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On August 18, 1990, the Federal Government enacted Public Law 101-381, entitled the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. This law was reauthorized and amended in both 1996, 2000, 2006, and 2009. The current CARE Act guarantees federal support for medical and support services for low-income, uninsured and underinsured people living with HIV disease through and February 28, 2011. The current legislation is called the Ryan White HIV/AIDS Treatment Extension Act of 2009. It represents the largest dollar investment to date specifically for the delivery of services for poor or underserved People Living With HIV/AIDS (PLWHA). The intention of the CARE Act is to help communities and States increase the availability of primary health care and support services, in order to reduce utilization of more costly inpatient care, increase access to care for underserved populations and improve the quality of life of those affected by the epidemic. Briefly, the CARE Act is divided into five distinct Part A thru E and directs assistance to:

(Part A) Metropolitan areas, such as Cities or Counties, with the largest number of reported cases of AIDS to meet emergency care and treatment service needs of PLWHA.

(Part B) States Health Departments to improve the quality, availability and organization of health care and support services for PLWHA and their families, especially Women, Infants & Children and special HIV
health services programs, such as Special Projects of National Significance (SPNS), AIDS Drug Program and Consortia.

(Part C) Health services organizations such as Community and Migrant Health Centers to support early intervention services.

(Part D) Health services organizations to provide clinical research on therapies for pediatric patients and women living with HIV/AIDS, and health care to pediatric patients and their families.

(Part E) Regionally based AIDS Educational & Training Programs (AETCs) to train health care personnel in the diagnosis, treatment, and prevention of HIV infection. Title-V also includes the dental reimbursement program run by dental schools.

As a national healthcare program, the CARE Act builds on health care financed by Medicaid, Medicare, HUD's Housing Opportunities For People With AIDS (HOPWA) and other Federal, State and Local programs and provides emergency relief funding as a measure of last resort to communities with the highest number of reported AIDS cases.

CARE Act programs are typically partnerships of public and private non-profit organizations and PLWHA. Together they plan and establish more appropriate and cost-effective community-based HIV health care programs tailored to community needs.

How Was the Ryan White CARE Act Conceived?

Ryan White was a youth living in the State of Indiana who as a hemophiliac that acquired HIV infection from blood transfusions. His advocacy efforts while alive and his death from complications from AIDS helped move the United States Congress and the President's Office to create the Ryan White CARE program in 1990.

What Is the Purpose of the CARE Act's Part A Program?

The purpose of Part A of the CARE Act is to provide emergency assistance to localities that are disproportionately affected by the AIDS epidemic. Part A reflects Congressional recognition of the variations among municipal health care systems as well as differences in the epidemiology of HIV from one urban/suburban/rural area to another. Part A funding supports a continuum of care, treatment and support services (including case management) to prevent the unnecessary hospitalization of PLWHA or allow them to be discharged more quickly from hospitals/clinics. The HIV health care and support services supported by the CARE Act must be accessible to low-income individuals living with HIV disease.

What Are Transitional Grant Areas (TGA)?

Eligible grantees for Part A are metropolitan areas reporting a cumulative total of more than 2,000 cases of AIDS as measured over the most recent five (5) year period to the Centers for Disease Control (CDC).
In addition, the EMA must have a population of 500,000 or more persons. A city or county qualifying for Title-I is defined as an Eligible Metropolitan Area (EMA). Boundaries of EMAs are based on those used by the Department of Commerce's Bureau of Census. Both the escalating epidemic and the change by the Centers for Disease Control and Prevention of the definition of AIDS as of January 1, 1993 have led to an expansion in the number of Title-I EMAs. In the first year of Title-I funding, 16 EMAs were eligible, including the Newark EMA. Today there are a total of 51 EMAs, five of which are entirely in New Jersey:

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Who Are the Major Participants in the CARE Act for the Middlesex-Somerset-Hunterdon TGA & What Is Their Role & Responsibilities?

I. Health Resources and Services Administration (HRSA)

What is HRSA?

The United States Department of Health and Human Services' Health Resources and Services Administration (HRSA) is the designated funding agency for the CARE Act within the Federal government. The HIV/AIDS Bureau's Division of Service Systems is responsible for administering all of the titles.

Title-I grants are awarded on both a Formula and Supplemental basis. Half of all of the appropriated funds in Title-I are awarded through Formula grants that are based upon the number and incidence of AIDS cases in the EMA. The remaining Title-I funds are awarded as Supplemental grants and are based upon a competitive and discretionary process accepting applications from the EMAs that demonstrate severe need for financial assistance beyond the Formula grant. Applications for Formula and Supplemental grants must include a plan for spending funds based on an assessment of needs, a high incidence of AIDS, and proof of the existing commitment of area resources. The fiscal year for Ryan White Title-I grants starts on March 1 and ends on February 28 or 29 of the following year.

II. Grantee of the Newark EMA

Who and what is the Grantee?

Title-I grants are awarded to the chief elected official (CEO) of the city or county that administers outpatient and ambulatory public health services to the greatest number of PLWHA. Agencies designated by CEOs of EMAs to administer the awarded Title-I funds range from directors of departments of public health to county managers to non-profit agency directors. In the NEMA, the Mayor of the City of Newark serves as the CEO and has delegated the role of administrator of funds to the Ryan White Unit of the Newark Department of Health and Human Services. The Ryan White Unit is ultimately responsible for the fiscal management, including the awarding and disbursement of funds to service providers in the NEMA and is referred to as the "Grantee." The grantee's office is located in the Ryan White Unit of the Newark Department of Health and Human Services at 110 William Street, Newark, New Jersey 01702. The Ryan White Unit's telephone number is (973) 733-5450 and fax number is (973) 733-5444.
III. Newark EMA HIV Health Services Planning Council

Who is the "Planning Council?"

The "Planning Council" is the HIV Health Services Planning Council for the five-county New Jersey region known as the Newark Eligible Metropolitan Area. It is a health services planning agency under the Ryan White Title-I CARE program and is referred to as the "Planning Council".

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What is the purpose of the Planning Council?

The receipt of funds under Title-I of the Ryan White CARE Act requires that the CEO appoint a planning council of diverse community, non-paid representatives who have expertise in the field of HIV/AIDS care and treatment. The Planning Council determines the local care and treatment needs of PLWHA and assures that Title-I funds are directed toward meeting those needs.

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Who determines the Planning Council membership?

The CARE Act legislation requires that the CEO appoint volunteer members to the Planning Council. As CEO of the NEMA Ryan White Title-I program, the Mayor of the City of Newark has the sole responsibility for such appointments. The membership of the Planning Council is required under the federal Ryan White legislation to include at least one representative from each of the following categories: 1) health care providers; 2) community-based and AIDS service organizations; 3) social service providers, including housing and homeless service providers; 4) mental health providers; 5) Substance abuse providers; 6) local public health agencies; 7) hospital planning agencies or health care planning agencies; 8) affected communities; including people living with HIV/AIDS (minimum of 33%); 9) non-elected community leaders; 10) State Medicaid Agency; 11) State Title-II agency 12) Title-III (early intervention services); 13) Title-IV (clinical research on therapies for pediatric patients and women living with HIV/AIDS); 14) grantees under other Federal HIV programs including but not limited to providers of HIV prevention services; 15) representatives of/or formerly incarcerated people living with HIV.

The By-laws of the Newark EMA HIV Health Services Planning Council state that there shall be a maximum of 34 members. Union County has six representatives, Morris, Sussex and Warren Counties each have one and the remaining 25 people are either from Essex County or fill one of the two above noted state government positions. The membership reflects the primary function of the Planning Council as a health-planning agency.

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Are People Living With HIV/AIDS represented on the Planning Council?

Up until the CARE Act was amended in 2000, HRSA required that at least 25% of Planning Council members be people living with HIV/AIDS. The CARE Act amendments of 2000 require that at least 33% of Planning Council members are people living with HIV or AIDS, a requirement that the Newark EMA HIV Health Services Planning Council has met for at least several years already. The actual numbers and identities of these individuals have not been made public except to the Grantee and HRSA.

A list of those individuals who have chosen to self-disclose their HIV status is available from the Planning Council. The right to privacy for People Living with HIV/AIDS is of highest concerns of the Planning Council and its staff. In addition, the Planning Council and all of its committees have assured the participation of People Living With HIV/AIDS without the fear of the stigma often associated with self-disclosure.

The important activities of the Planning Council include more than its general meetings. Much significant and important work is accomplished through each of the Planning Council's 13 committees and involves the dedicated work and participation of a wider group People Living With HIV/AIDS and service providers. The Planning Council has been successful in recruiting representation and the energetic participation of PLWHA in the full Planning Council, standing and ad-hoc committees.

Is the Planning Council paid for its work?

Members of the Planning Council are appointed by the CEO. Theirs is a voluntary activity and without salary or other compensation.

Does the Planning Council have a staff?

The Planning Council, as provided for under Title-I of the CARE Act, maintains an office with paid professional staff. Through the leadership of the Executive Director of the Planning Council, the staff organizes, manages and carries out all of the administrative activities of the Planning Council and all of its committees. This task is required in order for the work of the Planning Council to go forward. Since the recruitment of staff in 1994 the Planning Council has made marketed accomplishments and has assisted in the large increases in the NEMA's annual federal funding from HRSA.

The Planning Council maintains an office at 315 North Sixth Street, Second Floor, P.O. Box 7007, Newark, New Jersey 07107-2311. Its office telephone number is (973) 485-5220 and fax number is (973) 485-5085.
What is the Planning Council's mission statement?

The mission of the volunteer-driven Planning Council is to plan for the development, implementation and continual improvement of the health care and treatment services for PLWHA who reside in the five New Jersey Counties of Essex, Morris, Sussex, Union and Warren.

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What are the legislative mandates and functions of the Planning Council?

The Planning Council has the following mandates:

1) Determine the size and demographics of the population of individuals with HIV disease;

2) Determine the needs of such population, with particular attention to:

   Individuals with HIV disease who know their HIV status and are not receiving HIV-related services; and

   Disparities in access and services among affected subpopulations and historically underserved communities;

3) Establish priorities for the allocation of funds within the eligible area, including how best to meet each such priority and additional factors that the grantee should consider in allocating funds under a grant based on the:

   Size and demographics of the population of the individuals with HIV disease;

   Demonstrated (or probable) cost effectiveness and outcome effectiveness of proposed strategies and interventions, to the extent that date are reasonably available;

   Priorities of the communities with HIV disease for whom the services are intended;

   Coordination in the provision of services to such individuals with programs for HIV prevention and for the prevention and treatment of substance abuse, including programs that provide comprehensive treatment for such abuse;

   Availability of other governmental and non-governmental resources, including the State Medicaid plan under Title XIX of the Social Security Act and the State Children's Health Insurance Program under Title XXI of such Act to cover health care costs of eligible individuals and families with HIV disease; and

   Capacity development needs resulting from disparities in the availability of HIV-related services in historically underserved communities;
4) Develop a comprehensive plan for the organization and delivery of the health and support services described in section 2604 that:

Includes a strategy for identifying individuals who know their HIV status and are not receiving such services and for informing the individuals of and enabling the individuals to utilize the services, giving particular attention to eliminating disparities in access and services among affected subpopulations an historically underserved communities, and including discrete goals, a timetable, and an appropriate allocation of funds;

Includes a strategy to coordinate the provision of such services with programs for HIV prevention (including outreach and early intervention) and for the prevention and treatment of substance abuse (including programs that provide comprehensive treatment services for such abuse); and

Is compatible with any State or local plan for the provision of services to individuals with HIV disease;

5) Assess the efficiency of the administrative mechanism in rapidly allocating funds to the areas of greatest need within the eligible area and, at the discretion of the planning council, assess the effectiveness, either directly or through contractual arrangements, of the services offered in meeting the identified needs.

6) Participate in the development of the statewide coordinated statement of need initiated by the New Jersey's Title-II Grantee, namely the Division of HIV Prevention & Control of the New Jersey Department of Health and Senior Services.

7) Establish methods for obtaining input on community needs and priorities which may include public meetings, conducting focus groups, and convening ad-hoc panels; and

8) Coordinate with Federal grantees that provide HIV-related services within the eligible area.

**How does the Planning Council determine the HIV care and treatment needs?**

In order to gather the necessary and objective data regarding the needs of individuals infected and affected by HIV and AIDS, Ryan White funding requires the Planning Council to conduct a "Community-Based HIV/AIDS Needs Assessment." In 1993, the Planning Council conducted what was, at that time, one of the largest and most comprehensive assessments of care and treatment needs of people living with and affected by HIV/AIDS in the entire nation. This project utilized focus groups, Delphi groups, community forums, open hearings, public testimonies, and one-on-one interviews with approximately 1,000 HIV infected and affected individuals and regional experts. The Needs Assessment was updated in 1995 and 1997.

The 1999 Comprehensive Needs Assessment, the methodology for which was even more extensive that that utilized for the 1993 Needs Assessment, was conducted in two phases. The first phase took place in the late spring of 1998 and the second in the spring of 1999. Between both phases of the 1999 a total of
nearly 1,500 consumers (including 477 consumers who were not at that time accessing any HIV care services) and 99 key informants (individuals who had authority and expertise in dealing with the HIV+ population in the Newark EMA) were interviewed. The methodology also included data collection and a literature search.

The cumulative data from all of the needs assessments conducted so far is central to the work of the Planning Council and is made available to Ryan White Title-I funded and other HIV/AIDS organizations throughout the NEMA for planning purposes. More than 400 organizations are in receipt of the Planning Council's health planning documents.

The material gathered from the on-going needs assessments is an objective, statistically valid, and reliable source of information, not biased by political, religious, monetary, institutional or other interests. These documents represent the voices of thousands of individuals from all five counties of the NEMA.

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**Has the Planning Council developed a Health Plan for HIV Services?**

Yes. In 1994, the Planning Council published Phase I of an HIV/AIDS Comprehensive Health Plan for the NEMA. This document represented the consensus of a number of discussion groups which included People Living With and Affected By HIV/AIDS, community leaders, service providers, HIV/AIDS experts and others totaling over 125 participants. This document described the ideal, necessary and optimum ingredients for a working plan to provide needed HIV/AIDS services throughout the NEMA. Phase II and III were successfully carried out in 1996 and 1998.

In the year 2000 the Planning Council undertook another major Comprehensive HIV/AIDS Health Plan. This document an epidemiological description of the people with HIV in the Newark EMA who are receiving services and those not receiving services; it also provided epidemiological projections to the year 2003 to assist in short- and medium-term planning. Like the 1994 Health Plan, the 2000 Health Plan described the ideal continuum of HIV-related services focusing on how this continuum might be different for various key communities and then compared the ideal with the current situation, offering prioritized recommendations on how to get from where we are now to the ideal.

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**How does the Planning Council determine the priorities?**

The recommendations for the funding allocations to specific service categories are made by the Priority Setting Committee. This Committee is made up of People Living With HIV/AIDS as well as service providers and other affected individuals, some of who also sit on the Planning Council. Members of the group represent all five counties of the EMA and at least 25% are consumers. The Committee decides not only what percentage of the overall award goes to services in each of the Newark EMA's five counties, but it also sets the percentage of the Ryan White Title-I award that will be put into each of 23 service
categories (these categories are listed in the section entitled "What services are eligible for Ryan White Title-I funds?" on page 8).

The Priority Setting Committee's percentages are a description of the most efficient use of Ryan White Title-I dollars to complement services funded by non-Ryan White funding streams in creating the optimal continuum of services for the Newark EMA's people living with HIV. The final priority percentages are based on a review of a wide range of information including:

a. The most recent HIV/AIDS Needs Assessments and the most recent Health Plans,

b. Service utilization data as reported by the Newark EMA's management information system (CHAMPS),

c. The epidemiological profile of People Living With HIV and AIDS in each county, as well as trends/changes in HIV-related demographics,

d. Cost and outcome effectiveness of the proposed strategies and interventions;

e. Priorities of PLWHA for whom the services are intended; and

f. Availability of other governmental and non-governmental resources in the Newark EMA.

The Priority-Setting Committee develops a report, which includes the priority percentages, service category definitions and objectives for the coming year. This report is submitted to the full Planning Council for discussion and ratification. The approved priorities are then forwarded from the Planning Council to the Grantee, which is obligated under the CARE Act, to follow the funding recommendations.

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Does the Planning Council have any role in providing services for PLWHA?

No. The provision of direct care, treatment, prevention and/or clinical research services for PLWHA are provided by Local, County, and State Service Providers, HIV/AIDS Consortia, HIV Infected & Affected Caucuses, HIV Task Forces, and other service provider organizations. The Planning Council works closely with all of these groups to assist in coordinating the NEMA-wide continuum of care and to monitor the changing pattern of need in the community.

The Planning Council is a health services planning body. It does not represent any specific interest group, special population group, or region other than the entire HIV/AIDS community within the NEMA. It has the ability to influence the long-term availability and provision of care and treatment services in the region. It has no authority or influence over any other HIV/AIDS related issues.

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How has the local HIV/AIDS community benefit from the work of the Planning Council?

The success of the Planning Council is reflected in steadily increasing annual awards from HRSA, culminating in an award of more than $17.7 million dollars in fiscal year 2003. This is the second largest award within the tri-state area of New Jersey, New York and Connecticut. The Planning Council plans for the long-term care and treatment needs of the NEMA community and the effects of its work and planning are realized in the building of treatment, care and support services throughout the hardest hit areas of HIV/AIDS within the NEMA.

Progressively, the hard and dedicated work of the Planning Council has demonstrated to both the state and federal governments its abilities to plan and implement HIV/AIDS services in the NEMA, to objectively determine the EMA’s needs and to work together with the Grantee in meeting the challenge of this epidemic.

The awarding of funds by HRSA is, in a large part, in recognition of the Planning Council's successful work and is based upon the Planning Council's on-going needs assessment, health plan, quality improvement projects, political advocacy, effective networking with several hundred service provider agencies/consortia/task forces, and working in concert with the Grantee to rapidly allocate and disburse the EMA’s Title-I funds in the areas of greatest need within the NEMA.

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Who decides where, to whom and how funds are given?

The Ryan White Unit of the Department of Health and Human Services of the City of Newark, or the "Grantee," issues Request For Proposals, determines the process to evaluate, award, and monitor all Ryan White Title-I funds to service providers throughout the NEMA. The grantee determines which individual service providers receive funds, how much they receive and awards these funds among all types of service provider organizations, including community-based organizations, hospitals, social service agencies, and others. The funds are, by federal mandate, directed to the service categories prioritized by the Planning Council.

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What is the relationship between the Planning Council, Grantee and Service Providers?
The Planning Council determines the care and treatment needs of the HIV/AIDS community within the NEMA and sets the percentage allocations to be used by the grantee in the funding of broad service categories.

Once the Planning Council makes its determination of care and treatment service priorities (ranking of services) for the fiscal year it submits these to the Grantee. The process of allocating Title-I funds and monitoring all awarded contracts throughout the entire year is completed exclusively by the Grantee.

Eligible HIV/AIDS service providers submit proposals to the Grantee in response to the Grantee's request for proposals and in accordance with the Planning Council's priorities. Through an open contract process, service providers are reviewed and selected solely by the Grantee's external peer review committee. If selected, the successful service provider receives a contract with the Grantee ("City of Newark"). The service providers offer their specific services to People Living With and Affected By HIV/AIDS who reside within the Newark Eligible Metropolitan Area. These service providers report directly to the Grantee and are regularly monitored solely by the Grantee regarding their programmatic and fiscal performance, including cost and program outcomes.

The Planning Council and the Grantee work together to assure that the Ryan White Title-I funds are awarded in a rapid, fair and lawful process and that the identified care and treatment needs of the HIV/AIDS community are met to the best of the Planning Council and Grantee's abilities.

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What types of services are eligible for funding under the Ryan White Title-I funds?

Specifically excluded from funding and authority of the Planning Council and Grantee is HIV/AIDS education and prevention, counseling and testing, prevention, needle exchange, employment initiatives, clinical research, demonstration projects, and others are excluded from being funded by Title-I of the Ryan White CARE Act and therefore the Planning Council, Grantee and from the Title-I funds received by Service Providers.

Title-I of the CARE Act restricts the allocation of funds to the care, treatment and support services for people living with HIV or AIDS. The Division of Service Systems within HRSA provides a complete list of service categories that are eligible for funding under this program. The services are primary medical care, housing and housing related services, direct emergency assistance (i.e. provision of short-term payments for critical needs such as utility bills), dental care, case management and case management training, mental health therapy and counseling, substance abuse treatment/counseling, medications, legal assistance and client advocacy, outreach, health education/risk reduction, capacity building, home health care, rehabilitation care, hospice care (funerals/burials are not eligible), permanency planning, day and respite care, buddy companion services, nutritional services, transportation, complementary therapy and other care & treatment related services (e.g. translation & interpretation).
Is it a conflict of interest for Ryan White service providers to sit on the Planning Council?

The Planning Council does not discuss individual agencies or service providers. The deliberations of the Planning Council and its committees are restricted to general areas and categories of service. All members of the Council, whether they are service providers, consumers or others from the affected community, are expected to ensure that the discussion remains at a system-wide or public health level, rather than provider-specific level.

The Planning Council has a Conflict of Interest policy that covers both deliberations at the Planning Council and in its committees. The policy states that anyone with an "interest" in a particular agency cannot vote on the allocation or prioritization of any service categories for his/her county/region. The policy also states that this should not be construed as preventing any member from full participation in discussion about community needs, allocation of funds to broad service categories and the processes for the results of evaluation of service effectiveness. Individual members are expected to draw upon their lay and professional experiences and knowledge of the HIV service delivery system when such matters are under deliberation. All members of the Council are expected to assist in keeping the Council focused on directing funds to meet the needs of individuals affected by the HIV epidemic without regard to the benefit to specific agencies or programs.

Why does the Planning Council hire paid consultants to assist in the development and publication of documents, such as, the Community-Based HIV/AIDS Needs Assessment and Comprehensive Health Plan?

The Planning Council membership is made up of individuals who volunteer their time and energies to benefit the quality of life for People Living With and Affected By HIV/AIDS. At times, the Planning Council seeks the services of professional agencies to assist in the development of meaningful, scholarly and functional projects. The relatively small investment that the Planning Council has made in hiring professional consultants to help develop high quality, valid and reliable research (Needs Assessments and Comprehensive Health Plans), has brought the NEMA many additional millions of dollars for care and treatment services.