



# LOS ANGELES COUNTY COMMISSION ON HIV

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## Ryan White Reauthorization\* Principles

Recommendations for a comprehensive HIV strategy as we prepare for the next version of Ryan White legislation  
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### Development of the Commission's Ryan White Reauthorization\* Principles.

A subcommittee formed by the Commission's Joint Public Policy (JPP) Committee, along with service consumers and representatives of HIV service providers, met for most of 2007 to agendaize Los Angeles County priorities for the next version of Ryan White legislation. In total, there were 11 meetings, representing close to 500 individual stakeholder hours of discussions on these topics. These principles represent the JPP Committee's effort to reflect the care and treatment needs of local consumers, to proactively assert Los Angeles County's interests and priorities, and to help frame the context and discussion for the next incarnation of the legislation. They are intended to present a unified approach and strategy from Los Angeles County, and set the stage for a collaboration with interested stakeholders around the country.

### Why the Ryan White Program is Important to Los Angeles County.

As the most populous county in the US, and the 13<sup>th</sup> largest county geographically, Los Angeles County is a vast and diverse region, with urban, suburban and rural mixes and a complicated political structure (88 separate

municipalities plus dozens of other governmental jurisdictions). Los Angeles County is a rich racial, ethnic and cultural tapestry: it incorporates over 100 officially translated languages, is home to the largest number of more than a dozen immigrant populations from around the world, has greater proportions of undocumented and uninsured residents than any other US region, and has the largest majority/minority population in the country.

That same complexity, however, makes responding to the HIV epidemic a unique challenge, as evidenced by alarming HIV infection rates among its transgender, transient youth and other vulnerable populations, along with other indicators of severe and unmet need. Since the days when AIDS was first identified in Los Angeles County, the County has confronted the HIV crisis within this demanding context. In spite of a publicly funded health care system that faces constant budgetary crisis, the lack of a sound transportation system, and cost-of-living and medical/health care costs that outpace most other parts of the country, Los Angeles County has developed a wide range of innovative approaches to HIV care and delivery, and has created new model systems of care management and service quality assessment.

*\* Although commonly referred to as "reauthorization", the next version of Ryan White will require new legislation since the current Ryan White Treatment and Modernization Act will sunset on September 30, 2009.*

## Detailing Principles as a Framework for Further Discussion.

The JPP Committee envisioned this work generating “a comprehensive strategy for addressing HIV disease in this country” (Ryan White Subcommittee Vision Statement). The Committee and other participants felt that development of these principles would help “advance federal legislation and other initiatives that provide access to and delivery of equitable, high quality, efficient care and prevention services for people living with or at risk of HIV disease” (Ryan White Subcommittee Mission). These principles serve as the Commission’s framework to guide and motivate more specific thought and study throughout 2008 and 2009 of important issues to address in the next iteration of Ryan White legislation.

### 1. HIV is unique.

In spite of constant claims of “AIDS exceptionalism”, HIV remains a unique health condition. It is the only terminal illness that is both communicable and chronic (some might also classify Hepatitis that way as well, which is a primary HIV co-morbidity). However, due to both its terminal and communicable nature and because experts are still learning more about the disease and the efficacy of its treatments every day, HIV cannot be treated like other chronic conditions: it demands more complex care and treatment and population-based public and personal health responses.

Among certain age and ethnic groups, and in certain areas/regions, HIV disease is the number one killer. It is a disease that is directly linked with poverty and low socio-economic status, and is one of the principle co-morbidities of mental illness, substance use and homelessness. It is unique because early, preventive care can delay onset of symptoms and mortality longer than almost all other chronic illnesses. As a communicable disease, prevention initiatives will not only prevent individual infections but also its spread to others and other populations.

Services for HIV are distinctive, and they must remain that way. Otherwise, the assumption is that a pre-determined, conventional response is a sufficient solution. Even if a cure and vaccine were found tomorrow, HIV would still be prevalent due to its communicability, the populations it most impacts, the constant mutation of the underlying virus, and the lack of access to proper medical and pharmaceutical response both domestically and globally. Together, these factors underscore the continuing need for a combined prevention and treatment response and an ongoing federal and local investment and commitment that continues to grow and adapt with the increasing and changing impact of the disease.

### 2. HIV disease is a continuum.

HIV is a chronic disease that spans a spectrum from healthy status to terminal illness. “AIDS”, as the term used to describe the condition, has become less explanatory as the years have passed, and no longer accurately illustrates the continuum of the health condition. Someone diagnosed with AIDS [less than 200 or 14% T-cell count, or identified by an Opportunistic Infection (OI)] at one point in his/her life can be perfectly healthy at a later point, while someone with HIV could be very sick although not diagnosed with AIDS. The term “AIDS” has increasingly become an arbitrary marker that often misrepresents the progression of the disease, and undermines the necessity of an individualistic health care response or a comprehensive strategy for a population significantly impacted by it.

The disease is “HIV”. While “HIV/AIDS” describes the full spectrum of its impact, “AIDS” as a marker at one point along that continuum of the disease progression is a less and less reliable indicator. While “HIV disease” would be the most accurate descriptor, a broad cross-section of the public only pays appropriate attention or knows the disease as “AIDS”, and that terminology cannot be wholesale discarded until the public is truly and comprehensively educated about the nature of this increasingly chronic condition. The principles call for a change in the language used to depict HIV disease and its impact more accurately, but also for a strong educational campaign that would support such a change.

There are not only semantic and perceptual distinctions derived from the use of the old terminology, but practical and legal consequences as well. People diagnosed with AIDS are eligible for Medicaid services, for example, while people with HIV (non-AIDS diagnosed) are denied that eligibility—although there may be no detectable difference in their respective health conditions or income status. New legislation and current federal and local programs must veer away from use the old and outdated terminology to drive policy decisions that are arbitrary and/or inaccurate, and must embrace efforts like ETHA (Early Treatment for HIV Act) in the next version of Ryan White to ensure adequacy, fairness and equity of access to and provision of services based on today's realities.

### 3. New Ryan White legislation must entail a comprehensive HIV strategy.

HIV is foremost a disease. The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was initially established to address its health care consequences, although, at the time, there were few effective medical responses. With the advent of HIV/AIDS Anti-Retroviral Therapy (HAART) and other medical and pharmaceutical advances, medical treatment can reliably delay the development of the disease or stall its impact. Federal and local Ryan White commitment must continue to focus on the core services that enable medical care and treatment.

However, patients, for example, who do not understand their prescriptions, who cannot get to their appointments, whose medical care is interrupted by mental illness and/or substance addiction, who receive substandard care because their providers are not thoroughly trained in HIV care practice, and/or who cannot access basic necessities such as food and shelter, represent money wasted, lives lost and potential further spread of the disease. HIV continues to disproportionately impact people with multiple conditions, people in poverty who have severe need, and groups that have been traditionally disenfranchised from the health care system. Consequently, a single response for all patients is not effective and a complex matrix of services is necessary to meet the needs of patients with equally complex sets of circumstances. Potentially

short-sighted concerns about the cost of expanding coverage (e.g., opposition to ETHA), or limiting certain service responses (e.g., reducing psychosocial support networks) ignores long-term cost savings that result from effective, sustainable care and treatment.

A comprehensive HIV plan will help define and guide how policy and decision-makers address and resolve these complicated equations and integrate the many different response components (e.g., surveillance, prevention, care, housing, research, etc.) seamlessly. It is no longer acceptable for federal stakeholders to trivialize HIV care and treatment by forcing a debate over the definition of health/medical care. That discourse has only served to unnecessarily divide the HIV community and is superfluous when there are numerous federal funding resources inefficiently addressing different aspects of the disease impact.

Consolidating the varied federal responses would engender a better planned and more fully integrated comprehensive system of addressing HIV needs efficiently and effectively. The time has come to merge the various federal agency funds (e.g., HRSA's Ryan White, HUD's HOPWA, SAMHSA's substance abuse services, CDC's prevention and surveillance, etc.) into an omnibus HIV initiative that truly and effectively addresses the multiple layers and myriad ramifications of HIV nationally, spans the spectrum of HIV services from prevention through care and treatment, and combines HIV data, record, surveillance and technology needs into a single, integrated effort.

Consolidating the numerous federal efforts is not, however, an excuse to reduce the overall federal HIV commitment: all existing federal funding directed toward HIV should be preserved and increased. Consolidating the various federal HIV initiatives is, instead, aimed at making the limited federal resources more efficient and less redundant and to improve positive outcomes overall.

#### 4. Ryan White's "last resort" response is not practical.

The premise of Ryan White-funded services has long been based on using the funds as "last resort"—meaning that Ryan White grantees and recipients must first demonstrate that they have exhausted all other sources of funding before tapping into Ryan White resources. It is a strong, but unrealistic, concept. Non-entitlement resources (or limited funds) cannot be effectively used as "last resort" because there is a finite amount that can be exhausted regardless of need or utilization. In California, the counties are held accountable as health care of the last resort. Los Angeles County has no choice but to expend the funds for health care as long as people need the health care—regardless of budgetary restraints. Further complicating the use of Ryan White funds, federal restrictions do not allow local jurisdictions to combine Ryan White with other federal resources (e.g., Medicaid) for the most efficient response.

Unless the framers intend to advance Ryan White funding as an entitlement resource in the future—as the Institute of Medicine (*Measuring What Matters: Allocation, Planning and Quality Assessment for the Ryan White CARE Act*, November 7, 2003) suggests—then the arcane "last resort" premise should be removed as a condition of its use. Instead, Ryan White should be re-tooled for the role in which it can be most effective: as an essential "wrap-around" or supplement to existing sources of service and funding. There is no debate that HIV disease, due to its chronic nature, costs more than most other health conditions to treat. Conventional Medicaid and other federal reimbursement rates are not adequate for the type of care that practitioners must provide to people with HIV, resulting in vast inefficiencies and administrative circumventions. Re-engineer Ryan White as a critical wrap-around and supplementary component resource intended to enhance and expand other HIV prevention, care and treatment services—or supply those services where there are none—and Ryan White becomes a more cost-efficient and clinically effective program.

This new application of Ryan White funding better prepares it for a more integrated role in the inevitable universal health care access dialogue. Using Ryan White as a wrap-around and cost supplement resource not only comprises an improved application of this source of funding, but unravels the criticism of HIV/AIDS exceptionalism. It is a financing model that can be used for other chronic conditions also exceeding the constraints of current funding limits.

#### 5. "Emergency" and "urgency" are not synonymous.

The Ryan White CARE Act was originally crafted as an "emergency" response to an epidemic that was devastating urban centers, other areas and various populations. It was intended for immediate use for people who, after being diagnosed with the disease, only had a short time left to live. Back then, the "triage" and "quick fix" aspects of an "emergency" response were primary in importance. Now—almost three decades into the epidemic—"urgency" is needed more, indicating a purposeful response, guided by expedited but thorough planning and implementation. Ryan White's continued focus on an "emergency" over "urgency" response leads to an administrative emphasis using the funds more quickly, rather than thoughtfully or deliberately.

Twenty-five years later, the emergency is not the same. The "urgency," however, is even more acute and should compel us to:

- Refocus our efforts to facilitate easy health care access and overwhelming care early on in the disease progression to slow its impact on the individual and the spread to others.
- Review program administration for burdensome, outdated procedures that no longer serve their original purpose (e.g., annual applications), and only slow the local response and/or service delivery.
- Devote expenditures to integrated prevention and care, where grantees have been obliged to distinguish between the two in the past.

- Devote specific funding allocations to address “unmet need,” rather than simply planning for it.
- Emphasize the increased prevalence of the disease in emerging communities lacking access, not always assimilated, without adequate resources, and disenfranchised for various reasons and those that continue to be marginalized.
- Invest funding in incorporating HIV expertise into existing systems of care rather than sustaining separate systems.
- Increase investment in HIV care and services because the more we are successful fighting HIV with proper care, the less our population with and impacted by HIV expands.

## 6. HIV disease is a chronic disease that can be managed, but is not always manageable.

Framing the disease as an emergency often produced quick results, but not always long-term benefits. HIV is now, in part, a chronic condition that must be addressed in both the short- and long-term, and we must enhance and care and treatment service delivery with best practices learned from other chronic conditions. Good care for a chronic condition is untenable in solely a short-term mindset. While HIV is a condition that exceeds the capacity of many components of our health system, how can HIV care be integrated into the larger system so that both HIV medicine and US health care benefit? In the 90s, the emergency had more to do with the community’s response; in the first and second decades of the 21<sup>st</sup> century, the HIV community needs to advance its service, funding and policy response to a level commensurate with strides we have made in health/medical care.

That response entails managing the disease more effectively and comprehensively, toward more positive clinical outcomes, and reducing stigma and protecting affected populations by normalizing health care routines. To the degree the next version of

Ryan White requires more systemic, coordinated care management from providers, the more manageable the condition is for people who live with HIV day-to-day. The more manageable it is for them, the more they can contribute to health care improvements and reduced health care costs.

## 7. A united vision leads to a unified response.

Opponents of HIV care expenditures often cast discussion in light of an increasingly smaller pool of resources. Regions go to battle claiming their special needs demand more attention, their health care systems are in greater decline, and that resources are inadequate. Compatriots in the war against HIV become adversaries. We do not accept the premise that these discussions must ensue in a climate of fewer resources. In the next round of national Ryan White discussions, there must be a more coherent and cohesive strategy for making Ryan White and other HIV services about more than funding and “pieces of the pie.”

We strive for more parity of access to services nationally for all people with HIV and believe that it calls for all state and local jurisdictions and federal partners to make strong commitments to HIV services, prevention and responses. Insisting on parity, equity and portability of care cannot be used as an excuse to reduce federal support of those jurisdictions that have made extraordinary commitments of their own resources (such as California, Los Angeles and San Francisco). This is a call, however, for federal, state, local and other resources to advance and accelerate their resource obligations to levels that will effect a unified service, prevention and treatment response. Jurisdictions must play on the same field:

- Receiving resources directly linked to the prevalence of the disease.
- Eliminating arbitrary measures (subjective scoring) of funding.
- Receiving comparable levels of additional funding to address the special needs of their HIV-impacted communities.

Similarly, unity of vision must engender parity of care, lead to universality of access, and reduce geographic disparities. Movement in the Ryan White 2006 reauthorization toward a more uniform response nationally must be accelerated significantly in the next version of the legislation. Ryan White resources cannot be used to widen the differential gap in care.

- People with HIV in one state should be able to get the same care in another state.
- Waiting lists in one area, where there are none in others, are unacceptable.
- Someone using medications in one region should be able to expect them in another area.
- To the extent this is a national program, care and documentation must be portable.
- ADAP formularies (like the VA or Medicare prescription plans) need to include all HAART and OI medications, not just a partial selection of them.
- ADAP must be consistent and universally applied throughout the country, rebates available in all of the states, and prescription access best practices (such as California and New York) should be the standard, not the ideal.

## 8. The necessity of a national strategy.

If we ever expect to contain the impact of this disease, Ryan White legislation must represent a national strategy and not a band-aid solution stretched too thin. The strategy must comprise not only prevention, services and care, but a deliberate federal initiative aimed at stopping HIV in its tracks—much as polio and TB were addressed in the 20<sup>th</sup> century. In the absence of a vaccine or cure, other more radical approaches must be enabled.

- The educational system, where so much of our behavior is learned and practiced, cannot be held immune to federal attention. No child should be left vulnerable and ignorant to the threats of HIV; and comprehensive K-12 HIV education is critical.
- The medical community must embrace the HIV proficiency of its practitioners and mandate the offer of HIV testing and resultant linked referrals to medical providers as the standard of care.

- There should be a national social marketing campaign that local communities can enhance, embellish, and adapt to their own populations, incorporating culturally specific anti-stigma and normalization messages.
- The media and medical communities should contribute to efforts that reduce HIV stigma and barriers by normalizing HIV care in the medical setting and HIV messages in for other purposes.
- While, as the richest country in the world, the US must take the lead on addressing the devastating economic, health and moral consequences of HIV globally, a priority focus on the domestic impact of the disease must be sustained (it is ironic that while the US has defined a global HIV strategy, it has not yet done so domestically).

At this juncture, when the entire federal HIV response is up for review and consideration, it is pivotal that the resulting federal legislation represents a collective spirit to solve the scourge of HIV, not just tolerate it.

## 9. Financially support quality and efficiency.

While there is more effort invested in quality management and clinical outcomes nationally, there does not seem to be a commensurate quality improvement at the local level, except as a response to federal mandates. Threshold funding must be available and adequate for all of the jurisdictions, but should be used to enhance clinical outcomes and cost-efficiency efforts and to reward improvements in health and clinical status and improved administrative and care efficiencies. For example:

- funding should not be awarded simply because more drugs have been disseminated, but because better and more efficient drug regimens are producing better health outcomes;
- resources should be used to support the standard medical visit, but also to encourage more effective use and efficiencies from resistance testing;
- Electronic Medical Record (EMR) systems are a costly investment, but an investment that will yield financial savings when it leads to more efficient administrative processes; and

- just the demonstration of unmet does not necessarily merit funding, but proof that the funds have generated increased access and visits from the targeted communities does.

Coordinated care has been modeled across the country and across health conditions to produce better health outcomes, so providers should be financially encouraged to adopt disease management models that rely on high quality care, and that incorporate inter-disciplinary, team-oriented service delivery, medical and primary health care accountability, and a patient-centered focus. Efficiency of care liberates resources for other purposes, in particular prevention which, in turn, results in lower transmission and infection rates.

In the same vein, Ryan White resources can be used as incentive to improve local commitment.

- Federal funding can encourage regions to address HIV in their respective areas, and the investment must be significant enough that local communities cannot disregard it.
- Rather than solely designating Maintenance of Effort (MOE), it should be combined with matching requirements incentivized with the promise of additional funding when the match increases.
- Local communities should identify factors to measure the effectiveness of financing and administrative processes, and should be awarded additional resources when their indicators show more efficient operations and/or less cumbersome service delivery.

## An Opportunity to Improve our HIV/AIDS Response.

The Ryan White CARE Act has served this country well during the first three decades of the HIV epidemic. However, the epidemic, its impact and the way we deal with it have all changed dramatically during that time. Our response must change too. This is the time to do it.

The upcoming sunset of the Ryan White Treatment and Modernization Act in 2009 represents a unique opportunity to re-examine and potentially redefine our federal HIV/AIDS policy. It is an exciting chance to create and implement an improved strategy for addressing HIV/AIDS in our country. Los Angeles County looks forward to engaging a constructive and collaborative national dialogue to craft legislation outlining the most effective use of resources and delivering the best services to people living with HIV/AIDS.

*The Commission on HIV is chartered in Los Angeles County Code 3.29 to "study, advise and recommend to the board of supervisors and the grantee on matters related to HIV/AIDS" (3.29.090 D), and serves as LA County's Ryan White planning council.*