing negative.<sup>74</sup>

- Three quarters of all respondents (75.2%), regardless of HCV status, said they were unaware of HCV workshops and trainings at their program.



- More than half (54.4%) said they were unaware of HCV support groups at their program.
- More than half (53.6%) reported no knowledge of HCV educational materials such as pamphlets and posters at their program.

Support groups and peer educators are valuable for motivating people to seek out and adhere to HCV treatment. Support groups offer peer-based communication about the experience of dealing with HCV and explanations of test results, liver biopsies, treatment options and potential side effects, all of which help patients seek and adhere to treatment.<sup>75, 76</sup> Peer education and workshops help de-stigmatize the disease and prevent new HCV transmission by creating an environment where people are more willing to seek out information and treatment.

Patient counseling by staff is another important component of comprehensive HCV services. Increasing staff awareness and understanding of HCV through training enables them to better assist patients seeking treatment. Several focus group participants shared their thoughts about the lack of information, services and support for HCV:

*“As far as I’m aware, they don’t have any services or information about Hep C...they seemed to be pretty indifferent overall.... My counselor doesn’t know anything about Hep C.” - (Focus Group # 2)*

*“There is not enough information out there for people. I almost lost my best friend this summer because he didn’t know he had it [HCV]. He was all yellow. He had some problem with his liver because the HCV had got to his liver. In most [methadone] clinics, if you don’t ask you won’t get the answers. It shouldn’t be that way.” - (Focus Group # 1)*

*“For me it is more personal. If I talk to someone that I know is in the same situation as me, it is easier for me to talk to them. I don’t think my counselor is all that informed; actually, I know she is not.” - (Focus Group # 2)*

## Summary

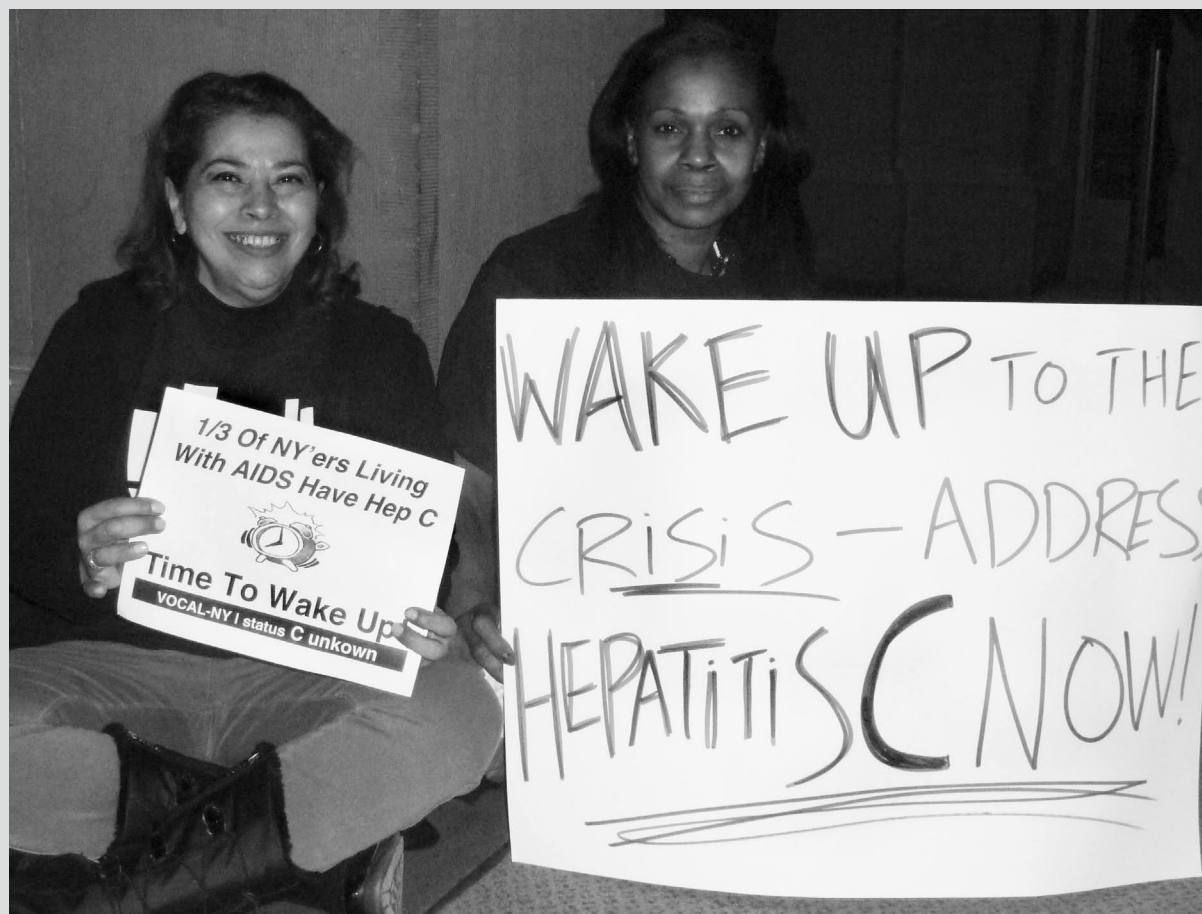
Through its research, VOCAL-NY found that OTPs are failing to adequately inform methadone patients about their HCV status or assist HCV-positive patients in determining whether they have chronic infection and connecting them to care and treatment. Overall awareness and education in programs is very poor, given the prevalence of HCV among methadone patients. Despite annual screenings required by OASAS, many of those surveyed reported that they do not receive HCV testing at their clinics, are unaware of their test results or are confused about their HCV status. Among those who do know their HCV status, many report that OTP staff do not provide adequate information, support or assistance regarding treatment.

It is imperative that OTPs more aggressively work to improve HCV knowledge and expand patients’ access to treatment, especially as new treatments become available. The urgency of expanding this access is further underscored by rising morbidity and mortality due to chronic HCV, despite clear evidence that the virus can be treated in former and active drug users. Because of the high prevalence of HCV among and the daily potential for interactions with methadone patients, OTPs provide a unique site for scaling up access to diagnostic, treatment and care services for people with chronic HCV.

### Best Practices for HCV Treatment in OTPs

Patients in OTPs have distinct characteristics that can present challenges for HCV treatment, including poly-substance use (using multiple drugs), co-morbidity with other infectious diseases such as HIV/AIDS, psychiatric illness, socioeconomic marginalization and involvement in the criminal justice system.<sup>77</sup> Therefore, services and programs must be tailored to meet the complex and challenging needs of patients receiving methadone. Model programs, including those offered by Albert Einstein College of Medicine and Montefiore Medical Center, prove the effectiveness of integrated HCV care and treatment within OTPs.

Albert Einstein College of Medicine began offering comprehensive on-site HCV care and treatment at one of the nine OTPs they operate in the Bronx in 2003. All clinic staff received intensive training in HCV, and peer support groups for HCV and other health issues were available to all patients. Basic HCV counseling was provided at program admission and during annual health screenings. Those who tested positive for HCV antibodies were offered additional evaluation, including on-site viral load testing and referral for liver biopsy at nearby hepatology clinics, although the latter was not required to begin treatment. Treatment was available on-site and contraindications that could interfere with treatment were considered on a case-by-case basis. However, patients were not excluded solely because of active drug use, psychiatric illness or co-morbidities. One advantage of the program was that primary health care was already available on-site for Medicaid patients, which enabled it to have a full-time physician and physician's assistant and part-time psychiatrist. Despite numerous potential complications, treatment outcomes compared well to those in other settings.<sup>78</sup>





## ISSUE 3: Treatment Interruptions

*“I missed a dose last month...I have to rely on myself to get to and from the program and that particular day I couldn’t get to the program.” – (Focus Group # 2)*

### Background

Most methadone patients are required to make visits to their program three to six days per week to receive medication. Patients who miss a dose can begin experiencing painful withdrawal symptoms within as few as 24 hours after their last dose. In light of this, OTPs are required to provide transportation assistance to OTP patients in the form of “carfare,” or stipends for transportation costs.

Missing a methadone dose and experiencing withdrawal symptoms can increase the likelihood of drug use or relapse, as well as disease transmission or overdose. A methadone patient in this situation may inject heroin or other substances in order to alleviate withdrawal symptoms and, if no plan is in place, is likely to share injection equipment, increasing risk of HIV and HCV transmission. Furthermore, as non-regular users have reduced tolerance, they are put at higher risk of drug overdose. Interruptions in treatment can also cause patients to drop out of their programs.<sup>79</sup> All of these factors underscore the importance of preventing interruptions in treatment.

OTPs are specifically encouraged to adopt flexible hours, with state regulations stating, “Staffing and staff hours must be sufficient to meet the medical and clinical needs of patients.”<sup>80</sup> Federal CSAT guidance requires programs “to ensure that patients are provided a medication schedule (dosing times/program hours) that is the most accommodating, least intrusive and least disruptive schedule for the majority of patients.”<sup>81</sup>

Despite the risks and regulations outlined above, VOCAL-NY found that methadone patients regularly miss doses due to a number of barriers, most of which are preventable. While interruptions in treatment are due to a variety of factors, the most frequently cited by study participants were limited clinic hours, delays in transportation assistance and Medicaid case closures or “cut-offs.”<sup>82</sup>

### **KEY FINDINGS: Interruptions in methadone treatment occur because of limited clinic hours, delays in transportation assistance and Medicaid case closures, which undermine programs’ effectiveness and lead to risky behaviors.**

#### **A. Many methadone patients reported experiencing transportation assistance delays and Medicaid case closures.<sup>83</sup>**

- 84.0% experienced a delay in receiving transportation assistance (subway fare) during the past two years.
- About one third of respondents (34.7%) experienced a Medicaid case closure in the previous two years. There was substantial variation across different programs among respondents who reported a Medicaid case closure.

Focus group participants shared their experiences with transportation assistance and insurance issues.

*“I have not received a carfare check since April 2008. If you try to ask anyone about anything they are completely evasive about it. There is a general indifference to the clients.” – (Focus Group # 2)*

*“I haven’t missed a dose yet but I’ve had trouble because of my (Medicaid) card. I had to run to get papers and send the papers through the mail and they received it late.” – (Focus Group #3)*

*“When I first got on the program I was working, and I had a counselor that got fired a month after I was working with her, so I sort of fell between the cracks. And it was six months before they came up with a*

payment of what I should give them, and they handed me a \$1,600 bill.” – (Focus Group #5)

**B. Limited clinic hours was the most commonly reported cause of missing a methadone dose, followed by delays in transportation assistance and Medicaid case closures (see Figure 3).<sup>84</sup>**

- More than half of respondents (53.65%) reported missing a methadone dose due to limited clinic hours.
- About one third of respondents (34.1%) reported missing a methadone dose due to a delay in transportation assistance.
- Nearly one in ten respondents (8.8%) reported missing a methadone dose due to a Medicaid case closure or “cut-off.”

**Figure 3: Respondents that Missed a Methadone Dose due to Treatment Barriers**

Reason for Missing Methadone Dose	% of Respondents that Missed Dose
Limited Clinic Hours	53.7%
Delay in Transportation Assistance	34.1%
Medicaid Closure or Cut-off	8.8%

Delays in transportation assistance can mean patients are unable to afford the subway or bus ride to their program. This is highly problematic, given the daily visits most patients are required to make. A patient’s inability to afford travel to a program, and a resultant dose lapse, can mean the onset of painful withdrawal symptoms. Medicaid cut-offs, which can occur due to something as simple as a missed recertification appointment, are also a serious barrier. A program may refuse to dispense medication to a patient, thereby causing abrupt detoxification. The negative consequences of unplanned detoxification or withdrawal emphasize the importance of OTPs’ working with patients to avoid Medicaid cut-offs and to immediately re-open Medicaid cases when inadvertent closures occur.

Additionally, patients miss doses due to limited clinic hours and failure to accommodate patients’ schedules. Competing scheduling demands include taking care of family obligations, looking for a job and parole or probation requirements. Focus group participants described some of the challenges they experienced in getting to their program and the lack of support they felt from their OTPs:

*“I missed a dose because of the clinic closing. I made the effort to get there and I missed because of a train going to local because I am not in the habit of giving myself two hours to get there. There is no room for exception or room for mistakes.” – (Focus Group #3)*

*“I missed a dose last month. I’m on a Medicaid spend-down so at the beginning of each month I have to wait until the bill from the program goes into the system and until then my Medicaid is off so I have to rely on myself to get to and from the program and that particular day I couldn’t get to the program.” – (Focus Group # 2)*

*“I’ve missed before. At one point I wasn’t even allowed to get medicated at the clinic. I had to go to the hospital to get medicated because my Medicaid card was messed up from some time I spent in the hospital.” – (Focus Group #3)*

Across programs, there was notable variation in the number of respondents who reported treatment interruption due to limited clinic hours or delay in transportation assistance, which suggests that some programs are more effective than others at preventing those barriers to treatment. Nevertheless, patients interviewed at all programs reported barriers to treatment.

**C. Patients who miss a methadone dose because of these treatment barriers have high rates of heroin, illegal “street methadone” and other drug use (see Figure 4).<sup>85</sup>**

- More than one quarter (28.5%) of all respondents reported using heroin after they missed a dose due to limited clinic hours.
- Among those who reported missing a methadone dose due to limited clinic hours, four out of five (81.5%) used heroin.
- Among those who reported missing a methadone dose because of a Medicaid closure, 63.6% said they used heroin, 38.6% used illegal methadone and 18.2% used other pills.
- Among those who reported missing a methadone dose because of a delay in transportation assistance, 43.9% said they used heroin, 39.8% used illegal methadone and 10.5% used other pills.

**Figure 4: Patients with treatment interruptions that used heroin**

Missed Dose Due to:	Percent That Used Heroin After Missing Dose
Limited Clinic Hours	<b>81.5%</b>
Medicaid Closure	<b>63.6%</b>
Delay in Transportation Assistance	<b>43.9%</b>

Many focus group participants shared that after missing a dose, they would use heroin. Below are several comments from participants.

*“I didn’t have money to take a taxi so I missed the hours and I didn’t get dosed. So I went and hustled some money up and got a bag and went and got high. I was trying to get 90 days clean so I could get extra take home. So missing a dose made me pretty sour. I was back to square one.” – (Focus Group #2)*

*“I was running extremely late. I’m in a three-quarter house so my living situation played a role. The [methadone] program tells you to call and they say they will work with you. When I called, I spoke to security and then I got there and the door was locked. So, I went and got a bag to hold me over. I had to do something illegal. I used and it threw me off track.” – (Focus Group #2)*

*“For me, the first day when I miss, right away in my mind I get nervous, and I have to get at least one bag. Just to get through the night. You start thinking you won’t be able to sleep. You go into flashbacks of when you were having withdrawals.” – (Focus Group #5)*

*“[When I missed] I had to try other things like Xanax, Klonopin.” – (Focus Group #5)*

**D. The frequency of illegal methadone and drug use increases with the number of times a patient reports missing a methadone dose due to treatment barriers, especially limited clinic hours.<sup>86</sup>**

- There were higher rates of illegal methadone and drug use reported among respondents who said they missed their methadone dose on three or more occasions because of the barriers described above.
- The highest increase in the frequency of illegal methadone and drug use was among those who reported missing their dose due to limited clinic hours.
- The percentage of respondents who reported using illegal methadone or pills was more than twice as high among those who missed a methadone dose on five or more occasions compared to those who missed their dose just once or twice.

### Summary

The majority of survey respondents experienced some sort of interruption to their methadone treatment. Respondents reported missing doses due to limited clinic hours, delays in transportation assistance and Medicaid cut-offs, with limited clinic hours representing the most commonly reported barrier. The research also indicates that missing a daily methadone dose may lead to illegal drug or methadone use, causing potential health and safety risks for methadone patients. This is clear from the survey results, which show high percentages of patients using heroin, street methadone and other illegal drugs after they missed a dose. While such barriers to treatment are not always directly under the control of individual OTPs, variation across programs suggests that some agencies are more effective than others at preventing these treatment barriers.





## ISSUE 4: Patient Rights & Involvement

*“A lot of times things are done without the client’s involvement and that is a big part of the problem....” – (Focus Group #2)*

Involving patients in treatment decisions, providing services that are tailored to their needs and allowing opportunities for feedback and input into the governance of OTPs promotes retention in care. Accordingly, this section analyzes the extent to which OTPs empower patients to take control over their own health through involvement in their treatment plans and organizational procedures. The wide variation in the quality of OTPs in New York City may be partially explained by conflicting approaches to patient involvement in decision-making.

### Patient-Centered Approaches

Patient satisfaction is a critical factor in the success of opioid treatment. Patients who feel they have greater control over their treatment, including dosing levels, are more likely to remain enrolled and have better health outcomes than those who perceive their program to be overly controlling.<sup>87, 88</sup> Patient satisfaction is also enhanced by the availability of services that meet a range of needs, such as flexible hours, childcare, vocational training, HCV treatment and evaluation, and overdose prevention. One study evaluating program quality concluded, “Where patients are consumers, programs feel an increased responsibility to adapt procedures and services to meet the scheduling needs of patients.”<sup>89</sup> In contrast, less successful programs tend to perceive patients as “beneficiaries of services for whom treatment is a privilege provided by the clinicians and the public health service.”<sup>90</sup>

### Program Involvement & Grievance Procedures

Conflicts with program rules and policies are a major barrier to consistent treatment and program retention. One study investigating causes for premature discharge in a methadone program found that 40% of patients who left the program did so because of program-related reasons, such as inconsistent application of rules, conflict with program staff and inflexible clinic hours.<sup>91</sup> Often, conflicts with program staff centered on disagreements about treatment plans.<sup>92</sup>

Two sets of OASAS regulations require that OTP patients are informed of their rights, staff are trained on those rights, and patient advisory committees are implemented. Federal CSAT guidelines for OTP accreditation also describe a range of patient rights that should be recognized, including “a grievance and appeal process... [and] input into program policies and services through patient satisfaction surveys.”<sup>93</sup> CSAT recommends that OTPs publicize information about patient rights and grievance procedures in “multiple formats, appropriate to culture, language, and literacy level,” offering examples such as “signs in the waiting room, pamphlets, electronic media (video, tapes), and ‘talk through’ with staff.”<sup>94</sup> Findings from the current study show that most patients are not aware of their rights, nor are they involved in their treatment at OTPs. Consequently, patients are often dissatisfied with their programs.

## **KEY FINDINGS: Patients are not properly informed of their rights regarding treatment alternatives, advisory bodies and grievance procedures.**

### **A. Most patients are unaware of advisory bodies at their program, and those who are aware believe they have no power.<sup>95</sup>**

- Nearly seven out of ten respondents said they were either unaware of a patient advisory board (36.1%) or reported that one did not exist (31.7%) at their program, even though OASAS requires all OTPs to have them.
- About three quarters of all respondents reported that they either did not know (51.6%) or did not believe (24.7%) that participant advisory boards had any power to make changes.

Focus group participants shared their experiences with patient advisory boards at their programs. While most participants agreed that their programs did little in the way of patient advisory groups, some noted that their programs had recently begun to offer more patient groups.

*“[OTPs] would have to make a much more concerted effort to get clients involved with PACs [Patient Advisory Committees] and CABs [Community Advisory Boards]. They need to actively solicit opinions of clients. They also need to do a better job of posting the information they are supposed to: grievance procedure; patient advocate number; OASAS number; patient bill of rights. You never see that in 99% of the clinics and if you ask for it they will deny you.” – (Focus Group #2)*

*“Our program is starting to run meetings, groups. There’s one almost every day now. I go to the one on Tuesdays, it’s really good.” – (Focus Group #5)*

**B. In general, patients are unaware of basic rights and grievance procedures at their clinics (see Figure 5).<sup>96</sup>**

- Half of respondents (51.6%) said they were not aware of posted information about a patient advocate at their program.
- Nearly four in ten respondents (38.6%) said they were not aware of a patient bill of rights posted at their program.
- More than two thirds of respondents (66.9%) reported there was no information posted about how to file a grievance and more than one (35.8%) did not know how to file a grievance if there was a problem with their counselor.

**Figure 5: Patients that are not aware of their rights at OTPs**

Information that must be posted at OTPs	Percent of respondents that were NOT aware of posted information
Information about a patient advocate	51.6%
A patient bill of rights	36.8%
How to file a grievance	66.9%

For the most part, focus group participants confirmed that they were either unaware or skeptical of the patient rights and grievance procedures in place at their OTPs.

*“[The program] might even have a patient bill of rights thing hanging up, but I can tell you nine out of ten of those rules are subject to change at whim[.]” – (Focus Group #5)*

*“I don’t like that they are always changing policies and procedures without letting people know about the changes that they are making.” – (Focus Group #2)*

*“I don’t know anyone who has put in a grievance to the director of their program and felt like they got resolution, so I think you really do have no choice. It’s either just watch it and let it go, or make a phone call [to OASAS].” – (Focus Group #5)*

**C. A concerning proportion of patients reported an overall poor experience at their program and said they did not feel respected by their counselors.**

- Nearly one in five survey respondents (17.9%) rated their overall experience at their program as “poor” or “very poor.”
- More than one in seven survey respondents (15.8%) either strongly disagreed or disagreed with the statement, “My counselor respects my opinions.”



Focus group participants also shared a number of negative experiences with their programs.

*“You have to be sensitive to people who are on methadone. They assume that since we are on methadone we are stupid or we don’t have brains or something. You don’t talk to them like they are children. You don’t scream at them.” – (Focus Group #1)*

*“My relationship with my counselor is little to none. They want you to come in there and sign some papers every now and again. Other than that, they could care less.” – (Focus Group #3)*

## Summary

Many patients are unaware of basic rights and grievance procedures to follow if they have problems at their program, and OTPs do an unsatisfactory job publicizing this information. Lack of patient satisfaction in OTPs has real consequences, including premature discharge and low rates of success in treatment.<sup>97</sup>



Drawing: Erik Haberlen

## ISSUE 5: Police and Security Harassment

*“Some people, if they want to turn their life around and take that first step and get on methadone, they are not going to do it if they see the police around and out harassing people. It is going to discourage people that need the help.” – (Focus Group # 2)*

Methadone maintenance treatment reduces criminal activity and incarceration among individuals with opioid dependency, as compared with opioid users who do not receive methadone.<sup>98</sup> At the same time, OTPs may act as a magnet for law enforcement activity, given that patients tend to experience multiple layers of marginalization, including poverty, homelessness and mental health issues, and may continue actively using drugs and alcohol while participating in methadone treatment.

While there appears to be limited research into the impact of clinic security and law enforcement activities on methadone access, program retention and patient satisfaction, one useful parallel could be studies on policing in the vicinity of syringe exchange programs (which more explicitly serve active drug users). Multiple studies on this topic have found that policing activity targeting syringe exchange participants has a negative impact on program participation and increases risky behaviors like syringe sharing.<sup>99</sup> It is possible that aggressive security or law enforcement activity around OTPs similarly discourages patients from remaining in their program and increases the stigma attached to participating in an OTP.

OASAS regulations permit OTPs to hire security personnel but require training in confidentiality and prohibit security guards from directly confronting patients outside clinics.

### **Section 828.14 - Staffing<sup>100</sup>**

(k) Each OTP can employ guards to provide security for the OTP, its occupants and operations. Security guards are not clinical staff and shall not have any clinical responsibilities or be involved in clinical services or clinical activities. However, since security guards interact with patients, security guards must receive training on the confidential nature of patient information and of chemical dependence treatment, and must adhere to all applicable confidentiality requirements.

(l) Security guards can be utilized to conduct community patrols to ensure that patients are not loitering; however, when security guards are used in this manner they must receive appropriate training and be advised not to confront individuals outside of the OTP, but rather that clinical staff must address the matter within the OTP.

## **KEY FINDINGS: Police and security guards at or near methadone clinics target methadone patients for arrest and harassment.**

### **A. Police harassment is common near OTP sites.**

- Nearly four in ten patients surveyed (38.2%) reported being stopped and frisked by police outside their clinic site, although there was variation across agencies.
- Seven in ten respondents (69.7%) witnessed someone else being frisked or harassed by police while entering or leaving the clinic.

It became clear during focus groups that police harassment around OTPs is in fact another barrier to methadone treatment.

*“The thing I most dislike is police harassment. Maybe a couple times a month you get stopped and frisked and they are asking where you are coming from. I know they know where I’m coming from because they have a clean line of vision to the clinic and I’m always being searched down without provocation.” – (Focus Group # 2)*

*“The police came and arrested a few of the people on the program.... If they need a spot to meet their quotas, they just come to the methadone programs and mess with people, search them for no reason; they don’t even identify themselves.... I have missed a dose because of the police. I just didn’t want to go to the program because [police] were just coming on certain days of the week to meet their quotas and I didn’t feel safe.” – (Focus Group # 2)*

*“Some of those people who are arrested lose self-esteem. They think ‘the program is not helping me out’ and at the end of the night they lose out. They say ‘Why should I go there and get my methadone just to be harassed by the cops?’” – (Focus Group # 1)*

*“I know it is a problem. Just like police profile people of color – they are racially profiled – [we] methadone patients are medically profiled. They single us out when they see us coming and going from the program.” – (Focus Group #2)*

## **B. Some patients feel disrespected by security officers at their OTP.**

- One out of seven respondents (14.4 %) said they did not feel respected by security officers at their program, a finding that was fairly consistent across programs.

Focus group participants also spoke about their negative experiences with OTP security guards.

*“I have seen instances where the warrant squad has tried to get upstairs in the clinic to look for a person. If you looked like the person that they are looking for, they would put you up against the wall and frisk you. You complain to the security that ‘You aren’t supposed to allow this’ and they look at you like you have three heads. It goes back to the clinic not being there for us. They just kick us out the door and whatever happens, happens.” – (Focus Group #1)*

## **Summary**

Negative interactions with law enforcement and security often create a hostile environment in OTPs, which is unacceptable for a medical treatment facility. In addition to creating more stress for an already marginalized patient population, harassment may actually deter people from enrolling in methadone treatment and cause existing patients to miss doses.

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## CURRENT POLITICAL CONTEXT

Treatment programs for opioid dependence may be poised for more interest from policymakers and the criminal justice system due to a number of factors. Recent drug policy reforms grant judges more discretion in sentencing alternatives to incarceration, which should include OTPs. Budget deficits in Albany and at City Hall have also drawn attention to people with opioid dependence because they are more likely to be frequent users of Medicaid and public services, and interventions that can create stability in their lives (from “health home” models to supportive housing) have been discussed as solutions. At the same time, budget deficits have led to significant cuts for Medicaid and public services on which OTP patients depend. Governor Andrew Cuomo has also begun reorganizing state government, which will likely involve consolidation and review of OASAS.

OASAS has recently expressed renewed interest in methadone and buprenorphine treatment for people with opioid dependence. The agency recently joined with the Committee on Methadone Program Administrators (COMPA), an association of methadone treatment providers that see pharmacotherapy as a key component of a comprehensive biopsychosocial approach to addiction treatment, to issue a letter encouraging OTPs to help develop new guidelines for “Low-Threshold Treatment” in an effort to expand access to methadone maintenance treatment for those discouraged by burdensome program requirements. Throughout 2010, the agency developed a new system for financing OTPs that is now in its early stages of implementation, and launched a new quality improvement effort called the Gold Standard Initiative. Although the agency specified that consumer input would be part of the review process, no one involved in or interviewed for this report reported having been invited to participate.

The recent introduction of a new billing system for OTP services also creates new opportunities for patient-centered approaches and enhanced services. As noted earlier in the report, OASAS overhauled the Medicaid reimbursement structure for methadone and other OTP services through their new “Ambulatory Patient Group (APG)” rates. Under the new fee-for-service APG system, up to five percent of billing can be for additional health services for OTP patients, allowing flexibility to address related health issues like HCV. In NYC, direct contract oversight for OTPs is also shifting from OASAS to the NYC Department of Health and Mental Hygiene, giving the local health authority a larger role in overseeing the programs.

Several medical and health policy advances are also worth noting. A new generation of HCV treatments with shorter durations and higher cure rates is now becoming available. Overdose prevention is another area where policymakers have shown interest, due in part to media reports of rising overdose fatalities in some areas of the state, along with legislation in Albany that would encourage more people to call 911 and intervene if they witness an overdose. As a result of regulatory changes in the past decade, access to naloxone (overdose reversal medication) and buprenorphine (an alternative to methadone) continues to grow, albeit slowly. Additionally, VOCAL-NY worked with state legislators in 2010 to expand syringe access and safe disposal by amending the New York State Penal Code. Representing an important policy advance, this amendment clarifies that possessing new and used syringes obtained through a public health program does not violate the law, which has implications for both methadone patients and OTP providers.

## INNOVATIVE APPROACHES

Alternative treatment for opioid dependence and other methods for delivering methadone can address some of the problems identified in this report, including treatment interruptions and feelings of limited autonomy among patients.

### Alternative Methods of Delivering Methadone

Expanding access to methadone is one important strategy to reduce treatment interruptions and promote greater patient autonomy. As noted earlier in the report, methadone maintenance in community settings outside of OTPs is available in other countries; however, it is severely limited in the U.S. due primarily to the federal regulation of methadone. Several domestic programs, including a few in New York City, have demonstrated the feasibility and effectiveness of “Methadone Medication Maintenance,” whereby patients are given 30-day take-home supplies with fewer restrictions than those at OTP clinics. Patients have reported that this approach reduces the feeling of intrusiveness that frequent in-person dosing can cause.<sup>101, 102</sup>

### Maintenance Treatment for Benzodiazepines (BZD)

Dependence and misuse of benzodiazepines (BZDs) appears to be a serious health problem among many methadone patients, which indicates the need for a more proactive response. Programs overseas suggest that BZD dependence can effectively be treated through medication-assisted therapy. These models, which use clonazepam in OTPs, have reduced misuse and increased patient stability.<sup>103, 104</sup> In particular, clonazepam maintenance treatment (CMT) has been found to be an effective alternative to detoxification from BZDs, especially for those with a long history of use and previous attempts at detoxification.

### Heroin Maintenance

About half of methadone patients surveyed (51.2%) in this report support offering prescribed heroin as an alternative to methadone. Heroin maintenance, also known as heroin-assisted therapy, is a successful treatment for chronic opioid-dependent users who continue using or frequently relapse, even while in treatment. The therapy is already available in a number of European countries. Multiple randomized controlled trials (RCTs) have found that, for patients who have “failed” in treatment programs or have not stopped using opioids, offering prescribed heroin (including diacetylmorphine or hydromorphone) as an alternative to methadone reduces the use of illicit drugs and criminal activity while improving links to care and treatment.<sup>105, 106, 107, 108, 109</sup> One study concluded, “supervised coprescription of heroin is feasible, more effective, and probably as safe as methadone alone in reducing the many physical, mental, and social problems of treatment-resistant heroin addicts.”

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## RECOMMENDATIONS

Opioid treatment is widely recognized as a highly successful and cost-effective treatment for dependence on heroin and other opioids, with numerous benefits for both individual patients and the broader community. However, as findings in this report indicate, OASAS and OTPs are failing to meet patients' critical health needs, including harm reduction services for active drug users and access to HCV care and treatment. Moreover, OASAS and OTPs must do more to prevent methadone treatment interruptions, allow patients to meaningfully contribute their input and protect patients from police harassment.

OTPs should promote patient autonomy to the greatest extent possible. While VOCAL-NY urges OASAS and OTPs to adopt more comprehensive services to address the health needs of methadone patients, it also recognizes the importance of patient-directed care and voluntary participation in all services. The recent initiative by OASAS and COMPA to introduce the Low-Threshold Treatment model is a potentially important step to expand access to methadone treatment and should not be seen as counter to the following recommendations. It is important, however, that methadone patients participate meaningfully in any discussion of new treatment models.

VOCAL-NY believes it is important to deliver patient-centered services in a manner that the patient deems most appropriate, including outside of a comprehensive system. As such, all recommendations for enhanced services in this report should be seen as strictly voluntary on the part of the patients. Based on the findings in this report and the political and policy developments discussed above, VOCAL-NY recommends the following to OASAS and New York City OTPs.

### Hepatitis C

#### ► **Promote greater access to HCV prevention, care and treatment.**

*VOCAL-NY recommends that all OTPs:*

- Ensure adequate HCV training for staff that reflects the prevalence of HCV among methadone patients.
- Incorporate basic HCV counseling in the initial intake and all annual health screenings, and require post-test counseling for those who test positive for HCV antibodies so they understand their test results, possibilities for further evaluation, and treatment options.
- Provide all patients with a copy of their HCV antibody test results from the annual exam and an explanation of results within two weeks of their health exam (and immediate results once rapid testing is available).
- Offer a viral load test to all patients who test positive for HCV antibodies in order to determine if they have chronic HCV infection.
- Train and hire (through full-time, part-time and/or stipend positions) peer navigators who can support adherence to care and treatment for patients with chronic HCV, which can be reimbursed through under the APG rate for peer support.
- Provide on-site HCV treatment and care at clinics equipped to provide primary care services. Programs that are unable to offer on-site viral load tests, liver biopsies and/or treatment for HCV should establish a concrete referral system and enter into memoranda of understanding (MOUs) with medical providers for follow-up care for methadone patients with chronic HCV.
- Develop and support peer-run HCV support groups that help raise awareness about HCV, provide social support and promote access to care. Support groups can also address other health issues that may impact patients besides HCV.



VOCAL-NY recommends that OASAS:

- Track how well OTPs link patients with chronic HCV to care and treatment by monitoring the following indicators at each program on an aggregate basis: prevalence of HCV; availability of diagnostics and on-site treatment; number of patients receiving treatment on-site; number of patients enrolled in treatment through the OTP; and participation in HCV support groups.
- Update regulations to require training in basic HCV issues for all counseling staff and establish a standard protocol outlining best practices for HCV diagnostic follow-up and treatment.
- Issue best practices for HCV testing, care and treatment at OTPs.
- Review APG rates to ensure implementation of HCV-related services commensurate with the prevalence of the virus among methadone patients.

## Harm Reduction & Other Medical Interventions

### ► ***Offer harm reduction services, including syringe access and overdose prevention, for methadone patients who continue using drugs.***

VOCAL-NY recommends that all OTPs:

- Register with the New York State Department of Health (DOH) for the Expanded Syringe Access Program (ESAP), which would allow OTPs to make syringes available to patients without a prescription.
- Register with the DOH Safe Sharps Collection Program, which would allow patients to safely dispose of used syringes.
- Register with the New York State Opioid Overdose Prevention Program to become certified to train patients in administering naloxone. Programs should offer training and prescribe naloxone to all methadone patients, especially those who are newly enrolled, are being discharged or have toxicology results indicating outside opioid use.
- Integrate harm reduction counseling into patient encounters, including overdose-prevention education around managing poly-substance use, especially BZDs, cocaine and alcohol.

VOCAL-NY recommends that OASAS:

- Require all OTPs to enroll in ESAP, the Sharps Collection Program and the Opioid Overdose Prevention Program, and consider creating new APG rates to support compliance.
- Require OTPs to make naloxone and overdose prevention counseling available to all patients – especially those who are newly enrolled, are being discharged or have positive toxicologies for outside opioid use – and create an APG reimbursement rate.

## Buprenorphine

### ► ***Provide full and accurate information about treatment options to all patients, including buprenorphine as an alternative to methadone maintenance treatment.***

VOCAL-NY recommends that all OTPs:

- Include an explicit offer of buprenorphine on the patient consent and intake form.
- Educate all new patients about buprenorphine as an alternative to methadone during the initial enrollment process.
- Train counseling staff on providing accurate information on buprenorphine and responding to common concerns.
- Ensure existing patients are provided with information about buprenorphine maintenance and that

## RECOMMENDATIONS

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patient records document such counseling. This can occur during periodic treatment plan reviews, and it is especially important whenever a patient is tapering off (i.e., progressively reducing the level of their dose) or being administratively detoxified when the risk for relapse is high.

- Explain the pros and cons of transitioning off methadone to patients who are interested in buprenorphine and work with them to taper off their existing dose and transition to buprenorphine once they are ready.
- Make buprenorphine prescriptions available on-site for patients who choose it as an alternative to methadone maintenance treatment and connect them with a physician for ongoing treatment.

*VOCAL-NY recommends that OASAS:*

- Require OTPs to offer all patients the option of receiving buprenorphine as an alternative to methadone during their initial intake, and to modify methadone enrollment consent forms so that they discuss buprenorphine as an alternative to methadone.
- Notify all waived physicians authorized to prescribe buprenorphine about options for methadone maintenance as an alternative and work with the Department of Health to ensure that all patients offered buprenorphine are also informed about methadone.
- Require all OTP clinical staff to receive training in regulations, treatment options and how to counsel patients regarding buprenorphine.
- Change regulations to allow OTP-based physicians to prescribe buprenorphine for 30 days, which is already permitted for buprenorphine prescribed outside OTP settings, instead of requiring daily in-clinic dosing. Requirements for patients receiving buprenorphine through OTPs should not exceed those that exist for patients who receive treatment through office-based settings.

### Treatment Interruptions

*VOCAL-NY recommends that OTPs:*

- Create a toll-free number and designate a staff person that patients can call if they are running late for their program and need to make alternative arrangements to obtain medication.
- Contact the New York City Human Resources Administration (HRA), the agency responsible for transportation assistance and public assistance benefits, and OASAS about transportation assistance delays for Medicaid patients in order to prevent future delays.
- Ensure that counselors work with patients to have their Medicaid cases reactivated if they are cut off.
- Require counselors to immediately inform patients when they qualify for additional take-home doses, and document it in their record, in order to promote maximum patient autonomy.
- Require counselors to inform patients about the risk for relapse during detoxification, whether administrative or voluntary, and a signed informed consent by the patient in their record, along with information for harm reduction services.

*VOCAL-NY recommends that OASAS:*

- Require OTPs to report data on treatment interruptions, including frequency and reported causes, and reasons for patient discharges.
- Improve coordination between OTPs and HRA to prevent Medicaid closures and transportation assistance delays that can lead to treatment interruptions.
- Encourage HRA to deliver transportation assistance through electronic benefits cards in order to prevent transportation assistance delays.
- Enforce regulations requiring flexible clinic hours in order to meet patients' needs.

- Explore having one OTP in each borough remain open in the afternoon with a guest dosing referral system that can accommodate people who miss their dose at their primary OTP due to limited clinic hours.
- Ensure that OTPs exercise maximum flexibility to offer patients take-home doses as soon as they qualify, including requiring that programs do not add eligibility restrictions beyond what is already mandated by state and federal regulations.
- Avoid incentivizing more frequent in-person dosing through new APG rates.
- Advocate that federal regulators enact reforms that will enable patients to qualify for take-home doses sooner with fewer restrictions.
- Require OTPs to inform patients about the risk for relapse during detoxification, whether administrative or voluntary, and a signed informed consent by the patient in their record, along with information for harm reduction services.

## Patient Rights & Involvement

### ► ***Increase patients' understanding of their rights, enhance patients' decision-making authority within OTPs, and take steps to reduce police harassment of patients.***

VOCAL-NY recommends that OTPs:

- Invest in creating active, meaningful patient advisory committees (PACs) through staff support, funding, and training opportunities that empower patients with greater decision-making authority.
- Publicize patient rights by prominently displaying informational posters in several places around the clinic and near the dispensary.
- Create a PAC liaison to OTP security staff to discuss any concerns among patients that arise.

VOCAL-NY recommends that OASAS:

- Enforce regulations that require OTPs to create PACs and that limit the role of security guards.
- Survey current caseloads for each OTP and recommend optimal case ratios that enable counselors to provide patients with adequate health information, discuss treatment plans and address treatment interruptions.
- Provide dedicated funding for supporting active PACs.
- Establish an alliance of PACs across clinics to facilitate information sharing.
- Consider input from individual patients and PACs in evaluating program performance through the Gold Standard Initiative.
- Educate law enforcement about opioid dependence and the importance of OTPs in order to prevent police harassment of patients.

## Innovative Approaches

VOCAL-NY recommends that OASAS:

- Seek federal approval and public or private funding for a pilot program that offers prescribed heroin (e.g., diacetylmorphine) or dilaudid (hydromorphone) as a methadone alternative to long-term OTP patients with low treatment success rates.
- Initiate a pilot project to treat dependence on benzodiazepines (BZDs) using clonazepam maintenance therapy in an OTP
- Expand alternative approaches to delivering methadone maintenance treatment, including Methadone Medical Maintenance opportunities for OTP patients.

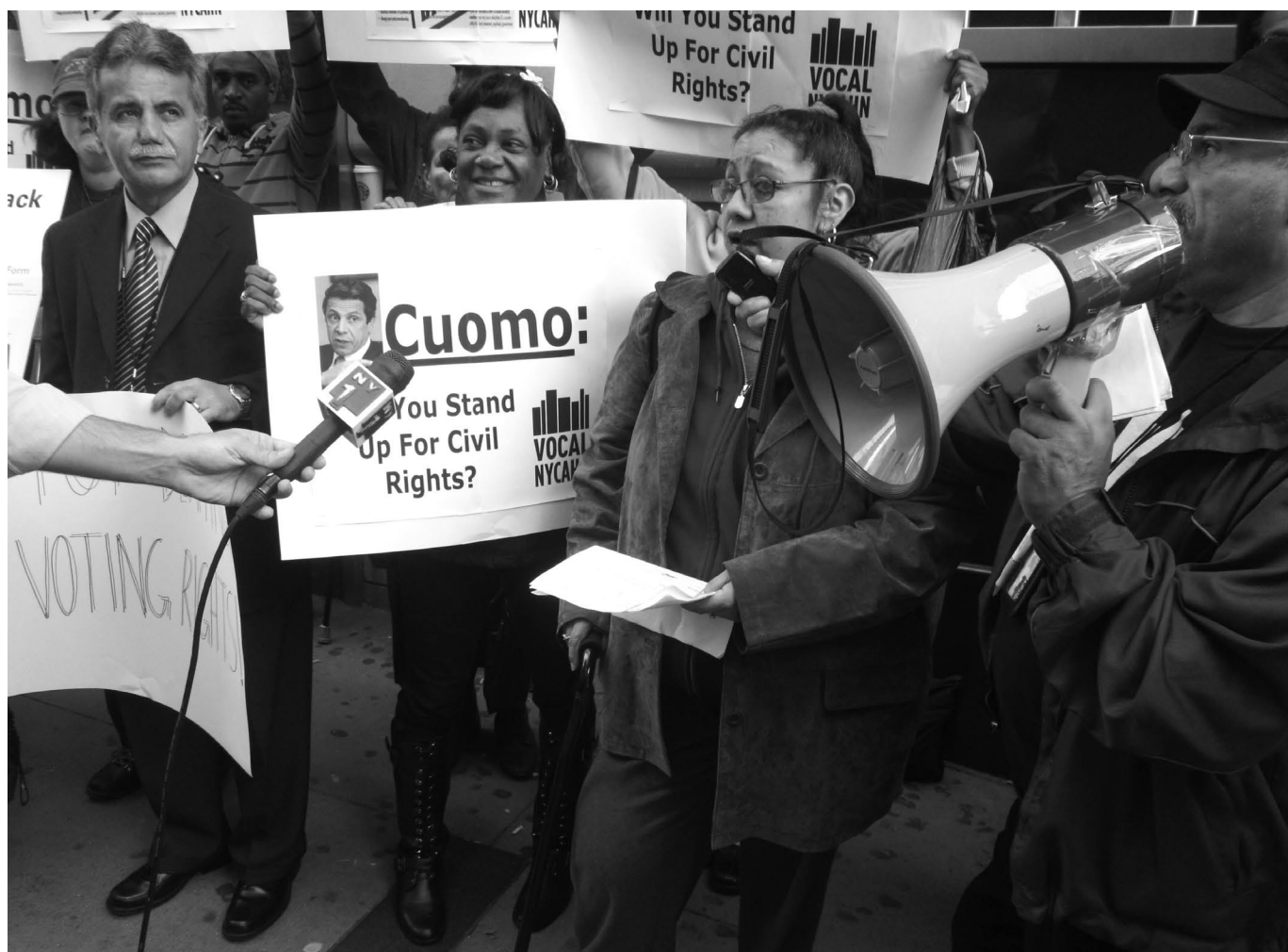
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## CONCLUSION

This report documents the experiences of patients enrolled in methadone maintenance treatment through OTPs in New York City. In addition, this report identifies several key health care needs related to methadone maintenance, including HCV treatment and care, overdose prevention, syringe access, and alternative opioid treatment options. The report also explores options for increasing access to methadone treatment, improving patient education and protection of patient rights, and preventing harassment by police and security guards.

There are exciting opportunities available to improve the health of people who are active and former drug users enrolled in OTPs in New York. Revolutionary improvements in HCV treatment have recently been approved, and there is solid evidence that the harm reduction interventions highlighted in this report save lives. There is also evidence that OTP patients who are satisfied with their program are more likely to remain in care. New initiatives that transform the way methadone treatment and care are financed, along with openness to innovation by OASAS and individual OTPs, are important signals that these programs can be improved with leadership by patients.

In light of the findings from this project and the current political context, VOCAL-NY is calling on OASAS and OTPs to demonstrate leadership in implementing the recommendations made in this report. As current and former methadone patients, VOCAL-NY leaders involved in this report strongly believe that making lifesaving improvements to OTPs will strengthen New York's growing commitment to a health-and-safety approach to drug use.



## APPENDIX: SURVEY RESPONSES BY AGENCY

**Table 1: Percent of respondents who were not told about Buprenorphine/Suboxone by their counselor or medical professional by agency**

AGENCY	(NUMBER) PERCENT
ARTC	(70) 62.5%
Beth-Israel	(148) 70.8%
NarcoFreedom	(82) 61.7%
Other	(24) 51.1%

**Table 2: Percentage of respondents who reported never being tested for HCV at clinic by agency**

AGENCY	(NUMBER) PERCENT
ARTC	(18) 16.1%
Beth-Israel	(45) 21.5%
NarcoFreedom	(46) 34.6%
Other	(6) 12.8%

**Table 3: Percentage of respondents who reported ever tested HCV-positive at clinic by agency**

AGENCY	(NUMBER) PERCENT
ARTC	(33) 35.10 %
Beth-Israel	(68) 39.77%
NarcoFreedom	(33) 31.43
Other	(14) 34.14 %

**Table 4: Percent of respondents who tested positive for HCV at each clinic that reported not receiving HCV-related health care services by agency**

	NOT given viral load test	NOT explained the role of a liver biopsy in treatment	NOT referred to Someone Else for a Viral Load	NOT referred to medical professional for HCV care	NOT given any services
AGENCY	(NUMBER) PERCENT	(NUMBER) PERCENT	(NUMBER) PERCENT	(NUMBER) PERCENT	(NUMBER) PERCENT
ARTC	(18) 54.5%	(22) 66.7%	(29) 87.9%	(23) 69.7%	(6) 18.2%
Beth-Israel	(41) 60.3%	(59) 86.8%	(68) 100.0%	(38) 55.9%	(17) 25.0%
Narco-Freedom	(20) 60.6%	(27) 81.8%	(30) 90.9%	(17) 51.5%	(12) 36.4%
Other	(7) 50.0%	(12) 85.7%	(14) 100.0%	(6) 42.9%	(0) .0%
% of all HCV+ respondents	(86) 58.1%	(120) 81.1%	(141) 95.3%	(84) 56.8%	(35) 23.6%



**Table 5: Consumers who are NOT aware of HCV Workshops and trainings by agency**

AGENCY	HCV+	HCV-	HCV STATUS UNKNOWN
ARTC	(16) 48.5%	(42) 71.2%	(7) 77.8%
Beth-Israel	(62) 91.2%	(65) 74.7%	(15) 93.8%
Narco-Freedom	(27) 81.8%	(52) 82.5 %	(1) 50%
Other	(3) 21.4%	(18) 72.0%	(1) 50%
% of all consumers who are NOT aware of HCV Workshops and trainings	73.0%	75.7%	82.8%

➤ **75.2 % of all respondents were not aware of HCV workshops and trainings.**

**Table 6: Consumers at each agency NOT aware of HCV Support Groups by agency**

AGENCY	HCV+	HCV-	HCV STATUS UNKNOWN
ARTC	(12) 36.4%	(21) 35.6 %	(1) 50%
Beth-Israel	(45) 66.2%	(54) 62.1%	(3) 18.8%
Narco-Freedom	(20) 60.6%	(35) 55.6%	(13) 81.3%
Other	(2) 14.3%	(12) 48.0%	(1) 50%
Total Population	53.4%	52.3%	75.9%

➤ **54.4% of all respondents were unaware of Hep C support Groups.**

**Table 7: Consumers at each agency NOT aware of HCV Pamphlets and Posters by agency**

AGENCY	HCV+	HCV-	HCV STATUS UNKNOWN
ARTC	(20) 60.6%	(44) 74.6%	(1) 50%
Beth-Israel	(21) 30.9%	(27) 31%	(12) 75.0%
Narco-Freedom	(23) 69.7%	(48) 76.2%	(6) 66.7%
Other	(3) 21.4%	(13) 52.0%	(2) 100%
Total Population	(67) 45.3%	(133) 56.6%	(21) 72.4 %

➤ **53.6% of all respondents reported no knowledge of pamphlets and posters.**

**Table 8: Consumers at each agency NOT aware of any HCV services by agency**

AGENCY	HCV+	HCV-	HCV STATUS UNKNOWN
ARTC	(4) 12.1%	(1) 1.7%	(0) .0%
Beth-Israel	(6) 8.8%	(5) 5.7%	(3) 18.8%
Narco-Freedom	(5) 15.2%	(6) 9.5%	(2) 22.2%
Other	(1) 7.1%	(3) 12.0%	(0) .0%
Total Population	(16) 10.8%	(15) 6.4%	(5) 17.2%

➤ **19.0 % of all respondents did not know of any HCV services available at the clinic.**

Table 9: Respondents experiencing a Medicaid-Cutoff by Agency	
AGENCY	% RESPONDENTS THAT EXPERIENCED A MEDICAID-CUTOFF BY AGENCY
ARTC	(32) 28.57 %
Beth-Israel	(74) 37.37 %
Narco Freedom	(44) 52.38 %
Other	(20) 45.45%

➤ **34.66 % of all respondents experienced a Medicaid cut-off in the past 2 years.**

Table 10: Respondents experiencing a delay in getting carfare by Agency	
AGENCY	% OF RESPONDENTS THAT EXPERIENCED A DELAY IN GETTING CARFARE
ARTC	(79) 86.81%
Beth-Israel	(145) 87.34%
NarcoFreedom	(82) 79.61%
Other	(29) 70.73 %

➤ **83.59 % of all respondents experienced a delay in their carfare in the past two years.**

Table 11: Respondents missing methadone dose due clinic hours that engaged in heroin use by Agency	
AGENCY	% OF RESPONDENTS WHO USED HEROIN DUE TO MISSING A DOSE FROM CLINIC HOURS
ARTC	(29) 25.9%
Beth-Israel	(64) 30.6%
NarcoFreedom	(32) 24.1 %
Other	(18) 36.4%

Table 12: Respondents missing a methadone dose due to a carfare delay that engaged in illegal methadone and drug use by Agency				
AGENCY	USED HEROIN	USED STREET METHADONE	USED OTHER PILLS	OTHER BEHAVIOR
ARTC	(15) 40.5%	(12) 32.4%	(3) 8.1%	(4) 10.8%
Beth-Israel	(32) 37.6%	(36) 42.4%	(8) 9.4 %	(10) 11.8%
NarcoFreedom	(15) 53.6%	(12) 32.4 %	(4) 14.3%	(1) 3.6%
Other Agencies	(12) 60.0%	(11) 55.0%	(2) 10.0%	(1) 5.0%
% of total population who missed a dose due to a carfare delay that engaged in high-risk behaviors	(75) 43.9%	(68) 39.8%	(18) 10.5%	(16) 9.4%

**Table 13: Respondents who missed a methadone dose due to Medicaid cut-off that engaged in illegal methadone and drug use by Agency**

AGENCY	USED HEROIN	USED STREET METH	USED OTHER PILLS	PAID OUT OF POCKET	OTHER
ARTC	(4) 44.4%	(3) 33.3%	(3) 33.3%		
Beth-Israel	(10) 58.8%	(5) 29.4%	(2) 11.8%		
NarcoFreedom	(7) 77.8%	(5) 55.6%	(2) 22.2%		
Other	(7) 77.8%	(4) 44.4%	(1) 11.1%		
% of total population who missed a dose due to Medicaid cut-off that engaged in high-risk behaviors	(28) 63.6%	(17) 38.6%	(8) 18.2%	(7) 15.9%	(4) 9.1%

**Table 14: Reported Illegal Methadone and Drug Use Resulting From Medicaid Cut-offs**

	CUT OFF 1-2 TIMES	CUT OFF 3-5 TIMES	CUT OFF MORE THAN 5 TIMES
Used Heroin	24.6%	38.1 %	0%
Used Street Methadone	13.4 %	28.6%	0%
Used Pills	4.2%	4.8%	0%
Waited for it to get turned back on	28.9%	28.6%	0%
Paid out of Pocket	9.9%	14.3%	0%
Other	7.0%	9.5%	0%

**Table 15: Reported Illegal Methadone and Drug Use Resulting From Transportation Assistance Delays**

	DELAYED 1-2 TIMES	DELAYED 3-5 TIMES	DELAYED MORE THAN 5 TIMES
Used Heroin	23.1%	33.0%	25.3%
Used Street Methadone	23.1 %	22.3%	34.5%
Used Pills	5.2%	7.8%	8.1%
Other	10.5%	13.0%	21.2%

**Table 16: Reported Illegal Methadone and Drug Use Resulting From Limited Clinic hours**

	MISSED DOSE 1-2 TIMES	MISSED DOSE 3-5 TIMES	MISSED DOSE MORE THAN 5 TIMES
Used Heroin	41.6% (42/101)	57.6 %	64.1%
Used Street Methadone	30.7 %	56.5%	67.2%
Used Pills	8.9%	21.7%	26.6%
Other	4.0%	5.4%	1.6%

- **68.68 % of all respondents either do not know (36.56 %) or reported no PAC or CAB (32.12 %) existed at their clinic**

**Table 17: Respondents who either do not know or reported no PAC or CAB existed at their clinic by agency**

AGENCY	(NUMBER) PERCENT
ARTC	(40) 37.03%
Beth-Israel	(159) 76.44 %
NarcoFreedom	(130) 80.45%
Other	(33) 70.21%

- **78.33% of all respondents either do not know (52.97%) or reported that PAC's or CABS (25.36 %) have no power to make change.**

**Table 18: Respondents who either do not know or reported that PAC's or CABS have no power to make change by agency**

AGENCY	(NUMBER) PERCENT
ARTC	(81) 75.0%
Beth-Israel	(169) 81.64%
NarcoFreedom	(97) 72.93%
Other	(35) 74.47%

- **36.59 % of all respondents did not know of the process necessary to file a grievance if there is a problem with their counselor (12.60 % and 23.98 % respectively).**

**Table 19: Respondents who did NOT know of the process necessary to file a grievance procedure if there is a problem with their counselor by agency**

AGENCY	(NUMBER) PERCENT
ARTC	(32) 29.63%
Beth-Israel	(71) 34.63%
NarcoFreedom	(58) 44.27%
Other	(18) 38.3%

**Table 20: Awareness of Information posted at the clinic by agency**

	% NOT aware of posted information about a Patient Advocate in clinic	% NOT aware of posted Patient Bill Of Rights in clinic	% NOT aware of posted OASAS contact information in clinic	% NOT aware of Posted Grievance Procedure in clinic	% of Respondents who indicated None of Above
AGENCY	(NUMBER) PERCENT	(NUMBER) PERCENT	(NUMBER) PERCENT	(NUMBER) PERCENT	(NUMBER) PERCENT
ARTC	(53) 47.3%	(48) 42.9%	(52) 46.4%	(59) 52.7%	(34) 30.4%
Beth-Israel	(100) 47.8%	(63) 30.1%	(124) 59.3%	(154) 73.7%	(33) 15.8%
NarcoFreedom	(86) 64.7%	(68) 51.1%	(84) 63.2%	(91) 68.4%	(58) 43.6%
Other	(19) 40.4%	(14) 29.8%	(22) 46.8%	(31) 66.0%	(11) 23.4%
% of whole population	(259) 51.6%	(194) 38.6%	(283) 56.4%	(336) 66.9%	(137) 27.3%

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## ENDNOTES

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- 84 See Tables 11-13 in the Appendix for agency variation.

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For more information contact:

**VOCAL New York**

80-A Fourth Ave.

Brooklyn, NY 11217

718-802-9540 | [info@vocal-ny.org](mailto:info@vocal-ny.org) | [www.vocal-ny.org](http://www.vocal-ny.org)

**Community Development Project of the Urban Justice Center**

123 William St., 16<sup>th</sup> floor

New York, NY 10038

<http://cdp-ny.org>