

**PUBLIC WELFARE FOUNDATION**

# **Harm Reduction**

**A Critical Strategy  
in AIDS Prevention**

Adisa Douglas, Director of Programs

Revised Edition

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## F O R W A R D

It is wonderful to see new life breathed into the pages of *Harm Reduction: A Critical Strategy in AIDS Prevention*. In 1999, when it was originally published and distributed, the paper quickly became one of the most important and credible educational materials available on the subject. It remains so today.

The pages that follow provide a sound, scientific rationale for why harm reduction and needle exchanges work to prevent the transmission of blood-borne illnesses. But they also tell the deeply personal story of Adisa Douglas' own understanding and advocacy of harm reduction as a legitimate and effective approach to prevention of HIV and other blood-borne infections. She and the Public Welfare Foundation are champions of harm reduction programs and treatment approaches and an angel for those of us who are working directly with injection drug users. I cannot say enough to praise and thank Adisa for her groundbreaking work.

Much research conducted since the mid-90s has confirmed what we knew to be true: harm reduction is an indispensable HIV prevention strategy, especially for those of us on the front lines, day after day after day.... The approach fosters a much more personal relationship between program staff and clients, which enables virtually every participant to have a personalized recovery program that meets his or her needs.

Harm reduction has gained much acceptance since the early 1990s, but it has a long way to go. This paper will again pave the way, as it did seven years ago, with accuracy, honesty and poignancy too powerful to be ignored.

*Patricia S. Fleming*

*Board Member, Prevention Works!*

*Former Director, White House Office of National AIDS Policy*

# INTRODUCTION

**“We are out here saving lives.”<sup>1</sup>**

**Ron Daniels, Program Manager**  
**Prevention Works!, a harm reduction program in Washington D.C.**

**W**hen I wrote the original version of this paper in 1999, I understood that harm reduction services that include providing clean syringes to injecting drug users (IDUs) and providing safe disposal of dirty syringes were saving lives. I had visited harm reduction programs and needle exchange sites and had seen men and women, young and old, who came to get clean needles so that they would not get infected with HIV. However, as the years have gone by since the Public Welfare Foundation began funding harm reduction programs and as I have spent more time at needle exchange sites, I have a greater appreciation that this is indeed life-saving work. Today, I would call this publication *Harm Reduction: A Life-Saving Strategy in the Fight against AIDS*. Now more than ever, there is a greater urgency for government, at all levels, to recognize the life-saving nature of harm reduction strategies. As former U.S. Surgeon General Joycelyn Elders stated: “We must recognize the spread of AIDS through dirty needles as the public health problem that it is. We must accept the scientific data and stand up for needle access programs and begin to save precious lives!”<sup>2</sup>

When the Foundation distributed the first edition of this publication, our primary audiences were policymakers and other funders to convince them of the need for both public and private

financial support for harm reduction services. We wanted to share our experience of supporting harm reduction as a part of our funding of efforts to prevent the spread of HIV/AIDS. The Foundation received very positive responses about the publication from other foundations, members of Congress, and officials in the Clinton Administration, including Surgeon General Dr. David Satcher.

To our surprise, however, the biggest response came from organizations that are providing harm reduction services across the country. They told us that they appreciated the fact that a foundation had come forward with a public document that in straightforward and accessible language made a case for supporting needle exchange as an AIDS-prevention strategy. They told us that they carried the publication with them when they met with their local health and police officials to get their support. They told us that they have copied it over and over and taken it to every meeting where they advocate for harm reduction.

This response to the paper prompted us to prepare this updated and revised version with a forward by Patsy S. Fleming, a White House director of AIDS in the Clinton Administration. In addition, while the scientific evidence supporting the effectiveness of needle exchange was there in the past, today, there is an even clearer picture of the relationship of needle exchange and the decline in HIV/AIDS among populations with the highest rates. For example, in November 2005, in New York, where needle exchange programs were introduced as a harm reduction strategy in 1992, a state health official acknowledged that such programs helped explain declining HIV infection rates.<sup>3</sup> In Philadelphia, an eight-year study conducted by the University of Pennsylvania's Center for Studies of Addiction documented the relationship between the introduction of Prevention Point Philadelphia's syringe exchange

program, needle-sharing behaviors among injectors, and new infections of HIV. The study showed that among IDUs followed during the eight years of the study, the rate of new HIV infections dropped from 6.8% per year to less than .05% per year.<sup>4</sup> A recent report released from the Centers for Disease Control and Prevention (CDC) stated that although African Americans are still eight times as likely as whites to be diagnosed with AIDS, the rate of *newly reported* HIV cases among African Americans has been dropping by about 5% a year since 2001. It stated that this falling rate seemed to be tied to overlapping declines in diagnoses among injection drug users and heterosexuals.<sup>5</sup>

Another purpose of this revised and updated version is to provide information about the organizations that we have supported. Through our relationship with these grantees, we have learned about the complex challenges harm reduction programs face, including: their legal vulnerabilities; their need to address the serious Hepatitis C epidemic that is so prevalent among injection drug users; their work to engage and garner the support of the low-income communities where they work; their commitment to involve their clients in setting the directions of their programs; their recognition of the needs of a very diverse population of IDUs; and their tireless efforts to advocate for policy changes, such as their work to increase resources for drug treatment and federal funding of needle exchange programs. In spite of these challenges, these organizations have successfully helped to prevent the spread of HIV/AIDS and other blood-borne diseases, have helped injection drug users get into treatment, have reached thousands of people who are out of the reach of health and social services, and have saved lives.

*Adisa Douglas*

## H A R M   R E D U C T I O N

**I**n May 1992, I was watching the local news on a Washington, D.C. television station with my friend. There on the TV screen was Mayor Sharon Pratt Kelly, talking about the need to provide clean needles to injection drug users in order to reduce the spread of HIV in the District of Columbia. Mayor Kelly kept referring to this concept as needle exchange and was proposing that local medical clinics provide sterile needles to drug addicts who turn in their used syringes. I exclaimed, “She wants to do what?” I didn’t understand. How could our mayor be proposing something that enabled drug use? Won’t this just encourage people to use injection drugs? My friend explained to me that contamination of needles through injection drug use was one of the main reasons the AIDS epidemic was growing so rapidly, particularly in the Black community.

Two years later, I came across a statistic that made me stop in my tracks: in 1991, the year before Mayor Kelly advocated for needle exchange in D.C., 52% of AIDS

cases among African Americans and 45% of cases among Latinos were associated with intravenous drug use. The corresponding percentage for whites was only 19%.<sup>6</sup> I now fully understood the importance of needle exchange. By then, I was a Program Officer at the Public Welfare Foundation, responsible for the Population and Reproductive Health Initiative (now the Reproductive and Sexual Health Program), which included most

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of the Foundation's AIDS funding. I thought, as I read this statistic over and over again, that the Foundation needed to find a way to address this public health problem.

The Foundation was already well established as an AIDS funder, having supported programs in this area since 1986. In 1994, the Foundation's Board of Directors further defined our AIDS funding as support for programs that work to prevent the spread of HIV/AIDS among populations in which the rate of infection is growing most rapidly, including women, teens, and people of color. This guideline was established in the context of the overall mission of the Foundation to support low-income people in their development and implementation of strategies to address the problems in their own communities.

The Foundation's overall mission and board guidance provided the context for my review of our first needle exchange proposal, which came in 1996 from an organization called Prevention Point Philadelphia. Prevention Point is a comprehensive harm reduction program providing needle exchange, street outreach, basic medical care, referral services, and a drop-in center. Its staff and volunteers, including then Executive Director Julie Parr, educated me on the concept of harm reduction, the broader term encompassing needle exchange. During my site visit to Prevention Point, I joined staff and volunteers at a needle exchange site in North Philadelphia.

The site visit was on a beautiful day in early fall; so we were able to set up outdoors instead of operating from the mobile van. At a vacant corner lot located on a block of mostly abandoned row houses, we placed folding tables and chairs to create stations—one for informational brochures and condoms, another for exchange of needles, and another for bleach kits. As if some silent

bell had rung, in just a few minutes of our getting the site ready, people started to line up. There were men and women, young and old; although most looked old beyond their years. They seemed to come from nowhere and were clearly representative of a very marginalized population that traditional social services and health agencies were not reaching. However, they understood that in order to prevent getting the HIV virus, they had to come “above ground” to get clean needles. They knew the routine: provide your identification number, the number of needles being exchanged, and the number of people using the needles; bundle the needles with a rubber band and carefully place them in the used-syringe bucket; pick up bleach kits and condoms, maybe a brochure or two; and be on your way.

For the Reverend Edwin Sanders, an African American minister who initiated a harm reduction program as part of his ministry at the Metropolitan Interdenominational Church in Nashville, this *routine* is “sustaining life.” He sees harm reduction as a medical intervention that saves lives. In response to the question often posed to him as to why he provides bleach kits and clean needles to injection drug users, he states: “I can’t reach people if they are dead. Needle exchange has enabled us to reach a population in our community that has been totally ignored. It provides us an opportunity. It can be a bridge to treatment and recovery.”<sup>7</sup>

Today, in 36 states and the District of Columbia, 162 known harm reduction programs<sup>8</sup> are “sustaining life” by preventing the spread of HIV and other blood-borne diseases, such as Hepatitis C, through infected needles. These harm reduction programs are essential in the fight against AIDS because *they reduce HIV transmission among intravenous drug users, their sexual partners and their children.*

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Harm reduction is more than needle exchange. Most harm reduction programs, despite limited resources, provide a range of services that they consider essential. In a survey of 126 programs in 102 cities in 31 states and the District of Columbia, a broad range of services were identified: educational materials on risk-reduction and risk elimination; distribution of male and female condoms; alcohol pads and bleach kits; referrals for substance-abuse treatment and other medical and social services; and on-

site counseling and testing for HIV, Hepatitis C and Hepatitis B. In addition, some programs provided hepatitis vaccinations; sexually transmitted disease screening; on-site medical care; tuberculosis screening; abscess prevention and care and vein care.<sup>9</sup>

In *Health Emergency 1999*, Dr. Dawn Day, an activist scholar and director of the Dogwood Center, an independent research organization in Princeton, points out that the concept of harm

reduction is not new. She notes: “We as a society practice harm reduction all of the time. *We reduce the harm* of riding a motorcycle by requiring riders to wear helmets. *We reduce the harm* from car accidents by requiring people to wear seat belts. *We reduce the harm* to non-smokers by requiring that smoking be done only in designated areas. *The goal of needle exchange is to reduce the harm from injection drug use.*”<sup>10</sup>

The critical nature of needle exchange as a strategy in AIDS prevention becomes clear when one looks at the extent to which injection drug use has played a role in the epidemic. In the U.S.,

24% of the *reported AIDS cases cumulative through 2003* among adults and adolescents in the U.S. were injection drug users. An additional 10% of reported AIDS cases were sexual partners of injection drug users, both heterosexual and male-to-male contact.<sup>11</sup>

The HIV/AIDS epidemic has had an especially disproportionate effect on people of color, especially among African Americans and Latinos, and injecting drug use has been a significant mode of transmission among these populations. In 2003, African Americans accounted for 49% of the *estimated AIDS cases diagnosed in the U.S.* The rate of AIDS diagnoses for African Americans was almost 10 times the rate for whites.<sup>12</sup> While Hispanics made up 14.2% of the U.S. population in 2004, they represented an estimated 19% of total AIDS diagnoses.<sup>13</sup>

*Reported AIDS cases cumulative through 2003* among African American men were mostly attributed to sexual contact with other men (36.9%) and to heterosexual contact (9.6%). However in 31% of the cases, injection drug use was the mode of transmission. For Latino men, injection use was in 33% of the cases.<sup>14</sup>

Women accounted for a growing proportion of *new AIDS diagnoses*, rising from 8% in 1985 to 27% in 2003.<sup>15</sup> African American women accounted for 67% of new AIDS diagnoses among women in 2003, and Latinas accounted for 16%.<sup>16</sup> The mode of transmission in 37% of the *reported AIDS cases* among African American women through 2003 was injection drug use, and it was the same for Latina women—37%. In addition, in 13% of the reported AIDS cases among African American women and 19% among Latina women, the mode of transmission was sex with an injection drug user.<sup>17</sup> *This means that 51% of reported AIDS cases among African American and Latina women were related to injecting drug use.*

If harm reduction, in fact, does reduce the spread of HIV/AIDS and if 31% of African American men and 33% of Latino men have been diagnosed with AIDS because of their injecting drug use, and if 51% of the AIDS diagnoses of African American and Latina women were related to injecting drug use, why are we as a country not investing millions in harm reduction and drug treatment programs?

A study commissioned by CDC and conducted by the University of California shows: that intravenous drug users utilizing harm reduction programs decrease HIV drug-risk behaviors (e.g., decreased sharing of injection equipment, decreased frequency of injection); that such programs are effective in recruiting intravenous drug users to enter drug treatment; and that HIV prevalence in syringes returned to needle exchange programs decreases.<sup>18</sup>

I now realize that my initial reaction in 1992 to the idea of needle exchange is common. Most people who oppose needle exchange believe that it only encourages people to use drugs, that it gives the wrong message about drug use and that it hampers law enforcement's ability to combat drug use. As Beverly Flemming, a recovering addict who in 1992 coordinated street outreach in Washington, D.C. for the Whitman-Walker Clinic, said, "A clean needle has never made anybody start or stop drugs, but it will slow down the virus out there."<sup>19</sup>

As the California study shows, harm reduction programs can increase the number of injection drug users seeking treatment and, as Rev. Sanders points out, *can be a bridge to treatment*. All harm reduction programs give intravenous drug users information about treatment programs and provide counseling for those who indicate they are ready to take this step. While not everyone exchanging needles takes this step, a significant number do. Former Surgeon

General David Satcher said in a 2002 interview on National Public Radio: “The science showed, very clearly, that needle exchange programs could, in fact, reduce the spread of HIV and that they did it without increasing drug use. In fact, later, studies showed that people involved in the needle exchange program were more likely to go into treatment programs and stop using drugs.”<sup>20</sup>

Staff and volunteers of needle exchange programs, many of whom are recovering addicts, regularly ask clients about their readiness for treatment. For example, Prevention Works! in Washington, D.C. operates its needle exchange program out of a van that is designed with distinct areas. Each client can speak individually with a staff or volunteer either to register as a new client, to make an exchange, to pick up other supplies such as condoms and bleach kits, or to discuss treatment, get referrals, or receive other counseling. On a site visit to Prevention Works!, I volunteered to interview new clients and to conduct exchanges. I was interviewing a man for whom this was his first visit to the van. The staff coordinator of the van heard me ask, “So, you are exchanging one needle today?” He came over and spoke with the man. “Look, man,” he said, “You only asked for one needle. One needle is so close to no needles. Would you consider treatment?” On that day, the man declined the offer, but it was clear to me the priority this program places on helping drug users begin treatment and recovery.

Efforts by harm reduction programs to refer clients to treatment can be thwarted because of the woeful lack of drug treatment programs in this country. “Medically appropriate treatment remains out of reach to the vast majority of drug users who need it.”<sup>21</sup> In 2000, the national “treatment gap” (persons who needed treatment for drug abuse in the previous year but did not receive that treatment) was estimated to be 83.4% of the population

needing treatment.<sup>22</sup> “Only 15% of the estimated 1-1.5 million IDUs in the United States are in drug treatment on any given day.”<sup>23</sup> For some programs, this has meant becoming advocates and working in coalition with others to increase funding for drug treatment. In Chicago, a major hub for the distribution of illegal drugs throughout the Midwest, the Chicago Recovery Alliance, one of the largest harm-reduction programs in the U.S. started its own mobile treatment center, Mobile Opiate Substitution Therapies, because of the difficulty in getting its clients into treatment, particularly those who are not HIV-infected.

The other issue that has greatly affected the ability of harm-reduction programs to do their work is the federal government’s refusal to provide any federal funding to support them. In 1998, just when things looked good for a reversal of this policy, the ban on federal funding was reinforced. On April 20, 1998, after a bitter debate within the Administration, President Clinton declined to lift the nine-year old ban.

Many Administration officials supported lifting the ban, including Health and Human Services Secretary Donna E. Shalala. At a press conference before the President announced he would not lift the ban, Shalala made the following statement: “A meticulous scientific review has now proven that needle exchange programs can reduce the transmission of HIV and save lives without losing ground in the battle against illegal drugs.”<sup>24</sup> In office for just over two months, Surgeon General Satcher responded to the House vote to ban the use of federal funds for needle exchange programs by stating: “Well, I’m disappointed because I’m concerned that it’s a repudiation of science. And yet I understand the complexity of this issue. And let me just briefly say that the science which comes not only from the federal government’s scien-

tists at NIH [National Institutes of Health] and a consensus conference but the National Academy of Science's Institute of Medicine, the American Medical Association, the American Public Health Association all agree that when you examine needle exchange programs scientifically, you find the following

things: Number 1, needle exchange programs, if conducted properly, can prevent the spread of the ... HIV virus. Number 2, they do it without encouraging drug use. And, more than that, many needle exchange programs have been very successful at getting people who are addicted to drugs into treatment programs."<sup>25</sup>

Other leaders vehemently spoke out against the federal ban. For example, on the day President Clinton announced his decision, Dr. Nancy W. Dickey, President-Elect of the American Medical Association stated: "The American Medical Association recognized one year ago, in a policy statement adopted by our House of Delegates, that important advances to arrest the AIDS epidemic could be made through responsible needle exchange and drug treatment programs. Traditionally, AMA policy follows science, and as Secretary Shalala notes, scientific evidence clearly shows that needle exchange is effective in curtailing HIV transmission and that the availability of clean needles does not increase drug abuse."<sup>26</sup> In speaking for the Congressional Black Caucus, which called on the Administration to reverse its position, U.S. Representative Maxine Waters stated: "This is a life-and-death issue. We can save lives with needle exchange as we try to work at getting rid of drugs in our society."<sup>27</sup>

**Well, I'm disappointed because I'm concerned that it's a repudiation of science. And yet I understand the complexity of this issue.**

Former U.S. Surgeon General Satcher

On July 11, 2002, former President Clinton, speaking at the XIV International AIDS Conference in Barcelona, Spain, stated in response to a question about what he had done to fight AIDS as a president, said: "Do I wish I could have done more? Yes, but I do not know that I could have done it." In particular, he cited his stance on needle-exchange programs saying, "I think I was wrong about that; I should have tried harder to do that." At the time of his decision, Mr. Clinton's advisers said they feared a political disaster for him if he lifted the ban.<sup>28</sup>

Today, national health organizations and leaders continue to speak out in support of needle exchange. For example, in February 2006, the American Academy of Pediatrics toughened its 1994 policy in which it stated that clean needle programs should be "encouraged and expanded." In its updated policy statement, the Academy states that pediatricians should speak out in support of needle exchange programs to reduce the spread of HIV among injection drug users. It further states: "Pediatricians should advocate for unencumbered access to sterile syringes and improved knowledge about decontamination of injection equipment."<sup>29</sup>

While the controversy about needle exchange continues, the costs of *not* doing it also continue to rise. According to a 1997 study published in the British medical journal, *The Lancet*, in the District of Columbia, 294 to 650 injection-drug users could have been prevented from getting AIDS and as much as \$16.4 million to \$36 million could have been saved in medical treatment if the city had started needle exchange 10 years before. The study was based on estimates of how many drug addicts in the District were infected with HIV.<sup>30</sup> Former U.S. Surgeon General Dr. Joycelyn Jones Elders cites the costs of not doing needle exchange: "We have got to be about preventing disease! We have better drugs,

but we still don't have a vaccine or a cure for this disease. We have watched people die from this disease; now they must learn how to live with HIV/AIDS. But why can't we help prevent this disease by providing clean needles? We do not allow people to get the clean needles that would reduce the spread of HIV disease, yet we spend thousands of dollars to treat each person who develops AIDS, to take care of them to watch them die."<sup>31</sup>

The District began a much needed harm reduction program in 1996. However, after less than two years of operation, Congress, using its veto power over Washington's budget, prohibited the District from using any of its own local funds for needle exchange. Washington's House Delegate, Eleanor Holmes Norton, responded by saying, "This Congress has said, 'Drop dead' to thousands of Americans, most of them people of color. I view it as a callous death sentence with profound racial overtones. It puts the District in a class by itself: the only jurisdiction that flies the American flag that can't prevent the AIDS epidemic from swallowing the city whole."<sup>32</sup>

Although some harm reduction programs have been able to get funding from local and state government, they mostly have to rely on private funding, contributions from individual donors and grassroots fundraising. Some of these programs have not been able to survive because of the lack of adequate funding, including two of the foundations grantees.

Among the earliest direct supporters of needle exchange was the New York Community Trust through the New York City AIDS Fund. Other funding organizations that have played a crucial role

**But why can't we help prevent this disease by providing clean needles?**

Former U.S. Surgeon General Elders

in providing support include the George Williams Fund and the Syringe Access Fund at the Tides Foundation, the Open Society Institute, the Comer Foundation, the Drug Policy Foundation, and the Levi Strauss Foundation.

Despite the controversy and continued public debate on the issue of needle exchange, the Directors of the Foundation continue to support this life-saving work. From its first grant in 1996 to the present (June 2006), the Public Welfare Foundation has made \$2.2 million in grants to 13 organizations. These organizations include:

Access Works (formerly Women with a Point)  
Minneapolis, Minnesota  
[www.accessworks.org](http://www.accessworks.org)

AIDS Resource Center of Wisconsin  
Milwaukee, Wisconsin (Offices throughout the state)  
[www.arcw.org](http://www.arcw.org)

Atlanta Harm Reduction Center  
Atlanta, Georgia

Chicago Recovery Alliance  
Chicago, Illinois  
[www.anypositivechange.org](http://www.anypositivechange.org)

Harm Reduction Coalition  
New York, New York  
[www.harmreduction.org](http://www.harmreduction.org)

North Carolina Harm Reduction Coalition  
Jamestown, North Carolina  
[www.ncharmreduction.org](http://www.ncharmreduction.org)

Point Defiance AIDS Project/North American Syringe  
Exchange Network  
Tacoma, Washington  
[www.nasen.org](http://www.nasen.org)

Prevention Point Philadelphia  
Philadelphia, Pennsylvania  
[www.preventionpointphilly.org](http://www.preventionpointphilly.org)

Prevention Works!  
Washington, District of Columbia  
[www.preventionworksdc.org](http://www.preventionworksdc.org)

## END NOTES

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