

## **ISSUE BRIEF**

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# Reducing Infectious Diseases in the U.S.: FOCUS ON HIV/AIDS AND HEPATITIS





he worldwide hepatitis and HIV/AIDS epidemics are overwhelming. Globally, 200 million people -- more than three percent of the world's population -- are infected with hepatitis C, and nearly 33 million people are reported to be living with HIV.<sup>1,2</sup>

The global situation often overshadows the need to also address these diseases domestically.

- An estimated 3.2 million Americans have chronic hepatitis C infections, costing the country an estimated \$15 billion annually in health care costs.<sup>3,4</sup> Approximately 8,000 -10,000 people die every year from hepatitis C related liver disease.<sup>5</sup> It is the leading cause of cirrhosis and liver cancer and the most common reason for liver transplantation in the United States. In 2006, there were approximately 19,000 new hepatitis C virus infections in this country.<sup>6</sup> This number is believed to be conservative, since many Americans are unaware they are infected.<sup>7</sup>
- An additional 800,000 to 1.4 million people are estimated to have chronic viral hepatitis B infection in the United States.<sup>8</sup> This number is also likely to be an underestimate because most people who are infected do not know they have the disease until they show symptoms of illness.
- An estimated 1.0 to 1.2 million Americans are living with Human Immunodeficiency Virus (HIV) and/or Acquired Immunodeficiency Syndrome (AIDS).<sup>9</sup> There are an estimated 56,300 new cases of HIV diagnosed in this country every year.<sup>10</sup> More than 583,000 Americans have died of AIDS since 1981.<sup>11</sup> In Fiscal Year 2007, total federal spending on HIV/AIDSrelated medical care, research, prevention, and other activities in the United States was \$23.3 billion.<sup>12</sup>

One of the most effective, scientifically-based methods for reducing these diseases -- needle exchange programs -- has become embroiled in politics, based on some long-held misperceptions, creating a serious challenge for the medical community and policymakers.

This paper examines the scientific basis for removing existing federal restrictions on needle exchange programs.

APRIL 2009 PREVENTING EPIDEMICS. PROTECTING PEOPLE.

## I. SCIENCE SAYS NEEDLE EXCHANGE EFFECTIVELY REDUCES RATES OF DISEASE

**66** THERE IS NO LONGER DOUBT THAT [NEEDLE EXCHANGE] PROGRAMS WORK, YET THERE IS A STRIKING DISJUNCTION BETWEEN WHAT SCIENCE DICTATES AND WHAT POLICY DELIVERS. **99**<sup>13</sup>

-- NATIONAL INSTITUTES OF HEALTH (NIH) CONSENSUS MEETING

66 CLEARLY NEEDLE EXCHANGE PROGRAMS WORK. THERE IS NO DOUBT ABOUT THAT. 914

-- ANTHONY S. FAUCI, DIRECTOR, NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES

The research shows that needle exchange programs can effectively and dramatically reduce the number of Americans who become infected with hepatitis and HIV. The programs help meet the health and humanitarian goals of helping people who are already dealing with substance abuse problems avoid contracting and transmitting these serious, life-altering diseases.

A major U.S. policy goal should be to prevent and reduce drug use. Enough resources should be devoted to treat drug abuse and help individuals quit.

In addition to providing drug abuse treatment, support must be provided to protect individuals who are struggling with drug abuse from contracting hepatitis B and C and HIV. Currently, "injection" drug users are at high risk for these diseases, because they often end up sharing needles when clean needles are not available, and sharing needles is one of the ways these illnesses can be spread. Public health officials designed "needle exchange" programs, where drug users can exchange used needles for clean ones so the disease is not passed on from one drug user to another, to help control the spread of these diseases.

By helping prevent the spread of disease, it increases the odds that a person struggling with drug abuse can be helped, because it is significantly harder to treat people for drug use when their problems become compounded by acquiring HIV or hepatitis B or C.

Needle exchange programs have been endorsed by leading scientific organizations and individuals, including the Institute of Medicine (IOM); the World Health Organization (WHO); the American Academy of Pediatrics (AAP); the American Medical Association (AMA); the American Nurses Association (ANA); the American Public Health Association (APHA): Anthony Fauci, director of the National Institute of Allergy and Infectious Diseases; Julie Gerberding, former director of the U.S. Centers for Disease Control and Prevention (CDC); Donna E. Shalala, former secretary of Health and Human Services; David Satcher, former assistant secretary for health and surgeon general; and Harold Varmus, former director of the National Institutes of Health.<sup>15, 16</sup>

Alternative approaches to needle exchange, such as disinfection and decontamination and outlawing the sale of needles, have been shown to be much less effective.<sup>17</sup> Many needle exchange programs often also work to target the underlying problems of drug use by providing and/or referring individuals to substance abuse treatment and other health and social services.

Injection drug users account for one-fifth of the 1.0 to 1.2 million Americans living with HIV/AIDS and most of the hepatitis C infections in the United States, according to estimates from CDC.<sup>18</sup> AIDS is the number one cause of death among injecting drug users.<sup>19</sup> Injection drug users currently account for 12 percent of all new HIV infections, according to a 2009 report from the CDC.<sup>20</sup> Nearly 32 percent of injecting-drug users report sharing needles.<sup>21</sup> As of November 2007, at least 185 syringe exchange programs were operational in 36 states, District of Columbia and Puerto Rico.<sup>22</sup>

## 2. NEEDLE EXCHANGE PROGRAMS DO NOT PROMOTE DRUG USE

Some have worried that needle exchange programs could promote increased drug use or create the perception that the government is supporting illegal drug use. The programs are controversial and federal funding to support needle exchange has been banned for more than 20 years, since 1988.<sup>23</sup> Only an act of Congress can overturn the ban. A number of state and local health departments continue to fund and sustain these programs in many communities. To address potential concerns, a number of communities have placed some restrictions on the programs, such as prohibiting them from being located near schools, parks, and churches.

While the programs are politically controversial, hundreds of scientific studies have been conducted that have found needle exchange programs can help to reduce HIV transmission and do not promote illegal drug use. There is also evidence that needle exchange programs do not increase unsafe disposal of unused syringes among participants in these programs.<sup>24</sup>

#### SCIENCE: REDUCING DISEASE RATES WITHOUT INCREASING DRUG USE

A wide range of domestic and international research on needle exchange has found that needle exchange programs significantly reduce rates of disease and do not lead to increased drug use.

In 2008, CDC concluded that the incidence of HIV among injection drug users had decreased by 80 percent in the United States in part due to needle exchange programs: "those exposed [to HIV] through injecting drug use have reduced needle sharing by using sterile syringes available through needle exchange programs or pharmacies and have reduced the number of individuals with whom they share needles."<sup>25</sup>

#### Some of the most prominent studies include:

- A National Institutes of Health (NIH) Consensus Conference: A consensus panel of non-governmental scientific experts convened by NIH in February 1997 reviewed hundreds of scientific studies and heard presentations by 15 researchers. The panel strongly endorsed the use of needle exchange programs to curb the AIDS epidemic in the United States.<sup>26</sup> The experts concluded that the scientific evidence was clear that behavioral intervention programs such as needle exchange were successful, and did not increase illicit drug use among current drug users, did not increase the number of drug users, and did not increase the amount of discarded drug paraphernalia.<sup>27</sup> The group issued a strong recommendation in favor of removing government restrictions on needle exchange programs, and urged that pharmacy sales of sterile injecting equipment become legal.<sup>28</sup>
- A Review by the Surgeon General: In March 2000, U.S. Surgeon General David Satcher, prepared an analysis of all peer-reviewed scientific studies of syringe exchange programs that had been conducted since 1998. This review concluded that needle exchange programs are sound public health interventions that reduce HIV transmission and do not promote illegal drug use.<sup>29</sup>
- An Analysis by the World Health Organization (WHO): In 2004, WHO, the Joint UN Programme on HIV/AIDS (UN-AIDS), and the United Nations Office on Drugs and Crime, analyzed more than 200 studies and found "compelling"

evidence that increasing the availability and use of sterile injecting equipment "contributes substantially to reductions in the rate of HIV transmission."<sup>30</sup> In addition, the report said, there was "no convincing evidence of major unintended negative consequences...such as initiation of injecting among people who have not injected previously, or an increase in the duration or frequency of illicit drug use or drug injection."<sup>31</sup> WHO concluded that "the international experience across countries and regions is so convincing that there is no longer any real justification for ... small-scale [pilot] programs."<sup>32</sup>

- ▲ The report cited a study published in 2002 that compared HIV rates in 103 cities in 24 countries, which found that the HIV infection rate declined by an average of 18.6 percent annually in 36 cities with needle exchange programs. It increased by an average of 8.1 percent annually in 67 cities without such programs.<sup>33,34</sup> Other research has reached similar conclusions. For instance, a 1997 study compared HIV infection rates among injecting drug users in 52 cities without syringe exchange programs, and 29 cities with needle and syringe programs in North and South America, Europe, Asia and the South Pacific. On average, the HIV infection rate increased by 5.9 percent per year in the former and decreased by 5.8 percent among the latter, according to the WHO report.
- ▲ The report found limited evidence to support the efficacy of disinfection and decontamination approaches, an alternative prevention strategy promoted by U.S. public health officials in the absence of federal support for needle exchange. WHO recommended these approaches should only serve as temporary measures when it was not possible to establish needle exchange.<sup>35</sup> The global health organization concluded that paraphernalia laws were "barriers" to HIV control, and that pharmacy-based programs and vending machines that increase availability to syringes -- while useful -- were not as effective as face-to-face contact via exchange programs. They found that face-to-face programs also allowed for additional services, such as education, recruitment into drug treatment, and access to primary care medical treatment.

According to the WHO: "Communities or countries threatened by or experiencing an epidemic of HIV infection among injecting drug users should urgently adopt measures to increase the availability and utilization of sterile injecting equipment and to dispose of used equipment. They should provide risk-reduction education, referrals to drug-dependence treatment and abscess management, promote condom use, HIV testing and counseling, and provide care, treatment and support for persons with HIV/AIDS and treatment of sexually transmitted infections. If necessary, legislation related to drug dependence and drug paraphernalia should be reviewed and amended in order to allow for and promote the implementation of needle and syringe programmes."<sup>36</sup>

■ A 2006 Review of the International Evidence: A study published in 2006 reviewed a wide range of the international evidence regarding the efficacy of syringe exchange programs.<sup>37</sup> The authors concluded that there was "compelling evidence" that access to sterile syringes "reduces HIV infection substantially," and that there was "no convincing evidence of any major unintended consequences," such as an increase in illicit drug use.<sup>38</sup> Furthermore, the researchers found that needle exchange programs were cost-effective and provided additional benefits, apart from reducing HIV infection, saying: "There is reasonable evidence the [needle exchange programs] can increase recruitment into drug user treatment and possibly also into primary health care."<sup>39</sup> As with all previous reviews, the researchers stressed that needle exchange programs by themselves were not enough to control HIV infection among injecting drug users and should be part of a comprehensive prevention approach.

■ A U.S. Department of Health and Human Services Report to Congress. A 1997 report to Congress by the U.S. Department of Health and Human Services (HHS) concluded that syringe exchange programs were a valuable part of a comprehensive strategy to prevent the transmission of infectious diseases, chief among them HIV.<sup>41</sup>

## CASE STUDY IN NEW YORK

"[Needle exchange] programs...have been effective in reducing both incidence and prevalence rates by 75 percent in New York City. The HIV epidemic in injecting drug users in New York City has been the largest HIV epidemic in injecting drug users in the world. HIV was introduced into the injecting drug population in New York City during the mid-1970s and it spread very rapidly during the late 1970s and early 1980s. Substantial risk reduction efforts began with injecting drug users in New York City during the mid-1980s, and HIV prevalence stabilized at approximately 50 percent among this population. The legalization and large-scale expansion of syringe exchange programs which began in 1992, the provision of HIV prevalence and peer outreach interventions were associated with drastic reductions in HIV prevalence and incidence rates. These declines were seen in multiple studies, including injecting drug users recruited from drug detoxification programs, methadone maintenance programs, and through street outreach. HIV prevalence among injecting drug users declined from approximately 50 percent in 1990 to the current level of 15 percent to 20 percent and HIV incidence declined from an estimated 4/100 person-years at risk to an estimated 1/100 person-years."<sup>42</sup>

## **ELIMINATING PROGRAMS HAS ADVERSE EFFECTS**

One case study in Windham, Connecticut found that following the closure of the community's needle exchange, "significant increases were found in the percentage of respondents who reported an unreliable source as their primary source of syringes, in respondents' reports of the frequency of reusing syringes, and in the percentage of respondents who reported sharing of syringes. Surveys of outdoor drug-use areas found that the closure of the needle exchange did not reduce the volume of discarded syringes and other drug-injection debris. The problems in Windham that led to the closure of the exchange still remain[ed], and the city's drug injectors [we]re engaging in higher levels of HIV risk behavior."<sup>43</sup> "Given consistent evidence that multi-component HIV prevention programs that include sterile needle and syringe is associated with reductions in drug-related HIV risk behavior, such programs should be implemented where feasible."<sup>40</sup>

-- Board on Global Health, Institute of Medicine 2006 Other Studies: A few studies have raised doubts about the impact of needle exchange programs. However, the authors of one of the most widely cited studies which was conducted in Vancouver and Montreal in 1977, argue that their work has been misinterpreted. They found that HIV rates were higher for a set of drug users who participated in needle exchange programs, but also could purchase syringes in pharmacies. The researchers concluded that because these drug users could also purchase needles directly and that study was focused on inner-city users where injection drug use is particularly high, it was not possible to evaluate the impact of the needle exchange programs on HIV transmission based on their study.

"True, we found that addicts who took part in needle exchange programs in Vancouver and Montreal had higher HIV rates than addicts who did not. That's not surprising. Because these programs are in inner-city neighborhoods, they serve users who are at greatest risk of infection. Those who didn't accept free needles often didn't need them since they could afford to buy syringes in drugstores. They also were less likely to engage in the riskiest activities.

Also, needle exchange programs must be tailored to local conditions. For example, in Montreal and Vancouver, cocaine injection is a major source of HIV transmission. Some users inject the drug up to 40 times a day. At that rate, we have calculated that the two cities we studied would each need 10 million clean needles a year to prevent the re-use of syringes. Currently, the Vancouver program exchanges two million syringes annually, and Montreal, half a million."

--Julie Bruneau and Martin T. Schecter, writing for the New York Times, op-ed page about their 1977 study in Vancouver and Montreal.<sup>44</sup>

## RETURN ON INVESTMENT: HEPATITIS AND HIV PREVENTION SAVES LIVES AND MONEY

A number of studies have shown syringe exchange programs to be cost-effective and money saving, particularly for HIV.<sup>45</sup> In the United States, Medicaid covers HIV-related treatment costs for many injecting drug users, so HIV prevention can save significant taxpayer dollars. Those with late-stage liver disease as a result of hepatitis B or C also often become dependent on Medicaid.

A syringe costs less than one dollar,<sup>46</sup> "compared to the \$25,000-\$30,000 a year for treating somebody for hepatitis C. But you really can't put a dollar value on people whose lives have been saved because they didn't get an infectious disease."<sup>47</sup>

--Bernard Lieving, Former Harm Reduction Program Manager for the New Mexico Department of Health

- One 1997 analysis estimated that between 4,394 and 9,666 cases of AIDS infection could have been avoided in the United States, if syringe exchange programs had been established during the early days of the epidemic.<sup>48</sup> Researchers calculated the cost to the U.S. health system at between \$244-538 million.<sup>49</sup>
- Another study using mathematical modeling to calculate potential savings resulting from the work of syringe exchange programs estimated that 100 percent coverage of sterile syringes for a hypothetical one million injecting drug users in the United States would require 954.8 million needles at a cost of \$423 million, and prevent 12,350 HIV cases and \$1.3 billion in treatment costs.<sup>50</sup> A policy of funding comprehensive syringe exchange programs would cost about \$423 million for one year, with one-third of these costs paid as out-of-pocket expenditures by drug users who purchased needles in pharmacies. This would cost about \$34,278 for each HIV infection prevented -- considerably less than the estimate lifetime costs of medical coverage for HIV, about \$108,469.

- Another study predicted that needle exchange programs could prevent HIV infections among clients, their sex partners and children at a cost of about \$13,000 per infection.<sup>51</sup> A study conducted in Ontario, Canada conservatively predicted that the program would prevent 24 cases of HIV infection over five years, thereby providing a savings of \$1.3 million after the program expenses were taken into account.<sup>52</sup> A study conducted in New York found seven needle exchange programs exchanged 1,667,682 syringes in a year with an annual cost of \$1,822,426, and resulted in preventing 87 infections, saving \$7.6 million in HIV treatment costs.<sup>53</sup>
- A cost-effectiveness study of needle exchange programs in Svetlogorsk in Belarus evaluated a comprehensive strategy that included syringe exchange, safe sex counseling, condom promotion, bleach distribution, and referrals for sexually transmitted disease services. The estimated cost per each prevented HIV infection was only \$68, notably cost effective.<sup>54</sup> This is considered to be a significant study because it confirms that needle exchange programs are cost-effective even in a "resource-poor" setting.<sup>55</sup>

A few studies have looked at the financial impact of needle exchange programs regarding the costs associated with hepatitis C. However, at least one review of the existing scientific literature predicted that the combined effect of needle exchange programs on all viruses' transmission would be larger than that of HIV alone, and that current research, by failing to include hepatitis C, may have underestimated the overall cost-effectiveness of syringe exchange programs.<sup>56</sup>

An Australian study, which looked at the impact of syringe exchange programs on both HIV and hepatitis C between 1991, when needle exchange became well established in the country, and 2000, found that the government's investment in syringe exchange programs produced substantial financial benefits and cost savings.<sup>57</sup> During that period, Australia spent a total of \$150 million on syringe exchange programs. This included \$130 million by the government, the remainder by consumers. During that time, the government estimated that 25,000 cases of HIV were prevented, at a savings of \$7 billion for lifetime treatment. For hepatitis C, the government estimated that 21,000 cases were prevented and that it saved about \$783 million in total treatment costs over the lifetime of cases. Overall, total treatment costs saved by preventing cases of HIV and HCV totaled approximately \$7.8 billion. The report pointed out that including hepatitis C increases the return because no additional investments are required.



## BACKGROUND ON NEEDLE EXCHANGE POLICY

A ban on the use of federal funds for needle exchange programs has been in effect since 1988 out of concern that they could have the inadvertent consequence of promoting drug use, despite the evidence that these programs reduce disease without increasing drug use.

Ten years ago, in 1998, the Clinton Administration convened federal experts to evaluate the research and reassess the policy. Nine leading public health officials signed a unanimous memorandum to then-Secretary of HHS Donna Shalala finding there was "conclusive scientific evidence that needle exchange programs, as part of a comprehensive HIV prevention strategic, are effective public health interventions that reduce the transmission of HIV and do not encourage the use of illegal drugs."<sup>58</sup> The nine officials included:

- David Satcher, assistant secretary for health and surgeon general, Department of Health and Human Services;
- Harold Varmus, director, National Institutes of Health;
- Claire Broome, acting director, Centers for Disease Control and Prevention;
- Anthony Fauci, director, National Institute of Allergy and Infectious Diseases;
- Helene Gayle, director, National Center for HIV, STD and TB Prevention, CDC;
- Margaret Hamburg, assistant secretary for planning and evaluation, Department of Health and Human Services;
- Nelba Chavez, administrator, Substance Abuse and Mental Health Services Administration;

- Eric P. Goosby, director, Office of HIV/AIDS Policy, Department of Health and Human Services; and
- Alan I. Leshner, *director*, *National Institute* on Drug Abuse.

Despite the scientific consensus, the administration was concerned about political pressures and potential negative perceptions, and left the federal funding restrictions in place. Former President Bill Clinton has since expressed regret for not removing the restrictions, stating in 2002 at the XIV International AIDS Conference "I was wrong."<sup>59</sup> He said in a Frontline interview in 2008 that at the time he felt that "politically, the country wasn't ready for it."<sup>60</sup>

The U.S. Surgeon General from 1998 to 2002 David Satcher said he "had the responsibility to communicate directly with the American people. So [he] chose to speak out about the efficacy of needle exchange programs, and [he] went around the country doing that and many localities decided to fund these programs, despite the absence of federal funding."<sup>61</sup> In 2007 he testified before the U.S. Congressional House Committee on Oversight and Reform that "the White House had decided not to support federal funding for needle exchange programs, despite the science, because of a political environment in Washington that would not support it."<sup>62</sup>

Anthony Fauci, director, National Institute of Allergy and Infectious Diseases, also testified before Congress in support of needle exchange programs about the science supporting how the programs are effective for reducing disease transmission rates without leading to increased drug use.<sup>63</sup>

Exchange between **Representative John Tierney (D-MA)**, and **Anthony Fauci**, **director of the National Institute of Allergy and Infectious Diseases**, during a September 16, 2008 hearing before the House Committee on Oversight and Government Reform.

**Tierney:** So, Dr. Fauci, let me start with you, if I could. In your professional scientific judgment, does the public health evidence support the federal ban on funding needle exchange programs?

**Fauci:** No, it doesn't. Actually, I was part of a group that I helped co-chair years and years ago to look in a somewhat

meta-analysis way of all the data that you referred to asking the two questions: A, does needle exchange help promote illicit drug use? And, B, does it impede or block in many respects the transmission of HIV? And the answers to both of those questions were: It doesn't increase the injection drug use, and it does prevent HIV infection. So the scientific data are really rather firm and totally convincing that injection drug use and the transmission of HIV through injection drug use can be decreased significantly by needle exchange programs.

## **Overview of State and Local Policies**

Laws and regulations enacted in many cities and states make possession of needles a crime, which creates barriers to obtaining sterile needles legally and creating regulatory hurdles for needle exchange programs. Among these are: drug paraphernalia laws, syringe prescription laws, pharmacy regulations and practice guidelines, and restrictions that often are imposed on syringe exchange programs themselves. This creates a paradox: injecting drug users are advised to use only sterile syringes, but, at the same time, they are unable to purchase or acquire sterile needles.

Drug paraphernalia laws establish criminal penalties for the manufacture, sale, distribution, possession, or advertisement of any item used to produce and use illegal drugs, including syringes. In 2002, at least 47 states, the District of Columbia and the Virgin Islands had such laws.<sup>64</sup> Syringe prescription laws, which prohibit dispensing or possessing syringes without a valid medical prescription, were in effect in eight states and one territory in 2002.<sup>65</sup> A 2000 analysis showed that it was illegal for a physician to prescribe sterile syringes to injecting drug users in 46 states.<sup>66</sup> Finally, as part of their oversight responsibilities, state boards of pharmacy develop and enforce regulations and guidelines that cover many issues related to the sale of syringes. These include display, advertising, record-keeping, customer identification and assessment of customers' probable use.<sup>67</sup>

For examples of some state or local programs, see Appendix A.

## POLICY APPROACH: PROGRAMS CAN ALSO PROVIDE SUBSTANCE ABUSE AND DISEASE TREATMENT

Syringe exchange programs are an effective way to find hardto-reach drug users and connect them with a wide range of important health and social services. They provide referrals to substance abuse treatment and other social and medical serv-

"Syringe exchange programs were shown to be effective [in reducing the spread of HIV] in the mid-to-late 1990s, and nothing much has changed in that regard. The one thing that has changed substantially, particularly in the United States, is that they have become multi-service organizations. They not only address HIV, but hepatitis C, abscesses, overdoses, and drug treatment, among other things. Preventing HIV is obviously important, but it is only one of many important functions they provide."<sup>68</sup>

-- DON DES JARLAIS, Director of Research for the Baron Edmond de Rothschild Chemical Dependency Institute at Beth Israel Medical Center, New York ices. Some offer HIV/AIDS education and counseling, condom distribution, on-site testing for HIV, hepatitis B, hepatitis C, and tuberculosis, and instruction on how to prevent abscesses and other bacterial infections.

"Because most syringe and harm reduction programs that work have mobile outreach vans, they are able to reach marginalized populations -- not only people who have substance use issues, but who aren't able to access other services. The trust that syringe exchange staff builds with these people over time significantly increases the likelihood that these otherwise underserved people will actually access care -- not just drug treatment, but all kinds of health services on a preventive basis, rather than in an emergency room."<sup>69</sup>

-- KANDY FEREE, President and Chief Executive Officer of the National AIDS Fund

#### **DISPARITIES IN INFECTIONS**

Racial and ethnic minorities are disproportionately affected by HIV/AIDS. Of AIDS cases diagnosed in 2006, 49 percent were African Americans, 19 percent were Hispanics, and 30 percent were whites.<sup>70</sup>

African Americans accounted for 45 percent of new HIV infections diagnosed in the United States in 2006, even though they comprised only 12 percent of the population.<sup>71</sup> The HIV infection rate among African Americans is seven times higher

than the rate among whites. The infection rate among Latinos is three times higher than the rate among whites.<sup>72</sup>

These disparities are also reflected in rates of transmission from injection drug use. Twenty-two percent of AIDS cases among African-American men and 22 percent among Hispanic men occurred through injection drug use, compared with 11 percent among white men.<sup>73</sup>

## 4. BACKGROUND ON DISEASE TRANSMISSION AND NEEDLE EXCHANGE PROGRAMS

#### NEEDLE EXCHANGE FAQ

#### How Does Needle Sharing Transmit Disease?

Transmission of blood-borne diseases, including HIV and hepatitis, can occur:

- Directly when an infected drug user shares a syringe;
- Indirectly when an infected injector shares injection equipment, such as water, cookers, cotton, and spoons; or
- When drug users jointly prepare and share drugs with others.

#### Why Do Drug Users Use Dirty Needles?

A typical intravenous drug user injects about 1,000 times a year.<sup>74</sup> Drug users are often unable to buy sterile needles at a pharmacy due to cost or laws that prohibited them from buying drug paraphernalia in many states. Additionally, the social stigma of purchasing syringes stops others from purchasing needles.

Drug users then find other ways to obtain needles, such as sharing with other users, finding needles previously used by diabetics, or purchasing them illegally from street dealers, who often resell used needles.

#### How Do Needle Exchange Programs Work?

Syringe exchange programs operate in different settings, including health and substance abuse treatment clinics, storefronts, vans, and sidewalk tables. The requirements of how many syringes can be exchanged and the circumstances under which these exchanges occur also vary. Some programs are limited in the number of needles they can exchange; others require clients to carry a special registration card in order to participate. Many programs require a "one-for-one" exchange. For examples of needle exchange programs, see Appendix A.

## HEPATITIS C VIRUS (HCV) INFECTION

Hepatitis C is a contagious liver disease that ranges in severity from a mild illness lasting a few weeks to a serious, lifelong illness. It results from infection with the hepatitis C virus (HCV), which is spread primarily through contact with the blood of an infected person. Hepatitis C can be either "acute" or "chronic."

**Acute hepatitis C** virus infection is a short-term illness that occurs within the first six months after someone is exposed to the hepatitis C virus. Approximately 75 to 85 percent of people who become infected with hepatitis C virus develop chronic infection.

**Chronic hepatitis C virus infection** is a long-term illness that occurs when the hepatitis C virus remains in a person's body. HCV can last a lifetime and lead to serious liver problems, including cirrhosis (scarring of the liver) or liver cancer. Chronic hepatitis C, for example, can cause liver damage, liver failure, liver cancer, and death.

Globally, 200 million people, or more than three percent of the world's population are infected with HCV.<sup>75</sup> CDC estimates that 3.2 million Americans have chronic HCV infection.<sup>76</sup>

#### **HIV/AIDS**

HIV is the virus that causes AIDS. CDC defines AIDS to mean the later stages of when a person's immune system is severely damaged, marked by the presence of HIV infection as shown by a positive HIV-antibody test plus at least one of the following: the development of an opportunistic infection -- an infection that occurs when a person's immune system is impaired, such as Pneumocystis carinii pneumonia (PCP), or a CD4 lymphocyte count of 200 or less (a normal count ranges from 800 to 1,200). Some early symptoms of HIV can include: swollen lymph nodes, diarrhea, weight loss, fever, and cough and shortness of breath. Some later symptoms of HIV/AIDS can include: persistent fatigue, soaking night sweats, shaking chills or fever higher than 100 F (38 C) for several weeks, swelling of lymph nodes for more than three months, chronic diarrhea, persistent headaches, persistent white spots or unusual lesions on the tongue or mouth, and blurred and distorted vision.

Globally, nearly 33 million people were reported to be living with HIV.<sup>77</sup> An estimated 1.0 to 1.2 million Americans are living with HIV/AIDS. Nearly 30 years after emerging as a deadly infectious disease, there is still no vaccine or cure for HIV. A combination of pharmaceutical interventions, when used correctly, can mitigate the effects of the disease and allow individuals infected to live many years with HIV.

## **GLOBAL PERSPECTIVE**

Worldwide, as of 2006, only eight percent of injecting drug users had access to HIV prevention programs, including syringe exchanges.<sup>78</sup> More than 40 countries operate needle and syringe programs, including, Australia, Belgium, Brazil, Bulgaria, Canada, China, Croatia, Czech Republic, Denmark, El Salvador, Estonia, Finland, Germany, Greece, Hungary, India, Kazakhstan, Latvia, Luxembourg, Nepal, Netherlands, Norway, Philippines, Poland, Portugal, Slovak Republic, Slovenia, Thailand, Ukraine and the United Kingdom.<sup>79</sup>

Authorities in many developing countries have resisted establishing syringe exchange programs, based on concerns they could be viewed as undermining the global commitment against illegal drug use.<sup>80</sup>

Although injecting drug use has been a longtime problem within developed nations, 78 percent of the world's estimated 13 million injecting drug users now live in developing countries. Ten percent of global infections and 30 percent of infections outside of sub-Saharan Africa are attributed to injecting drug use. Unsafe injections are the most common cause of hepatitis C infection in developing countries, causing two million new infections each year and accounting for 42 percent of cases.<sup>81</sup>

"HIV is under control among injecting drug users in Australia," according to Alex Wodak, director of St. Vincent's Hospital Alcohol and Drug Service in Sydney, who has spent more than two decades providing care to drug users in Australia, and initiated an unsanctioned syringe exchange program there in 1986.<sup>82</sup> Needle exchange services exist in every state and territory in Australia, providing nearly 20 million syringes a year.

## 5. RECOMMENDATIONS



The science supporting the public health value of needle exchange in preventing deadly and costly infectious diseases is compelling and overwhelming. Needle exchange programs must be considered an integral part of U.S. drug control policies. Overall, the U.S. must improve drug control policies and drug abuse treatment. One important aspect of treating drug abuse is to ensure that people who are drug users do not also contract serious diseases that create increased hurdles for trying to treat them. The evidence also clearly shows that needle exchange programs do not result in increased illegal drug use. TFAH strongly recommends that U.S. policy makers embrace the science by lifting the ban on use of federal funds for needle exchange programs. This is critical for two reasons: (1) it will free up important resources to support life-saving interventions; and (2) it will de-stigmatize existing programs and people.

We recommend that the following steps be taken:

 Congress should remove the ban on use of federal funds for needle exchange programs as part of consideration of the FY 2010 appropriations bill. The ban has been a recurring "rider" on the Labor, Health and Human Services, Education and Related Agencies appropriations bill since 1988; by omitting it during the next appropriations cycle, Congress will effectively repeal the ban. As part of its 2010 budget submission, the Obama administration should specifically recommend removal of the ban, throwing the weight of the federal government's public health agencies behind the science. A more affirmative message could be sent through Congressional passage of legislation permanently lifting the ban. Legislation to that effect was introduced in the 110th Congress by Representative José Serrano of New York (D) and is expected to be reintroduced in 2009.

- 2. Removal of the ban is only the first step in assuring that needle exchange programs are widely available to those at risk for HIV, hepatitis C and other blood-borne diseases. CDC, the Surgeon General, and the Substance Abuse and Mental Health Services Administration should:
- Actively encourage use of HIV prevention dollars and substance abuse block grant funds for syringe exchange programs;
- Assure technical assistance to communities and programs wishing to undertake syringe exchange programs with federal dollars. Because these programs have been stigmatized and often run "underground" there is not a standard set of best practices or technical assistance programs available for those communities wanting to adopt this intervention.
- Jointly educate mayors, governors, public safety officials, and the drug treatment community about the scientific value of syringe exchange programs -- to overcome years of inaccurate messaging.
- Undertake a social marketing campaign informing the public and those at risk of the value of needle exchange programs -- so they will be welcomed and used as an effective public health intervention against HIV, hepatitis C, and other blood-borne diseases.
- 3. As the Obama administration and the Congress develop prevention interventions in the context of health reform, they should assure that clinicians can prescribe syringes for the purpose of preventing infections and that associated costs are covered as part of a preventive benefit.

## APPENDIX A: EXAMPLES OF STATE, LOCAL, AND PHILANTHROPIC INITIATIVES

Local and state health departments, substance abuse treatment facilities, HIV clinics, health philanthropies and other foundations have found creative ways to establish and/or financially support needle exchange programs in the absence of federal funding. Some programs function openly, with authorization; others, believing they must respond to the public health urgency regardless of the law, operate "underground." For unauthorized programs, law enforcement officials often are either unaware of these activities or ignore them.

## A. California

Currently, there are more than 40 syringe exchange programs operating in the state.<sup>83</sup> The California Department of Public Health plans to provide a total of \$2.25 million in funding over the next three years to 10 programs.

Among 24 California syringe exchange programs evaluated between 2001 and 2003, 83 percent also provided onsite HIV testing and counseling, and all sites offered safe sex and safe injection information, first aid, and referrals for substance abuse treatment. Among 560 program participants who were interviewed for a survey, 76 percent received medical and preventive care exclusively through needle exchange programs.<sup>84</sup> This is important because syringe exchange programs are often the only health care providers injecting drug users ever see. This study, however, did not collect data from injecting drug users who did not use syringe exchange programs, so it was not possible to compare efficacy.85 A number of studies, however, have found that more generous syringe dispensing results in a lower risk of transmission among program clients.86

In an earlier study conducted before programs in the state became legal, researchers studying a San Francisco syringe exchange program during a five-year period found that the program did not encourage drug use, either by recruiting new injecting drug users, or by increasing drug use among current drug users.<sup>87</sup> In fact, injection frequency decreased from 1.9 injections per day to 0.7, and the percentage of new injecting drug users in the community dropped from three percent to one percent.

In California, local governments must authorize needle exchange programs before they can operate.<sup>88</sup> The law provides that staff members for authorized programs be exempt from arrest for possession or distribution of drug paraphernalia laws, but there is no such protection for injecting drug users.<sup>89</sup> In a survey of 935 individuals who visited authorized syringe exchange programs between 2001 and 2003, 17 percent reported being arrested or receiving a citation for drug paraphernalia possession in the preceding six months.<sup>90</sup>

In 2005, laws took effect that allow pharmacies to provide 10 or fewer syringes to adults without a prescription, and for adults to possess 10 or few syringes from an authorized source, including syringe exchange programs. However, like the needle exchange programs, only local governments can approve these exemptions – and they apply only to those specific jurisdictions. That means possessing 10 or fewer syringes may be legal in one town and illegal in the neighboring town.

#### **B.** Wilmington, Delaware

The cumulative number of AIDS cases (3,458) in Delaware was 0.4 percent of all reported U.S. cases in 2005.<sup>91</sup> Delaware ranks 33rd among states in the total cumulative number of reported AIDS cases and, despite being the second smallest state in the United States, had the seventh highest incidence of new AIDS cases in 2005.

In July 2006, the state legislature approved a five-year pilot needle exchange program limited to the city of Wilmington. It is the only program in Delaware, and is restricted to city residents. The state authorized Brandywine Counseling, a long-established substance abuse treatment center, to administer the program. Now in its second year, the program has

#### C. District of Columbia

The District of Columbia has the highest rate of new AIDS cases in the country; an estimated one of every 20 residents of the city is living with HIV.<sup>92</sup> PreventionWorks! began in October 1998 in order to provide needle exchange and other harm reduction services in the District of Columbia. The program incorporated as a nonprofit organization after Congress passed legislation that same year forbidding both the District from using its local funds to support needle exchange services, and private organizations that receive any federal funds from operating needle exchange, even if funded with private donations. Federal lawmakers repealed the ban in late 2007. Within days, D.C. Mayor Adrian M. Fenty announced \$650,000 in District funding for needle exchange, including \$300,000 for PreventionWorks!93

## received \$200,000 for each of its first two years of operation. It requires a one-for-one needle exchange, and serves injecting drug users ages 14 and older. The program must be mobile, meaning that needles cannot be distributed from stationary or office sites, and rotates among eight different locations in the city.

There are 336 participants enrolled in the Wilmington program, which exchanged 9,677 needles between February 1, 2007 and September 15, 2008. Participants receive a membership card, which protects them from legal action under the state's paraphernalia law, and allows them to exchange needles. There are no names or photographs on the cards, only a unique identifier linking them to the program.

The program dispenses clean needles and accepts dirty ones two afternoons a week from its office on 14th Street, and runs a mobile unit that visits nine sites near active drug strips five days a week, Tuesday through Saturday, with repeated visits to target locations. The program also plans to establish a neighborhood harm reduction center with expanded hours and clinic services.

In 2007, PreventionWorks! served an estimated 1,851 participants with education, referrals and sterile needles. This included exchanging and disposing of nearly 180,000 sterile syringes. The program also made nearly 500 drug treatment referrals.

#### **D. New Mexico**

New Mexico has adopted what is believed to be the nation's most comprehensive harm reduction program. In 1997, the state legislature approved needle exchange coverage throughout the state. About 15 communitybased organizations and 40 public health offices provide needle exchange and other services. During its ten years, the program has collected and dispersed almost ten million syringes. The state also funds primary medical care and other services for those who use the program. To be sure, the prevalence of HIV in New Mexico is relatively low -- the state reports only about 150 new cases every year -- but cases among injecting drug users dropped from 26 in 1998 to five in 2007.<sup>94</sup> There is not enough data yet about lowering hepatitis C infections, which are a bigger problem in the state, with an estimated 3,500 new cases annually.

#### CASE STUDY: CHIMAYO, NEW MEXICO

"When we ask someone when they first 'used,' they often will respond that they were given drugs at their 13th birthday party by an uncle."

-- MARTIN WALKER, Director of Adult Health Services, for the Santa Fe Mountain Center.

In Chimayo, a small village located in Rio Arriba County, north of Santa Fe in the north central part of the state, there are staggering rates of opiate addiction. County-wide, overdose rates are three times the national average.<sup>95</sup> The county also has higher than national average rates of hepatitis C, due to needle sharing among injecting drug users. The Santa Fe Mountain Center provides numerous health services to try to curb drug addition and reduce related diseases, including harm reduction counseling, basic wound care, condom distribution, prevention information on HIV, hepatitis A, B, and C; HIV counseling and testing, community information and referrals, and food distribution. They also provide needle exchange and conduct overdose prevention classes, which teach drug users how to identify an overdose, perform rescue breathing, and safely administer naloxone. A nurse, who rides in the mobile van, has the authority to dispense naloxone, obtained via a doctor's prescription.

The program budget, most of which comes from state funds, is \$130,000 for fiscal 2009. The program enrolls participants using a unique identifier, and serves everyone who has an enrollment card, including those who live outside the area. The well-publicized program, which operates from a van, works four shifts a week, Monday through Thursday. Each shift lasts six hours. This past year, the Chimayo area program exchanged 240,000 syringes.

#### E. Pittsburgh, Pennsylvania

In November 2001, the Allegheny County Board of Health declared a public health emergency with regard to HIV and hepatitis C, effectively making needle exchange legal in the county. Allegheny County has an estimated 12,000 injecting drug users, and injecting drug use is the second leading risk factor for HIV. Data from the Pittsburgh exchange site between July 2003 and January 2005 showed that almost half of those who requested hepatitis C screening tested positive.<sup>96</sup>

Prevention Point Pittsburgh is the only legal needle exchange program in the southwestern part of Pennsylvania. The Pittsburgh program runs two needle exchange sites, one at the local health department, also the site of overdose prevention classes/naloxone distribution, and also from an unmarked white van in the Hill District, where the program originally began. Prevention Point Pittsburgh serves about 200 injecting drug users each week. In 2007, the program exchanged approximately 330,000 needles.

Prevention Point Pittsburgh relies solely on individual donations and grants from area foundations as the Maurice Falk Medical Fund, Three Rivers Community Foundation, Jewish Health Care Foundation, Staunton Farm Foundation and the Birmingham Foundation. Pennsylvania bars the use of state money for needle exchange and the city does not fund the program either. The city and state support the organization's other programs, including HIV and hepatitis C prevention education, condom distribution, overdose prevention, and referrals to other health services, such as primary and mental health care, and drug treatment. The program also runs an innovative overdose prevention/education training in the county jails -- because inmates upon release are vulnerable to severe overdose reactions due to their reduced drug tolerance.

## F. Wisconsin

The AIDS Resource Center of Wisconsin is one of the largest and most comprehensive AIDS service agencies in the country. It provides numerous health and social services to more than 3,000 state residents living with HIV. It also offers an array of AIDS prevention services, including needle exchange programs that operate in 11 Wisconsin cities: Milwaukee, Racine, Kenosha, Beloit, Appleton, Green Bay, Wausau, Au Claire, Superior, La Crosse and Madison. In 2007, the needle exchange program in all cities combined had 14,300 exchanges (transactions), totaling 775,000 needles.

Needle exchange began here in 1994. Since then, the program has seen a 66 percent decrease in HIV infection among injecting drug users.

Known as "Lifepoint," the program began with needle exchange, but later expanded to include HIV prevention education and risk reduction counseling, HIV and hepatitis C counseling and testing, and referrals for drug treatment and other social services. The Milwaukee program makes about 150 drug treatment referrals a year, and also provides intensive outpatient treatment to about 70 individuals.

The program's fleet of vans visits more than 20 exchange sites at community locations convenient to participants. In Milwaukee, the program also uses several 'satellite' sites, which are locations where organizations, such as churches and community health centers, are willing to conduct exchanges.

The state health department's AIDS program provides \$200,000 a year for the center's needle exchange program. The program also receives about \$310,000 from private foundations, as well as an additional \$200,000 from local fund raising efforts.

## EXAMPLES OF PHILANTHROPIC EFFORTS

Because there is no federal money available for syringe exchange programs, and state and local dollars can be scarce and unpredictable, numerous philanthropies have stepped in to support programs. Some examples include:

#### Syringe Access Fund

The Syringe Access Fund was created in 2004 to respond to the deadly connection between injection drug use and HIV. A grant-making collaboration among several philanthropies, the Syringe Access Fund has reviewed 353 proposals and awarded 148 grants totaling more than \$4.4 million in 26 states, the District of Columbia, and Puerto Rico since 2004.<sup>97</sup>

#### **National AIDS Fund**

The National AIDS Fund, one of the founding partners of the Syringe Access Fund, has been supporting syringe exchange since the earliest days of such programs. Many needle exchange programs were seed-funded with support from the National AIDS Fund and its Community Partnerships, a network of grassroots AIDS/HIV organizations. In 2007, the National AIDS Fund and its Community Partnerships awarded more than \$500,000 in grants to support syringe exchange.

#### **AIDS Foundation of Chicago**

The AIDS Foundation of Chicago, founded in 1985 by community activists and physicians, collaborates with community groups to develop and improve HIV/AIDS services, fund and coordinate prevention, care, and advocacy projects; and works for effective, compassionate HIV/AIDS policy. The foundation supports at least seven needle exchange programs in the Cook County area. In fiscal 2009, it will distribute an estimated \$529,500 to support harm reduction programs in the area. The foundation also conducts outreach to pharmacies to promote implementation of the non-prescription syringe purchasing law, a state measure which allows persons older than 18 to buy up to 20 syringes without a prescription. Finally, the group runs a program that provides free "sharps" [disposal] containers to pharmacies so injecting drug users can safely dispose of used needles.

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