

# **How to end AIDS in the United States: Community-oriented HIV service delivery, treatment education, and mobilization**



*A review of the history, issues, and strategies for community organizations and advocates*

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## **Introduction**

And that's part of what makes today so remarkable, because back in those early years, few could have imagined this day -- that we would be looking ahead to "The Beginning of the End," marking a World AIDS Day that has gone from that early beginning when people were still uncertain to now a theme, "Getting to Zero." Few could have imagined that we'd be talking about the real possibility of an AIDS-free generation. But that's what we're talking about. That's why we're here. And we arrived here because of all of you and your unwavering belief that we can -- and we will -- beat this disease. So, make no mistake, we are going to win this fight. But the fight is not over -- not by a long shot. The rate of new infections may be going down elsewhere, but it's not going down here in America. The infection rate here has been holding steady for over a decade. There are communities in this country being devastated, still, by this disease.

President Barack Obama  
World AIDS Day, December 2011

In 2011, clinical studies revealed that HIV treatment, already well known to drastically reduce AIDS deaths and illness, also provides protection against HIV infection. This new prevention approach, used in combination with other prevention interventions, creates significant opportunities to reduce HIV incidence and AIDS-related illnesses across the United States and the world. For the first time, it is possible to consider the end of AIDS in the U.S.

As a result of these findings and as a result of changes in the way that health care will be accessed and paid for in the United States, organizations serving communities at increased vulnerability for HIV will need to alter the ways in which they prioritize and provide information and support, as well as how they structure and seek funding for these efforts.

With concerted, targeted efforts to mobilize communities, scale up HIV testing, and improve linkage to and retention in care, we can dramatically reduce both AIDS-related illness and HIV incidence. This paper outlines key opportunities and challenges to achieving this goal, examines the role of community-oriented services that are a key element for success, and discusses approaches to support the scale up of these services.

### **1. Background**

#### **1.1 New opportunities in treatment and prevention can help end the U.S. HIV epidemic.**

The advent of effective triple-combination antiretroviral treatment (HIV treatment) in the late 1990s changed the course of the AIDS epidemic. The expanded use of HIV treatment – now to more than 6.6 million people in low- and middle-income countries<sup>1</sup> – has led to dramatic reductions in new cases of pediatric HIV and in adult AIDS-related illness and deaths. In the United States since 1995, deaths from AIDS have fallen by 77%<sup>2</sup> and HIV treatment has become safer, easier to administer and less expensive.

In May 2011, the results of a groundbreaking study begun in 2005 (known as HPTN 052) established that successful suppression of viral replication with HIV treatment can prevent sexually transmitted HIV infection.<sup>3</sup> These HPTN 052 results confirmed indications from less

rigorous trials and observations showing that high rates of HIV treatment use by HIV-positive people cause a significant drop in subsequent HIV infection rates in certain populations and cohorts. Altogether, the findings offer clear proof that population-wide access to treatment with ARV drugs is an important new addition to the toolkit of HIV prevention interventions.<sup>4</sup>

In San Francisco, decreases in annual measures of mean and total community viral load (CVL) were significantly associated with temporal decreases in the number of new HIV diagnoses and accompanied by a decline in estimated HIV incidence by over one-third from 2006–2008.<sup>5,6</sup>

In New York, over a 3-year period, investigators found significant declines in CVL and modest declines in new diagnoses of HIV and estimated incidence in the population overall in addition to two epidemiologically important populations, MSM and black men.<sup>7</sup>

Recently revised U.S. guidelines for HIV treatment use in adults and adolescents, issued in March 2012, now reflect these new research developments, and for the first time, recommend offering HIV treatment to people living with HIV at all CD4 levels in order to realize the added prevention benefit.<sup>8</sup>

The preventive effect of HIV treatment is an important additional component of combination prevention packages that will lead to reduced HIV transmission and incidence. This opportunity is further bolstered by other new prevention approaches including male circumcision; microbicides; and oral pre-exposure prophylaxis, also known as PrEP. Already in the prevention toolkit and implemented at varying scales and with varying impact were awareness and behavior-change programs; condoms; interventions aimed to prevent mother-to-child transmission; and access to clean needles and other drug-injecting paraphernalia.

Perhaps most important, treatment as prevention offers a new way to conceptualize how AIDS services are delivered. In particular, it provides new opportunities to integrate HIV treatment and prevention services, which may require significant restructuring of current programs that consider them distinct and separate HIV service domains. HIV service delivery is already being re-configured with a primary focus on ensuring that all those who meet current treatment guidelines have access to HIV treatment—along with the scale-up in HIV testing this requires. This will not only maximize the prevention benefit that treatment provides, but also provide a more efficient framework through which a combination of additional prevention interventions can be offered to people testing either positive or negative. What has not changed is the importance of community-oriented approaches that engage those most at-risk for HIV infection and ensure that services are provided in ways that best meet their needs.

## **1.2 The extent of who needs HIV services is well defined.**

*"We've known for a long time what keeps people out of HIV treatment and care: poverty, drug abuse, mental illness, incarceration, low health literacy, younger age, immigration problems, and yes, race and ethnicity. None of that can be fixed with a lollipop and a prescription. It's going to take serious time and effort on the part of many non-profit community-based organizations to find the funding and build infrastructure needed to support HIV treatment and care retention beyond what's already being done."*

— David Evans, Project Inform, September 2011

Ending the AIDS epidemic in the U.S. requires a concerted, targeted strategy that is focused on those most at-risk for HIV infection and those living with AIDS, and providing them with the types of services, information and support that are proven effective in preventing transmission, protecting health and improving quality of life.

#### *Targeting services to those most at-risk*

Since 1981, more than 1.7 million people in the U.S. have been infected with HIV and approximately 1.2 million are estimated to be living with the disease today<sup>9</sup>. With approximately 50,000 new HIV infections annually - a number that has not changed for several years<sup>10</sup> - it is crucial to focus services on the hardest hit communities.

- Racial and ethnic minorities have been disproportionately affected by HIV/AIDS since the beginning of the epidemic, and represent the majority of new AIDS diagnoses, new HIV infections, people living with HIV/AIDS, and AIDS deaths<sup>11</sup>. Blacks accounted for 57% of deaths due to HIV in 2007 and Latinos accounted for 13%<sup>12</sup>. There are approximately 545,000 Blacks living with HIV/AIDS in the U.S. Blacks also have the highest rate of new HIV infections and new AIDS diagnoses of any racial/ethnic group<sup>13</sup>.
- Most new HIV infections are among gay and bisexual men and other men who have sex with men (61% in 2009). Most of these men are between 13 and 29, the only group for whom new HIV infections increased between 2006 and 2009. Young Black gay men experienced the largest increase in new infections - 48% over three years<sup>14</sup>.
- More than 290,000 women are living with HIV/AIDS in the U.S. Black women accounted for two thirds (64%) of new AIDS diagnoses among women in 2009; Latinas represented 18% and white women, 15%<sup>15</sup>. Black women also accounted for the largest share of new HIV infections among women in 2009 (57%)<sup>16</sup>.
- Teens and young adults under the age of 30 continue to be vulnerable, with those between the ages of 13 and 29 accounting for 39% of new HIV infections in 2009, the largest share of any age group<sup>17</sup>. Black teens represented 68% of AIDS diagnoses among 13–19 year-olds in 2009; Latino teens represented 21%<sup>18</sup>.
- The District of Columbia has the highest AIDS diagnosis rate in the nation. Seven of the top 10 states by AIDS diagnosis rate are in the South. AIDS diagnoses are concentrated primarily in large U.S. metropolitan areas (more than 80% cumulatively and in 2009)<sup>19</sup>. HIV prevalence is higher among those with less education and lower incomes, and among the unemployed<sup>20</sup>.

#### *Getting HIV treatment services to those who most need them*

Despite tremendous progress over the past ten years in reducing AIDS deaths and illness, there are still many communities that have yet to fully benefit from improved HIV treatment and prevention approaches.

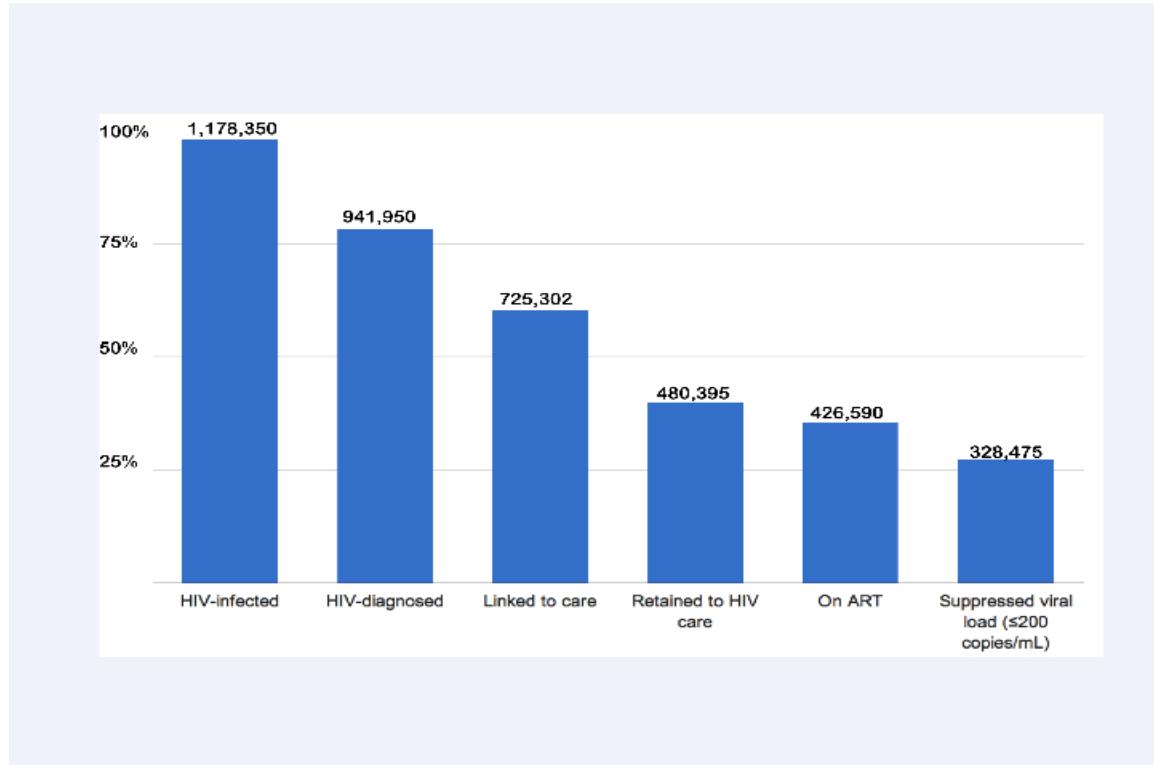
- Approximately 20% of people infected do not know their HIV status<sup>21</sup> and, therefore, cannot benefit from early treatment and are more likely to transmit the virus. Up to 33% of people living with HIV are diagnosed late in their illness<sup>22</sup> when treatment is less effective.
- Of those who test positive for HIV, one in three fail to get a confirmatory test and one-third fail to establish care within six months of testing.
- Only 426,590 people are on HIV treatment, and even fewer have undetectable viral loads<sup>23</sup>.

According to current guidelines, over 900,000 would currently benefit from treatment<sup>24</sup>.

- More than 600,000 of the 1.17 million Americans living with HIV are not retained in clinical care (i.e. at least one primary care visit in each 6-month period over a 2-year span)<sup>25</sup>.
- Of all with HIV infection, 850,000 individuals do not have suppressed HIV RNA (72%)<sup>26</sup>

When comprehensive HIV services – including testing, treatment, prevention and support services – are provided and effectively used, health outcomes improve, costs are reduced, and HIV infection rates decline.

### THE CONTINUUM OF HIV CARE IN THE U.S.<sup>27</sup>



### 1.3 Closing the gap requires HIV treatment literacy, empowerment, and mobilization.

#### Treatment literacy

Decades of research and experience show that when people have an understanding of and involvement in their own health options, their health is better. On average, people are healthier when they have knowledge, motivation, negotiation skills, self-efficacy (i.e. self-perceived power to follow through on decisions), and social efficacy (i.e. beliefs that collective action can happen and can bring benefits). This is as much the case in HIV treatment and care as it is in treatment and care of cancer, hypertension, or diabetes<sup>28</sup>.

Individual health literacy has been shown to contribute to maintaining the well being of people living with HIV/AIDS.<sup>29</sup> Education in the proper use of HIV treatments and other medicines can

particularly help people in managing side effects, maintaining treatment adherence, and monitoring for potential treatment failure and need for revised treatment regimens. Research among people living with HIV has shown that most people want an understanding and involvement in that decision-making dynamic – i.e., people do want to be empowered. Research also shows that some level of patient choice and involvement in decision-making in health services increases utilization of and benefit from those services<sup>30</sup>.

Efforts to improve HIV treatment literacy are most likely to be sustainable and cumulative at a community level, as trained literate individuals interact with those around them. Treatment literacy is also likely to have an impact on other HIV and health behaviors, including HIV testing and prevention.

Treatment advocacy and education requires a particular and specific expertise, which can transcend the focus and capacity of many HIV organizations and networks. HIV treatment advocates have already created national, regional and international collaborations based on their commitment to this specific and important area of work, sharing their expertise and working in solidarity.

#### Community and individual empowerment

Individual-empowerment is an essential component of any effective HIV responses. Empowerment refers to the process of individuals, organizations and/or communities gaining control over “the planning and implementation of solutions to individually and locally felt problems, typically by decentralizing decision-making authority.”<sup>31</sup> Individual empowerment often refers to one’s own personal sense of efficacy or self-esteem. Organizational empowerment can include groups where individuals collaborate to share knowledge and experiences to raise their critical consciousness. Community empowerment refers to social and political activities in which individuals or groups participate. One commentator has suggested that:

Empowerment is...easier understood by its absence: powerlessness, helplessness, hopelessness, alienation, victimization, subordination, oppression, paternalism, loss of a sense of control over one’s life and dependency.<sup>32</sup>

The role of empowerment in community health is well-defined in social science literature<sup>33</sup>. Health empowerment is not just about the individual’s personal psychology and abilities, but is also relational – their interaction with health care providers and other sources of support in the context of their social and economic environment. Decisions about HIV treatment are the result of interplay between what the patient needs, what providers can provide and will recommend, and the patient’s interpretation, judgment, and follow-up on that recommendation. Several studies show the effectiveness of empowerment techniques on various patient outcomes, including patient satisfaction, adherence to therapy, and functional status.<sup>34</sup> These are not new concepts in the response to HIV/AIDS. The GIPA principle (Greater Involvement by People with AIDS, broadly interpreted to also include those at-risk of infection and those impacted by HIV in their communities), defined in the 1980’s, embodies the empowerment model as an important, proven strategy to improve public health.

### Mobilization

Mobilization is another essential component of an effective HIV response. Here, mobilization refers to the process and outcomes of building local community-based and peer-based networks and organizations as a mechanism to support treatment preparedness. These include advocacy, education, and support programs that value the role and participation of people living with HIV/AIDS, provide people with opportunities to be useful and valuable in their communities, become role models for other HIV-positive individuals, and show their communities that people living with HIV and AIDS are not to be feared, but, rather, respected.

Two recent studies highlight the value of community mobilization in HIV service provision.

HPTN 043 compared two approaches to uptake of HIV testing and counseling in sub-Saharan Africa.<sup>35</sup> One approach used standard methods for offering testing. The second approach included a community mobilization component. The study found that the testing provided with the added community mobilization component not only significantly increased the demand for HIV testing, but also reached greater numbers of HIV-infected individuals.

The second study, *The Bronx Knows*, was a three-year, large-scale public health initiative launched on June 27, 2008 to increase voluntary HIV testing so that every Bronx, NY resident would learn his or her HIV status and would have access to quality care and prevention<sup>36</sup>. *The Bronx Knows* brought together community-based organizations, community health centers, hospitals, colleges and universities, and faith-based organizations to improve the health of Bronx residents and decrease new HIV infections in New York City. The New York City Health Department and community partners employed a three-pronged approach to accomplish its goal of helping all Bronx residents learn their HIV status:

- Clinical and non-clinical partners set out to make HIV testing more available throughout the borough by offering HIV testing as part of their ongoing services.
- The Health Department and community partners sought to raise awareness and increase the demand for HIV testing in the Bronx by making an HIV test a routine part of health care, thereby lessening the stigma still associated with getting an HIV test.
- All partners agreed to ensure prompt linkage to HIV primary care.

The Bronx Knows initiative surpassed its key goals ***because of its collaboration with community partners.*** By June 2011, *The Bronx Knows* partners:

- Conducted 607,570 HIV tests.
- Confirmed over 4,800 HIV positive tests.
- Of those, at least 1,700 were reported to be newly diagnosed cases.
- Linked more than three-quarters of newly diagnosed individuals to HIV primary care.

#### **1.4 History of HIV community mobilization and community-based services**

The response to the AIDS epidemic started with community mobilization. Before any response from government, the public health establishment, research institutions or the pharmaceutical industry; communities immediately affected by what would eventually be known as AIDS were mobilizing to provide care and support and protection. This community response has been the

core of all effective approaches to HIV prevention, care and treatment since 1981 and remains as important today as always.

Building from earlier histories of individual empowerment and community health organizing by feminist, civil rights, LGBT rights, and immigrant rights movements, communities affected by HIV developed key interventions in fighting AIDS: home-based care, rights-based services, safer sex, harm reduction, and advocacy which changed the shape of clinical research and drug development, leading to the life-saving treatment now available today.

In the earliest years, there were no treatments at all for HIV or for its associated opportunistic infections. Almost immediately, growing networks and organizations of people living with and affected by HIV engaged in advocacy, education, research, and service delivery to make HIV a treatable illness. Notable examples include:

- Community-based HIV physicians, many of whom were living with AIDS, discovered and tested prophylaxis for PCP, thus preventing the leading cause of AIDS-related death. This led to the development of a community-based research network including the Community Research Initiative on AIDS and the American Foundation for AIDS Research (AmFAR).
- Advocacy by groups like ACT UP, the Treatment Action Group, and Project Inform led to vastly increased resources for AIDS research and drug development, early access to experimental drugs, and a cut in drug development time by half.
- The Community Constituency Group at the National Institutes of Health brought patients for the first time in history into the process of clinical trial design and implementation. The outcomes of this work led to better trial design and through it, better science. The model created in the AIDS program was replicated in research program for many other diseases.
- Many groups, including NMAC, Project Inform, Gay Men's Health Crisis, WORLD (Women Organized to Respond to Life-threatening Disease), and the Black AIDS Institute developed innovative treatment education approaches; teaching people how to prevent opportunistic infections, access care, make informed treatment decisions and improve adherence to HIV treatment.
- NMAC, AIDS Action Council and other national AIDS organizations successfully advocated for the passage of the Ryan White Care Act, which ensured community participation in the development and implementation of funding priorities for HIV services in cities and states around the country and created the AIDS Drug Assistance Program (ADAP), still an essential component of AIDS care in the U.S.
- In the mid-1990's, activism by many community AIDS organizations, including NMAC, catalyzed national attention to the disproportionate impact of HIV/AIDS on communities of color, leading to the 1998 creation of the Minority AIDS Initiative.
- Community-based service delivery at organizations throughout the United States provided ancillary support services and case management essential for effective treatment and prevention.

## **2. Components and examples of current work**

Today, community-based organizations and advocates throughout the US and around the world work to help people test for HIV, seek and access health care, and where needed, start and

adhere to HIV treatment. The key themes of this work are patient-centered and community-oriented health services, and community education so that people are informed and vocal.

## **2.1 Health services that are community-oriented and patient-centered**

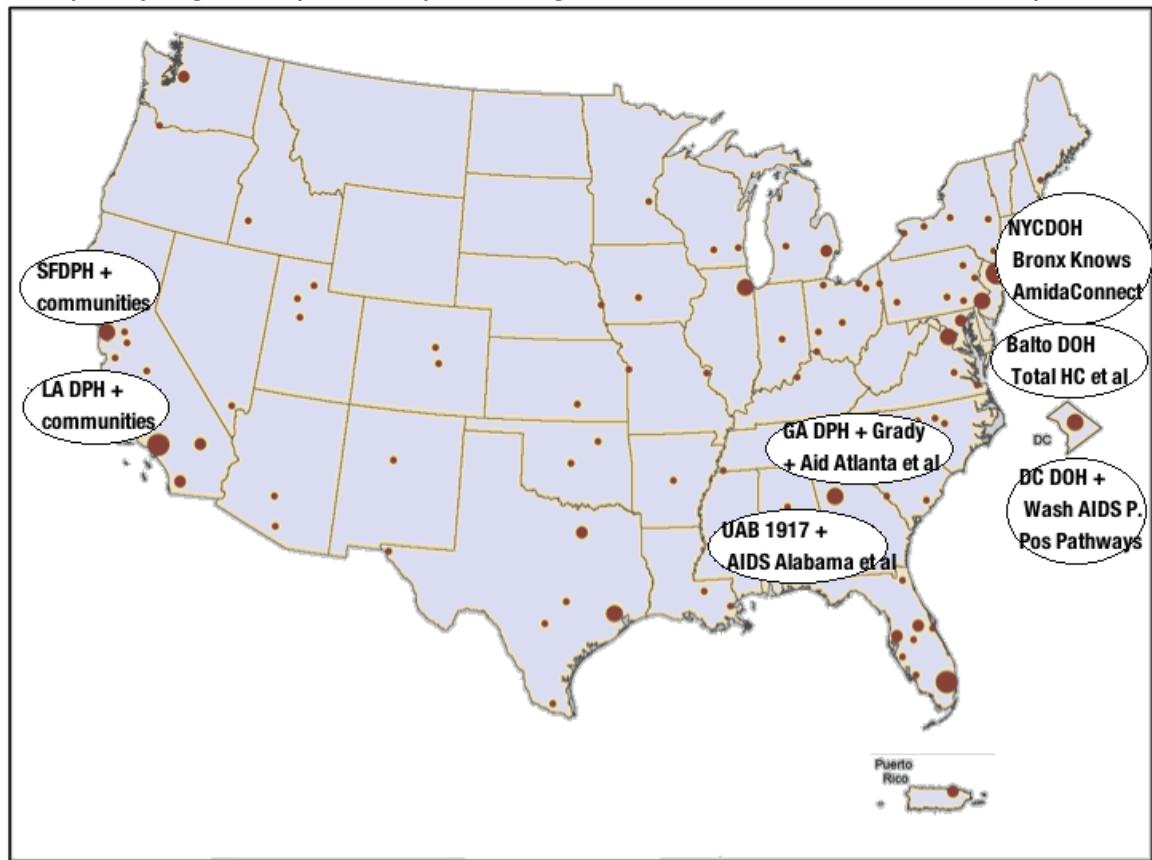
There are now numerous examples of community-based HIV treatment education and adherence programs across the United States. The most successful can be characterized as being community-oriented, patient-centered, and multidisciplinary.

**Community-oriented:** Effective scale-up of HIV treatment cannot happen without services being located in the communities hardest hit by HIV and health disparities, such as communities of people lacking healthcare due to poverty, incarceration, immigration status, race/ethnicity, youth, gender, sexual orientation, and gender identity. Where health departments, hospitals, and clinics have successfully engaged large numbers of people in HIV treatment, they have done so by extending outreach, case-management, and services out into community settings. Furthermore, effective health programs communicate about health and services in ways that reflect the ways that people in a community already communicate about health and self-identify and organize as a community. Evidence suggests that HIV-related health outcomes are better in communities in which there are social values and networks that reinforce accurate health messages, support health-seeking behavior, and link people to health services when needed.<sup>37 38</sup>

**Patient-centered:** Effective HIV treatment programs also promote and measure people's health literacy, focusing on people's likely understanding, motivation, and demand for health, the reasons why individuals do or don't seek health services, how people interact and communicate with health services, and factors that influence health maintenance and outcomes. Many of the most successful programs not only measure patient 'engagement' as adherence to medication and keeping of scheduled appointments, but also indications of a person's understanding of their treatment decisions, discussion with a provider about their options and success in meeting broader health-related needs, such as housing, mental health and substance use.

**Multidisciplinary:** The concept of a multidisciplinary approach to HIV treatment and care has been promoted for more than a decade.<sup>39</sup> Combination programming includes not only community outreach and case management focused on medical appointments and treatment adherence, but also case management to link people to health insurance, housing, and mental health and substance use services. Accumulated data show that combination programming, such as intensive outreach and case management, can push rates of retention in care and successful viral suppression to 80% or more of people starting HIV treatment.<sup>40 41 42</sup>

### **Examples of large-scale partnerships involving communities in HIV treatment scale-up**



#### Case studies:

##### **Citiwide Harm Reduction Services – Bronx NY**

*Peer-based patient navigators can help active drug users to succeed in HIV treatment.*

Citiwide is a South Bronx community organization that provides clinical healthcare and other professional health and social services while remaining committed at its core to peer-based support for community members who are active substance users to be informed, empowered, and successful in achieving health. Citiwide, in collaboration with Montefiore Medical Center and others (including the NYC DOH and partners in the Bronx Knows initiative), has demonstrated that peer-based patient navigation that blends outreach, care coordination, and accompaniment to appointments results in HIV health care utilization and viral load suppression.

##### **Harlem United – New York NY**

*Community outreach and peer support help to improve average viral load and CD4s*

During the past five years, Harlem United has implemented a zone-based universal HIV testing program in East and Central Harlem, using mobile units and local venues to test thousands of people each year in a block-by-block approach. In addition, Harlem United runs mini-clinics, stationing teams of health workers at partnering businesses throughout Harlem for four hours each day, to provide free HIV/STI/HCV screening, treatment education, and referrals to primary medical care. For the hundreds of people testing HIV-positive, Harlem United not

only refers people to care but tracks and supports their enrollment and follow-up through case-management by staff and trained peer leaders (an effort funded through HRSA, CDC, and SAMHSA-funded programs, and also linked to the AmidaConnect initiative). Beginning in 2010, Harlem United began monitoring CD4 and viral load counts of all of its HIV-positive clients. A sampling of clients has showed increases in the number of clients accessing HIV treatment, increased numbers with undetectable viral loads, and increased average CD4 counts among those with initial CD4 counts of less than 350.

### ***Positive Pathways – Washington DC***

#### *Peer community health workers helping 200+ people overcome barriers to care*

Positive Pathways is a new initiative led by the Washington AIDS Partnership that has hired and trained 12 peer Community Health Workers to assist more than 200 HIV-positive African Americans to participate in HIV medical care and supportive safety net services. Working with more than 15 local community organizations and clinical care providers, Positive Pathways first sponsored training of 12 peers in community health outreach and HIV care navigation, and then worked to identify and enroll out-of-care HIV-positive individuals in specific neighborhoods in DC. The 12 peer Community Health Workers have subsequently worked with those individuals to provide information and education; overcome fear, denial, and stigma; develop plans and strategies for managing health and healthcare; and to navigate healthcare appointments and visits. Through a Social Innovation Fund Access to Care initiative, Positive Pathways is working with Johns Hopkins University to collect data that will document the effect of this work on average group viral load and other health indicators.

### ***Center for Prisoner Health and Human Rights – Providence RI***

#### *Supporting formerly incarcerated people living with HIV to engage and remain in care*

As a collaboration of healthcare providers, researchers, lawyers, and community activists, the Center conducts research, education, and advocacy to advance the health and human rights of criminal justice populations. Beginning in 1997, the Center obtained federal research funding to establish Project Bridge, a demonstration project to ensure continuity of medical care and social stabilization of HIV-positive ex-offenders being released from the Rhode Island state prison. The program has shown success, demonstrating that with intensive case management and support, more than 80% of a cohort of formerly incarcerated people living with HIV can remain engaged in HIV treatment and care for more than a year.

### ***St. Louis Effort for AIDS – St. Louis MO***

#### *Care navigation teams aiming to help 130 people each year overcome barriers to care*

In St. Louis as of 2010, more than 5,000 people are living with HIV and only 3,000 are calculated to be in regular medical care and access to HIV treatment. Studies sponsored by Washington University and the St. Louis Department of Health have shown disparities in healthcare access and HIV treatment outcomes for women, young adults, and African Americans, particularly correlated with socioeconomic factors such as educational attainment. In response to this challenge, St. Louis Effort for AIDS has launched the BEACON project, which aims to find approximately 130 people each year who are not in regular medical care, assign them to a care navigation team consisting of a nurse, a case manager, and two peer advocates, and help them to access healthcare and support services. Through a Social Innovation Fund Access to Care initiative, St. Louis Effort for AIDS is working with Johns Hopkins University to collect data that will document the effect of this work on average group viral load and other health indicators.

### **Total Health Care – Baltimore MD**

#### *Contributing to city-wide progress in HIV treatment scale-up and success*

Total Health Care is a longstanding primary healthcare provider, and with Ryan White HIV/AIDS funding has been able to field community outreach workers, case managers, and patient advocates at eight sites in Baltimore to inform, encourage, and support people in HIV testing, linkage to treatment and care, and navigation of related services such as housing, mental health services, and substance abuse services. From 2006-2010, Total Health Care and other HIV service providers were able to document significant improvements in HIV-related health indicators for a population of more than 500 HIV-positive men and women, demonstrating in the Baltimore Clinical Quality Management data a significant increase in regular medical visits and CD4 testing and a doubling of the percentage of patients with undetectable viral loads.

### **University of Alabama 1917 HIV Clinic – Birmingham AL**

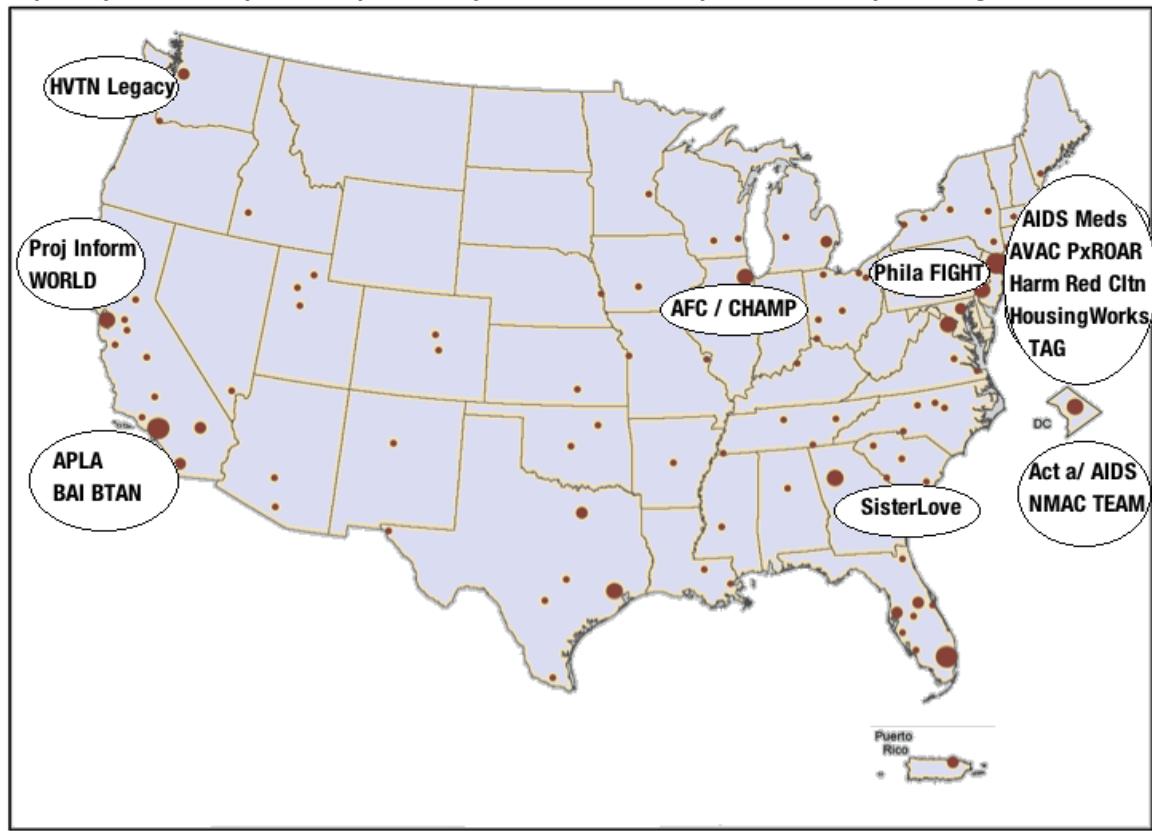
#### *Clinic-based case management increases enrollment and retention in care*

Since 1990, the UAB 1917 Clinic has been the primary provider of clinical health services for people living with HIV in Birmingham Alabama. Project Connect is a case management program that assists people who test HIV-positive to enroll in regular medical care, access and understand health information, make decisions about health options, and navigate health and support services. Research has documented that this case management has significantly increased enrollment and retention in care.

## **2.2 Community education so that people are informed and vocal**

A second theme of community-based HIV treatment work has been a focus on building the capacity of individuals and communities to be informed and vocal about their HIV treatment needs so that HIV-positive people and can have a voice in personal and public health decisions. This has included training HIV-positive people and their advocates about individual-level HIV treatment options and decision-making, and also training advocates about municipal, state, and federal policies and programs. One important aspect of this work has been recruitment and training of individuals who live and work in communities with relatively low healthcare access, low health literacy, and/or historic mistrust of health institutions. Another important theme has been the use of web-based treatment information, networking, and peer dialogue to help HIV-positive people and their advocates to answer questions and gain treatment literacy.

**Examples of community-based sponsors of treatment literacy and advocacy training**



Case studies:

**AIDS Project Los Angeles – Los Angeles CA**

*Community-based treatment advocates provide support outside of a medical setting*

At APLA, trained “Treatment Advocates” work with clients to understand treatment options, assess their treatment needs, set goals, and navigate healthcare services. In evaluation interviews, people served by this program say that they appreciate having this support outside of the healthcare setting, believe that their healthcare is better as a result, and are better equipped and more confident in seeking information and services from healthcare providers.

**Black AIDS Institute’s Black Treatment Advocates Network (BTAN) – Los Angeles CA**

*Training and mobilizing Black advocates to lead in treatment education and advocating*

Beginning in 1999 with the African American HIV University (AAHU), Black AIDS Institute has conducted multiday trainings throughout the U.S. for Black HIV advocates to increase literacy and advocacy capacity about strategies for scaled-up HIV testing, linkage to treatment and care, counseling for people about when to start HIV treatment and treatment options, support for retention in care, and advocacy to increase healthcare access and reduce health disparities in African-American communities. Many of the graduates of this training effort remain linked through Black AIDS Institute and other networks to share information and coordinate advocacy.

**Mpowerment Detroit and Young Brothers United (YBU) – Detroit MI**

*Peer-based social organization works to empower young black gay men*

Mpowerment Detroit is a social movement involving approximately 400 young black gay men in their teens and 20's, drawing from community organizing models such as Black fraternities, house ball communities, and 100 Black Men empowerment effort. The group runs social events and a gathering space, and is focused on developing shared community, leadership capacity, and life skills. Mpowerment is entirely led by peers, drawn from approximately 35 "Young Brothers United" interns and a larger set of regularly participating members.

Mpowerment Detroit, alongside the Horizons Project at Wayne State University and Michigan AIDS Coalition (and with funding from CDC and HRSA), worked to increase its members' health literacy and rates of testing for HIV, and although it has not published data about HIV treatment literacy in its group, it presents a model for community empowerment for health.

**Philadelphia FIGHT – Philadelphia PA**

*Training people living with HIV to become health activists*

Project TEACH (Treatment Education Activists Combating HIV) is a program aimed training people living with HIV/AIDS to act as peer educators, activists and advocates in the underserved communities hardest hit by the AIDS pandemic — low-income communities and communities of color. Started in 1996, Project TEACH has graduated more than 2,000 HIV-positive people through a training about the basics of sustaining one's health, how to navigate treatment and medical care, and ways to use this information in education of others and advocacy for change.

**POZ / AIDSmeds.com Community Forums – New York NY**

*On-line HIV treatment information and peer dialogue*

More than a decade ago, Individuals in the HIV community created several HIV-specific websites, such as thebody.com and aidsmeds.com, to provide comprehensive health information to HIV-positive people, their caregivers, and their advocates. AIDSmeds.com has maintained a notable round-the-clock discussion forum, facilitated by non-professional peers, in which people can ask questions and talk about their HIV treatment options and decision-making, allowing them to be better informed in their interactions with healthcare providers.

**Act Against AIDS Leadership Initiative – National**

*Mobilizing communities from a rights-based perspective*

As a \$16 million six-year partnership between the CDC and more than 20 national organizations, the Act Against AIDS Leadership Initiative has integrated basic messages about early HIV treatment and treatment-as-prevention into community town halls throughout the country, radio and print campaigns, and a physician toolkit mailed to 2000 African-American doctors. Through this work, partners have begun to educate people about HIV treatment in the context of work to confront broader health disparities and social and economic injustice.

**NMAC Treatment Education, Adherence, and Mobilization (TEAM) Navigators – National**

*Contributing to community mobilization for HIV treatment scale-up*

Launched in 2011, the NMAC TEAM initiative is a new program to promote community leadership and capacity to support increased HIV testing, linkage to treatment and care, treatment decision-making, support for retention in care, and increased healthcare access. With an initial meeting of peers at the 2011 U.S. Conference on AIDS, NMAC anticipates

working alongside other national advocate training initiatives and networks to contribute to an energized and informed community movement for HIV treatment scale-up.

### **3. Looking ahead, new opportunities to support community-oriented service delivery**

The context of the HIV response in the United States is now changing. New evidence about HIV treatment and treatment-as-prevention, health care reform, and on-going human rights struggles create a context in which HIV programs must integrate prevention and treatment, community mobilization with clinical care, and health with rights.

#### **3.1 Meeting the needs of people at-risk: multiple constituencies fulfilling multiple roles**

Adapting the complex apparatus of funding bureaucracy into service delivery approaches that are palatable and compatible with those who most need HIV prevention and treatment services is possibly the hardest of tasks and certainly one of the most important if these efforts are to be successful. This requires a newly energized and integrated approach for community-based HIV treatment mobilization and community-oriented service delivery. Those most in need of HIV prevention and treatment services are often those that are the most marginalized. They face multiple health challenges including a high degree of mental health issues and poverty. They often face stigma and discrimination within their communities that hinders their ability to safely access health care. Multiple constituents have roles to play to develop, implement and support new efforts to scale up HIV services in ways that target those in greatest need.

- Federal, state and local governments need to provide resources for health care and social services and do so in ways that foster partnerships between health care providers, social service agencies, community-based organizations and mental health service providers. Without providing support to community-based agencies that understand and have the trust of target populations, efforts to further reduce HIV incidence and improve health outcomes will fail. Governments also have a key role in providing comprehensive epidemiology about HIV and related health concerns as well as research findings regarding effective prevention and treatment interventions.
- National and state-level NGOs and networks are key advocates for continued resources for HIV services through the Ryan White program, CDC, SAMHSA, HRSA and ensure that the implementation of the Affordable Care Act guarantees continuing provision of comprehensive HIV prevention and treatment services. These national organizations are also primary sources of information for community-based service providers and local level advocates regarding methods to increase demand for and effective use of health and social services. These organizations also provide essential technical assistance to community-based organizations regarding service delivery and education methods, organizational capacity, and advocacy training. A particularly important role for national and state-level groups is to coordinate opportunities for local organizations to develop new funding streams utilizing new reimbursement strategies available through the Affordable Care Act, changes in the Medicaid and Medicare programs and through the more traditional HIV funding sources such as Ryan White and the CDC. The national organizations provide an

essential bridge between large government funding mechanisms and community-based approaches to care and support.

- The private sector, including private foundations and industry, have been a key means of support for community-based HIV advocacy and service provision since the beginning of the epidemic. Their support is as important as ever. Moving from pilot projects funded through grants to long-term program development paid for through reimbursement mechanisms is the HIV care of the future. The private sector must support the development of models of new service delivery approaches that are effective in reaching target populations, increasing their engagement in testing, prevention and health care services and better integrating treatment and prevention interventions. Successful models can then be scaled up through government-funded and insurance programs. The private sector also has a unique role in its ability to support advocacy, which must be funded independently from government to be effective.
- Community-based organizations are the front-line in the HIV response. These organizations – often started and run by the very people that most need services – have a keen and unique understanding of the needs and challenges of their communities. Health care systems lie at the heart of HIV care. However, to be effective, healthcare programs need to provide – either through the development of their own community-driven service models or through partnerships with community-based organizations – services that are tailored to gain the acceptance and trust of target populations. Working with community-based groups is an essential component. Community-based organizations will need to either grow and begin to provide health care services – as is already the case with such groups as Harlem United and Housing Works – or they need to develop partnerships with health care facilities, providing them with the social and support services needed by their target populations.

### **3.2 Leveraging new government funding opportunities to link clinics and communities.**

HIV testing, treatment and care in the United States is primarily funded by (and heavily influenced by) several national health programs, including the multiple programs supported through the Ryan White Program, Medicaid, Medicare, Title X family planning and a number of CDC-sponsored programs. These programs will continue to provide essential support for HIV care, treatment and prevention.

However, an important trend in U.S. healthcare, primarily through healthcare reform, is that the Federal and State governments are now providing contracts, grants, and financial incentives to healthcare providers to better prevent and manage chronic health issues. In particular, this means funding to reimburse providers who expand access to preventive screening (such as HIV testing), early treatment, and patient empowerment programs that train and support people in self-management of basic diagnostics and medicines.<sup>43</sup> For example:

- Medicaid already provides health coverage for more than 212,000 HIV-positive people (approximately 1 in 6 of all people living with HIV and at least a third of all HIV-positive people in care). Healthcare reform legislation passed in 2010 will expand eligibility for Medicaid, which means that Medicaid will become even more important.

- Beginning in 2011, Medicaid has offered increased reimbursement rates for “health home” services for people with chronic conditions, encouraging the creation and expansion of person-centered systems of care that facilitate access to and coordination of a full array of clinical and non-clinical health-related services.
- Medicare awarded contracts in late 2011 to 500 health centers (such as Unity Health Care in Washington DC and Total Health Care in Baltimore) to conduct demonstration projects that advanced primary care for people with multiple chronic conditions, including use of community health team approaches.
- In 2011, the Substance Abuse and Mental Health Services Agency (SAMHSA) recently issued grants to 64 sites for co-location of substance abuse services, mental health services, and primary care.
- In the Affordable Care Act, a new Centers for Disease Control and Prevention (CDC) Community Health Worker Program is defined under which the CDC should make grants to hospitals, health centers, and clinics to hire and train Community Health Workers to promote health in medically underserved communities with a preference to be given to “populations with high uninsurance, chronic illness, or infant mortality.” Health care reform also offers an opportunity for the CDC to expand training of health care providers and increase investments in initiatives to eliminate health disparities in the U.S.
- The Affordable Care Act also reauthorized a grant program within the U.S. Health Resources and Services Administration (HRSA) to fund clinics to hire “patient navigators” to help individuals with chronic diseases, particularly in populations likely to have health disparities, to access care and achieve better health outcomes. These patient navigators are intended to help people realize the promise of expanded health coverage under health care reform by educating people about health insurance options, facilitating enrollment in health insurance and health care, and otherwise providing consumer assistance.

In combination, these initiatives create a powerful incentive to providers to get health workers out into communities in need and to ensure that people are informed, literate, and empowered about health. Community organizations, with their unique expertise around the needs of their constituents, can have a key role in the effective delivery of these services through stand-alone programs and particularly through the development of partnerships with health care providers. Developing model programs utilizing these funding mechanisms should be a priority activity for HIV community organizations in the coming year. Community networks can assist through the dissemination of information about the parameters of these funding opportunities and the provision of technical support to enable community-based groups to develop programs, partnerships and funding proposals.

Community groups also have a special role in monitoring and supporting the quality of HIV service delivery, looking at:

- The extent to which programs are working with high-need communities where the HIV burden and health disparities are highest due to poverty, incarceration, immigration status, race and ethnicity, youth, gender, and sexual orientation and gender identity.
- How healthcare providers are using new funding streams to ensure services beyond clinical care, such as case management to link people to health insurance, housing, and mental health and substance use services.
- How HIV programs are promoting and measuring people’s broader health literacy and engagement, going beyond adherence to medication and keeping of scheduled

appointments, but also measuring people's understanding of treatment decisions, quality of engagement with providers, and meeting broader health-related needs such as housing or mental health and substance use services.

### **3.3 Integrating HIV treatment advocacy into broader movements for health and justice.**

HIV treatment advocacy has long been linked to and embedded within a range of rights-based health and social activism. Wherever community advocates are working to help people access food, housing, welfare services, drug treatment, and the like, they could also do more to communicate at a basic level about the potential benefits of early treatment and treatment-as-prevention. This means that work can be done to integrate HIV treatment as an issue in campaigns for universal health care, sexual health services, immigrant health services, LGBT health services, and programs to eliminate health disparities.

## Endnotes

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<sup>1</sup> UNAIDS Global Report 2011

<sup>2</sup> NCHS, *Health, United States 2010*; 2011

<sup>3</sup> The HPTN 052 study was a prospective, randomized trial (the “gold standard” of clinical trials). It compared two groups of heterosexual couples (a total of 1,750 couples in all) in which one partner was living with HIV, with the important caveat that at enrolment the HIV-positive partner was required to have a CD4 count above 350 cells/mm<sup>3</sup>. In one group, the person living with HIV was immediately provided with ART; in the other group, treatment was delayed unless and until the CD4 cell level dropped to <250 or clinical symptoms of AIDS developed. Interim results announced in May 2011 showed a 96 percent reduction in risk of HIV transmission in favour of the group receiving ART. The findings were so overwhelmingly positive and statistically significant that the trial was immediately stopped four years ahead of schedule.

<sup>4</sup> More in-depth information about the results of HPTN 052 may be found online at *The Lancet*:

[www.thelancet.com/journals/lancet/article/PIIS0140-6736%2811%2960713-7/fulltext?rss=yes](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736%2811%2960713-7/fulltext?rss=yes).

<sup>5</sup> Das M, Chu PL, Santos G-M, Scheer S, Vittinghoff E, et al. (2010) Decreases in Community Viral Load Are Accompanied by Reductions in New HIV Infections in San Francisco. *PLoS ONE* 5(6): e11068. doi:10.1371/journal.pone.0011068

<sup>6</sup> Truong HH et al. Dramatic improvements in early ART initiation reveal a new disparity in treatment. 19th CROI, Seattle. Abstract 139. February 2012.

<sup>7</sup> <http://www.retroconference.org/2012b/Abstracts/43933.htm>

<sup>8</sup> <http://www.aidsinfo.nih.gov/guidelines/pdf/1337/recommendations-only/>

<sup>9</sup> CDC. *HIV Surveillance Report*, Vol. 21; 2011. CDC. *MMWR*, Vol. 60, No. 21; 2011.

<sup>10</sup> CDC. *Fact Sheet: HIV in the United States: An Overview*; August 2011.

<sup>11</sup> CDC. *HIV Surveillance Report*, Vol. 21; 2011. CDC. *MMWR*, Vol. 60, No. 21; 2011. Prejean J et al.

“Estimated HIV Incidence in the United States, 2006–2009.” *PLoS ONE*, Vol. 6, Issue 8, 2011.

<sup>12</sup> NCHS. “Deaths: Final Data for 2007.” *NVS*, Vol. 58, No. 19; 2010.

<sup>13</sup> McQuillan GM et al. *NCHS Data Brief*, No. 4; January 2008 (ages 18-49).

<sup>14</sup> Prejean J et al. “Estimated HIV Incidence in the United States, 2006–2009.” *PLoS ONE*, Vol. 6, Issue 8, 2011.

<sup>15</sup> CDC. *HIV Surveillance Report*, Vol. 21; 2011.

<sup>16</sup> CDC. *Fact Sheet: Estimates of New HIV Infections in the United States, 2006–2009*; August 2011.

<sup>17</sup> Prejean J et al. “Estimated HIV Incidence in the United States, 2006–2009.” *PLoS ONE*, Vol. 6, Issue 8, 2011.

<sup>18</sup> CDC. *HIV Surveillance Report*, Vol. 21; 2011.

<sup>19</sup> Ibid.

<sup>20</sup> CDC. *MMWR*, Vol. 60, No. 31; 2011.

<sup>21</sup> Ibid.

<sup>22</sup> CDC. *HIV Surveillance Report*, Vol. 21; 2011.

<sup>23</sup> <http://www.retroconference.org/2012b/Abstracts/45258.htm>

<sup>24</sup> <http://www.aidsinfo.nih.gov/guidelines/pdf/1337/recommendations-only/>

<sup>25</sup> El Sadr. ART for Prevention: The Science and the Art. March 2012.

<http://www.retroconference.org/2012b/Abstracts/45258.htm>

<sup>26</sup> Ibid.

<sup>27</sup> Ibid

<sup>28</sup> Johnson, M., The Shifting Landscape of Health Care: Toward a Model of Health Care Empowerment, *Am J Public Health*. 2011;101:265–270.

<sup>29</sup> Kalichman SC, Rompa D. Functional health literacy is associated with health status and health-related knowledge in people living with HIV/AIDS. *J Acquir Immune Defic Syndr*. 2000 Dec 1;25(4):337-44. According to this study by Kalichman and Rompa, about 1 of 4 people living with HIV had difficulty comprehending simple medical instructions and therefore had lower health literacy. HIV-infected people with lower health literacy had lower CD4 cell counts, higher viral loads, were less likely to be taking antiretroviral medications, reported a greater number of hospitalizations, and reported poorer

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health than those with higher health literacy. In addition, after adjusting for years of formal education, lower health literacy was associated with poorer knowledge of one's HIV-related health status, poorer HIV-related disease and treatment knowledge, and more negative healthcare perceptions and experiences. The authors of the study concluded that health literacy is a significant factor in the health and treatment of persons living with HIV/AIDS.

<sup>30</sup> Beach MC, Duggan PS, Moore RD. Is patients' preferred involvement in health decisions related to outcomes for patients with HIV? *J Gen Intern Med.* 2007; 22(8):1119–1124

<sup>31</sup> Perkins, DD. Speaking truth to power: Empowerment ideology as social intervention and policy. *American Journal of Community Psychology;* 1995; 23: 765-783

<sup>32</sup> Roberts, KJ. Patient empowerment in the United States: a critical commentary. *Health Expectations,* 1999; 2:82-92, citing Gibson, CH. A Concept analysis of empowerment. *Journal of Advanced Nursing,* 1991; 16:354-361

<sup>33</sup> For an excellent overview of the literature of empowerment theory and research, see Perkins, D.D. & Zimmerman, M.A. (1995) Empowerment theory, research and application. *American Journal of Community Psychology,* 23, 569-579.

<sup>34</sup> Roberts, KJ. Patient empowerment in the United States: a critical commentary. *Health Expectations,* 1999; 2:82-92, citing Gibson, CH. A Concept analysis of empowerment. *Journal of Advanced Nursing,* 1991; 16:354-361

<sup>35</sup> Sweat M, Morin S, Celentano D, et al. Community-based intervention to increase HIV testing and case detection in people aged 16–32 years in Tanzania, Zimbabwe, and Thailand (NIMH Project Accept, HPTN 043): a randomised study. *Lancet Infectious Diseases;* published online May 4, 2011

<sup>36</sup> <http://www.nyc.gov/html/doh/downloads/pdf/ah/bronx-knows-summary-report.pdf>

<sup>37</sup> Joseph, JG, Montgomery SB, Emmons CA, et al. Magnitude and Determinants of Behavioral Risk Reduction: Longitudinal Analysis of a Cohort at Risk for AIDS. 1987. *Psychology and Health* 1:73–96.

<sup>38</sup> Latkin, C., M. R. Weeks, L. Glasman, C. Galletly, and D. Albarracin. 2010. A Dynamic Social Systems Model for Considering Structural Factors in HIV Prevention and Detection. *AIDS Behavior* 14:S222–S238.

<sup>39</sup> Sherer R, Stieglitz K, Narra J, et al. HIV multidisciplinary teams work: support services improve access to and retention in HIV primary care. *AIDS Care Vol* 14, Suppl 1, S31-44. 2002.

<sup>40</sup> Naar-King S, Bradford J, et al. Retention in care of persons newly diagnosed with HIV: Outcomes of the outreach initiative. *AIDS Patient Care & STDs.* 2007;21(s1), S40-S48.

<sup>41</sup> Magnus M, Jones K, Phillips G, et al. Characteristics associated with retention among African American and Latino adolescent HIV-positive men: Results from the outreach, care, and prevention to engage HIV-seropositive young MSM of color Special Project of National Significance Initiative. *JAIDS.* 2009 Sep 11.

<sup>42</sup> Hightow-Weidman LB, Smith JC, Valera E, Matthews DD, and Lyons P. Keeping Them in “STYLE”: Finding, Linking, and Retaining Young HIV-Positive Black and Latino Men Who Have Sex with Men in Care. *AIDS Patient Care and STDs Volume* 25, Number 1, 2011.

<sup>43</sup> One important driver behind the Federal government's movement toward improved patient empowerment and self-management in chronic conditions is the demonstrated cost-effectiveness of these approaches. In diabetes, hyperlipidemia, and hypertension, research has found large potential healthcare cost savings in the use of integrated approaches to help more people screen for the condition, engage in early treatment, and manage their own basic diagnostics and medications.