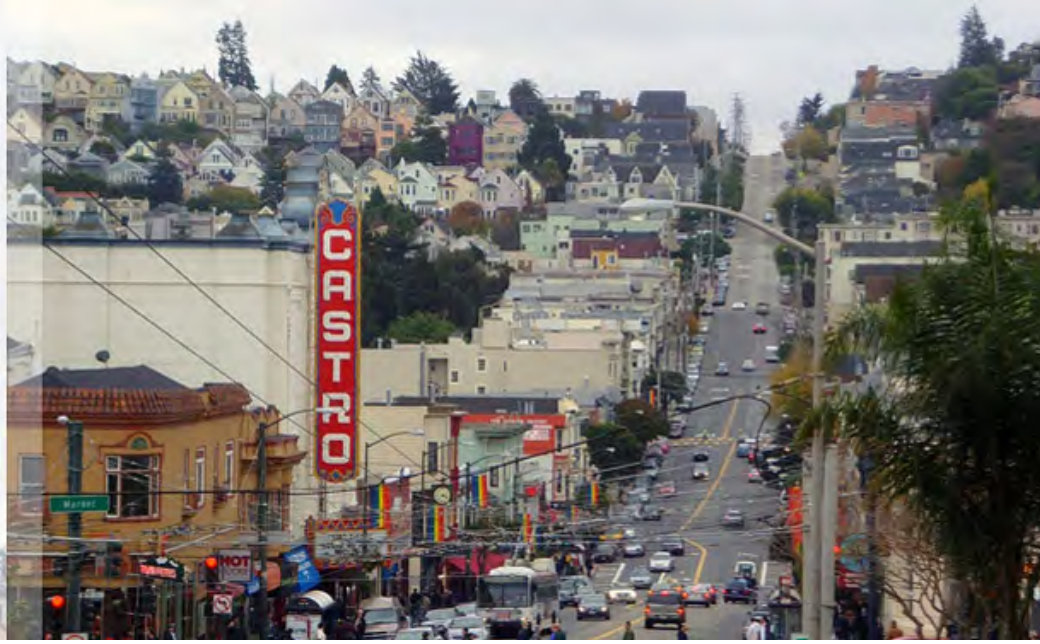
In the early days of the epidemic, San Francisco's Castro District was one of the Nation's hardest hit urban centers. Not surprisingly, this area gave rise to impassioned efforts to combat the disease.



Program Origins

PART A
Eligible Metropolitan Areas/ Transitional Grant Areas

The first HRSA-funded AIDS Service Demonstration Grants, in 1986, brought care to four urban centers. By 1991, when Title I (now Part A) programs began, the number of cities receiving funds had increased fourfold, to 16.

Part A: Responding in High-Impact Urban Areas

"We were trying to make a difference in peoples' lives for the short amount of time they were going to be around," says Jeff Cheek, Associate to the Chairman, Board of Commissioners, Fulton County, speaking of the early days of the Ryan White Title I (now Part A) Program. Cheek, who has worked for the Atlanta Title I grantee's office since 1992, says, "We weren't thinking about sustaining programs, just getting money out on the street to make a difference."[1]

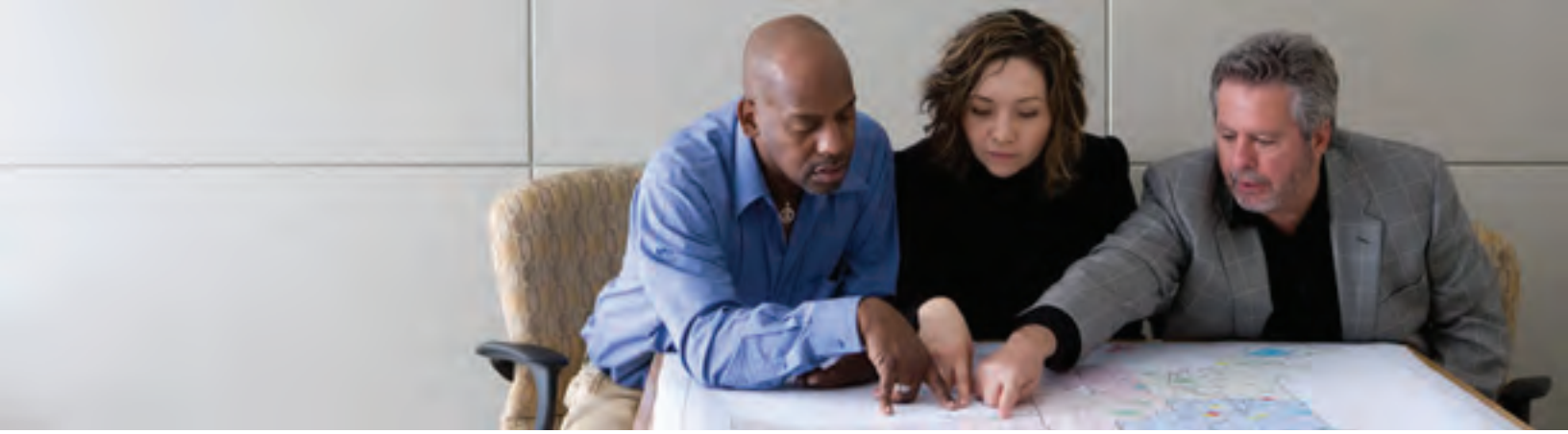
His recollections echo those of others at HRSA and in local communities as they launched the new Federal initiative in the Nation's urban centers hardest hit by HIV. In that era, myths and fears about the disease were rampant, and gay community newspapers were filled with pages upon pages of obituaries.

"It was a volcano of emotion and passion," remembers Theresa Fiaño,[2] who worked in Seattle in the years before the Ryan White Program and helped launch that city's Title I program. "The people I worked with were mostly there for the same reasons I was. We all knew someone who was affected, and [we] wanted to do something, whatever we could. We didn't see an end in sight, but at the same time we thought something had to come around the bend."

"It was truly an incredible time, the energy was incredible," says HRSA's Sheila McCarthy.[3] "There were not that many of us, not more than 30 people working on AIDS programs at HRSA at the time the legislation was passed, and we had the feeling that we would be able to do something to make a difference, and there was just extraordinary need."

In all the original 16 Title I communities (known as Eligible Metropolitan Areas, or EMAs) funded in FY 1991, Ryan White Comprehensive AIDS Resources Emergency (CARE) Act programs were built on the foundations of existing public and private initiatives. HRSA's AIDS Service Demonstration Grants and the Robert Wood Johnson (RWJ) Foundation's AIDS Health Services Program were launched in 1986 to support community-based care networks in urban communities that were grappling with how best to respond to the new and growing epidemic.

View the list of urban communities receiving EMA funding. (PDF – 68.2 KB)



Above: The Denver Mayor's Office of HIV Resources successfully coordinates Ryan White funding across a nearly 4000-square-mile area, relying on Planning Council members to help oversee clinical and support services.

A Time of Critical Need

These programs were launched at a time when people with AIDS often required extensive medical and support services, despite high fatality rates and short life expectancies. Hospitals in communities with relatively large caseloads were especially strained by the lack of out-of-hospital placement options.[4] "They were filling up hospitals in New York, but there was no back door; there was nowhere to send them," says Mervyn Silverman, who served as director of public health in San Francisco and went on to run the RWJ program.[5] His observation reflected what HRSA was finding in communities across the country: The critical challenge was "coordinating medical and related services into a system of care."[6]

Federal Grants to Fight Specific Disease Authorized for First Time

President [George H.W.] Bush signed . . . an $882 million AIDS emergency measure that for the first time will allow federal grants to 16 cities, including Washington, hit hardest by the deadly viral epidemic . . .

—The Washington Post, August 19, 1990

"There were . . . not more than 30 people working on AIDS programs at HRSA at the time the legislation was passed, and we had the feeling that we would be able to do something to make a difference."

—Sheila McCarthy

"It was a volcano of emotion and passion. . . . The people I worked with were there for the same reasons I was. We all knew someone who was affected, and [we] wanted to do something, whatever we could."

—Theresa Fiaño

Drawing on Community Efforts

Recognizing that many communities had taken steps to structure such care, HRSA designed the demonstration grants to support and strengthen existing efforts. The HRSA project funded 4 communities in its inaugural year, which grew to 25 in its final year, FY 1990. Total annual funding for all the communities grew from $10 million to $17.2 million 5 years later.

Tailoring Interventions to Local Needs

The RWJ grants, meanwhile, provided $17.1 million to support 4-year demonstration projects in 11 communities to help them develop community-based systems of care similar to the one that had evolved in San Francisco, which was shown to have a positive impact on hospitalization rates, costs, and patient satisfaction.[4]

According to Silverman,5 however, the local programs were not carbon copies of the San Francisco model or of one another but were developed to reflect the needs of local communities. This local flexibility set an important precedent for the future Title I program, as did requirements for community advisory boards.

Today's Planning Councils are models of participatory decision making and reflect more than ever the demographics of the communities they serve.

Among other changes, the first congressional reauthorization in 1996 placed a new priority on women and children, particularly on the prevention of perinatal transmission of HIV.

"When. . . HAART came around, the difference was night and day. People who got on those meds, suddenly they looked healthy instead of ill, and they were able to participate and maybe even go back to work."

—Theresa Fiaño

"We put money in the middle of the table and asked everyone to come sit around the table," says Silverman of the RWJ program. "We wanted to fund cooperative, collaborative projects." There was also close collaboration between HRSA and RWJ, which were funding the same agencies in some communities and often made site visits together.[3]

HRSA's Demonstration Projects: A Blueprint for the Future

According to McCarthy, much of the structure and legislative language for Title I came from HRSA's demonstration projects. As passed, CARE Act Title I had relatively brief, broad language about the types of services to be funded: outpatient and ambulatory health and support services and inpatient case management designed to keep people out of the hospital or expedite their discharge. "Case management was heavy, and so was home health care. In those days, it was more palliative care. People were really sick and hospitalized, then they'd come out and have 1 or 2 months to live," said Fiaño.[2]

The law brought a large influx of new resources. In FY 1991, Title I provided $87.8 million to the first 16 jurisdictions—much more than the $17.2 million HRSA had been able to make available to 25 jurisdictions the year before. "One day you didn't have resources, and the next day you had all these resources and a very limited time to expend them," says Rich Stevens, a community organizer in Miami during the first few years of the Ryan White Program.[7] According to Cheek, "in the early days, there wasn't a lot of guidance from HRSA because it was new to them as well."[1]

Shift to Local Stewardship

The CARE Act required that Title I funds be administered by the chief elected official in a jurisdiction, who in most cases delegated responsibility to the local health department. This structure was a major change from HRSA and RWJ demonstration projects, which in some communities had directed funds to local nonprofits rather than local health departments. According to McCarthy, the shift to local government stewardship reflected Congressional intent to increase accountability.

The legislation also required each funded jurisdiction to have an HIV health services Planning Council that had the authority to establish local spending priorities and was mandated to develop a plan for the organization and delivery of Title I–funded services. "The Planning Council took its job seriously in looking at resources outside the Ryan White [Program] to determine how the Ryan White [Program] could be used to fill in the gaps," says Fiaño of her experience in Seattle. According to McCarthy, many chief elected officials disliked the authority vested in the Planning Council. "At one point someone called because their mayor was going to change the priorities. We had to call the mayor's office and tell them that if they did that, they would lose the money."

The Planning Councils themselves were not without their challenges. McCarthy recalled HRSA's push to require that all planning bodies have by-laws, and Stevens notes that "for the most part, providers dominated the Planning Councils, so they prioritized according to their interest. That had to be corrected in Years 2 and 3, when provider composition had to be curtailed."

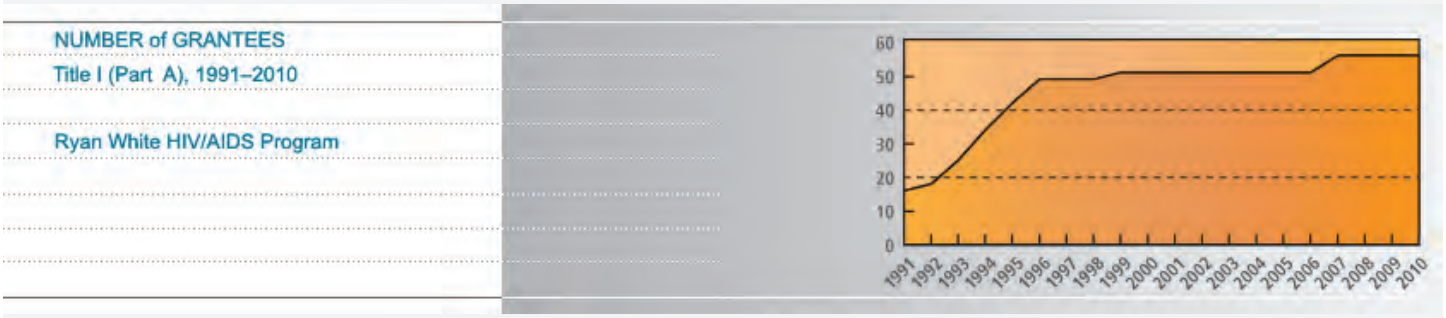
New Priorities for Distributing Funds

As more jurisdictions qualified for Title I funds, the number of EMAs grew to 25 by 1993 and to 42 in 1995, when Congress prepared to reauthorize the program. That first congressional reauthorization in 1996 reflected the evolution of the epidemic, including the emergence of some treatment options and the experiences of communities and HRSA with the program.

New Priorities for Distributing Funds

The most notable change was to the formula for distributing Title I funds. Rather than rely on cumulative AIDS cases, the new formula relied on estimated living cases of AIDS to more accurately reflect the current impact of the epidemic on a community.

NUMBER OF GRANTEES TITLE I (PART A), 1991–2010



Year	Number of Grantees	Year	Number of Grantees	Year	Number of Grantees
1991	16	1998	49	2005	51
1992	18	1999	51	2006	51
1993	25	2000	51	2007	56
1994	34	2001	51	2008	56
1995	42	2002	51	2009	56
1996	49	2003	51	2010	56
1997	49	2004	51		

Beginning with the 2006 reauthorization, the Ryan White HIV/AIDS Program included support for care in small cities under its Transitional Grant Area program. Several cities, like Denver, CO, made a successful transition from EMA to TGA status.

Closely linked to that provision was another provision to ensure that no jurisdiction saw a drastic cut in resources as a result of this change. Funded services also now made explicit mention of prophylactic treatment for opportunistic infections, and Title I placed a new priority on women and children, emphasizing the prevention of perinatal transmission. The updated law also laid out new requirements for Planning Council membership and operations by mandating that they reflect affected communities, participate in statewide planning efforts, and maintain conflict-of-interest policies and grievance procedures.

Advent of HAART

"When. . . HAART[8] came around, the difference was night and day. People who got on those meds, suddenly they looked healthy instead of ill, and they were able to participate and maybe even go back to work," says Fiaño. The second reauthorization in 2000 reflected the new reality that learning one's HIV status and getting into treatment as early as possible could slow disease progression. New service categories for outreach and early intervention were aimed at finding people with HIV who were not in care and linking them to the care system. Also added were requirements to ensure that care provided through Title I was consistent with Federal guidelines for the treatment of HIV and the prevention of related infections.

The 2006 reauthorization brought sweeping changes to Title I, as it did to other components of the program. Much of the change was rooted in the movement toward a more medically based model of HIV care. The new law mandated that 75 percent of all funded services meet the definition of core medical services and narrowed the definition of support services as those that help people living with HIV/AIDS achieve medical outcomes. It also changed the criteria for distributing formula funds from estimated living cases of AIDS to cases of HIV and stipulated new requirements related to the timely expenditure of funds. The subsequent reauthorization in 2009 kept these programatic requirements in place.

Transitional Grant Areas

In another major change, the new law divided funded jurisdictions into two categories: EMAs and transitional grant areas (TGAs). EMAs include cities with 2,000 AIDS cases in the most recent 5-year period, and TGAs include those with 1,000 to 1,999 AIDS cases in that period. The change caused anxiety in some jurisdictions that became TGAs. Under the new law, TGAs were no longer protected from dramatic annual funding shifts, and some faced the end of their Part A status at the end of the 3-year reauthorization. A change in qualifications for Part A status added five new jurisdictions to the program, but for the first time in the act's history, Congress provided no new funds to support the addition of new service areas.

See Part A funding information by State.

Read more about Part A.

SUMMARY OF LEGISLATIVE CHANGES

PART A Ryan White Legislation 1990 Act	• Sixteen Eligible Metropolitan Areas (EMAs) were created. • EMA status was based on more than 2,000 AIDS cases in the most recent 5 years and a population of at least 50,000. • EMA funds were to be distributed by the chief elected official of the EMA. • HIV Planning Councils were composed of HIV-care providers and consumers.
Ryan White Reauthorization 1996 Act	• EMAs were required to prioritize funds for women, infants, children, youth, and their families to combat perinatal transmission and increase support services. • A severity-of-need provision was added to the supplemental grants to EMAs to take into account both the resource needs of people living with HIV/AIDS and the costs of care delivery.
Ryan White Reauthorization 2000	• Early intervention services became eligible for funding. • Reauthorization required inclusion of people representing disproportionately affected communities, including providers of housing services and representatives of former inmates with HIV.
Ryan White Reauthorization 2006	• Jurisdictions were divided into Transitional Grant Areas (TGAs) and EMAs. • TGA status was based on at least 1,000 but not more than 1,999 cumulative reported AIDS cases during the most recent 5 years, and a population of 50,000 or more. • 75 percent of funds were to go to core medical services.
Ryan White Reauthorization 2009	• Continuing use of code based reporting of living HIV status. • Directing efforts to identify those individuals who are unaware of their HIV status; persons who have never been tested as well as those who have been tested and never received results. • Returning to formula distributon of MAI funds that are synchronized with Part A and Part B award dates.

Credits and Sources

Sources

1. Personal communication with J. Cheek, March 2008.
2. Personal communication with T. Fiaño, March 2008.
3. Personal communication with S. McCarthy, April 2008.
4. Jellinek P, Hearn R, Cluff L. Responding to AIDS: The Robert Wood Johnson Foundation's Experience, *AIDS Publ Pol J.* 1990;4:212-7.
5. Personal communication with M. Sliverman, March 2008.
6. Sundwall D, Bailey D. Meeting the needs of people with AIDS: local initiatives and federal support. *Public Health Rep.* 1988;103:293-8.
7. Personal communication with R. Stevens, April 2008.
8. Highly active antiretroviral therapy.

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