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II. INTRODUCTION

A. HIV/AIDS Services Planning in the Rochester Region

The Rochester Area Task Force on AIDS (RATFA) was established in the fall of 1983. The New York State Health Department's AIDS Institute had been created a few months earlier and had immediately begun planning a network of regional agencies to encourage education and service programs for AIDS. In this region, RATFA recommended that AIDS Rochester be funded as that education and service entity. Few other areas of the state (or nation) retained an umbrella organization such as RATFA separate from the state-supported community service program.

The initial mission of RATFA was to serve as consultant, facilitator, and a resource for those agencies providing HIV/AIDS-related services such as testing, counseling, prevention/education, treatment, social services and patient advocacy. Through the forum provided by RATFA, consensus statements were developed on policies related to HIV/AIDS affecting the community, and service coordination was achieved. From its inception RATFA membership has included HIV-related direct service providers and interested agencies and individuals. From about 10 early agencies, membership grew to more than 50 agencies by 1990.

By late 1985, the need for a long range planning committee for RATFA was clear. Finger Lakes Health Systems Agency (FLHSA), a RATFA participant from the beginning, was requested to assist. In April 1986, a Strategic Planning Committee was established with FLHSA providing staff. In early 1987, RATFA adopted and published the Committee report, AIDS Action Plan: Five Year Agenda for Rochester and the Finger Lakes Region. With financial assistance from the Monroe County Health Department, nearly 500 copies of the full report, and 1,000 copies of the Executive Summary, were distributed locally and, by request, nationally. The Xerox Corporation subsequently printed an additional 250 copies for distribution, and the Plan was presented as a model at three national conferences.

In April 1988, the Strategic Planning Committee issued a "Report to the Community" reviewing the implementation status of the 38 recommendations contained in the 1987 Plan. A substantial majority of those recommendations had been implemented. Major recommendations of the 1988 update included involvement of business/industry, growth of service capacity commensurate with increased case volume, expansion of services to area counties outside Monroe County, specific services targeting the IV-drug abuser and his/her sexual partner, services for pediatric AIDS cases, and development of ongoing funding mechanisms for education, support groups and other non-reimbursable services.

By 1989, the need to revise the regional plan was recognized, to define the service needs of subsets of the population affected by HIV/AIDS--rural areas, African-Americans and Hispanics, women, infants, IV-drug abusers, adolescents--and to review capacity needs of the area's HIV-related services. In November 1989, the AIDS Institute provided a grant to FLHSA to plan for AIDS services, including providing regional input into the New York State HIV/AIDS Five-Year Plan. In March 1991 the 1991-1995 AIDS Action Plan developed jointly by FLHSA and RATFA was completed.

Congress had passed the Ryan White CARE Act in May of 1990. The Ryan White CARE Act directed funds to communities which were the most seriously impacted by HIV to assist them in service development. In January 1991 RATFA filed an application to become a Not-For-Profit Corporation. Subsequently RATFA applied for, and in September 1991 was granted, designation as a Ryan White CARE Network. The Finger Lakes Health Systems Agency was designated by the Network as the lead agency.

B. Ryan White Assurances

As a Ryan White CARE Network, RATFA provides assurances that the Network will: include agencies and community-based organizations, which have a record of services to populations with HIV disease, include as many people who are living with HIV as wish to participate, and actively encourage their participation; and conduct business in sites which are easily accessible to people living with HIV/AIDS.

The Network recognizes that one of its primary functions is to assess the service needs of people living with HIV/AIDS in the nine county area, taking into account epidemiology data as well as information provided both by people living with and affected by AIDS, AIDS service providers, and other interested parties.

In keeping with the Ryan White assurances, the Network agrees to assure that:

- service needs will be addressed through the coordination and expansion of existing programs before new programs are created;¹
- consortium corresponds to the geographic boundaries of the health systems planning area;
- case management services planning in rural areas links clients to appropriate local and regional health and social support services;
- individuals with HIV participate in needs assessment and service delivery planning, and well as quality evaluation;
- the full continuum of health and social services needed for persons with HIV infection is evaluated and reassessed on an on going basis;
- planning includes consideration of the special needs of families affected by HIV, and that this planning is done in a manner which promotes the delivery of family centered care;
- the Network will develop a mechanism to periodically evaluate the success of its efforts; and
- the Network will provide the State, HRSA, and others whom may request it, HIV/AIDS data and information related to: epidemiology, planning, service needs, and evaluation study.

¹ RATFA does not have sole discretion on creation of new agencies for HIV services. This authority rests with the AIDS Institute which in the case of addressing state designated special needs populations makes awards to agencies without local input.

C. Service Plan Development Process

The process for developing the 2006 update of the Service Develop Plan had multiple stages to allow for maximum input throughout the updating process. The process began in April 2005 when the Coordinator prepared a preliminary draft plan that was intended to organize information in a manner that allowed for focused community input and response. After the draft was developed, it was put on the RATFA Inc. website, Knowingsbetter.org, to make it accessible to as many people as possible. Next a series of three hearings on the draft document were held in each of the region's sub-areas. A Power Point presentation on the essential elements of the draft was presented and all in attendance were invited to provide input. After the 3 public hearings were concluded, the Coordinator met with Executive Directors and program managers from 17 of the key AIDS service providing agencies in the region. Comments from the public hearings, and meetings with AIDS community leaders were compiled and became part of the materials which were shared with the Service Development Plan Update Committee.

The SDPUC was recruited to reflect consumer and provider expertise from across the region. The Committee met 9 times, and was responsible for the content of the final draft document. Even as they worked with staff to develop various elements of the document, the elements were referred back to Network Committees for review and comment. (e.g. identified barriers, populations with special needs, unmet needs were all fed back to the Case Management Committee and the Consumer Advisory Committee for review and comment.)

At the same time the softer input was being compiled, staff was working with the Data Work Group of the SDPUC to analyze epidemiology data obtained from New York State Department of Health Bureau of AIDS Epidemiology, and utilization data obtained from the AIDS Institute of the NYS Department of Health. In order to have the epidemiology and utilization data in forms that would allow us to assess trends in the epidemic utilization of services, and seek to assess unmet needs, countless hours were spent refining data formats and analyzing the information. While this work was underway, several students doing field placements at AIDS Rochester were used to interview clients of the agency to elicit clients' assessment of services available in the region.

Once the Plan was in final draft, it was presented to the general membership in October in Geneva and published on the RATFA website for comments. The plan was also presented to the Consumer Advisory Council in Bath in November. The comments were collated and made available to the Plan Update Committee and the Executive Committee. On November 14, 2006 the General Membership voted to approve the Plan.

An implementation workgroup of the Plan Update Committee will be meeting to develop proposals for how the Network should address its tasks of facilitating community collaboration to address priority needs.