

# Characteristics of Ryan White and non-Ryan White funded HIV medical care facilities across four metropolitan areas: results from the Antiretroviral Treatment and Access Studies site survey

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**Abstract** *The Ryan White Comprehensive AIDS Resources Emergency Act 1990 (CARE Act) is one of the largest federal programmes funding medical and support services for individuals with HIV disease. Data that report services and gaps in service coverage from the organizational perspective are very limited. The Antiretroviral Treatment and Access Studies included a mail survey of 176 HIV medical care facilities in four US inner cities on clinic characteristics, services and practices, and patient characteristics. Characteristics of 143 (85%) responding Ryan White (RW) funded and non-RW funded facilities are described. RW funded facilities reported offering more services than non-funded facilities including evening/weekend hours (49% vs. 18%), transportation (71% vs. 22%), and on-site risk reduction counselling (88% vs. 55%). More RW funded facilities reported offering on-site adherence support services, such as support groups (44% vs. 12%), formal classes (20% vs. 2%), and pillboxes (83% vs. 43%), and served a larger proportion of uninsured patients (41% vs. 4%) than non-funded facilities. Our analysis showed that the RW funded HIV care facilities offered more clinic, non-clinic, and adherence support services than non-RW funded facilities, indicating that the disparities in services were still related to CARE Act funding, controlling for private–public facility type.*

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## Introduction

Twenty years into the HIV/AIDS epidemic, the number of HIV infected persons in the USA is estimated to range between 850,000 and 950,000 individuals (Fleming *et al.*, 2001). It is estimated that 40,000 new HIV infections occur annually; the majority of these new infections (70%) are occurring among minority populations (Centers for Disease Control and Prevention, 2002). In 2000, an estimated 344,178 individuals were living with AIDS in the USA (Centers for Disease Control and Prevention, 2001). This number is likely to continue growing, creating strains on the funding mechanisms for HIV/AIDS medical treatment and care.

At the end of the last decade, the federal government was spending over \$8 billion a year on HIV/AIDS care and assistance (excluding research, prevention, and international funding) through various funding mechanisms (Summers *et al.*, 2003). One of the most important federal programmes that funds care and assistance services for individuals with HIV disease is the Ryan White Comprehensive AIDS Resources Emergency Act 1990 (CARE Act), administered by the Department of Health and Human Services' (DHHS's) Health Resources and Services Administration (HRSA).

The CARE Act was enacted by the US Congress to "improve the availability of care for low-income, uninsured and underinsured individuals and families affected by HIV disease" (HRSA, HIV/AIDS Bureau, 2002a). CARE Act programmes reach more than 500,000 HIV-positive individuals every year (HRSA, HIV/AIDS Bureau, 2002b) and had appropriations for fiscal year 2001 of \$1.8 billion for services such as outpatient health care, case management, HIV medications, and other types of social services, accounting for approximately 25% of federal expenditures on HIV/AIDS care and treatment (HRSA, HIV/AIDS Bureau, 2002a).

There is an ongoing effort to try to describe the characteristics of the populations that benefit from this programme, the types of services that facilities funded through the CARE act provide, and barriers to accessing these services (HRSA, HIV/AIDS Bureau, 2000). The HIV Cost and Services Utilization Study, which, in part, described the characteristics of clients utilizing facilities funded and not funded by the CARE Act, found that funded facilities served a greater percentage of women, minorities, persons infected through injection drug use, and persons infected through heterosexual contact (US General Accounting Office, 2000) than non-Ryan White (non-RW) facilities. Other studies have also found that females and minorities were receiving services covered by the CARE Act at a greater rate than the general AIDS population, and that the CARE Act was successful in equalizing access to care for women and racial/ethnic minorities (Marx *et al.*, 1997; Ashman *et al.*, 2000). AIDS service organizations surveyed in a study in Texas characterized the blend of health and social services provided by RW facilities as the most effective in meeting the needs of their HIV/AIDS population (Buchanan & Chakravotky, 1999), while another study in California indicated that the barriers to accessing RW services most commonly cited by patients were agency-related barriers such as inconvenient location or hours of operation, lack of bilingual staff, and inadequate services, among others (Marx *et al.*, 2001).

Studies assessing services and gaps in service coverage of the CARE Act have primarily examined these issues from the patient's perspective. Previous research has demonstrated the demographic and need characteristics of patient populations served by RW funded facilities compared to the overall AIDS case data (Ashman *et al.*, 2000) and the need characteristics of CARE Act clients (Marx *et al.*, 1997, 2001). In contrast to reports solely concerned with CARE Act clinics, there have been no studies to date contrasting services and service gaps for RW funded and non-RW funded facilities. The present study compares counselling, support

services, and referral services in 69 RW affiliated clinics and 74 non-RW affiliated clinics in four urban locations surveyed in 2000–01.

## Methods

The Antiretroviral Treatment and Access Studies (ARTAS) included a mail survey of HIV/AIDS treatment facilities in four US inner cities (Atlanta, Baltimore, Los Angeles, and Miami) during 2000–01. One hundred and seventy-six facilities known to provide HIV care across the four cities were identified through a variety of sources including the RW Title I and II programmes, the AIDS Drug Assistance Program (ADAP), Medicaid offices, local health departments, local HIV community planning groups, and infectious disease registries. The survey sought responses from clinic administrators with first-hand knowledge of the clinic characteristics, staffing, operations of the clinics, and patient flow. Prior to mailing the survey, study personnel called each clinic and confirmed the names and contact information of the clinic administrators. We also pre-tested the survey to ensure that clinic administrators felt that they had the required knowledge to answer the survey items.

Survey questionnaires were sent via US mail and were followed by telephone contacts and follow-up mailings for non-responders thereafter (Dillman, 1978). Upon receipt of the surveys, respondents were given \$25 for their participation in the study.

The site survey was organized into two major sections: 'Site information and characteristics'; and 'Characteristics of patients receiving care at this site'. In the 'Site information and characteristics' section, questions generated information on the type of clinic, number or percentage race/ethnicity of medical providers, and types of services offered. Additionally, a question reading "Does this site receive any Ryan White funding?" was used to differentiate between facilities that received RW funding and those that did not. In the section 'Characteristics of patients receiving care at this site', clinic administrators or directors reported number of patients seen, percentage racial/ethnic composition of patient population, referral sources, adherence to clinic appointments, clinic waiting time, and medication patterns. Frequency distributions and  $\chi^2$  analyses were used to describe differences between facilities that self-reported receiving RW funding and those that did not report such funding. The study was approved by the Human Investigations Committee of all participating institutions, as well as by the Centers for Disease Control and Prevention. Logistic regression,  $\chi^2$ , and Fisher's exact tests were performed with Statistical Analysis Software (SAS version 8.0, SAS Institute, Inc.).

## Results

Of the 176 site surveys mailed to site administrators, 145 returned them, resulting in a response rate of 82%. Of the 145 site surveys returned, 143 surveys had complete data regarding RW funding. Sixty-nine facilities (48%) reported receiving funding while 74 facilities (52%) reported not receiving any RW funding. Self-identified facilities receiving RW funding were, in general, hospital outpatient clinics, public health/county clinics, and community based clinics. Facilities not receiving RW funds were mostly private offices (85%). Only 10% of private offices reported receiving any RW funding (Table 1).

RW funded facilities were more likely to have five or more medical providers compared to non-RW funded facilities (41% vs. 14%,  $p=0.0001$ ). There were no differences regarding the total number of male medical providers reported working in both types of facilities, but RW funded facilities had a significantly greater percentage of female medical providers than

**Table 1.** *Characteristics of facilities*

	RW funded facilities (%) ( <i>n</i> = 69)	Non-RW funded facilities (%) ( <i>n</i> = 74)	<i>p</i> -value
Type of facility			0.001 <sup>1</sup>
Private office	10	85	—
Hospital outpatient facility	22	11	—
Public health/county clinic	16	0	—
Community based clinic	43	1	—
Other	9	3	—
Facility setting			0.187 <sup>1</sup>
Urban	80	75	—
Suburban	13	22	—
Rural	3	3	—
Other	4	0	—
<i>Provider composition</i>			
Number of medical providers			0.001
Less than 4 providers	59	86	—
5 or more providers	41	14	—
Gender of providers			0.0001
Male	50	71	—
Female	50	29	—
Race/ethnicity of medical providers: mean (standard deviation) <sup>2</sup>			
White	62.1 (35.8)	75.4 (38.5)	0.03
Black	21.6 (26.3)	10.0 (24.9)	0.008
Hispanic	18.7 (29.8)	22.7 (37.9)	0.48
Asian	6.5 (14.2)	6.5 (20.7)	0.54
Native Hawaiian/Pacific Islander	0.02 (0.12)	0.5 (3.9)	0.29
American Indian/Alaskan Native	2.8 (13.8)	0 (0)	—

<sup>1</sup>Fisher's exact test.<sup>2</sup>Reported percentages.

non-funded facilities. A slightly lower percentage of white medical providers were reported by RW funded facilities, and a significantly greater percentage of black providers were reported by RW funded facilities. Both types of facilities reported having similar percentages of Hispanic, Asian, Native Hawaiian and American Indian medical providers (Table 1).

RW funded facilities were more likely to report providing their patients with assistance in obtaining Medicaid, ADAP, drug treatment, mental health services, and other types of social services than were non-RW funded facilities. Additionally, RW funded facilities reported they were more likely than non-funded facilities to offer numerous on-site services including on-site evening/weekend hours (49% vs. 18%,  $p < 0.001$ ), walk-in appointments (84% vs. 47%,  $p < 0.001$ ), case management services (90% vs. 27%,  $p < 0.001$ ), a multi-lingual environment (78% vs. 42%,  $p < 0.001$ ), transportation (71% vs. 22%,  $p < 0.001$ ), mental health services (74% vs. 18%,  $p < 0.001$ ), drug treatment (44% vs. 26%,  $p = 0.025$ ), pharmacy services (61% vs. 22%,  $p < 0.001$ ), and risk reduction counselling (88% vs. 55%,  $p < 0.001$ ) (Table 2). Risk reduction counselling was offered in 36 (51%) private offices compared to 60 (91%) public clinics, i.e. any of hospital, public health/county, or community based facilities ( $p < 0.0001$ ).

RW funded facilities reported having fewer white patients, but having more HIV patients who were Hispanic, Native Hawaiian/other Pacific Islander, and American Indian/Alaskan

**Table 2.** *Services of clinics*

	RW funded facilities (%) (n = 69)	Non-RW funded facilities (%) (n = 74)	p-value
<i>Assistance in obtaining</i>			
Medicaid	80	53	0.001
ADAP	94	51	0.001
Drug treatment	83	62	0.006
Mental health services	93	55	0.001
Other social services	94	66	0.001
<i>Services offered</i>			
Evening/weekend hours	49	18	0.001
Appointments within 48 hours	81	73	0.245
Walk-ins	84	47	0.001
Telephone consultation	65	64	0.831
Childcare facilities	9	3	0.119
Case management	90	27	0.001
Multi-lingual environment	78	42	0.001
Transportation	71	22	0.001
Health care other than HIV	90	80	0.093
Mental health	74	18	0.001
Drug treatment	44	26	0.025
Pharmacy	61	22	0.001
Infusion therapy	26	32	0.405
Risk reduction counselling	88	55	0.001
Other social services	74	26	0.001
Policy on drugs or alcohol	67	51	0.001

Natives, than non-RW funded facilities. When analysing medical insurance coverage, RW funded facilities were more likely to serve uninsured patients (41% vs. 4%,  $p < 0.0001$ ) and were also less likely to have patients with private insurance (Table 3).

RW funded facilities were more likely to report that patients were referred from public hospitals, STD clinics, HIV testing sites, prison system/state custody, drug/alcohol treatment centres, and homeless shelters. Non-RW funded facilities were more likely to report having patients referred by private hospitals and private practices.

RW funded and non-RW funded facilities did not differ in their reports of the amount of time patients had to wait before seeing a provider for a scheduled appointment (Table 4). However, RW funded facilities were more likely to report that their patients spent more time (defined as  $> 1$  hour) in the clinic than did non-funded facilities, and were also more likely to report that more of their patients missed their scheduled appointments than non-RW funded facilities.

The majority of clients at both types of facilities were reported to be eligible to receive antiretroviral therapy according to the DHHS treatment guidelines; however, RW funded facilities were more likely to report providing formalized classes (20% vs. 2%,  $p = 0.001$ ), support groups (44% vs. 12%,  $p < 0.001$ ), individual discussions (99% vs. 86%,  $p = 0.007$ ), and pillboxes (83% vs. 43%,  $p < 0.001$ ) to enhance antiretroviral medication adherence.

Because private offices offered fewer services, less assistance in obtaining outside services, and fewer adherence support options than community based facilities, a logistic

**Table 3.** *Patient characteristics*

	RW funded facilities (%) ( <i>n</i> = 69)	Non-RW funded facilities (%) ( <i>n</i> = 74)	<i>p</i> -value
Percentage of HIV-positive patients			0.001
0–25	36	45	—
26–50	6	20	—
51–75	3	11	—
76–100	55	24	—
Race/ethnicity of patient: mean (standard deviation) <sup>1</sup>			
White	22.8 (18.2)	35.8 (24.2)	0.0005
Black	45.9 (30.8)	42.0 (26.4)	0.42
Hispanic	29.8 (25.2)	21.0 (24.2)	0.04
Asian	0.9 (1.5)	1.2 (3.6)	0.54
Native Hawaiian/Pacific Islander	0.4 (1.0)	0.1 (0.5)	0.04
American Indian/Alaskan Native	0.4 (1.0)	0.04 (0.4)	0.004
Insurance: mean (standard deviation) <sup>1</sup>			
Private	8.9 (17.1)	39.1 (33.2)	0.0001
Medicaid	25.6 (24.1)	29.1 (28.3)	0.43
Self-paid	1.0 (2.2)	3.7 (8.1)	0.001
Uninsured	41.0 (35.5)	3.7 (14.5)	0.0001
Major referral sources <sup>2</sup>			
Public hospital	57	29	0.001
Private hospital	25	56	0.001
Private practice	26	75	0.001
STD clinic	22	8	0.023
Community/health department	29	25	0.560
Family planning clinic	7	4	0.417
HIV testing site	38	19	0.014
HIV research centre	9	11	0.651
Prison system/state custody	16	4	0.018
Drug/alcohol treatment centre	36	11	0.001
Homeless shelter	17	3	0.003

<sup>1</sup>Reported percentages.<sup>2</sup>Up to three reported sources per site.

regression analysis was performed to determine if RW funded facilities differed from non-RW funded facilities on these characteristics while controlling for ‘clinic status’ (i.e. any of hospital, public health/county, or community-based facilities) vs. private offices. When the dependent variable was median split (high vs. low) responses to assistance and adherence support items (defined by a median split of total positive responses to 5 external assistance and 5 adherence support items in Tables 2 and 4), the odds ratio for RW vs. non-RW facility was 3.5 (95% confidence interval (CI) 1.1, 10.5) and the odds ratio for clinics vs. private facility was 5.2 (1.7, 15.9). When the dependent variable was high vs. low responses to internal services offered (defined by a median split on total positive responses to 15 internal services, Table 2), the odds ratio for RW vs. non-RW facility was 6.5 (95% CI 2.0, 21.1), and the odds ratio for public clinics vs. private clinic was 9.7 (3.0, 31.1). In both cases the results indicate RW funded clinics had higher levels of services than non RW funded facilities controlling for public vs. private clinic.

**Table 4.** *Clinical care*

	RW funded facilities (%) (n = 69)	Non-RW funded facilities (%) (n = 74)	p-value
Waiting time to see a provider in clinic			0.492
Less than 30 minutes	57	62	
More than 30 minutes	43	38	
Total patient time at clinic			0.001
Less than 1 hour	16	47	
More than 1 hour	84	53	
Percentage of patients missing scheduled appointments			0.013
0–25	74	90	
26–100	26	10	
Percentage of patients eligible for antiretroviral therapy			0.955
0–50	15	15	
51–100	85	85	
Time from eligibility to HAART <sup>1</sup>			0.908
Less than 1 month	65	64	
More than 1 month	35	36	
Number of visits before beginning HAART <sup>1</sup>			0.048
0–3 visits	88	97	
More than 3 visits	12	3	
Adherence information provided by the clinic			
Formalized classes	20	2	0.001
Support groups	44	12	0.001
Individual discussions	99	86	0.006
Pamphlets/brochures	90	78	0.061
Pillboxes	83	43	0.001

<sup>1</sup>Highly Active Antiretroviral Therapy.

## Discussion

Financial barriers are critical factors limiting who will be able to pay for the costly treatment for HIV. Because differing state eligibility requirements mean many medically needy patients are not eligible for Medicaid, the RW title grants provide the only available mechanism to pay for care for many patients. Our analysis of clinics indicates that RW funded facilities in these four inner cities report higher numbers of direct services, assistance with non-clinic services, and adherence support than non-RW funded facilities. In addition, the analysis indicates that the RW funded facilities served a greater proportion of uninsured patients.

Our findings suggest that CARE Act funded providers are reaching their intended target population of uninsured, underinsured, women and minorities more so than non-RW funded clinics. Previous studies of CARE Act facilities (Ashman *et al.*, 2000; Marx *et al.*, 2001) focused exclusively on CARE Act facilities. Other providers were not sampled directly so information on non-CARE Act clinics or patients was inferred from or extrapolated from existing data supplied by the Centers for Disease Control and Prevention (see discussion in Ashman *et al.*, 2000). Clearly the provision of a wider range of services does not mean that the majority of critical unmet patient needs are being addressed. Nevertheless, the provision of

several critical non-medical services for persons who are in care has been associated with better retention in care, one measure of success in treating HIV infected patients (Cunningham *et al.*, 1999; Katz *et al.*, 2000, 2001; Kalichman *et al.*, 2002).

Facilities that did not receive RW funding were more likely to be private offices that provide care mainly to patients with private insurance. Clearly these patients do not have some of the needs that have been identified among clients seen at RW funded clinics. However, after controlling for private office vs. clinic setting, the overall number of directly provided services, adherence support activities, and assistance with non-clinic services remained greater in RW compared to non-RW facilities. Of particular concern was that very few private offices are offering adherence support services and only half provide risk-reduction counselling. While some of these facilities make passive referrals for these services, patients who have these services available on-site may be more likely to take advantage of them. Provision of adherence support services is of great concern, since near-perfect adherence is required for optimal HIV treatment outcomes (Bartlett, 2002).

In addition, the fact that risk reduction counselling is not routinely offered is a concern since recent studies have shown an increase in reported risk behaviour among HIV-positive persons receiving care (Ekstrand *et al.*, 2001; Klausner & Kim, 2001). Similarly, there has been a recent resurgence of syphilis among HIV-positive men who have sex with men in many cities across the USA (Centers for Disease Control and Prevention, 1999a, b; Ciesielski & Beidinger, 2000).

Limitations of these data should be noted. The site survey data are based on self-report by the clinic administrators and were not confirmed by either patients' reports or record abstraction. Secondly, while we systematically included all RW funded facilities, the non-RW facilities were those listed by the Medicaid offices, health departments, or community agencies as serving patients in the central metropolitan areas of these four cities; thus our findings may not generalize to all non-RW funded facilities. Nevertheless, because of the large number of non-CARE Act clinics included from the four cities, we feel that the differences between the two groups are noteworthy. Thirdly, we do not have information on the quality and content of the services provided.

In conclusion, the CARE Act is providing an option of a comprehensive care model available to minorities and the uninsured in these four cities. This multi-site survey suggests that CARE Act funded facilities participating in this survey are offering critically needed services to their patient populations, but future research needs to examine whether this greater provision of services is translated to better patient outcomes, or if it is cost-effective to extend this model to all HIV care providers in a delivery system.

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## Appendix

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