



August 7, 2012

Dr. Deborah Parham Hopson  
Associate Administrator, HIV/AIDS Bureau  
Health Resources and Services Administration  
United States Department of Health and Human Services  
5600 Fishers Lane  
Rockville, Maryland 20857

**Re: Comments in Support of the 2013 Reauthorization of the Ryan White Treatment and Modernization Act (HRSA-2012-0003-0001)**

Dear Dr. Parham Hopson:

Thank you for the opportunity to submit comments regarding the 2013 reauthorization of the Ryan White Treatment and Modernization Act. The Center for HIV Law and Policy (CHLP) is the only national legal and policy resource and strategy center for people with HIV and their advocates. CHLP works to reduce the impact of HIV on vulnerable and marginalized communities and to secure the human rights of people most affected by HIV. We support and increase the advocacy power and HIV expertise of attorneys, community members, and service providers, and advance policy initiatives that are grounded in and uphold social justice, science and the public health. We do this by providing high-quality legal and policy materials through an accessible web-based resource bank; cultivating interdisciplinary support networks of experts, activists, and professionals; and coordinating a strategic leadership hub to track and advance advocacy on critical HIV legal, health, and human rights issues.

The 2013 reauthorization of the Ryan White Program follows several years of innovative, forward-thinking government action under President Barack Obama supporting the rights and health of

persons living with HIV/AIDS (PLWHA). The President's full endorsement of the first comprehensive National HIV/AIDS Strategy illustrates the Administration's commitment to the prevention and treatment of HIV/AIDS. Federal HIV/AIDS funding is at record levels. Millions of uninsured and underinsured Americans, including PLWHA, will have access to health care under the Affordable Care Act (ACA).

The Ryan White Program's 2013 reauthorization is a crucial step in sustaining and enhancing the progress we have made in the fight against HIV/AIDS. It must ensure uninterrupted access to quality health care for PLWHA during the transition to coverage under the ACA. This includes filling the gaps in coverage of services under private insurance plans and state health exchanges. The Ryan White Program must fill these gaps for PLWHA living in states that refuse to comply with the ACA's Medicaid expansion provision, as well. The Ryan White Program must ensure access to health care for those PLWHA who are among the estimated 30 million Americans who will remain uninsured after the ACA is fully implemented.

Legal services is a central component in ensuring access and continuity for PLWHA in need of basic medical care and related programs provided through the Ryan White Program. Indeed, HRSA specifically identifies "legal services" among the service categories eligible for Ryan White Program support services funding. There is a fundamental reason for this: without access to free legal services and advocacy to help assert their legal rights, obtain benefits that have been inappropriately denied, and plan for their and their children's futures, thousands of eligible PLWHA would be excluded from the life-saving medical and support services the Ryan White Program was created to provide.

In 1999, HRSA's HIV/AIDS Bureau released a report assessing the role of legal services in ensuring access to care for PLWHA.<sup>1</sup> In consultation with HIV legal services experts, researchers

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<sup>1</sup> JOHN-MICHAEL ANDRIOTE & R. BRADLEY SEARS, HIV/AIDS BUREAU, HEALTH RESOURCES & SERVICES ADMINISTRATION, THE ROLE OF LEGAL SERVICES IN ENSURING ACCESS TO CARE FOR PEOPLE WITH HIV/AIDS, 13 (1999).

developed a questionnaire to disseminate to HIV legal services providers across the county.

Researchers obtained data on the legal services needs of PLWHA; the ability of providers to address these needs; budgetary and staffing limitations of providers; and the types of legal services that were actually provided given these limitations. Respondent providers also described the kinds of resources they needed to continue their work and how the Ryan White Program could provide support.

Researchers presented several major findings, including the following:<sup>2</sup>

1. **Legal services help people living with HIV/AIDS to access health care services by helping them overcome immediate barriers to care.** Legal services include brief advice and counseling, limited direct representation, referrals to other providers, client and provider education, and administrative hearings and proceedings.
2. **Most HIV-related legal services programs were founded in the late 1980s and early 1990s and many have relatively small budgets.** Researchers found that almost two out of three organizations with separate HIV legal services budgets benefit from Ryan White Program funding.
3. **Legal services programs provide essential support to address barriers to care for foreign-born PLWHA, incarcerated PLWHA, and families affected by HIV/AIDS.** Almost half of respondents reported providing legal services related to immigration, including assisting non-citizens in applying for temporary visas, permanent resident status, and naturalization. These services enable clients to work legally, obtain private health insurance, and become eligible for public benefits. Stable employment and access to health insurance and other benefits are essential for accessing health care services.
4. **Legal services also help PLWHA meet subsistence needs (e.g., housing, food, and clothing) that can compete with and prevent them from accessing essential health care services.** Researchers emphasized that legal services programs help eliminate barriers to care by helping PLWHA with employment, benefits, insurance, debtor/ creditor, and tax issues. Specifically, “[b]y ensuring that clients have quality housing, for example, they can provide a stable living environment that is essential for adequate health care. Legal service programs can also help gain access to temporary housing, shelters, residential drug treatment programs, and residential health care facilities on a non-discriminatory basis.”

The legal services model is particularly well-suited to address PLWHA’s needs. Many provider organizations use both legal and non-legal tools to address clients’ issues, including peer mediation

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<sup>2</sup> *Id.* at 15-17.

and alternative dispute resolution.<sup>3</sup> Many utilize an interdisciplinary approach to client advising and representation. Peer advocates, paralegals, counselors, and social workers often provide crucial out-of-court advocacy; law students' participation through internships and clinical programs helps build the next generation of rights-oriented, HIV-competent practitioners.<sup>4</sup>

Despite the clear benefits of HIV-related legal services, provider organizations struggle to maintain funding sources. HRSA found that the majority of respondents relied on Ryan White Program funding to provide services, but nearly 15 years later, this funding stream remains unreliable.<sup>5</sup> In fact, two highly-rated legal services programs that were honored in July 2012 by the American Bar Association AIDS Coordinating Committee for their consistent and essential services to PLWHA, HIV/AIDS Legal Services of Los Angeles (HALSA) and AIDS Law Louisiana, illustrate the funding crisis such programs are facing.<sup>6</sup> Just weeks before the awards were presented, HALSA was forced to close its doors; AIDS Law Louisiana, which works mightily to provide legal support to PLWHA throughout the state, now is down to one full-time attorney. Without Ryan White Program funding of legal services that is proportionate to other essential support services that get and keep PLWHA in medical care, it is inevitable that more such programs will pare down or close down, and more PLWHA will remain in the margins between diagnosis and consistent treatment.

The characterization of the type and scope of Ryan White-eligible legal services has been debated and amended over several reauthorizations. In 2010, HRSA released Policy No. 10-02, which is currently in effect:<sup>7</sup>

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<sup>3</sup> International Development Law Organization Health Law Program, *10 reasons why legal services must be central to a rights-based response to HIV* (Dec. 1, 2010).

<sup>4</sup> *Id.*

<sup>5</sup> JOHN-MICHAEL ANDRIOTE & R. BRADLEY SEARS, HIV/AIDS BUREAU, HEALTH RESOURCES & SERVICES ADMINISTRATION, *THE ROLE OF LEGAL SERVICES IN ENSURING ACCESS TO CARE FOR PEOPLE WITH HIV/AIDS*, 16 (1999).

<sup>6</sup> *Alexander D. Forger Awards for Sustained Excellence in HIV Legal Services and Advocacy*, [http://www.americanbar.org/groups/individual\\_rights/projects/aids\\_coordinating\\_project/events\\_cle/alexander\\_d\\_forger\\_awards.html](http://www.americanbar.org/groups/individual_rights/projects/aids_coordinating_project/events_cle/alexander_d_forger_awards.html).

<sup>7</sup> HRSA Policy No. 10-02.

Legal Services are an allowable support service under the Ryan White HIV/AIDS Program. Funds awarded under the Ryan White HIV/AIDS Program may NOT be used for any criminal defense, or for class-action suits unrelated to access to services eligible for funding under the Ryan White HIV/AIDS Program. Funds may be used for legal services directly necessitated by an individual's HIV/AIDS serostatus.

These services include but are not limited to:

- a. Preparation of Powers of Attorney, Living Wills
- b. Interventions necessary to ensure access to eligible benefits, including discrimination or breach of confidentiality litigation as it relates to services eligible for funding under the Ryan White HIV/AIDS Program, and
- c. Permanency planning for an individual or family where the responsible adult is expected to pre-decease a dependent (usually a minor child) due to HIV/AIDS; includes the provision of social service counseling or legal counsel regarding (1) the drafting of wills or delegating powers of attorney, and (2) preparation for custody options for legal dependents including standby guardianship, joint custody or adoption.

This policy is silent on a vast array of legal services, prompting many grantees to define the type and scope of permissive services in their respective Eligible Metropolitan Areas (EMAs) or Transitional Grant Areas (TGAs).<sup>8</sup> This inconsistent application of HRSA's policy has resulted in the deprivation of crucial services for PLWHA. Many EMAs and TGAs across the country prohibit the use of Ryan White Program funds to provide housing, immigration, family, and domestic violence-related legal services, despite incontrovertible evidence that these services are necessary to ensure the health and well-being of PLWHA.

The relationship between legal services for those facing domestic violence and both health care access and outcomes, for example, is well-documented. Domestic partner violence plays a direct role in harming HIV-positive women's health, especially since consistent health care is key for the well-being of persons living with the virus. In a University of California, San Francisco (UCSF) study

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<sup>8</sup> In the spring of 2009, HIV/AIDS legal services providers conducted a small, informal national survey which found that "the type of restrictions imposed upon legal services providers was based primarily on local interpretation of HRSA policy by the local grantee, rather than actual HRSA policy or enforcement." Letter from Cynthia Knox et al. to Mary Wakefield and Deborah Parham Hopson, HIV/AIDS Bureau, HRSA (Nov. 17, 2009).

presented at the International AIDS Conference in July 2012, women reported having partners who threatened to hurt or kill them, preventing them from seeing health care providers.<sup>9</sup> They reported that partners refused to let them seek HIV-related care for fear that others would think they, too, had HIV.<sup>10</sup> The UCSF program that was the genesis of the study, initiated to determine why one in five of their female patients do poorly, found that the lack of resources to assist patients facing intimate partner violence and other forms of abuse was the answer; trauma was the only factor significantly related to the failure of these women's treatment regimens.<sup>11</sup> It is difficult to dispute that legal support provided to women facing domestic abuse bears a direct relationship to access, retention, and consistency in HIV-related care. HRSA should explicitly acknowledge and prioritize such legal services in its guidance.

Numerous studies also have linked homelessness or unstable housing to “barriers to medical care, lower rates of service utilization, and poor adherence to complex treatment regimens.”<sup>12</sup> A 2001 study of PLWHA in New York City by Community Health Advisory and Information Network (CHAIN) and funded in part by HRSA found a “significant relationship between homelessness/unstable housing and remaining outside or marginal to HIV care.”<sup>13</sup> Study participants lacking stable housing had poorer mental health functioning and higher viral loads; only a small fraction of participants reported consistent, adherent use of antiretroviral treatments.<sup>14</sup> CHAIN researchers found that once PLWHA receive housing assistance, they are “almost four times more likely to enter into medical care . . . and twice as likely to enter into and continue in care that meets current clinical

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<sup>9</sup> Laura Whitehorn, *Domestic Violence Doubles Risk of Death for HIV-Positive Women*, AIDSMEDS, Jul. 31, 2012, [http://www.aidsmeds.com/articles/hiv\\_women\\_violence\\_1667\\_22757.shtml](http://www.aidsmeds.com/articles/hiv_women_violence_1667_22757.shtml).

<sup>10</sup> *Id.*

<sup>11</sup> *Id.*

<sup>12</sup> ANGELA A. AIDALA *ET AL.*, COMMUNITY HEALTH ADVISORY AND INFORMATIONAL NETWORK, HOUSING STATUS AND HEALTH OUTCOMES AMONG PERSONS LIVING WITH HIV/AIDS 2 (2001).

<sup>13</sup> *Id.* at 3.

<sup>14</sup> *Id.* at 2, 14.

standards for treatment of HIV/AIDS.”<sup>15</sup> Yet many people living with HIV who are transitioning from incarcerations – and, most recently, those who have been forced to register as sex offenders as a consequence of an HIV-specific criminal prosecution – are told their felony convictions and/or sex offender status make them ineligible for any and all government-supported programs, and thus find it nearly impossible to secure housing without the intervention of legal advocates. Program restrictions on such legal services related to housing assistance effectively serve as barriers to medical care and improved health outcomes for PLWHA – a consequence antithetical to the Ryan White Program mission.

Immigration services – including assisting undocumented immigrants obtain legal status in order to access HIV treatment and other health care – are also restricted in many EMAs and TGAs. Other locations do not allow providers to assist with family-related legal issues, including child custody, visitation, or adoption. Family disputes and separations profoundly affect the health and well-being of family members, including those living with or affected by HIV/AIDS. Housing, immigration, and family issues all fall within the continuum of care for PLWHA, and legal services supporting the resolution of such issues should be funded by the Ryan White Program. Access to a full array of these and other legal services are extremely cost efficient, and will ensure continued access and adherence to medical care.

CHLP recommends that HRSA clarify Policy No. 10-02 such that “legal services directly necessitated by an individual’s HIV/AIDS serostatus” includes all legal services, and explicitly those discussed above, that help to remove barriers to essential programs related to the health and well-being of PLWHA. The decision of whether a service is “directly necessitated” by an individual’s HIV status should be left to the legal services provider whose expertise and individual case assessment will inform

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<sup>15</sup> Angela A. Aidala *et al.*, *Housing and Health Care Among Persons with HIV/AIDS*, 130<sup>th</sup> Meeting of the American Public Health Association in Philadelphia, PA. (Nov. 9-13, 2002).

this decision. CHLP also recommends that HRSA prohibit grantees from unnecessarily narrowing this definition by restricting the type and scope of civil legal services allowable under Ryan White Program funding.

Incidentally, HRSA made very similar recommendations in its 1999 report. The report stated that “[b]asic needs such as housing, employment, and access to public benefits are critical to the health and well-being of PLWH.”<sup>16</sup> It suggested that HRSA “change guidance that severely limits the types of legal services that can be provided with CARE funds.”<sup>17</sup> The report also recommended that HRSA better identify PLWHA’s legal services needs by contracting out for needs assessments using Ryan White Program funds.<sup>18</sup> It also suggested formal networking and sharing of HIV-related legal materials.<sup>19</sup> CHLP offers HRSA its expertise and resources for such an initiative; in 2008, CHLP founded the HIV Legal Collaborative, a network of attorneys across the United States who have self-identified as sensitive to HIV-related issues.<sup>20</sup> Recruitment of attorneys and other legal services providers is ongoing. Our efforts are focused on providers not only in urban areas, but in rural and underserved communities, particularly in the South, as well. HIV-related legal services providers interested in joining the HIV Legal Collaborative should visit <http://hivlawandpolicy.org/forum/attorney-directory-signup-form> or contact Rashida Richardson at [rrichardson@hivlawandpolicy.org](mailto:rrichardson@hivlawandpolicy.org) for more information.

CHLP is optimistic that through the 2013 reauthorization of the Ryan White Treatment and Modernization Act, HRSA will continue the great precedent the Obama Administration has set in

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<sup>16</sup> JOHN-MICHAEL ANDRIOTE & R. BRADLEY SEARS, HIV/AIDS BUREAU, HEALTH RESOURCES & SERVICES ADMINISTRATION, THE ROLE OF LEGAL SERVICES IN ENSURING ACCESS TO CARE FOR PEOPLE WITH HIV/AIDS, 17 (1999).

<sup>17</sup> *Id.*

<sup>18</sup> *Id.* at 18.

<sup>19</sup> *Id.*

<sup>20</sup> The Center for HIV Law and Policy, HIV Legal Collaborative, <http://www.hivlawandpolicy.org/public/support/attorneydirectory>.



supporting PLWHA by acknowledging the direct link between legal services and improved health outcomes. Thank you for the opportunity to weigh in on this important issue.

Sincerely,

Adrian Guzman  
The Center for HIV Law and Policy