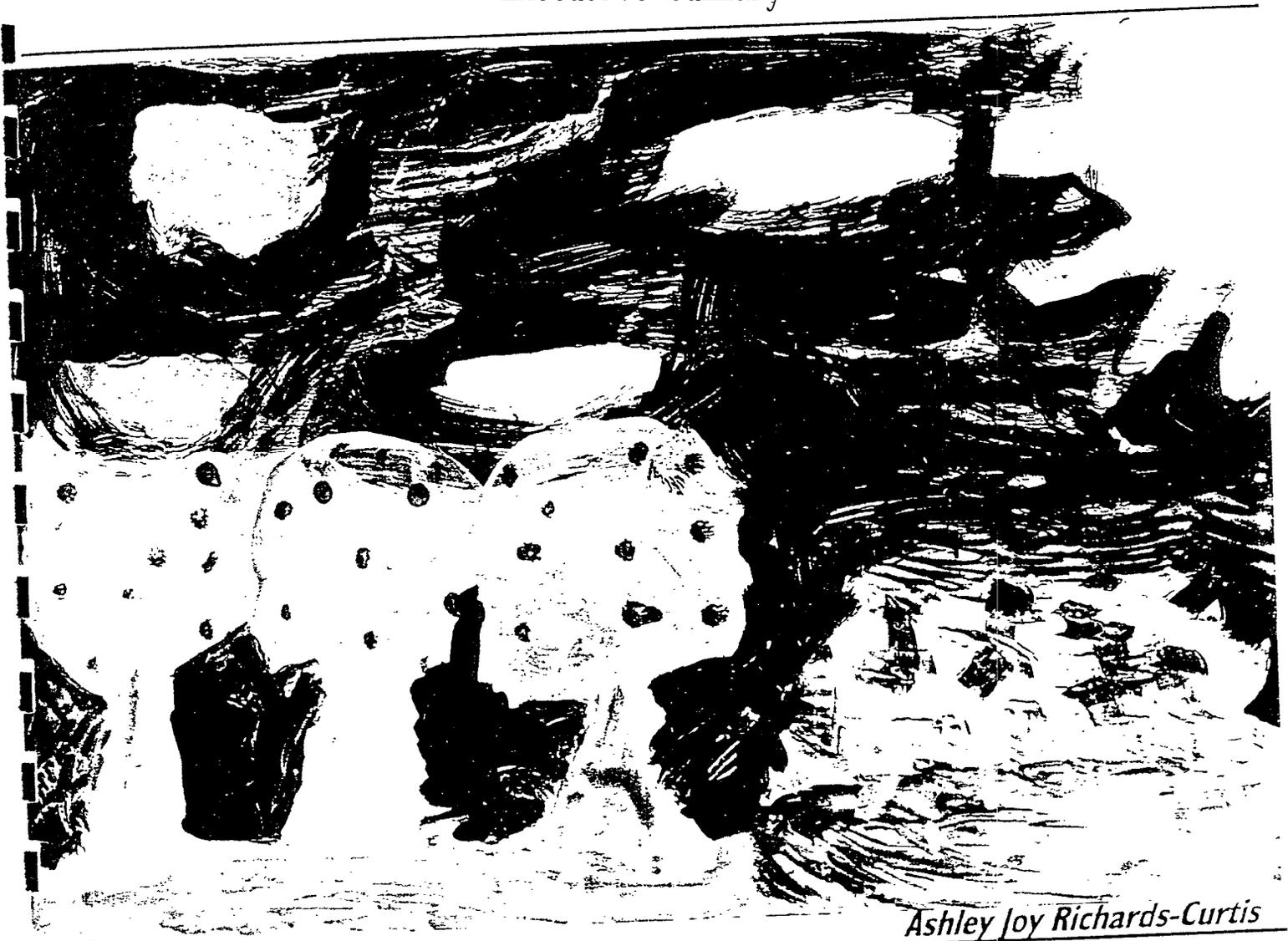


Ryan White Title IV Program for
Children, Youth, Women and Families

National Evaluation
Executive Summary



Ashley Joy Richards-Curtis

by.

Macro International inc.

submitted to:

Health Resources and Services Administration
Maternal and Child Health Bureau

Acknowledgments

The Macro study team would like to thank Ms. Pemell Crockett and Ms. Sylvia-Trent Adams, Maternal and Child Health Bureau (MCHB), Division of Children with Special Health Care Needs, for their support and guidance while serving as the Federal Project Officers for this study. We would also like to thank MCHB staff who reviewed project documents and provided guidance and input on the final report, particularly Beth Roy, Chief; Lauren Deigh, Deputy; and Karen Hench, Senior Nurse Consultant, Hemophilia and AIDS Program Branch. In addition, members of the Advisory Committee to this project contributed greatly to study efforts. We appreciate the time they spent reviewing and providing input to evaluation instruments and interim data analyses. The Advisory Committee Members are listed in Appendix B of this report.

The Macro project team is indebted to the many energetic and dedicated people who staff the Title IV projects, particularly in those sites that we visited. Site visitors were met with enthusiasm and a strong willingness to share information by all project staff who participated in site-visit discussions; they made the time to meet with us in the midst of tremendous responsibilities and sometimes overwhelming workloads. We are particularly grateful to the women, caregivers, youth, and their family members who participated in the focus group discussions. They provided valuable insights on how project efforts have affected their lives. We thank them for taking the time to meet with us and for their willingness and candor in sharing their experiences. Without this client perspective, the evaluation would have been incomplete. A complete list of Title IV projects is included in Appendix A of this report. Projects that were site-visited are marked with an asterisk and those in which focus group discussions were held are marked with a double asterisk.

Study team members and authors of this report include Macro staff Lela Noland Baughman (Project Manager), Erika Reed, Nicole Lezin, Todd Gordon, and Mary McCormack. Consultant site visitors include Jackie Williams and Marta Bustillo.

Cover art by: Ashley Joy Richards-Curfis, age 6, of the Cook County Hospital Women and Children's Program.

Ashley is the healthy, HIV-negative daughter of Kim Curtis who is living with HIV.

Executive Summary

1. Study Background

As of December 1994, 441,528 cumulative cases of AIDS were reported to the Centers for Disease Control and Prevention (CDC). Of these cases, 58,428 were women and 6,209 were children under the age of 13. Youth between the ages of 13 and 19 accounted for less than 1% of the cumulative cases of AIDS reported. Despite intensive prevention efforts nationwide, the number of cases of HIV infection and AIDS continues to grow. According to CDC surveillance data, the growth is fastest among women and adolescents. The largest proportionate increase in 1994 AIDS cases-- 17.1 percent--was attributed to heterosexual contact. The second largest increase was a 13.4 percent increase in perinatal transmission. Heterosexual transmission has overtaken injection drug use as the primary mode of transmission for the disease among women. Moreover, heterosexual transmission accounted for the greatest proportion of AIDS cases among women in their twenties, many of whom were probably infected as teenagers.¹

These trends, first identified in the early 1990s, have translated into steadily increasing caseloads for agencies serving women, children, youth, and families affected by HIV and AIDS. At both the prevention and treatment ends of the HIV/AIDS continuum, these populations have unique and complex needs that warrant more intense and more comprehensive services. Women, children, youth, and families affected by HIV/AIDS are disproportionately poor and minorities, with limited access to needed services. In addition, many youth affected by HIV/AIDS are part of the growing population of runaway and throwaway youth who live on and off the streets, exacerbating their poor health and further limiting their access to needed services.

This report documents the efforts of the Ryan White Title IV Grants for Coordinated Services and Access to Research for Children, Youth, Women, and Families. The program is funded by the Maternal and Child Health Bureau of the Health Resources and Services Administration (HRSA) to provide services that meet the complex and evolving needs of women, children, youth, and families affected by HIV/AIDS. Reflecting the needs of affected populations and an increased emphasis on research activities, the program's current goals are to:

- Foster the development and support of comprehensive care infrastructures, including primary care, that increase access to culturally competent, family-centered, community-based, coordinated care;

¹ Centers for Disease Control and Prevention. 1994. *HIV/AIDS surveillance report*. 6(no.1):8.

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¹ Centers for Disease Control and Prevention. 1994. *HIV/AIDS surveillance report*. 6(no.1):8.

- Emphasize **prevention** within the comprehensive care system in order to reduce the spread of HIV infection to vulnerable populations; and
- Link comprehensive systems of care with HIV/AIDS **clinical research trials and other research activities**, resulting in increased access for children, youth, women, and their families.

The Title IV funds are used to support 39 Pediatric/Family AIDS Projects, which were the subject of this evaluation. Title IV funds also support four additional types of projects that provide or coordinate comprehensive, family-centered health, social, and support services. The additional projects are:

- Eight planning and development grants to support needs assessment and initial planning activities to develop a comprehensive care system, including one Hemophilia/AIDS Special Initiative Project,
- Two cooperative agreements with national resource centers,
- Seven Women's Initiative for HIV Care and Reduction of Perinatal HIV Transmission projects (WIN), and
- Three adolescent clinical sites under NIH Adolescent Medicine HIV/AIDS Research Networks.

In the first 6 months of 1994, these projects served 17,732 enrolled clients. In addition, projects reached over 100,000 more individuals through HIV education and professional education activities. The majority of the projects' clients have been from poor, minority families.

2. **Objectives**

The purpose of this study was to assess the effectiveness of the Ryan White Title IV HIV Program in initiating, improving, and expanding systems of care and linkages to research for children, youth, women, and their families affected by HIV/AIDS. The elements of an effective system of care include comprehensive services that are accessible and available to families, coordinated, based in communities affected by HIV/AIDS, and responsive to clients' cultures and family structures.

The following research questions formed the centerpiece of the study design:

- Have systems of care been established, improved, maintained, or expanded?
- Do the systems have the desired attributes?
- Is the system reaching and serving intended unserved or underserved target populations?
- Are multidisciplinary providers accessible, available and trained to serve the target population?
- Are clients receiving the array of medical and social services they need?

- Has the program had an impact on increasing participation in clinical drug trials?
- Has the program had a positive impact on client and family life satisfaction?

3. **Methods**

In order to answer these questions, Macro applied an integrated, multi-method, multi-stage approach to data collection. Key indicators were identified for each question, and multiple data sources were used wherever possible to assess relevant aspects of existing programs. An important characteristic of this approach was its capacity to generate necessary data, while minimizing the burden on project sites. Existing data were used whenever possible, and new data were sought from only as many sites as were necessary to reflect the range of projects. The key data collection tools included:

- Reviews of existing grant applications
- Completion of self-study questionnaires by all current grantees
- Site visits to 18 grantees
- Focus groups of clients in 10 sites

Grant applications and data tables, available for all projects, were used to obtain baseline information about the projects and to develop the self-study questionnaire and site visit protocols. The self-study component was designed to yield a detailed, statistical portrait of each project's structures and functions. Site visits were used to corroborate and elaborate the self-reported data from study guides and to obtain detailed qualitative information that could not be collected through other means. Focus groups were held with clients in order to ascertain how the system operates from the point of view of the consumer. This report encompasses findings from the self-studies, site visits, and client focus groups.

Site visit reports and client focus groups were analyzed using Tally, a software package for analyzing textual data. Tally allows the researcher to mark specific sections of text with distinguishing codes, sort and extract the text associated with particular codes, and produce numeric reports or matrices based on the encoding. Quantitative analyses of project self-study guides were performed with the SPSS statistical package. Simple aggregate statistics were used to determine the distribution of the different variables among the project sites. The quantitative data presented in this report help verify and illustrate the detailed qualitative information that describes project approaches and client perspectives.

4. **Key Findings**

Findings from this study confirm that the Ryan White Title IV HIV Program for Children, Youth, Women, and Families has served as a catalyst for evolving systems of care. These systems of care are in different stages of development, reflecting varied stages of the epidemic in different communities. Additional sources of variation include the level and

extent of existing community resources with which projects can collaborate, the organizational base for each program, and the length of time that projects have been in operation. In general, the answer to the research questions posed above is overwhelmingly affirmative. The program has established, improved, maintained, or expanded systems of care. The systems have the desired attributes of providing family-centered, culturally competent, and community based services. As intended, they reach unserved or underserved target populations. Multidisciplinary providers are accessible and available, and are specifically trained to serve the target population. Clients report that they generally receive the array of medical and social services they need, although some gaps persist. The program has had a dramatic impact on increasing participation in clinical drug trials. And most importantly, the program has had a significant and lasting impact on client and family life satisfaction.

More specific findings are highlighted below. The findings are organized according to the most relevant study question, although many findings help answer more than one question.

Is the system of care reaching and serving the intended unserved or underserved target populations?

- Increasing numbers of infants, children, youth, and women are receiving comprehensive services in Title IV projects. Between January and June 1994, projects served 17,732 enrolled clients--a 17 percent increase over the previous 6 months.
- The Title IV program is serving the traditionally unserved or underserved target population. Eighty-three percent of clients are members of minority groups, two-thirds of clients are Medicaid recipients, and 10 percent are uninsured.
- Outreach efforts are successful in increasing the number of adolescents being enrolled in care. During the first half of 1994, nearly 30 percent of the 1,324 enrolled adolescent clients were newly enrolled.
- Women, including adolescent females and mothers under the age of 22 years, represent only 29% of currently enrolled clients. Outreach efforts to this population need to be increased.
- Injection drug use is prevalent and most likely to be underreported in the target population. This aspect of clients' lives has important implications for approaches to service delivery, including not only access to drug treatment services but also relapse prevention, support groups, and more intensive case management.

- Title IV projects link clients together and help create a crucial network of peer support for clients who might otherwise be isolated.
- Beyond affecting clients' basic survival, projects have helped many clients thrive--some for the first time in their lives.
- Although individual services and staff members are important, projects as a whole serve as an anchor and a safe haven in clients' lives.
- No form of assistance or encouragement is too small to have an impact on clients' lives.
- Resources devoted to both formal and informal peer support activities--support groups, recreational activities, and other outings--have a tremendous payoff in terms of clients' life satisfaction.
- Clients' participation in education, conferences, and/or staffing contribute to a personal sense of accomplishment that has a similarly dramatic impact on life satisfaction.
- Assistance with disclosure, death and dying, and answering questions about medical issues are three key areas where support from project staff is particularly meaningful, especially since few other sources of information and support are available.

Have systems of care been established, improved, maintained, or expanded to meet the needs of women, children, youth and families living with HIV?

- As a result of collaborative efforts, Title IV projects have **expanded** their systems of care across cities and even states, creating a web of services and agency networks designed to meet the current and changing needs of families living with HIV.
- Title IV projects have built on existing systems of care and have established linkages with existing services, thereby increasing the number of services available to clients and decreasing duplication of services and efforts across medical and social service agencies.
- An increasing number of Title IV projects are expanding their systems of care by extending their reach to more geographic regions and by increasing the number of agencies in their funded networks in an effort to reach more clients.

- Title IV projects have had the most success in developing strong collaborative relationships with medical service providers, AIDS service organizations, and social service agencies.
- Agencies with which Title IV projects have had difficulty collaborating--local schools, housing agencies, mental health agencies, local churches, and substance abuse treatment providers--have less experience and tradition in providing services to persons living with HIV/AIDS. Some of these agencies, such as local churches or schools, represent opportunities for outreach and prevention.

Are providers accessible and available who are multidisciplinary and trained to serve the target population?

- Projects are staffed with a broad range of multidisciplinary personnel and are looking beyond traditional disciplines in their efforts to respond to changing client needs. In addition, the use of multidisciplinary teams (nurses, physicians, case managers, etc.) provides a model of collaborative service delivery among various professions with the potential for increased client access to needed services and decreased duplication of efforts across various medical and social service agencies.
- The presence of knowledgeable, dedicated, and compassionate staff has contributed a great deal to the success of the Title IV projects and the subsequent impact projects have had on clients' lives. Focus group participants across projects constantly praised both the professional expertise of project staff as well as their sense of caring and understanding.
- Staff turnover among Title IV projects is surprisingly low, given the inherent difficulties of providing services to persons living with HIV/AIDS.
- Project administrators have had more difficulty *recruiting* experienced and appropriate staff than they have had *retaining* staff--94 percent reported some difficulties in hiring staff. Recruiting difficulties have been attributed to the complex institutional and professional guidelines of hospitals, universities, and unions as well as salary limitations and demanding job responsibilities.
- **Case managers, social workers, and nurses are the most difficult staff positions to both recruit and retain.**
- In almost half of the Title IV projects, clients **or family members are hired as paid or volunteer staff** and often serve as peer educators, advocates, and mentors.

- Increased staff retention is linked to positive client well-being as clients grow closer to project staff and often develop deep and trusting relationships with staff. These types of relationships provide emotional and personal support to clients and let them feel comfortable receiving services at the projects. As a result, clients continue to access needed services, share pertinent information with project staff, and have increased life satisfaction knowing that there are people who care about them.

Do systems of care have the desired attributes: are services accessible, family-centered and culturally competent?

- Title IV projects have organized staff and service schedules to be convenient and timely. Fifty-eight percent of Title IV projects can arrange client medical appointments within 6 days and another 33 percent can arrange appointments within 1 to 2 weeks.
- One way that projects facilitate physical accessibility is by addressing transportation issues. Forty-nine percent of Title IV projects provide public transportation passes or tokens to all clients while the remaining projects (51 percent) provide passes or tokens to some clients (based upon various eligibility criteria).
- To address other client needs and in response to expanding catchment areas, Title IV projects use multiple approaches, often simultaneously, to increase client access to needed services. These approaches include:
 - expansion of project service capacity by offering more services on site
 - coordination of service schedules and client appointments with other service providers
 - establishment of referral relationships and information exchange between adult and child medical providers
 - establishment of flexible appointment scheduling policies
 - establishment of satellite clinics that reach less accessible clients, such as adolescents or persons who live in outlying areas
 - concurrent clinics for adults and their children
- The level and depth of client involvement in task forces and advisory committees varies greatly across Title IV projects. While in many Title IV projects clients are active participants in task forces and advisory committees, there are a few projects in which client involvement remains somewhat *pro forma*. Although clients may hold a position on a task force or advisory committee, their role is minimal.

- Projects that have had **difficulty recruiting new clients to fill staff, advisory, or volunteer roles** attribute this to client reluctance or disclosure and confidentiality issues. The same client often serves multiple roles (advisory committee member, peer educator, and volunteer). In such instances, projects may not be receiving an adequate representation of client views and concerns if new clients are not being successfully recruited.
- Title IV projects that have been successful in **recruiting clients as staff, volunteers, or advisors** have developed a number of strategies to improve the quality and quantity of client involvement. These **strategies include**:
 - open, individual discussions with clients to assess their readiness to adopt more active roles within the project
 - client and family training in personal advocacy, HIV/AIDS policy, leadership skills, and public speaking (provided by 64 percent of Title IV projects)
 - use of more informal settings such as lunches or parties to elicit client perspectives and opinions about project staff and services
 - providing clients with the opportunity to decide when and how they wish to participate in project activities
 - hiring clients as staff (offered by 42 percent of Title IV projects)
- Sixty-one percent of Title IV projects provide **staff training in developing collaborative relationships with families**.
- Sixty-seven percent of Title IV projects provide **cultural sensitivity training and in-service sessions** to staff. However, these trainings are generally offered only once and without follow-up or educational reinforcement. Therefore, cultural competency must be incorporated into service delivery, project setting, and project administration if it is to be reinforced and effective.
- In projects **where client support groups have thrived, they have been client initiated and/or led** and have persevered despite periodic lapses in attendance. Project staff and clients have worked together to maintain support groups throughout the groups' various stages of development.

Are clients receiving the array of comprehensive medical and social services that they need?
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- Projects are providing **HIV outreach, education, counseling and testing services** by linking with existing community efforts or by developing their own efforts when none exist. Over 17,000 clients and 54,000 other persons have been reached through

individual counseling sessions. Over 115,000 people were reached through group sessions.

- **Peer educators are used by half of the projects** for outreach/casefinding, client education, and community education.
- Most projects are providing HIV testing, counseling, and referrals for ZDV treatment for pregnant women and many have initiated community-wide planning efforts to address counseling and testing issues. However, the **traditional split between pediatrics and ob/gyn** remains in most project sites, which could have implications for the effectiveness of such efforts.
- Title IV projects have **provided training to more than 32,000 health and social service professionals** including medical staff, case managers, substance abuse counselors, and outreach workers.
- The majority of projects provide pediatric medical **care in the same clinic space or in the same general location.**
- The majority of projects have linked with **outside medical care providers to facilitate the integration of HIV testing and counseling into standards of care.** Clinic rotations and internships are increasingly being used as mechanisms to accomplish this.
- Project directors across Title IV sites described case management **as the heart of the projects** and a focal point of project coordination and collaboration efforts.
- Nearly two-thirds of project clients are assigned to **high-intensity** case management services because of the complexity of their service needs.
- The majority of Title IV case managers interviewed report steadily increasing caseloads that are beginning to require more staff time and project resources than many projects can spare.
- Faced with steadily increasing caseloads, Title IV projects are beginning to consider (or already have implemented) more rigid limits on eligibility for **case management** services. In addition, projects may also be forced to limit the intensity of case management services provided to clients and reduce the number of home visits and personal contacts.

- Some of the services Title IV clients require are **either not available or are culturally inappropriate** or do not address the specific needs of adolescents or women with children. The services most frequently described as unavailable or inappropriate are:

Mental health services
Substance abuse treatment services
Child care services
Transportation assistance
Child welfare services

- In response to these gaps, projects are expanding their own array of services. Twenty-three projects have **added on-site mental health services** to their mix of direct services. Other mental health-related services provided by many projects include client support groups, family counseling, and art therapy.
- In response to the increasing numbers of adolescents with HIV, Title IV projects have **developed services specific to the adolescent population**. Projects treat adolescents as a unique population with unique service needs rather than as additional clients for existing services.

Has the program had an impact on increasing participation in clinical drug trials?

- Title IV projects have been **successful in enrolling nearly 1,000 children, youth, and women in clinical trials**.
- Title IV projects provide a **bridge between services delivery and research** through a range of approaches including conducting the trials on-site at the Title IV project location, implementing the research in community-based settings, and providing staff who have a linkage and educational role.
- Efforts to enroll and retain low-income, medically underserved families in clinical trials are enhanced when the **research is conducted within an established comprehensive system of outpatient and family support services**, such as those developed through the Title IV program.

5. Conclusion

It is clear from this evaluation study that the Title IV projects have **increased access** of children, youth, women, and families **to comprehensive care**. The programs served 17,732 enrolled clients during the first half of 1994, representing a 17 percent increase over the enrollment in the previous 6 months. The projects have been responsive to the growth and trends of the HIV epidemic, evolving and expanding to serve new and emerging HIV-affected populations, such as adolescents and women.

Title IV projects have **enhanced access to clinical trials** for children, youth, and women living with HIV, populations that traditionally have had limited access to research. A wide range of strategies has been employed to facilitate client participation in research, including shared research and care staff, new linkages with research sites, and provision of family and logistical support services. As a result of these strategies, nearly 1,000 clients participated in research during the first 6 months of 1994, including over 300 clients who were newly enrolled in a trial during this period.

From a **client perspective**, Title IV projects have had a tremendous impact. They have improved access to an array of needed services, meeting the immediate medical and social service needs of children, youth, women, and families. Beyond these services, Title IV grantees have fulfilled their mandate of making a difference in clients' lives by demonstrating that project staff care about their clients' overall well-being. Clients continually praised the compassion and dedication of staff. The combination of services and emotional support makes Title IV programs distinctive, and underlies the comment clients made repeatedly:

"Where would I be without them?"

Interagency collaboration; new linkages among diverse medical, social service, and family support providers; and innovations in service delivery among Title IV programs created **new and improved services** for the populations served by Title IV. In addition, **training and professional education** conducted by Title IV for community providers have resulted in more qualified personnel to deliver services to HIV-affected populations. New approaches to the organization of services, such as co-location of pediatric and adult care, has improved services to families.

Projects have **involved families in the development and implementation of programs**, with youth and family members as family liaisons, educators, and other support roles. Family involvement has been enhanced through training opportunities and leadership development sessions.

While this evaluation study has highlighted many project successes, it also provides insights into future **policy challenges** at the national and local levels. As the program as a whole and the individual grantees continue to grow and change to meet the evolving needs of their

client populations within the context of their communities, they will need to be attentive to training and technical assistance needs, program priorities and future directions, and opportunities for forging new relationships. Findings from this evaluation suggest areas for focus in the immediate future, including:

- **Training and technical assistance** in such areas as cultural competency; staff training and policy development; administrative roles, relationships, and authority related to reporting, data collection, and overall service delivery policies of multiple entities participating in funded networks of care; incorporating and maintaining meaningful client participation in program development and implementation; service provision to substance abusing populations; service provision to adolescents; and outreach to women of childbearing age.
- **Program goal and priority setting** as demand exceeds staff and financial resources, particularly related to relative emphasis on outreach versus direct services; definitions of client eligibility for services in general and especially for case management services; policies and procedures for transferring care to other service systems when clients no longer meet defined eligibility criteria; and strategic planning to address issues such as financial viability, service capabilities, and needs assessment.
- **Identifying and developing opportunities to forge new collaborative relationships** with such service arenas as housing, education, substance abuse treatment, mental health, research, other components of the Ryan White **CARE** Act, and managed care health care systems.

Addressing these issues requires complementary efforts at the local, state, and national levels, since the expertise, responsibility, and resources rest at all three levels. Perhaps the greatest challenge is to continue to build on evaluation and research findings such as those presented in this report and to link system-level evaluation findings to client outcomes to ensure that the evaluation feedback loop can continue to guide future directions.

APPENDIX A

RYAN WHITE TITLE IV GRANTEES
FY 1995

GRANTEE/ADDRESS	(YR. 1ST FUNDED) PROJECT PERIOD	CONTACT
Comprehensive Care/Research Grantees:		
<u>REGION I</u>		
Boston Pediatric AIDS Project Dimock Community Health Center 55 Dimock Street Roxbury, MA 02119	(1988) 8/1/94-7/31/97	Ruth J. Liberman 617-442-6758 617-445-0091 (fax)
Family AIDS Center for Treatment and Support (FACTS) 18 Parkis Avenue Providence, RI 02907	(1991) 8/1/94-7/31/97	Paul Fitzgerald 401-521-3603 401-861-2981 (fax)
◆Division for Children with Special Health Care Needs Massachusetts Dept. of Public Health 150 Tremont St., 7th Floor Boston, MA 02111	(1991) 8/1/94-7/31/97	Deborah Allen 617-727-6941 617-727-6108 (fax)
Connecticut Primary Care Association 30 Arbor Street North Hartford, CT 06106	(1990) 8/1/95-7/31/96	Richard J. Jacobsen, PhD 203-232-3319 203-236-0618 (fax)
<u>REGION II</u>		
Dominican Sisters Family Health Service 279 Alexander Avenue Bronx, NY 10454	(1993) 8/1/93-7/31/96	Margaret Sweeney, 718-665-6557 718-292-9113 (fax)
◆New Jersey DOH Special Child Health Services CN 364 Trenton, NJ 08625-0364	(1988) 8/1/94-7/31/97	Diane DiDonato 609-292-1078 609-292-3580 (fax)

New York University Medical Center 550 First Avenue New York, NY 10016	(1993) 8/1/93-7/31/96	Keith Krasinski, MD 212-263-6427
N. Manhattan Women and Children HIV Demonstration Project Columbia School of Public Health 600 W. 168th St., 7th Floor New York, NY 10032	(1988) 8/1/95-7/31/97	Cheryl. Heaton, Dr. PH 212-305-3616 212-305-6832 (fax)
◆Puerto Rico Pediatric AIDS Project Puerto Rico Dept. of Public Health P.O. Box 71423 GPO San Juan, PR 00936	(1988) 8/1/95-7/31/97	Rolando Jimenez Mercado 809-721-2000 x208 809-723-3565 (fax)
Bronx Pediatric AIDS Consortium Albert Einstein College of Medicine 1300 Morris Park Avenue Bronx, NY 10461	(1989) 8/1/95-7/31/98	William Caspe, MD 718-518-5764 718-518-5124 (fax)
The Family Center Medical and Health Research Association, Inc. 66 Reade Street New York, NY 10007	(1991) 10/1/95-9/30/98	Barbara Draimin, DSW 212-766-4522 212-766-1696 (fax)
Adolescent AIDS Program Montefiore Medical Center 111 East 210th Street Bronx, NY 10467-2490	(1989) 8/1/95-7/31/98	Donna Futterman, MD 7 18-882-0322 7 18-882-0432 (fax)
Brooklyn Pediatric AIDS Network SUNY-HSCB 450 Clarkson St., Box 49 Brooklyn, NY 11203	(1989) 8/1/95-7/31/98	Hermann Mendez, MD 7 18-270-382513826 7 18-270-3824 (fax)
Pediatric/Adolescent/Family Comprehensive Center AIDS Institute (NY DPH) Corning Tower, Room 321 Empire State Plaza Albanv. NY 12237	(1995) 9/1/95-8/31/96	Gloria Maki 518-473-7542 5 18-474-0419 (fax)

<u>REGION III</u>		
D.C. Pediatric AIDS Health Care Demonstration Project Dept. of Human Services 1600 L St., NW, Suite 907 Washington, DC 20036	(1990) 8/1/95-7/31/96	Linda Jenstrom 202-673-6724 202-727-902 1 (fax)
◆AIDS Administration Maryland Dept. of Health and Mental Hygiene 201 West Preston Street Baltimore, MD 21201	(1990) 8/1/93-7/31/96	Julia Hidalgo, ScD 4 10-767-5087 410-333-6333 (fax)
Circle of Care Project Family Planning of Southeastern Pennsylvania 260 S. Broad St., Suite 1510 Philadelphia, PA 19102	(1990) 8/1/95-6/30/96	Alicia Beatty-Tee 215-985-2657 215-732-1252 (fax)
<u>REGION IV</u>		
Georgia Dept. of Human Resources Division of Public Health 2 Peachtree St, NE, 8th Fl. Atlanta, GA 30303	(1988) 8/1/94-7/31/97	Virginia Floyd, MD, MPH 404-657-2850 404-657-2910 (fax)
Comprehensive Pediatric AIDS Project N. Broward Hosp. District 417 South Andrews Avenue Ft. Lauderdale, FL 33301	(1990) 8/1/94-7/31/97	Susan M. Widmayer, PhD 305-779-1955 305-779-1957 (fax)
S. Carolina Children's AIDS Care System S. Carolina Dept. of Health and Environmental Control 2600 Bull Street Columbia, SC 29201	(1993) 8/1/93-7/31/96	JoAnn Lafontaine 803-737-4016 803-734-3255 (fax)
Pediatric HIV/AIDS Health Care Demonstration Program U. Alabama @ Birmingham 751 Children's Hosp. Tower Suite 751 Birmingham, AL 35222	(1990) 8/1/95-7/31/96	Marilyn Crain, MPH, MD 205-934-7883 205-934-865 8 (fax)

U. of Miami School of Medicine Dept. of Pediatrics (D4-4) P.O. Box 016960 Miami, FL 33101	(1994) 8/1/94-7/31/97	Gwendolyn B. Scott, MD 305-547-6676 305-547-5562 (fax)
Tampa Bay Pediatric AIDS Project U. of South Florida 13201 Bruce B. Downs Blvd. MDC 56 Tampa, FL 33612-3805	(1992) 8/1/95-7/31/98	Jay Wolfson, Dr. PH, JD 813-974-6643 813-974-6642 (fax)
<u>REGION V</u>		
Family AIDS Clinic & Educational Services (FACES) Columbus Children's Hospital 700 Children's Drive, Rm. 6072 Columbus, OH 43205-2696	(1991) 8/1/95-7/31/97	Michael T. Brady, MD 614-722-4451 614-722-4458 (fax)
Women & Children's HIV Program @ Cook County Hospital (a.k.a. Hektoen Institute) 1835 West Harrison Street CCSN, Room 912 Chicago, IL 60612	(1991) 8/1/94-7/31/97	Mardge Cohen, MD 312-633-5080 312-633-4902 (fax)
Youth & AIDS Projects U. of Minnesota 428 Oak Grove Street Minneapolis, MN 55403	(1990) 10/1/95-9/30/96	Gary Remafedi, MD, MPH 612-626-2855 612-627-6819 (fax)
♦Great Lakes Hemophilia Foundation 3739 Watertown Plank Rd. P.O. Box 13127 Wauwatosa, WI 53213-0127	(1994) 8/1/95-7/31/98	Janice R. Hand 414-257-0200 414-257-1225 (fax)
Bureau of Child & Family Services Michigan Dept. of Public Health P.O. Box 30195 3423 N. Martin Luther King Blvd. Lansing, MI 48909	(1989) 19951996	Terri D. Wright, MPH 517-335-8969 517-335-9222 (fax)

<u>REGION VI</u>		
Tarrant Co. Pediatric AIDS Demonstration Project (a.k.a. Catholic Charities) Fort Worth, TX 76105	(1991) 8/1/94-7/31/97	Sue Smith, LMSW-ACP 817-536-1160 817-536-4671 (fax)
Pediatric AIDS Program Children's Hospital - New Orleans Kingsley House, 2nd Floor 914 Richards Street New Orleans, LA 70130	(1988) 8/1/94-7/31/97	Michael Kaiser, MD Beth Scalco, BCSW 504-524-4611 504-523-2084 (fax)
Houston Regional HIV/AIDS Resource Group 811 Westheimer, Suite 201 Houston, TX 77006	(1993) 8/1/94-7/31/97	Michael J. Springer 713-526-1016 713-526-2369 (fax)
U. of Texas Hlth. Science Center @ San Antonio 7703 Floyd Curl Drive San Antonio, TX 78284-7811	(1988) 8/1/95-7/31/97	Victor German, MD, PhD 210-692-3641 210-567-6921 (fax)
Pediatric AIDS Network of Dallas (PANDA) UT Southwestern Medical Center 1935 Motor Street Dallas, TX 75235	(1989) 8/1/95-7/31/98	Janet Squires, MD 214-640-287 1 214-640-5702 (fax)
<u>REGION VII</u>		
Washington University Research Office 724 S. Euclid Avenue St. Louis, MO 63110	(1995) 8/1/95-7/31/98	Gregory A. Storch, MD 314-454-6079 314-367-3765 (fax)
<u>REGION VIII</u>		
◆U. of Colorado Health Sciences Center 4200 E. Ninth Avenue, Box A081 Denver, CO 80262	(1995) 8/1/95-7/31/98	Myron J. Levin, MD 303-270-8501 303-270-7909 (fax)

REGION IX		
Alameda Co. Hlth. Care Services Agency Office of AIDS Administration 1970 Broadway, Suite 1130 Oakland, CA 94612	(1994) 8/1/94-7/31/97	Ivy Wagner 5 10-873-6500
Los Angeles Pediatric AIDS Network (LAPAN) Children's Hospital of Los Angeles 6430 Sunset Blvd., Suite 1003 Los Angeles, CA 90028	(1988) 8/1/95-7/31/97	Marcy Kaplan 213-699-5616 213-461-1394 (fax)
Project AHEAD San Francisco Dept. of Public Health 1242 Market Street, 3rd Floor San Francisco, CA 94102	(1990) 8/1/93-7/31/96	Janet Sihalwitz, MD 415-487-5777 415-487-5771 (fax)
REGION X		
Seattle - King Co. Pediatric AIDS Demonstration Project Northwest Family Center 1001 Broadway, Suite 210 Seattle, WA 98122	(1988) 8/1/94-7/31/97	Julia Sarkissian 206-720-43 19 206-720-4302 (fax)
Cooperative Agreements:		
Institute for Family-Centered Care (Reg. III) 7900 Wisconsin Ave., Ste. 405 Bethesda, MD 20814	(1993) 8/1/93-7/31/96	Elizabeth S. Jeppson 301-652-0281 301-652-0186 (fax)
National Pediatric & Family HIV Resource Center (Reg. II) 15 South 9th Street Newark, NJ 07107	(1993) 8/1/93-7/31/96	Carolyn Burr 201-268-8251 201-485-2752 (fax)
Hemophilia Special Initiative:		
Dartmouth-Hitchcock Hemophilia Center (Reg. I) One Medical Center Drive, 4B Lebanon, NH 03756	(1993) 10/1/94-9/30/96	Kathy Parsonnet, RN, MPH 603-650-5454 603-650-7791 (fax)

Planning/Initial Development:		
Maricopa County DPH (<i>Reg. IX</i>) 1845 East Roosevelt Street Phoenix, AZ 85006	8/1/95-7/31/96	Toby Urvater, CMSW 602-506-6853 602-506-6855 (fax)
Ventura County Public Health (<i>Reg. IX</i>) 3147 Loma Vista Road Ventura, CA 93003	8/1/95-7/31/96	Diane Seyl 805-652-6512 805-652-6617 (fax)
Orlando Regional Health Care Systems, Inc. (<i>Reg. III</i>) 1414 Kuhl Avenue Orlando, Fl 32806	8/1/95-7/31/96	Gidget Ruscetta, RN, BSN 407-841-5143 407-649-6824 (fax)
Metrolina AIDS Project (<i>Reg. III</i>) 1415 South Church Street Charlotte, NC 28202	8/1/95-7/31/96	Barbara Rein 704-333-1435 704-376-8794 (fax)
Houston Institute for the Protection of Youth (HIPY) (<i>Reg. VI</i>) 811 Westheimer, Suite 102 Houston, TX 77006	(1994) 11/1/94-10/31/96	Tracy Brown 713-942-9884
University Medical Center of Southern Nevada (<i>Reg. IX</i>) HIV Wellness Center 1800 W. Charleston Blvd. Las Vegas, NV 89102	(1994) 11/1/94-10/31/96	Ann Occhi, RN, MSN 702-383-2203
Research Foundation of SUNY (<i>Reg. II</i>) Office of Research Services State University of New York Stony Brook, NY 11794-3366	(1994) 11/1/94- 10/31/96	Sharon Nachman, MD 516-444-7692 516-632-6963 (fax)
Women's Initiative for HIV Care and Reduction of Perinatal HIV Transmission:		
Maryland Dept. of Health and Mental Hygiene S/A (<i>Reg. III</i>)	(1995) 1995-1998	Julia Hidalgo, ScD/ Alina Savat-Wright 410-767-5087 410-333-6333 (fax)
Univ. of Texas Southwestern Medical Center S/A (<i>Reg. VI</i>)	(1995) 1995-1998	Pam Newton 214-640-5897 214-640-5702 (fax)

Massachusetts Dept. of Public Health S/A (Reg. I)	(1995) 1995-1998	Gail Merriam 617-727-6941 617-727-6108 (fax)
N. Broward Hospital District S/A (Reg. IV)	(1995) 1995-1998	Gail "Stormy" Schevis 305-799-1970 305-799-1957 (fax)
Children's Hospital - New Orleans S/A (Reg. VI)	(1995) 1995-1998	Beth Scalco 504-524-4611 504-523-2084 (fax)
New Jersey Dept. of Health S/A (Reg. II)	(1995) 1995-1998	Beverly Kupiec 609-292-1078 609-292-3580 (fax)
Family Planning Council of Southeastern Pennsylvania S/A (Reg. III)	(1995) 1995-1998	Alicia Beatty-Tee 215-985-2657 215-732-1252 (fax)
NIH Adolescent Medicine HIV/AIDS Research Network Sites:		
Children's Hospital of Los Angeles Division of Adolescent Medicine P.O. Box 54700 Mail Stop 2 Los Angeles, CA 90054-0700		Marvin Belzer, MD 213-669-2390 213-913-3614 (fax)
Children's Hospital National Medical Center 111 Michigan Avenue Washington, D.C. 20010		Lawrence D'Angelo, MD 202-884-3066 202-884-5685 (fax)
New York University Medical Center 550 1st Avenue New York, NY 10016		Keith Krasinski, MD 212-263-6427 212-263-7806 (fax)

◆ Denotes projects with state-wide service areas.

APPENDIX B

**Ryan White Title IV Evaluation
Advisory Committee Members**

Sylvia Trent-Adams
Hemophilia and AIDS Program Branch
Maternal and Child Health Bureau, HRSA

Deborah Allen
Division for Children with Special Health Care Needs
Bureau of Family and Community Health
Boston Department of Public Health

Mary Boland, R.N., M.S.N.
National Pediatric AIDS Resource Center

Pemell W. Crockett
Hemophilia and AIDS Program Branch
Maternal and Child Health Bureau, HRSA

Sheila Catherine Fuoco
Consumer Representative

Christine Hager, Ph.D.
Office of Science and Epidemiology
Bureau of Health Resources Development, HRSA

Julia Hidalgo, Ph.D.
Maryland Department of Health
AIDS Administration

Linda Horton
Johns Hopkins University
Health Policy and Management

Rudolph Jackson, M.D.
AIDS Research Consortium
Morehouse School of Medicine

Ibby Jeppson, Ph.D.
Institute for Family-Centered Care

David Maglott
Office of Program Development
Maternal and Child Health Bureau, HRSA

Gloria Maki, Ph.D.
N.Y. State Dept. of Health AIDS Institute

Xandra Negron
Director, Massachusetts CARE
Bureau of Family and Community Health
Department of Public Health

Moses Pounds, Ph.D.
Office of Science and Epidemiology
Bureau of Health Resources Development, HRSA

Beth Roy
Hemophilia and AIDS Program Branch
Maternal and Child Health Bureau, HRSA

Jean Setzer, Ph.D.
University of Texas Health Sciences Center
Department of Pediatrics

Mildred Williamson; M.S.W.
Women and Children HIV Program
Cook County Hospital

Amette Wright, R.N., B.S.N., M.A.
Division of Programs for Special Populations
Bureau of Primary Health Care, HRSA

Macro Staff

Lela Baughman, Project Director
Mary McCormack, Ph.D.
Tom Chapel

David Maglott
Office of Program Development
Maternal and Child Health Bureau, HRSA

Gloria Maki, Ph.D.
N.Y. State Dept. of Health AIDS Institute

Xandra Negrón
Director, Massachusetts CARE
Bureau of Family and Community Health
Department of Public Health

Moses Pounds, Ph.D.
Office of Science and Epidemiology
Bureau of Health Resources Development, HRSA

Beth Roy
Hemophilia and AIDS Program Branch
Maternal and Child Health Bureau, HRSA

Jean Setzer, Ph.D.
University of Texas Health Sciences Center
Department of Pediatrics

Mildred Williamson; M.S. W.
Women and Children HIV Program
Cook County Hospital

Amette Wright, R.N., B.S.N., M.A.
Division of Programs for Special Populations
Bureau of Primary Health Care, HRSA

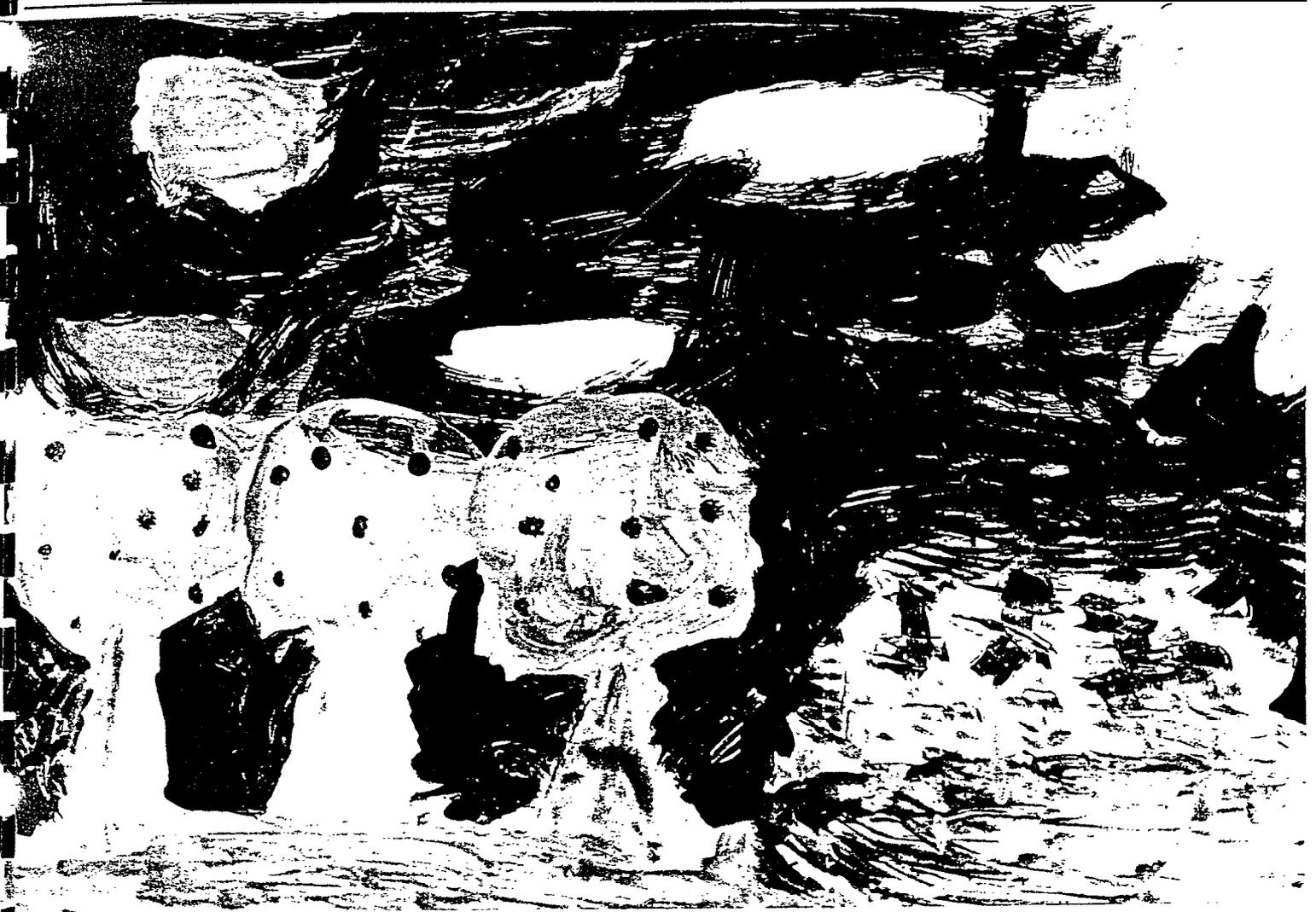
Macro Staff

Lela Baughman, Project Director
Mary McCormack, Ph.D.
Tom Chapel

Ryan White Title IV Program for
Children, Youth, Women and Families

5600

National Evaluation



Ashley Joy Richards-Curtis

by.

Macro International Inc.

submitted to:

Health Resources and Services Administration
Maternal and Child Health Bureau

June 30 1995

Acknowledgments

The Macro study team would like to thank Ms. Pemell Crockett and Ms. Sylvia-Trent Adams, Maternal and Child Health Bureau (MCHB), Division of Children with Special Health Care Needs, for their support and guidance while serving as the Federal Project Officers for this study. We would also like to thank MCHB staff who reviewed project documents and provided guidance and input on the final report, particularly Beth Roy, Chief; Lauren Deigh, Deputy; and Karen Hensch, Senior Nurse Consultant, Hemophilia and AIDS Program Branch. In addition, members of the Advisory Committee to this project contributed greatly to study efforts. We appreciate the time they spent reviewing and providing input to evaluation instruments and interim data analyses. The Advisory Committee Members are listed in Appendix B of this report.

The Macro project team is indebted to the many energetic and dedicated people who staff the Title IV projects, particularly in those sites that we visited. Site visitors were met with enthusiasm and a strong willingness to share information by all project staff who participated in site-visit discussions; they made the time to meet with us in the midst of tremendous responsibilities and sometimes overwhelming workloads. We are particularly grateful to the women, caregivers, youth, and their family members who participated in the focus group discussions. They provided valuable insights on how project efforts have affected their lives. We thank them for taking the time to meet with us and for their willingness and candor in sharing their experiences. Without this client perspective, the evaluation would have been incomplete. A complete list of Title IV projects is included in Appendix A of this report. Projects that were site-visited are marked with an asterisk and those in which focus group discussions were held are marked with a double asterisk.

Study team members and authors of this report include Macro staff Lela Noland Baughman (Project Manager), Erika Reed, Nicole Lezin, Todd Gordon, and Mary McCormack. Consultant site visitors include Jackie Williams and Marta Bustillo.

Cover art by: Ashley Joy Richards-Curtis, age 6, of the Cook County Hospital Women and Children's Program.

Ashley is the healthy, HIV-negative daughter of Kim Curtis who is living with HIV.

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Chapter I. Introduction

A. HIV/AIDS Among Children, Youth, Women, and Families

As of December 1994, 441,528 cumulative cases of AIDS were reported to the Centers for Disease Control and Prevention (CDC). Despite intensive prevention efforts nationwide, the number of cases of HIV infection and AIDS continues to grow. According to CDC surveillance data, the growth is fastest among women and adolescents. The largest proportionate increase in 1994 AIDS cases--17.1 percent--was attributed to heterosexual contact. The second largest increase was a 13.4 percent increase in perinatal transmission. Heterosexual transmission has surpassed injection drug use as the primary mode of transmission for the disease among women. Moreover, heterosexual transmission accounted for the greatest proportion of AIDS cases among women in their twenties, many of whom were probably infected as teenagers.¹

These trends, first identified in the early 1990s, have translated into steadily increasing caseloads for agencies serving women, children, youth, and families affected by HIV and AIDS. At both the prevention and treatment ends of the HIV/AIDS continuum, these populations have unique and complex needs that warrant more intense and more comprehensive services. Women, children, youth, and families affected by HIV/AIDS are disproportionately poor and minorities, with limited access to needed services. In addition, many youth affected by HIV/AIDS are part of the growing population of runaway and considered throwaway youth who live on and off the streets, exacerbating their poor health and further limiting their access to needed services.

This report documents the efforts of the Ryan White Title IV HIV Program for Children, Youth, Women, and Families. The program is funded by the Maternal and Child Health Bureau of the Health Resources and Services Administration (HRSA) to increase access to services and clinical research in order to meet the complex and evolving needs of women, children, youth, and families affected by HIV/AIDS.

1. HIV/AIDS Among Women

In 1981, the first year in which cases of AIDS were reported to the CDC, the 6 women with AIDS accounted for 3.2 percent of all cases. By December 1994, that number had increased to 58,428 reported cases and accounted for 13.2 percent of all cases. While cases of AIDS have been reported among all races, AIDS has disproportionately affected young women of color in large metropolitan areas. Of the cases of HIV-infected women reported through December 1994, 25.3 percent of reported cases were among white, non-Hispanic women, 52.8 percent were among African-American women, and 20.9 percent were among Hispanic

¹ Centers for Disease Control and Prevention. 1994. *HIV/AIDS surveillance report*. 6(no.1):8.

women.² The vast majority of women with AIDS were of child-bearing age at the time of diagnosis. Of all cases, half of the women with AIDS were infected through injection drug use, another 22 percent were sex partners of injection drug users, and 8 percent had high-risk sex partners who were not IDUs.³ Women infected through heterosexual contact represented the majority of new cases reported among women in both 1993 and 1994.

One of the many difficulties in preventing HIV is that an individual may be at risk due to more than one risky behavior. In women most at risk, drug- and sex-related risks often occur concomitantly, either through a woman's drug use and sexual activity or because her sexual partner uses drugs. In addition to the specific behaviors that place women at risk, the circumstances of women's lives may amplify the risk of infection to both women and their children. Drug use itself is rooted in a network of other social and economic problems. Poverty and lack of access to drug treatment and other health and social services can affect women's perceptions of their risk for HIV and their ability to reduce risk.

2. **HIV/AIDS Among Adolescents**

Youth between the ages of 13 and 19 accounted for less than 1 percent of the cumulative total of AIDS cases reported to the CDC through December 1994. However, the 81,646 AIDS cases reported among the next two groups--people between the ages of 20-24 and 25-29--accounted for 18.5 percent of reported cases.⁴ Given the average 8- to 10-year period between infection and onset of symptoms, the majority of these people were probably infected during their adolescent years.

In contemporary America, the adolescent years represent a period of relatively high risk--a risk that shows a particularly dramatic rise during the later teenage years.⁵ Between the years of early adolescence and late adolescence, mortality increases by over 300 percent;⁶ The trend is toward increased mortality even earlier in life. Higher rates of suicide and motor vehicle accidents, earlier onset of alcoholism and other drug use, and earlier initiation of

² Ibid.

³ Ibid.

⁴ Centers for Disease Control and Prevention. 1994. Ibid.

⁵ Traditionally, the adolescent period has been considered to span the ages of 13 to 18. In recent years, this definition has been expanded to include the early 20s--often up to the age of 24. This expanded definition reflects developmental and cultural markers that place many people in their early 20s in the "youth" segment of the population.

⁶ Irwin, 1990.

sexual activity have contributed to this trend.⁷ Although there are gender and race differences, the major risk behaviors that cause mortality and morbidity in adolescents are prevalent in all socioeconomic, racial, and ethnic groups in America today.

Unprotected sexual activity is a risk factor for HIV and other sexually transmitted diseases (STDs). The majority of adolescents are sexually active by age 18, often with multiple partners. Yet teens are unlikely to consistently use condoms or other methods of birth control.⁸ Drug use, another factor that puts people at risk for HIV, is also prevalent among teens. While only 3.1 percent of high school students use injection drugs, far greater numbers use alcohol (93 percent), marijuana (59 percent), and cocaine (16 percent).⁹ Non-injected drugs are implicated in HIV/AIDS by impairing judgment about safer sex practices.

As with women, adolescent health-related risk behaviors are interrelated. While young people may be labeled or identified in terms of a particular set of behaviors, research data confirm what service providers, parents, and teenagers have long known--that the adolescent with the drug problems also may be the one with problems in school, a history of STDs, contact with the juvenile justice system, and a tumultuous relationship with parents.

3. **HIV/AIDS Among Children**

As of December 1994, 6,209 cumulative cases of AIDS had been reported among children under the age of 13. Approximately 5,000 of these children are infants and toddlers under 5 years of age. The vast majority of these children--5,541, or 89 percent--had been exposed to HIV perinatally. Over 80% of HIV-infected children are minority and, as the offspring of the women described above, these children face many of the same problems their mothers do, including low or nonexistent family incomes, poor access to health services, and substandard or transient housing arrangements.

Despite such circumstances, today children with HIV infection are living longer than their counterparts a decade ago. With improved medical treatment, many perinatally infected children are living to the age of 10 and 12.

⁷ Earls, 1990.

⁸ Centers for Disease Control and Prevention. 1995. CDC Surveillance Summaries, March 24, 1995. *MMWR* 1995 44(55-1).

⁹ Rotheram-Borus and Koopman, 199 1.

B. History of MCHB: Response and Role

The focal point for the government's HIV/AIDS prevention and service delivery efforts is largely within the U.S. Public Health Service (PHS), which encompasses eight agencies with separate but overlapping responsibilities for the public's health. As part of PHS, HRSA is responsible for issues related to health services access, equity, quality, and cost. Throughout its history, HRSA has had a unique responsibility for filling gaps in the health care infrastructure.¹⁰ The agency's responsibilities encompass most Federally funded primary health care for underserved populations, including the Maternal and Child Health block grants (Title V), the Community and Migrant Health Center Programs, the National Health Service Corps, the Comprehensive Perinatal Care Program, and the Health Care for the Homeless Program.¹¹ Within this broad mission, HRSA administers the Ryan White CARE Act and a variety of programs related to AIDS within its four bureaus.

Within HRSA, the Maternal and Child Health Bureau (MCHB) has played a key role in the agency's response to the HIV/AIDS epidemic since the early 1980s. In 1984, as the number of children with pediatric AIDS increased noticeably in several large cities across the country, MCHB held an *ad hoc* meeting to discuss the nature of the problem in New York City. In the same year, MCHB co-sponsored the first National Meeting on Pediatric AIDS. At the meeting it became clear that AIDS among children was seriously undercounted by CDC's surveillance system and that many HIV-infected children and their families were not receiving the services they needed. In 1986, MCHB co-sponsored a second National Pediatric AIDS meeting. This meeting, attended by physicians, other health care workers, social workers, and educators, helped to coalesce the burgeoning body of knowledge about the etiology and transmission of AIDS, and demonstrated how many of the existing approaches towards the treatment of children with special health care needs could be applied to the care of HIV-infected children. Also, in 1986, HIV prevention and risk reduction was integrated into the national hemophilia treatment center network, supported through an interagency agreement with the CDC that is still in effect.

As both the epidemic and the state of knowledge about pediatric AIDS expanded, a third national meeting was held, this time hosted by the Surgeon General. This 1987 conference, named the Surgeon General's Workshop on Children with HIV Infection and Their Families, involved a wide range of government, professional association, and advocacy representatives. The conference proved to be influential. Workshop participants developed 82 specific recommendations on future directions in pediatric AIDS research, prevention, and services. These recommendations were later published and became a framework for much of the government's response to the problem. The MCHB has played a key role in monitoring the implementation of these recommendations.

¹⁰ Harmon, R.G., and R.H. Carlson. 1991. HRSA's role in primary care and public health in the 1990s. *Public Health Reports* 106(1):6-15.

¹¹ Sundwall, D.N. and C. Tavani. 1991. The role of public health in providing primary care for the medically underserved. *Public Health Reports* 106(1):2-5.

The 1987 workshop also helped stimulate a dialogue among the various Department of Health and Human Services (DHHS) agencies with a role in AIDS research and prevention and services. One result was the DHHS Secretary's Initiative on Pediatric AIDS and HIV Diseases. In 1988, as part of his overall AIDS initiative, the Secretary established an interdepartmental work group comprised of representatives of all the major elements of the Department: the Office of the Secretary, the Family Support Administration, the Office of Human Development Services (OHDS), the Health Care Financing Administration (HCFA), the Office of Minority Health, and the Public Health Service (PHS), including the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), the Food and Drug Administration (FDA), HRSA, the Indian Health Service (IHS), and ADAMHA (now Substance Abuse and Mental Health Services Administration, SAMHSA). The 16-member work group was given responsibility for making recommendations as to how the Department could mount a more coordinated Federal response to pediatric AIDS. A final report of the group was submitted to the Secretary in 1989.¹²

C. **Evolution of the Title IV Program for Children, Youth, Women, and Families**

The 1987 Surgeon General's Workshop helped provide direction for the Pediatric AIDS Health Care Demonstration Program. Thirteen grants amounting to \$4.43 million were awarded to organizations in 11 states and Puerto Rico for projects beginning August 1, 1988. These projects were approved for a 3-year period, and were to demonstrate new approaches and innovative models for providing and coordinating health care and supportive services for women of childbearing age and children infected or at risk of HIV infection.

In particular, the projects were to:

- demonstrate effective ways to prevent infection, especially through reduction of perinatal transmission, and
- develop community-based, family-centered, coordinated services for HIV-infected infants and children.

In 1994, the program was transferred to Title IV of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. Title IV was authorized in 1990 as part of the Ryan White CARE bill, although funds were not appropriated until FY 1994. The philosophy of care behind Title IV funding is that the populations served by the existing projects should continue to receive family-centered, community-based, coordinated, and culturally competent care that includes access to clinical research trials. Moreover, participation in clinical research trials is considered to be most successful when it takes place within an existing system of care that serves the patient and his or her family.

¹²Novello, A.C., P.H. Wise, A. Willoughby, P.A. Pizzo. 1989. Final report of the U.S. DHHS secretary's work group on pediatric HIV infection and disease: content and implications. *Pediatrics* 84(3):547-55.

Title IV is administered by MCHB, with consultation and close collaboration from other HRSA and Public Health Service AIDS programs. The Title IV HIV Program has also been greatly influenced by its proximity within MCHB to the Bureau's Maternal and Child Health Service Block Grant Program. Authorized under Title V of the Social Security Act and commonly referred to as Title V, these programs provide health care to pregnant women and their children. The population of women and children served by the program overlaps with the populations served by the Title IV HIV Program. In some states, its administrative infrastructure of health departments and strong ties to related agencies has enabled Title IV programs to be incorporated into the same structure, without "reinventing the wheel." Most importantly, the Title V program for children with special health care needs (CSHCN) pioneered the development of family-centered, culturally competent, community-based, coordinated systems of care for children with special health care needs and their families. The comprehensive support for families as well as individuals has been a feature common to both the Title V MCH services and the Ryan White Title IV HIV Program.

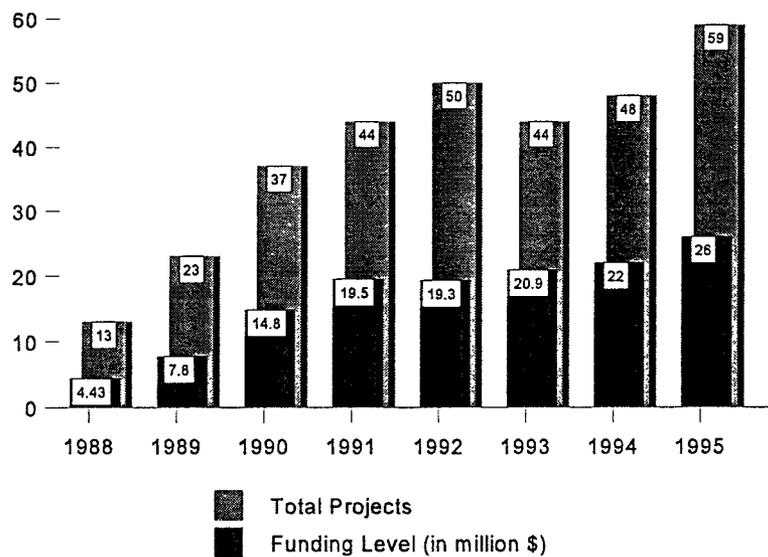
Reflecting the needs of affected populations and an increased emphasis on improving patient access to research, the program's current goals are to:

- foster the development and support of **comprehensive care infrastructures**, including primary care, that increase access to culturally competent, family-centered, community-based, coordinated care;
- emphasize **prevention** within the comprehensive care system in order to reduce the spread of HIV infection to vulnerable populations; and
- link comprehensive systems of care with HIV/AIDS **clinical research trials and other research activities**, resulting in increased access for children, youth, women, and their families.

Current Status

Funding for the demonstration projects and Title IV HIV programs has increased steadily since the program's inception, reaching \$26 million in FY 95 appropriations.

Figure 1
Funding Levels and Number of Projects
HIV Program for Children, Youth, Women, and Families



In addition, in the past 7 years of funding, the demonstration projects and their Title IV successors have proliferated; this was the initial intent of the demonstration program. As of August 1, 1995, the demonstration projects have grown from the original 13 grantees to a total of 59 projects in 26 states, Puerto Rico, and the District of Columbia. A map showing the locations of the Title IV program sites funded as of June 1995 is included as Exhibit I-1. A directory of the Title IV grantees is included as Appendix A.

The Title IV funds are currently used to support four additional types of projects in addition to the 39 Pediatric/Family AIDS Projects. These projects provide or coordinate comprehensive, family-centered health, social, and support services. The additional projects are:

- Eight planning and development grants to support needs assessment and initial planning activities to develop a comprehensive care system including one Hemophilia/AIDS Special Initiative Project
- Two cooperative agreements with national resource centers
- Seven Women's Initiative for HIV Care and Reduction of Perinatal HIV Transmission projects (WIN)

**Exhibit I-I
Ryan White Title IV HIV Programs for
Children, Youth, Women and Families**

As of 8/19/95



- Comprehensive Direct Service Projects
- ▲ Comprehensive Direct Service Projects and Women's Initiative for HIV Care and Reduction of Perinatal Transmission
- ◆ Hemophilia Special Initiative
- Cooperative Agreements for Training and Technical Assistance
- Planning and Initial Development Projects

- Three adolescent clinical sites under NIH Adolescent Medicine HIV/AIDS Research Networks

In the first six months of 1994, these projects served 17,732 enrolled clients. In addition, projects reached over 100,000 more individuals through HIV education and professional education activities. The majority of the projects' clients have been from poor, minority families. A more detailed discussion of the projects' clients is provided below.

D. Emerging Issues

The Title IV projects have responded not only to demographic changes in the epidemic, but also to research results affecting the provision of care and services, to shifts in legislative AIDS policy, and to reforms and changes in the health care system. Over the years, the Title IV projects have remained flexible and fluid in adapting to the HIV/AIDS epidemic and the dynamic health care and funding environment. As a result, the program continues to play a leadership role in the organization and provision of comprehensive systems of care for children, youth, women and families affect by HIV/AIDS.

Linking clinical care and research has always been integral to the Title IV concept of comprehensive care. As a result of pending reauthorization of the Ryan White CARE Act, Title IV's focus on linking primary/community-based medical and social services with research has expanded to further develop innovative models and to achieve the goal of increasing the access of infants, children, youth, and women to research trials. Close collaboration between comprehensive care and research not only enhances patient access to research trials but also enhances the ability to integrate the results of research into the care system. This is currently a major emphasis of Title IV under the new Women's Initiative for HIV Care and Reduction of Perinatal HIV Transmission (WIN).

In February 1994, the National Institutes of Health (NIH) announced the findings of the 076 study sponsored by the Pediatric AIDS Clinical Trials Group (ACTG), which found that a three-part regimen of Zidovudine (ZDV)¹³ reduced perinatal transmission of HIV by two-thirds in infants whose mothers met specific eligibility criteria.¹⁴ Many of the Title IV projects participated in ACTG 076 and as a result were well positioned to play a leadership role in responding to this new breakthrough. The Title IV program as a whole is positioned for a major role in incorporating the 076 findings into routine management and care of women at risk for and infected with HIV.

In addition to the role the Title IV program has played in participating the 076 trial, the program has also been actively involved in follow-up, post-trial activities. Title IV program staff at the federal

¹³ Zidovudine (ZDV) is also commonly referred to as AZT. The terms are used interchangeably in this report.

¹⁴ In order to be eligible for ACTG 076, HIV-positive women had to meet the following criteria: a) a CD4 T-lymphocyte count above 200; b) no prior ZDV use during that pregnancy; and c) enrollment between 14 and 34 weeks gestation.

and local level have provided extensive consultation to women with HIV, health care providers, representatives of public and private national organizations, and state and local governmental agencies to further disseminate the trial results and develop strategies for public and provider education on reducing perinatal transmission of HIV. In 1995 the Title IV WIN initiative was launched in direct response to the need to enhance outreach and care to female adolescents and women living with HIV so that increasing numbers of women can benefit from the trial results.

Ryan White Title IV HIV projects are also being impacted by broader changes in the health care system. The growth of managed care organizations, such as health maintenance organizations (HMOs), in Medicaid programs directly affects many of the populations served by the Title IV projects. In geographic areas where Medicaid recipients are enrolled in managed care plans, Title IV providers will need to develop new relationships with managed care companies in order to maintain their current systems of care and continue to serve Title IV clients.

E. Purpose of This Study

The purpose of this study was to assess the effectiveness of the Ryan White Title IV HIV Program in initiating, improving, and expanding systems of care and linkages to research for children, youth, women and their families affected by HIV/AIDS. The elements of an effective system of care include comprehensive services that are accessible and available to families, coordinated, community-based, and responsive to clients' cultures and family structures.

It is important to note at the outset that this study did not examine client outcomes. Desirable as that might have been, during the design phase it was apparent that many grantees were not able to capture valid and reliable data on client outcomes. HRSA continues to work with its grantees to identify client outcome measures that are most appropriate for the Title IV program, to conduct special studies of outcomes, to incorporate the use of client focus groups as part of evaluation, and to build grantee capacity to conduct outcome-related evaluations.

For this evaluation, it seemed most appropriate to focus on grantee success in meeting system-level outcomes--especially the creation of systems of care that demonstrate desirable characteristics such as family-centered, community-based, culturally competent, coordinated care. These systems of care are deemed by experts to make an important contribution to achieving client outcomes. Creating these systems was the major intent of the program's early guidance to its grantees.

A system evaluation can rightly be viewed as both an outcome and a process evaluation. On the one hand, the "system" is the intervention that is being implemented to achieve client outcomes. In that sense, examining the system can be viewed as a process evaluation. **Process evaluations** examine the actual implementation and delivery of an intervention as compared to the intent or program goals. Process evaluations also identify the factors related to successful and unsuccessful implementation of interventions. Additionally, process evaluations function as early warning mechanisms that can identify potential hazards and obstacles to successful implementation as well as validate and describe approaches thought to be effective.

The creation of such a system can also be viewed as an outcome in its own right. While the ultimate measure of program success is positive changes in the lives of children, adolescents, and women with or at risk of HIV infection, the nature of service delivery is the key tool at hand to achieve client outcomes. Examining success in creating such systems is an important intermediate step towards conducting an evaluation of client-level outcomes.

Consequently, the focus of the evaluation included the following:

- Description of the service population
- Description of the providers in the system
- Evaluation of system of care attributes
- Client perception of project impact on client and families

Chapter II. Methodology

A. Study Design

In October 1992, Macro International Inc. (Macro) completed a contract to develop an evaluation design for the Ryan White Title IV HIV Program (formerly known as the Pediatric HIV Demonstration Program). The study had several components. A logic model of the program identified the key activities and the intended relationship between activities and outcomes at the system and client levels (Exhibit II- 1) and guided the evaluation design. For each of the components of the logic model, a list of indicators was developed and operationalized. Site visits to nine of the originally funded Title IV projects assessed whether these indicators would yield relevant, analyzable data. Site visits also helped develop an in-depth knowledge of the process by which the sites developed and implemented systems of care for their target audiences. In this way the initial sites served as methodological laboratories for conceptualizing the evaluation.

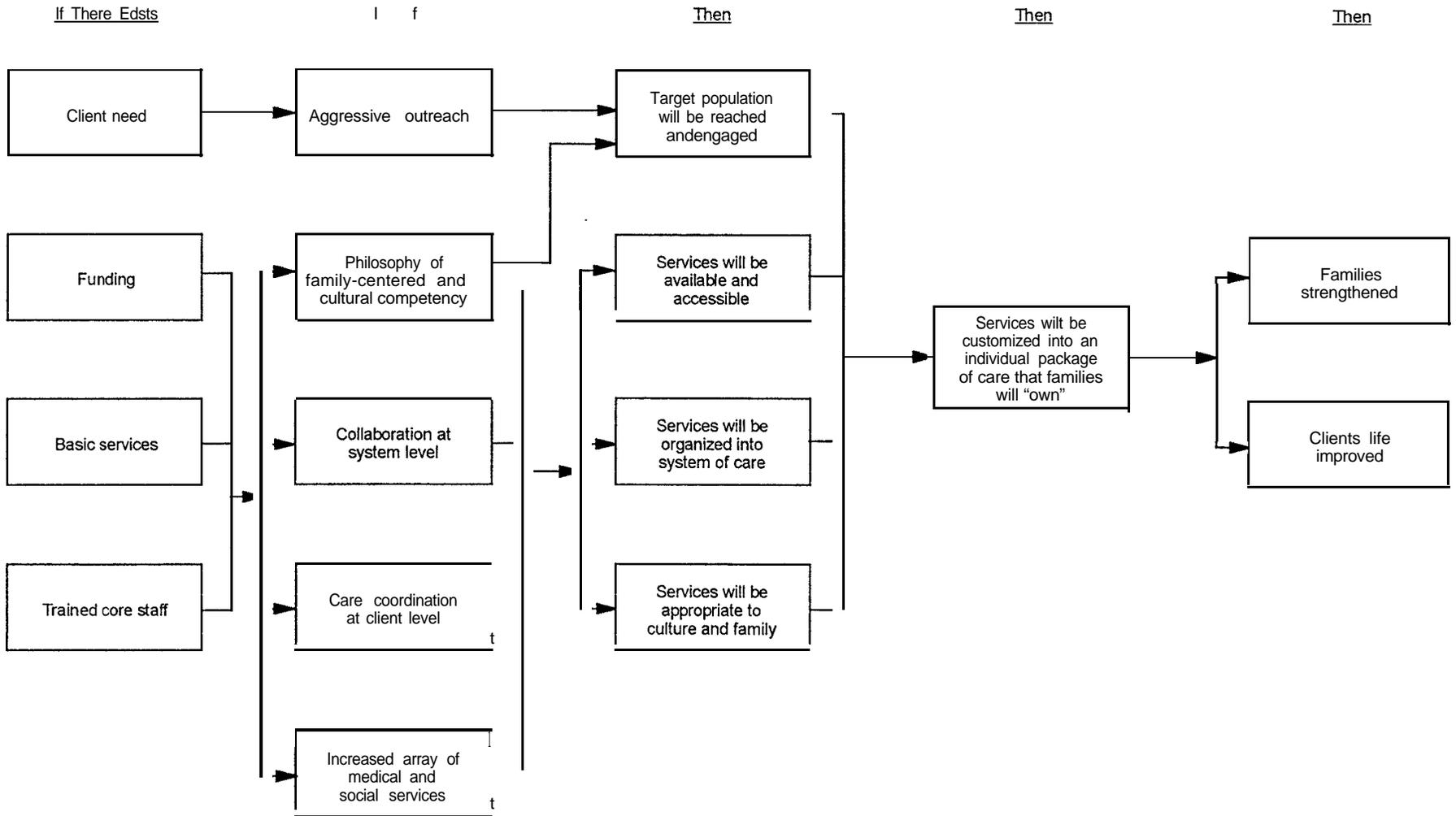
One of the key issues addressed in the design phase was the determination of the unit of analysis on which the evaluation should focus--the client or the system. While clearly neither mutually exclusive nor dichotomous, the choice between the client and system was driven by data availability. Although a client-focused evaluation was preferred because it would get to the core of the Title IV projects' mission and goals, valid and reliable outcome data at this level were not available across all projects. Therefore, the focus of the evaluation design became the system of care of itself.

System-level data were accessible from all of the projects and the evaluation could be designed to check the validity and reliability of those data. An additional strength of focusing on the system, was that given certain methodological choices, such as focus groups with clients, it would still be possible to gather some client outcome data concerning the interaction of the system and the client. Given the goals of the Title IV programs to develop models of care, the emphasis on system-level data was logical. Finally, a system based evaluation could generate information about what client outcomes are most relevant and desirable, thereby leading to future evaluation efforts aimed at measuring these outcomes.

Based on national program goals, findings from the nine initial site visits, and literature on health care systems, the following research questions became the centerpiece of the design:

- Have systems of care been established, improved, maintained, or expanded?
- Do the systems have the desired attributes?
- Is the system reaching and serving intended unserved or underserved target populations?
- Are multidisciplinary providers accessible, available and trained to serve the target population?
- Are clients receiving the array of medical and social services they need?
- Has the program had an impact on increasing participation in clinical drug trials?
- Has the program had a positive impact on client and family life satisfaction?

Logic Model of Program Activities and Outcomes



In order to answer these questions, the evaluation design included measures to capture information about the system, providers, and clients at each grantee site, as well as measures to determine the degree to which systems of care meet a standard envisioned for Title IV HIV programs. Data describing and evaluating systems were supplemented with client focus groups, which provided textual detail about actual, everyday experiences with the system of care.

Throughout this study, an advisory committee provided conceptual guidance and feedback. The advisory committee was convened prior to the start of data collection to contribute input to the evaluation approach, and after data collection to help further refine the integrated data analysis. The advisory committee included representatives from the Title IV HIV projects; other providers familiar with HIV service delivery issues for children, youth, women, and families; experts in developing coordinated systems of care; Federal program offices involved in evaluating HIV/AIDS programs; and clients from the Title IV programs. A list of advisory committee members is included in Appendix B.

B. Data Collection Methods and Sources

Macro employed an integrated, multi-method, multi-stage approach to data collection. Each evaluation question was deconstructed into a series of questions that could be operationalized and indicators were identified so that there was more than one source for each aspect of the system being studied. A complete list of evaluation questions, their components and indicators used to answer these questions, and the data sources are included as Appendix C.

Exhibit II-2 depicts the integrated approach used for data collection. Each successive data collection effort built on and filled gaps from the previous data collection. An important characteristic of this approach was its capacity to generate necessary data, while minimizing the burden on project sites. Existing data were used whenever possible, and new data were sought from only as many sites as were necessary to reflect the range of projects.

Grant applications and voluntarily reported data tables, available for all projects (36 at the time this study was conducted), were used to obtain baseline information about the projects. They also served as a framework for constructing Macro's instruments, which aimed to prevent duplication of data reporting and to illuminate gaps in existing data. The self-study component was designed to yield a detailed, statistical portrait of each project's structures and functions. Site visits were used to corroborate and elaborate the self-reported data from study guides and to obtain detailed qualitative information that could not be collected through other means. Focus groups were held with clients in order to ascertain how the system operates from the point of view of the consumer.

Because the information presented in this report is drawn from various sources, the time periods and denominators vary. For each of the data sources, the data collection methodology, the time period, and the number of projects from which data was collected is described in more detail below.

Exhibit II-2
 Ryan White Title IV HIV Programs for
 Children, Youth, Women, and Families

integrated Data Approach

Who

What

Why

10 Sites

Focus
Groups

. Provide client and family input

18 Sites

Site Visits

- Elaborate approaches to service delivery
- . Describe and confirm network
- Verify activities
- Document system change

All Sites

Self-Study Questionnaires

- Elaborate approaches to system attributes
- Fill data gaps

All Sites

Standardized Data Reporting Tables

- . Provide information on network, services, clients

All Sites

Grant Applications

- Identify approaches to system attributes

Met

gy
1-4

1. **Grant Application Narratives**

The Title IV HIV Program grant application requires projects to provide fairly extensive information on approaches to service delivery for key systems dimensions such as family-centered care, comprehensiveness, coordination, and collaboration. Additionally, basic information on funding, staffing, service capacity and needs are included in the application. The grant applications served as an excellent source of background information.

For each of the 36 Title IV HIV projects, content analyses of the open-ended questions and summaries of other basic information contained in the 1993 grant applications provided valuable initial information. Patterns in approaches to system development and service delivery were identified and categorized. This information was used to provide background information for each site to assist site visitors. In addition, the content analyses provided data on the diversity of approaches being employed to address the key dimensions of service delivery. Categories for each dimension contributed to the development of the closed-ended questions and check-offs for the self-study.

2. **Standardized Reporting Tables**

Data on clients served in 1994 were voluntarily provided by the Title IV projects to MCHB and were analyzed by Lewin/VHI. MCHB and Lewin/VHI developed standardized data reporting tables which provide information on the program's progress in reaching and serving women, children, adolescents, and their families. These tables provide information on client characteristics such as age, race/ethnicity, primary caregiver, clinical status, length of time receiving services, and the number of family members receiving services, the range of services provided by projects (either directly or by referral), and information on numbers of clients in clinical trials among other data. The tables utilized for this report included clients *enrolled* in a Title IV program between January and June 1994. For reporting purposes, enrolled clients are individuals (not families) who consent to keep provider-based clinical and demographic records and who receive ongoing services from the local provider network.

Key highlights from the analyses of the data tables are presented in parts of this report to help frame the evaluation findings. Non-client data also presented in this report cover the second half of 1993 in some cases, and the first half of 1994 in other cases. Data are reported by project, and the number of projects reporting varies by topic. The time period and the denominator of projects reporting is referenced in the text.

3. **Self-Study Questionnaires**

Self-study questionnaires were developed to obtain information that was not already available through other sources. The key purpose was to document current activities of all

projects. The questionnaire asked projects to reflect and report on their approaches to each of the key dimensions of service delivery, and identify barriers and issues that they encountered.

The specific items for each dimension and response categories were developed using the content analyses of the applications and the data tables for reference on already available data. A copy of the questionnaire is included in Appendix D.

A total of 33 (of 36) projects completed the questionnaire during the time period spanning September 1994 through March 1995. Data in this report is presented by project. The total number of projects reported varies somewhat by specific topic on the questionnaire.

4. **Site Visits**

Additional data were collected during site visits to 18 projects. The purpose of these visits was to gain a more extensive understanding of the dimensions of care provided at each site. Sites visits clarified and amplified the self-study information through review of project documentation and interviews with multiple project staff and representatives of the project network. The information collected was qualitative in nature and provided a richer understanding of *how* and *why* projects used particular approaches to developing their systems of care. A copy of the site visit protocol is included in Appendix E.

The criteria used for site selection emphasized diversity across several key program characteristics, including the following:

- Geographic location
- Institutional type
- Target population
- Service delivery approach
- Project size

The nine sites that were visited as part of the design phase of the study were excluded from the pool of sites for the current study.

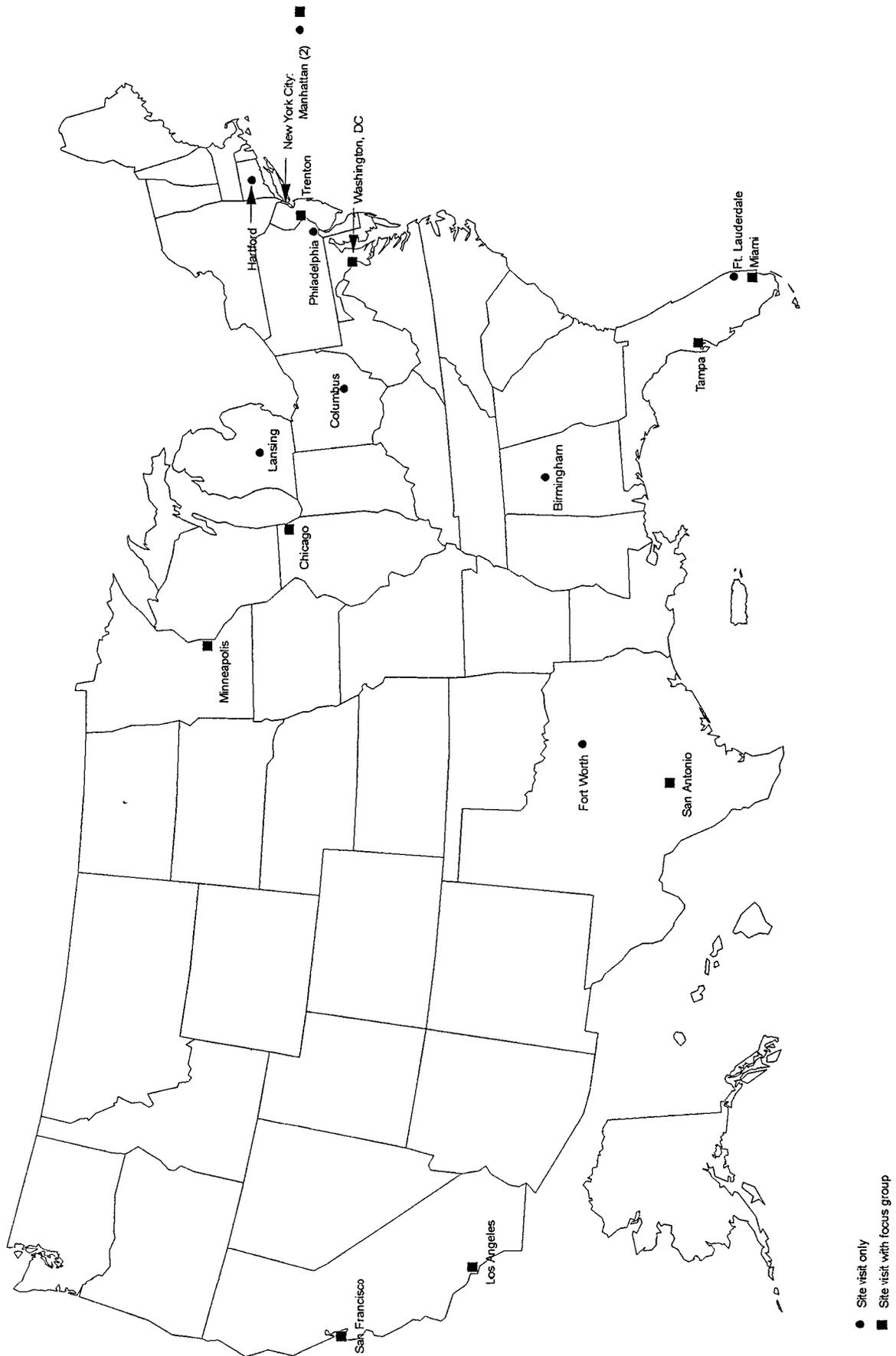
Site visit data were collected from September 1994 through March 1995. A map detailing all project sites, projects site-visited, and client focus group sites is included as Exhibit 11-3.

5. **Client Focus Groups**

The availability of standardized data on client-level outcomes was very limited. Therefore, client focus groups were used to provide proxy information on selected client outcomes.

Exhibit II-3
Ryan White Title IV HIV Programs for
Children, Youth, Women and Families

As of 6/95



Client focus groups were held at 10 of the 18 projects where site visits were conducted. An average of 10 people attended each focus group. The dimensions explored and the focus of the questions for each included:

- Accessibility--how easy or hard it is for clients to get to the service locations.
- Cultural competency--ways that the project makes families feel welcome.
- Family-centered care--how the families' needs are met, how the families are treated, and what roles they have in shaping project policies as well as their children's and their own care.
- Family and individual outcomes--how the project has affected family members' lives; for example, ability to continue daily activities.
- Prevention outcomes--how the project has affected clients' behaviors.

A copy of the focus group discussion guide is included in Appendix F.

Since information from focus group discussions is not generalizable nor quantifiable, findings from the focus groups are not expressed in terms of number of projects nor number of respondents.

C. Types of Analyses Performed

This report encompasses findings from the self-studies and site visits (including the focus groups). We employed a combination of qualitative and quantitative analyses, integrating the analyses of the various data collections for each site to obtain a more complete picture.

Site visit reports and client focus groups were analyzed using Tally, a software package for analyzing textual data. Tally allows the researcher to mark specific sections of text with distinguishing codes, sort and extract the text associated with particular codes, and produce numeric reports or matrices based on the encoding.

Quantitative analyses of project self-study guides were performed with the SPSS statistical package. Simple aggregate statistics were used to determine the distribution of the different variables among the project sites. The quantitative data presented in this report help verify and illustrate the detailed qualitative information that describes project approaches and client perspectives.

Chapter III. Title IV Evaluation Findings

Both client perspectives and staff perspectives have been a critical component of this evaluation. The first part of this section presents demographic information on current Title IV clients, followed by client perspectives on the Title IV projects derived from focus group discussions with clients at ten project sites.

In the following sections of this report, there is a discussion of project approaches to developing systems of care, staffing, ensuring accessibility, providing specific services, and linking clients to clinical trials. Staff perspectives and issues regarding the provision and coordination of client services are also presented, followed by descriptions of approaches developed by project staff to overcome barriers or otherwise strengthen the system of care in their communities. Each section begins with the research question that it addresses and ends with a discussion of the key findings.

A. Title IV Clients

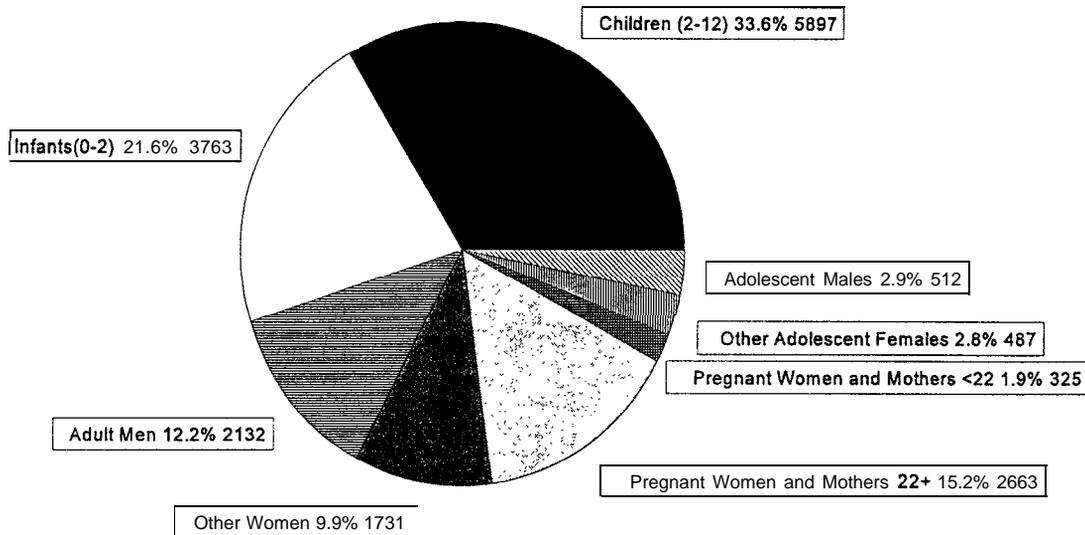
Is the system of care reaching and serving the intended unserved or underserved target populations?

1. Discussion

The toll of HIV/AIDS has been felt in families and communities across the country. As it has affected larger numbers of people, the disease has revealed the inadequacies of the health system to provide both prevention and treatment services. The impact is particularly acute among individuals with little or no access to both basic and HIV/AIDS-specific health care and social services. Women, children, and adolescents affected by HIV/AIDS are among those who traditionally have been unserved or underserved, despite the fact that escalating rates of new infection indicate a continued and growing need for services. Indeed, the gap between service needs and the availability of services was one of the catalysts for the Title IV program.

Between January and June of 1994, Title IV projects served 17,732 *enrolled* clients--a 17 percent increase over the previous 6 months. Figure 1 shows the proportion of enrolled clients by age, gender, and pregnancy status.

Figure 1
Total Enrolled Clients Served
January -June, 1994



*N=17,530. Data not available for 202 enrolled clients.
 Source: Lewin-VHI Tables 3A, 3B, and 4 data.

Larger numbers of individuals are served by Title IV projects, but are not reported as enrolled clients, generally because they are recipients of outreach and education activities for which individual records are not maintained. During the first half of 1994, Title IV projects reached over 100,000 individuals through outreach, HIV prevention and education, and professional education.

Reflecting the program's origins as pediatric AIDS demonstration projects, **infants and children continue to constitute the single largest category of clients.** For the first half of 1994, projects served 3,783 enrolled infants and 5,897 children who together accounted for 55.2 percent of the total number of enrolled clients. Vertical transmission accounts for almost all of these cases. Among enrolled infants, 95.2 percent contracted HIV perinatally (with another 2.9 percent of unknown transmission status). In addition, 87.3 percent of children contracted HIV perinatally (with another 4.3 percent of unknown transmission status). In terms of HIV status, the majority of enrolled infants (65.6 percent) had an indeterminate HIV status (P-O). Older children between the ages of 7 and 12, however, were

more likely to be in the later stages of the disease (17.4 percent P-2 AIDS and 17.2 percent P-3). Despite this trend, 17.5 percent of children were HIV-negative, which probably indicates that siblings of infected infants or children are enrolled clients.

Most enrolled infants (72.9 percent) and children (54.3 percent) live with one or both of their biological parents. Foster parents care for another 13 percent of infants and 15.1 percent of children. Although most infants (81.2 percent) and children (91 percent) live in permanent housing, this still leaves hundreds of HIV-affected infants and children in transient or unstable housing.

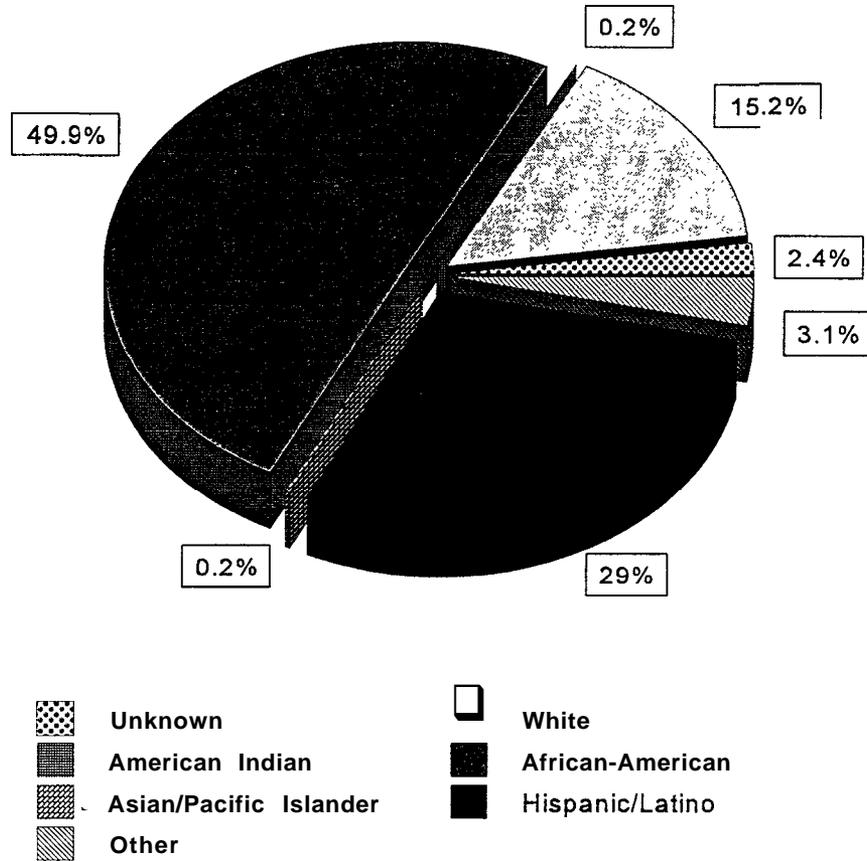
During the first half of 1994, 5,206 women were enrolled clients of Title IV programs, constituting **29 percent of all enrolled clients during that period.** Of these, 325 (1.9 percent) were pregnant young women and mothers under 22 years of age, 487 (2.8 percent) were other female adolescents, 2,663 (15.2 percent) were pregnant women and mothers aged 22 and over, and 1,731 (9.9 percent) were other adult women. Heterosexual contact accounts for 12 percent of the known exposures to HIV among adult Title IV clients during this period. In addition, 5.7 percent of clients reported unsafe sexual practices, defined as unprotected sex, sex with multiple partners, and prostitution/hustling/survival sex. Another 4 percent of clients reported multiple exposures.

Injection drug use was reported by 990 clients. Although this represents only 0.6 percent of all clients, it represents 13 percent of adolescent and adult clients. Moreover, this figure probably underestimates the prevalence of drug use in the Title IV client population, since it refers only to injection drug use, and drug using behaviors are underreported in general.

The younger women in this group are a testament to the convergence of two trends within the spread of HIV/AIDS--escalating rates of heterosexual transmission, and escalating infection rates among adolescents. Title IV programs have witnessed this change in the epidemic firsthand, and many have responded by offering services specifically designed to serve young people. During the first half of 1994, nearly 30 percent of the 1,324 enrolled adolescent clients were newly enrolled--the largest proportion of new clients for any population group. Another trend confirmed by the data is the poverty among program clients. Two-thirds of the enrolled client population had medical services covered by Medicaid, yet one in ten clients remained completely uninsured.

As noted in the introduction to this report, HIV/AIDS among women, children, and youth has disproportionately affected members of minority groups. The racial/ethnic backgrounds of Title IV enrolled clients reflect this national picture, as shown in Figure 2.

Figure 2
Racial/Ethnic Background of Enrolled Title IV HIV Program Clients
January - June 1994



The racial and ethnic backgrounds of adolescent clients differed somewhat from those of infants, children, and adults. Just over 20 percent of adolescent clients were white, compared to 7.5 percent of infants and 10.8 percent of children. Hispanic/Latino adolescents accounted for a smaller proportion of adolescent clients--24.1 percent of enrolled adolescents, compared to 32.5 percent of infants and 32.8 percent of children. Nearly half of enrolled adolescents (48 percent) were African-American.

Although over two-thirds of adolescents reported permanent housing arrangements when they enrolled, young people as a group reported the least stable housing arrangements of any enrolled age group. Almost 12 percent lived in a transient housing situation, and 4.7 percent were homeless. Among adolescent males, 7.1 percent were homeless. For another 6.4 percent of enrolled adolescents, housing status was unknown. Nearly one of every five pregnant young women and mothers under the age of 22 (19.1 percent) was living in transient housing during this period.

Title IV project staff and clients presented individual versions of these statistics during the Macro site visits and focus groups. In personal anecdotes, case management examples, and medical charts, the multiple problems faced by Title IV clients emerged repeatedly. Housing problems, a history of past or intermittent drug use, and underlying health problems--linked by the common risk factor of poverty--were often present before HIV was diagnosed. For many clients, previous encounters with the health and social service systems had been discouraging experiences. In fact, during focus group discussions, many clients pointed out the virtues of Title IV programs in contrast to their experiences with other providers.

The challenge before Title IV grantees is to meet clients' multiple needs, while encouraging and respecting their own decisions about their care and that of their families.

2. **Key Findings**

- Increasing numbers of infants, children, youth, and women are receiving comprehensive services in Title IV projects. Between January and June 1994 projects served 17,732 enrolled clients--a 17 percent increase over the previous six months;
- The Title IV program is serving the traditionally unserved or underserved target population. Eighty-three percent of clients are members of minority groups, two-thirds of clients are Medicaid recipients, and 10 percent are uninsured.
- Outreach efforts are successful in increasing the number of adolescents being enrolled in care. During the first half of 1994, nearly 30 percent of the 1,324 enrolled adolescent clients were newly enrolled.
- Women, including adolescent females and mothers under the age of 22 years, represent only 29 percent of currently enrolled clients. Outreach efforts to this population need to be increased.
- Injection drug use is prevalent and most likely to be underreported in the target population. This has implications for project's approaches to providing services.

B. Client Perspectives

Has the program had a positive impact on life satisfaction?

1. Discussion

Focus group participants highlighted two main areas of their lives where project staff and services had made an impact on their general satisfaction with their lives. These were the practical side of daily life on the one hand, and the emotional realm on the other--both of which are an ongoing struggle for many clients. Practical support includes arranging services as well as assistance with basic needs and transactions of day-to-day life, many of which are financially or logistically out of reach. Emotional support, while less tangible, seemed to play an equally important role in clients' lives. This type of support includes providing general encouragement and hope, an absence of judgment or criticism, reinforcing health behaviors and outlooks, and creating a sense of a safe haven. Additional program features that affect clients' life satisfaction are discussed below.

Quality of Life

The message that a healthy life is possible and even probable was tremendously encouraging to focus group participants. In fact, some stated that by getting off drugs, paying more attention to nutrition, and generally taking better care of themselves, they actually felt healthier than they could remember. As the focus group quote suggests, some clients, while devastated by their HIV diagnosis, did see it as a catalyst for making the most of the rest of their lives.

"The day I found out I was HIV-positive was the worst day of my life, but then it turned out to be the best thing that ever happened to me, because of the people here. They turned my life around."

Focus group participant

As clients realized they may live longer and healthier lives, however, some were concerned about how long they would continue to be eligible for services. Adolescent clients, in particular, were concerned about aging out of services when they reached their early or mid-twenties, and having to compete for services with a much larger pool of adults. Losing eligibility for services was also a concern for parents of children who had died.

In addition to improved health, Title IV sponsored activities have given clients a sense of accomplishment. Representing their peers at national meetings, serving on advisory committees, and being trained (and training others) as peer educators are all examples of leadership and accomplishment for which there were few other outlets in many clients' lives. A poignant example of this was a group of women who were trained to design and run their own call-in cable television show, with project encouragement and financial sponsorship. One participant said that this was the first time she had felt truly educated about something--even to the point where she was teaching others something they did not know.

Connecting with Peers

Although clients appreciated the support and concern they received from providers, the friendship and peer support that evolves among clients was also highly valued, especially for those isolated from other support systems. In one case, a group of women who met through a Title IV

"We were just talking about our kids. They hang together."

Two focus group participants

sponsored support group had eventually moved into housing near one another, creating what one described as a dormitory setting where conversation, child care, cooking, and transportation were more easily shared. Other clients described checking up on one another when someone had not shown up for support group or another planned activity.

Some youth participants noted that they enjoyed being with other HIV-positive youth not only in support group settings, but also in more recreational settings where they did not have to talk about HIV.

"We don't talk about dying--we talk about living."

Title IV client

During hikes and movie outings, they could relax with people who understood what they were going through. Other clients echoed these sentiments. As much as clients appreciated being able to talk about HIV with people who understood their situations, they also wanted to get away from it whenever they could. Recreational events for children, adults, and families were universally praised. Commemorating birthdays and holidays with celebrations, food, and donated gifts understandably were emotionally significant events for both staff and clients.

Disclosure Issues

Many clients discussed how their HIV status had created "a wall" between them and their relatives and neighbors--the very people who might otherwise support them as their illnesses progress. The fear of disclosing one's HIV status was particularly acute among Haitian and

Latino participants, many of whom said that they would be ostracized from families and communities if their HIV status were widely known. These clients feared any inadvertent disclosure to neighbors or relatives, including visiting home nurses arriving in “white coats” and causing gossip about what might be wrong. Assistance from project staff with this difficult and ongoing issue was both needed and welcomed by clients.

Respite Activities and Support

Child care and child-centered activities such as art therapy provide desperately needed respite to parents. In one project, art therapy had not only helped a little girl express her sorrow over losing her mother, but also became a new and enjoyable hobby that she had not had access to before. When her father mentioned how much his daughter looked forward to art therapy, staff collected donations of art supplies so that she could enjoy creating artwork at home as well.

For clients who had not felt comfortable disclosing to family and friends, the sense of safety in discussing HIV issues with understanding providers and other clients took on added importance. (The sense that outsiders could not understand what it is like to be HIV-positive—even if they wanted to—was palpable during many of the discussions.) In a number of groups, the “safe haven” aspect of the program attracted clients even when they did not have official appointments. As one woman put it, “Sometimes I just come here to hang out with my friends.”

Interaction with Project Staff

The personal impact of caring providers was described in glowing terms by participants in every focus group. Often, clients made the point that they had never been treated with as much respect and dignity as they had been by Title IV project staff. (In addition, they pointed out how poorly they had been treated in other agencies.) The concern that providers show by asking about how things are going, by noticing and praising small changes or accomplishments, and by interacting with clients’ children all elicited praise from clients. In terms of life satisfaction, this caring and concern made clients feel that someone was looking out for them and taking their needs seriously—for many, a novel experience.

“From the very beginning, they treated me like a person. They always show me that they care.”

Focus group. participant

Overall, clients were tremendously appreciative of how Title IV project staff had helped them and their families in obtaining needed services. A typical comment was, “I can’t imagine where I’d be without them.” In some cases, clients noted that their case managers

were overly dedicated--that is, that they did not modulate their efforts when client needs were less intense. In general, however, clients appreciated their case managers and wanted more time with them, not less. Many expressed sympathy for how overworked their case managers were.

Death and Dying Issues

Many focus group participants spoke of going through at least a short period when they tried to convince themselves that their HIV test results had been wrong. Others spoke of how hard it was to believe that they could be so ill, when they felt fairly healthy. As they grappled with the disease and its implications for their own survival, many clients found the peer network and staff support from the projects helpful in both practical and tangible ways. Access to counseling and pastoral care were cited as significant supports for addressing death and dying issues with children and other family members. Practical support provided in some Title IV projects, such as assistance with permanency planning for surviving children, funeral expenses, and legal documents was also mentioned by many clients. In one project, members of a family network sponsored by the project helped each other develop videotapes and other mementos for surviving children and partners.

Addressing Medical Concerns

Clients appreciated the time that Title IV project staff spent explaining medical procedures and medications. Although some clients felt that case managers and medical providers could do a better job-of this, most felt comfortable asking questions "even of doctors," as one client said. Having access to medical information by phone was very important to many clients, especially those with small children. One father mentioned how much he appreciated being able to have the pediatrician prescribe medications for his child's ear infection over the phone, without having to bring the child in every time.

In general, clients expressed a high level of interest in their medical condition and in medications. Several clients mentioned that their physicians let them make informed decisions about whether and when to start a course of medication; as one client put it, "he treated me like an intelligent person capable of making my own decisions." In another focus group, clients wanted to know their T-cell counts after the visit, without having to wait until the next visit.

2. Key Findings

- Title IV projects link clients together and help create a crucial network of peer support for clients who might otherwise be isolated.

- Beyond affecting clients' basic survival, projects have helped many clients thrive--some for the first time in their lives.
- Although individual services and staff members are important, projects as a whole serve as an anchor and a safe haven in clients' lives.
- No form of assistance or encouragement is too small to have an impact on clients' lives.
- Resources devoted to both formal and informal peer support activities--support groups, recreational activities, and other outings--have a tremendous payoff in terms of clients' life satisfaction.
- Clients' participation in education, conferences, and/or staffing contribute to a personal sense of accomplishment that has a similarly dramatic impact on life satisfaction.
- Assistance with disclosure, death and dying, and answering questions about medical issues are three key areas where support from project staff is particularly meaningful, especially since few other sources of information and support are available.

C. **Systems of Care Development**

Have systems of care been established, improved, maintained, or expanded to meet the needs of women, children, youth and families living with HIV?

1. **Discussion**

Title IV projects have created, sustained, and expanded systems of care to address these issues through combined and complementary approaches to **configure their own services** and to **coordinate and collaborate** with other community agencies. Title IV projects provide a wide range of

Categories of Services

• HIV education, prevention, and outreach	• Case management
• Medical services	• Housing
• Mental health and other psychosocial	• Child welfare
• Day and respite care	• Family and logistical support
	• Substance abuse treatment services
	• Legal services

services to families living with HIV. These services include medical care, case management, mental health services, and a variety of other needed services. The broad spectrum of medical and social services required by families living with HIV is rarely available within one program or project entity. Financial, geographical, and staffing restraints often limit the range of services individual Title IV projects can directly provide. In addition, clients may require a level or type of assistance that is beyond the scope of a particular project's capability or expertise. Increasing numbers of women and children with HIV infection create a higher demand for such services as foster care, child care, and general family support. And with increasing numbers of HIV-infected adolescents, there is a greater need for mental health services, housing for runaways, and assistance accessing entitlements.

Service Configuration

Title IV projects have configured both their programs and the services through several different approaches. While Title IV projects' service delivery approaches are unique to their respective geographic location, administrative base, and client population, these systems of care share numerous similarities in organization and service configuration.

One-third (6/18) of the site-visited projects have developed their programs to serve one designated service or catchment area. Each of these projects **is located within one geographic service area, is self-managed, and administers one or more programs (e.g., an adolescent HIV program, pre-natal care program, pediatric AIDS program)**. Four of these projects try to provide a "one-stop shopping" approach to service delivery. They offer a comprehensive array of services which are directly provided in the project setting. For services not available on-site, referrals are made to outside service agencies.

In contrast to the "one-stop shopping" approach, the other two single-service area Title IV projects are comprised of multiple programs. These programs or service components are part of the single Title IV project, both administratively and geographically. In addition, these programs are generally interrelated or connected, such as a pediatric program and an obstetric/gynecology program or an HIV medical care program and a case management program. This type of configuration requires an added level of coordination and administration.

In their dual roles as service providers and program administrators, these projects place a strong emphasis on providing and coordinating client services at the service delivery level. They are very aware of the many issues facing clients as they try to access services and know first-hand the difficulties associated with both delivering and coordinating services for their particular client populations.

Alternatively, the majority of Title IV projects visited, 67 percent (12/18), act as **lead agencies over several different, autonomous projects** and therefore do not act as a direct service providers. In some cases, the lead agency has brought together various

projects/service agencies to form a more comprehensive group of services. These programs represent different service components within the system of care, such as a medical care program, a case management program, and a substance abuse treatment program. Thus, clients move between various programs according to their service needs. In other cases, the lead agency has brought individual projects together to provide similar services but to different populations. Each project serves a particular population, such as pregnant women, while other projects serve adolescents, families, or children.

These individual agencies hire their own staff, design their own programs and deliver services in accordance to their respective agency mission and policies. In some cases, the lead Title IV agency exercises little influence over the hiring of staff or determining where, when, and how services are delivered. Instead, the lead agency works to form new collaborative relationships with outside agencies, seeks additional sources of funding, and works to increase the visibility of the project as a whole. Alternatively, some projects in their lead-agency role exercise a larger degree of influence over individual projects. They are more proactive in developing policies and protocols for service delivery, convene regular meetings with individual projects, and act as an umbrella organization under which projects deliver services according to established and consistent philosophies and procedures.

Of those Title IV projects which act as lead agencies, there are four which oversee a much more extensive and intricate system of care. These projects are characterized by **several different service locations spanning across several different city or county boundaries**. In most cases, these projects have been developed to address a number of issues on a much broader level, such as underserved subpopulations, lack of services in outlying or rural areas, or simply the expansion of the system of care to reach more populations in need. The individual projects/service components which comprise this expanded systems of care are autonomous in both administration and service delivery. In all cases however, the lead agency has established a formal agreement with individual projects to serve a particular client population or to provide a particular type of service.

Collaboration

While the configuration of Title IV projects reflects a number of different service delivery models and administrative styles, all of the projects can be described as the central point from which systems of care have been established. Title IV

Key Collaborating Agencies	
Percentage of projects reporting collaborative relationships with the following agencies: (N=18)	
• medical services providers	83%
• AIDS service organizations	83%
• social service agencies	77.7%
• local and state health departments	66.6%
• Title V agencies	55.5%
• child services-&d welfare agencies	50%
• substance abuse treatment providers	33.3%
• housing agencies	33.3%
• mental health agencies/providers	27.7%
• Ryan White Title I	44.4%
• Ryan White Title II	66.6%
• Ryan White Title III	38.8%

efforts have brought together key service agencies, such as child welfare agencies, medical care providers and social service agencies, and have highlighted the many commonalities and areas of shared and overlapping expertise that exist among agencies. These agencies range in type from service providers to state and local health departments. In this organizational role, Title IV projects have demonstrated the many ways in which agencies can work together in a complimentary manner through coordination. Coordination is particularly important to ensure that the broad range of services needed by families affected with HIV are available and to avoid duplicating existing services and efforts. This type of coordination occurs at two levels: **coordination** at the service provider level and **collaboration** at the agency or institutional planning level. This section focuses on collaboration at the agency level, especially as it relates to the development and expansion of systems of care. Section F (page 111-34) further describes coordination at the service provider level.

Collaboration entails a variety of formal and informal agreements between agencies to provide certain services, establish referral relationships, share client information, and cross-train staff. Collaboration also provides a forum for agencies within a system of care to explore common issues and overlapping concerns through joint conferences, joint committees, and task forces. Thus, the degree to which Title IV agencies and other agencies collaborate impacts systems of care as whole. It affects the availability of services by both directing the use of scarce resources and by increasing referral linkages with key service providers. It also affects how well services are coordinated between agencies in the system of care by establishing consistent policies and procedures, by preventing the duplication of services, and by ensuring that services are complimentary.

The nature and extent of the collaborative relationships formed by Title IV projects varies greatly and are affected by numerous factors. For example, although it cannot be replicated or even well-documented, it is worth noting that the force of individual personalities plays a key role in effective collaboration. In the majority of Title IV projects visited, the project director assumes leadership and responsibility for collaboration activities. These project directors possess the tangible skills required of effective collaboration, such as knowledge and experience of the local service delivery system, effective communication skills, networking skills, and organizational skills. In addition, they also possess intangible skills and qualities such as creativity and determination. In most Title IV projects, it has been this individual determination, creativity, and perseverance that has helped to erode departmental turf boundaries and foster linkages among agencies that were historically suspicious of each other's motives. For example, in an effort to meet more outside agency staff, one Title IV project has sponsored social activities such as luncheons or dinners. These social activities provided Title IV project staff with an opportunity to forge informal relationships with invited guests upon which more formal relationships can be built. In addition to these more informal efforts, Title IV projects have developed innovative, more formal approaches to coordinating client services and collaborating with outside agencies. These approaches reflect not only the type of relationships projects seek to establish with these agencies, but certain issues they wish to address.

Approaches

Routine meetings with outside agencies. Routine meetings with outside agencies have helped Title IV projects establish formal working relationships, develop procedures for exchanging information, and identify opportunities for staff across agencies to work together. In addition, these meetings provide projects with an opportunity to develop funding strategies, conduct needs assessments (both client-level and project-level) , and strategically plan for future project growth and development. These meetings are typically in the form of advisory groups and task forces that include several key community agencies. For many projects, the same groups that were formed to respond to the epidemic in its early stages continue to have a role in shaping policy as the service needs evolve.

Moving beyond task force meetings. Many Title IV project staff serve on task forces and other collaborative groups that bring together agencies working with similar client populations. Moving beyond general information-sharing at monthly meetings, some projects have taken these alliances a step further by formalizing client referral procedures, cross-training each others' staff, and sharing relevant client information, where appropriate. These alliances have been triggered by collaborative relationships at the policy level and/or by coordination among providers, such as case managers.

Joint applications for funding. Several Title IV projects reported that strong collaborative relationships were formed during the grant application process, when some groups opted to join others in a collaborative bid rather than competing for the same funds. Also, projects reported that joint application efforts have helped to uncover supplemental funding sources of common interest. Sharing or yielding financial and administrative control is a big step for any organization and, according to project staff, tends to accelerate the collaborative process.

Information-sharing protocols within and across agencies. Title IV projects reported that they have developed protocols for sharing client information both within the project as well as with outside agencies. These protocols have been developed mainly to ensure client confidentiality and obtain client consent. Policies or protocols for sharing client mental health, home health, or substance abuse information to facilitate coordination of services were reported as very informal. This level of client information is most often shared on an as-needed basis or per client request.

Single point of contact across agencies. The designation of a single point of contact has been used by projects to reduce the likelihood of duplication of services and clients getting "lost in the system." Such an approach increases the likelihood that clients will access the services that they need. Projects reported that the benefits of single point of contact are two-fold: it allows for the provision of leadership to other agencies in the system and offers a system-wide perspective on client services.

Issues

Title IV projects have demonstrated great success in forging new collaborative relationships as well as maintaining and improving existing relationships. However, various factors continue to impede efforts. While many of these factors are unique to specific agencies and often reflect the political and cultural milieu in which agencies are located, staff across Title IV projects identified common issues of concern.

Stigma associated with mental illness and substance abuse. Project staff expressed reluctance to share client information about mental health and substance abuse with medical and social service providers, particularly those outside of the project. Staff fear that such information could have a negative impact on clients and their families, particularly substance-abusing pregnant women and women with children. Consequently, coordination and collaboration efforts have been impaired as Title IV projects are forced to carefully choose both the agencies with which it is safe to share client information and the client information which is safe to be shared.

Philosophical differences. Staff across Title IV projects expressed concern that many outside agencies such as child welfare agencies, substance abuse agencies, and mental health agencies, are either child-focused or adult-focused and do not offer family-centered services. As a result, Title IV projects have found it difficult to negotiate services for *families*. Projects are forced to refer adult family members to one agency and children to another, thus further complicating coordination efforts and further fragmenting systems of care. In addition, outside agencies are often less likely to actively involve families in developing service plans or eliciting client input. Thus, Title IV project staff face the difficulty of not only ensuring that service needs are met for all family members, but also ensuring that the needs of the family as a unit are being appropriately addressed.

Philosophical differences also impede project efforts to collaborate with key agencies such as schools or churches. Local controversies have prevented many projects from providing HIV/AIDS education, prevention, testing, and counseling services in schools.

Increasing caseloads. As Title IV client caseloads increase, less staff time can be allocated to collaborative activities such as strategic planning, inter-agency meetings, or policy development. Rather, project directors reported that they are often forced to re-distribute staff time to direct service delivery and coordination of care in an effort to meet the plethora of service needs presented by each new client case.

Turf issues and increasing competition between agencies. As more agencies become involved in providing services for persons living with HIV/AIDS, there is increasing competition for a limited amount of resources among agencies which serve a specific population such as gay men, women and children, or minorities. Title IV projects have found this increasing competition and “turfism” particularly destructive to collaborative relationships as agencies grow more fearful of losing their funding to others. Thus, projects

have had difficulty establishing referral linkages, obtaining needed client information, and coordinating services as agencies have begun to safeguard their staff, resources, and even their clients.

Fear and insensitivity about HIV. Title IV projects frequently mentioned that collaborating with community organizations has at times been difficult due to fear and insensitivity surrounding HIV. Projects report that community-based organizations often fear being identified as an “AIDS” agency while others simply do not wish to be associated with persons who are HIV-infected and thus do not wish to establish any type of formal relationship with an “AIDS” project. This fear and unwillingness to collaborate with Title IV projects has hampered projects’ efforts to coordinate client services within their communities as well as increase project visibility and acceptability within certain communities.

2. **Key Findings**

- As a result of collaborative efforts, Title IV projects have expanded their systems of care across cities and even states, creating a web of services and agency networks designed to meet the current and changing needs of families living with HIV.
- Title IV projects have built on existing systems of care and have established linkages with existing services, thereby increasing the number of services available to clients and decreasing duplication of services and efforts across medical and social service agencies.
- An increasing number of Title IV projects are expanding their systems of care by extending their reach to more geographic regions and by increasing the number of agencies in their funded networks in an effort to reach more clients.
- Title IV projects have had most success in developing strong collaborative relationships with medical service providers, AIDS service organizations, and social service agencies.
- Agencies with which Title IV projects have had difficulty collaborating--local schools, housing agencies, mental health agencies, local churches, and substance abuse treatment providers--have less experience and tradition in providing services to persons living with HIV/AIDS. Some of these agencies, such as local churches or schools, represent opportunities for outreach and prevention.

D. Service Delivery Staffing

Are providers accessible and available who are multidisciplinary and trained to serve the target population?

1. Discussion

Given both the diverse population served by most Title IV projects (women, children, adolescents) and the medical and social complexities of HIV, it is imperative that clients have access to a wide range of staff from multiple disciplines. Core staff typically include

nurses, physicians, and social workers. Title IV projects also employ a large range of other disciplines. Most common were mental health professionals and health educators. Projects indicated that Title IV funds are used most often to fund case managers, nurses, and health educators/outreach workers.

In their continuing efforts to provide services to meet the evolving needs of persons living with HIV/AIDS, Title IV projects have added less traditional staff disciplines to their projects, such as alternative medicine, pastoral care, and art therapy.

The employment of a wide range of medical and social service disciplines is just as important as the ability of these disciplines to work together in a coordinated and efficient manner. Historically in the broader health care arena, it has been common for many medical and social service disciplines to strongly adhere to their own professional liaisons and roles with little effort or incentive to coordinate their efforts with those of other providers to serve a client in need. Often, referrals or consults are made to other providers and there is little, if any, discussion or follow-up between providers. However, the model of service delivery employed by many of the Title IV projects (along with some other MCHB programs) has brought together physicians, nurses, case managers, and mental health professionals in the

Title IV Staff Disciplines	
pediatricians	art therapists
nurses	outreach workers
adolescent medical specialists	peer educators
case managers	acupuncture specialists
obstetricians/gynecologists	massage therapists
clinical social workers	substance abuse counselors
psychologists	immunologists
mental health counselors	health educators
pastoral care staff	neurologists
child life specialists	

form of multidisciplinary teams. These teams function in unison to address several aspects of a client's or family's medical and social well-being. Within this model of service delivery, each team member provides professional services to clients and shares professional expertise with other team members, resulting in comprehensive, coordinated, and efficient client care. As a result, clients not only have access to a wider range and type of services, but they have access to more coordinated services. The coordination of these services by multidisciplinary provider teams reduces the number of referral appointments clients must attend and duplication of effort and services across agencies, and increases clients' well-being as their various needs are addressed and coordinated within one model of service delivery.

Hiring appropriate staff

Client focus group participants were asked about their opinions and experiences with Title IV staff. Across sites, participants indicated that compassion, patience, and dedication are just as important in a service provider as training, education, and years of experience.

Doctors are adults and can be intimidating, but not my doctor. He explains everything he does and gives young people the power to make their own decisions."

Adolescent focus group participant

They also expressed great appreciation for the time staff devoted to talking with them, answering their questions, and helping them make informed decisions. Title IV projects have concentrated on staffing their projects with experienced, compassionate people who can respond to clients' emotional needs, as well as their medical and social service needs. They recruit staff with experience in HIV disease or other chronic and terminal illnesses and also seek staff with experience working with culturally diverse populations, as well as staff who are comfortable working with different populations and types of people. A key indicator of availability of staff is their access via beeper and 24-hour call services, which are standard practice across most projects.

Project directors across several sites reported that in interviews they always ask potential hires about their level of comfort in working with people infected with HIV. Also, project directors reported that they look for staff who have a "fit" with the project and its clients. These individuals may be HIV-infected, or may share common cultural backgrounds or experiences with the clients served by the project. In almost half of the Title IV projects, clients or family members are hired as paid or volunteer staff and often serve as peer educators, advocates, and mentors. More detailed findings about cultural competency of project staff are presented in Section E (page 111-21).

Equally, if not more important than experience or common backgrounds, project directors report that they look for staff who will be dedicated to the project and its clients. The vast majority of the projects (94 percent) have experienced some difficulties in hiring staff. Many projects cannot afford to pay staff at salary levels comparable to other agencies or a salary

commensurate with the demands of the job. In most cases, physicians and nurses can only be hired part-time because the projects cannot afford to pay them a competitive, full-time salary. In addition, those Title IV projects which are based in public health agencies, hospitals, or academic institutions must often adhere to hiring and pay scales established by the institution in which they are based or pay scales established by professional unions. Thus, hiring becomes a more burdensome and complex process as projects have less flexibility in hiring and paying staff at levels to meet both project, staff, and client needs.

As a result of the inherent difficulties in both hiring staff and paying staff, a crucial quality in selecting staff is a desire to work in the field of HIV/AIDS and improve the lives of those infected with the illness. In addition, it has become a prerequisite, given the emotional strain staff endure as they work with a chronically ill population.

Retaining and supporting staff

While dedication helps carry many Title IV staff through physically and emotionally trying times, it is sometimes not enough. Although projects reported less difficulty retaining staff than hiring staff, 60 percent of the projects had experienced some attrition of staff, particularly case managers, social workers, and nurses between 1993 and 1994. In an effort to ease the

physical and emotional burdens of HIV-related work, projects have adopted a number of staff support strategies. Some projects have initiated support groups for staff to help them deal with client deaths, increasing caseloads, and everyday job frustrations. Despite the difficulties of dealing with death and dying issues on an ongoing basis, some staff noted that they feel particularly useful to families as they help them cope with these difficult issues. Project staff also indicated that opportunities for professional development are important staff support mechanisms as well. Release time and/or tuition reimbursement for continuing

It's often a case of self-selection...the people who come to work here are here because they want to be here, not because they have to; there are plenty of other places they could work."

Project director

Commonly used staff support mechanisms

- staff support groups
- staff outings and retreats
- office parties
- "mental health days"
- continuing education opportunities
- opportunities to publish or present work
- release time or monetary support for conferences

education provide staff with opportunities for career advancement. Additionally, opportunities to publish or present at professional conferences help staff keep up with innovations within their fields and network with colleagues and maintain professional affiliations.

Although retaining appropriate staff at appropriate levels was recognized as an important and crucial element to the success of the Title IV projects as well as the improvement of client well-being, several Title IV project directors noted that in some cases a small degree of staff turnover is good and even desired. New staff, according to these directors, often bring a fresh perspective to projects, including creative ideas about improving client services. In addition, new staff bring with them their previous knowledge and background as well as prior relationships with outside agencies and providers.

The staff who have dedicated themselves to working with the Title IV projects and their clients are the heart and soul of the projects. Their level of commitment and sense of compassion and understanding, coupled with their **professional** expertise, **have** not only contributed to the success of the Title IV projects, but also to the success of Title IV clients.

"They changed my life, helped to turn it around."

"They showed me a different world out there, outside from where we're from."

Two adolescent focus group participants'

2. Key Findings

- Projects are staffed with a broad range of multidisciplinary personnel and are looking beyond traditional disciplines in their efforts to respond to changing client needs. In addition, the use of multidisciplinary teams (nurses, physicians, case managers, etc.) provides a model of collaborative service delivery among various professions with the potential for increased client access to needed services and decreased duplication of efforts across various medical and social service agencies.
- The presence of knowledgeable, dedicated, and compassionate staff has contributed a great deal to the success of the Title IV projects and the subsequent impact projects have had on clients' lives. Focus group participants across projects constantly praised both the professional expertise of project staff as well as their sense of caring and understanding.
- Staff turnover among Title IV projects is surprisingly low given the inherent difficulties of providing services to persons living with HIV/AIDS.

- Project administrators have had more difficulty *recruiting* experienced and appropriate staff than they have had *retaining* staff--94 percent reported some difficulties in hiring staff. Recruiting difficulties have been attributed to the complex institutional and professional guidelines of hospitals, universities, and unions as well as salary limitations and demanding job responsibilities.
- Case managers, social workers, and nurses are the most difficult staff positions to both recruit and retain.
- In **almost** half of the Title IV projects, clients or family members are hired as paid or volunteer staff and often serve as peer educators, advocates, and mentors.
- Increased staff retention is linked to positive client well-being as clients grow closer to project staff and often develop deep and trusting relationships with staff. These types of relationships provide emotional and personal support to clients and lets them feel comfortable receiving services at the projects. As a result, clients continue to access needed services, share pertinent information with project staff, and have increased life satisfaction knowing that there are people who care about them.

E. System of Care Attributes

Do systems of care have the desired attributes: are services accessible, family-centered and culturally competent?

1. Discussion

Title IV clients, 83 percent of whom are minorities, represent a traditionally underserved population. Needed medical and social services historically have been unavailable and inaccessible, mainly because of the fragmented system of services provided by different agencies and organizations, each of which is set up to serve a specific and usually narrowly defined target population. These multiple service agencies often are not prepared to respond to the complexity of issues brought by families affected by HIV/AIDS. Consequently, a primary focus of the Title IV projects is to improve and maintain the accessibility of services by addressing two dimensions of accessibility: *physical accessibility*--the ease with which clients can physically reach and obtain services; and *acceptability*--the degree to which services and the manner in which they are provided are perceived by the intended clients as responsive to their needs.

Although a broad range of services may be available in a community, clients must be able to make their way to the service locations. Given the fragmentation and segmented nature of many services, families affected with HIV/AIDS find themselves going to different service locations in different parts of their communities, depending on which family member is being served. For families living in urban settings, this usually means traveling by bus or other forms of public transportation (and sometimes making multiple transfers) with one or more small children in tow. In rural areas, these issues can be compounded by a lack of services and public transportation. And in all cases, the illness of a child or caregiver further exacerbates any travel that must be endured.

Even when clients are able to get to the service locations, the final test of accessibility is acceptability--the degree to which clients feel welcome and respected and the extent to which services meet their needs within the context of their cultural and family values. A system of care that seeks to meet the service needs of such a population must not only attempt to provide needed services, but provide these services in an environment and manner that is accessible to clients from a variety of different backgrounds.

Title IV projects have addressed issues of client eligibility, physical accessibility, and client acceptability of services through a number of different approaches. While these approaches may differ across project sites, in general, projects have responded to issues of accessibility by developing approaches reflective of geographic location, surrounding cultural milieu, and client input.

Project's approaches to easing physical accessibility, providing family-centered care, and ensuring cultural competency in their service provision are described below.

a. Physical Accessibility

Title IV projects have taken various approaches to easing physical access to services for their clients. Key strategies include expanding service capacity by bringing services on-site, reorganizing service locations and coordinating service schedules, establishing flexible appointment scheduling policies, and providing transportation assistance.

Expanding Service Capacity and Reorganizing Service Locations and Schedules

Of the 18 projects visited, 7 offer mothers access to medical care during the same clinic visit and in the same clinic space as their children, an approach often referred to as "one-stop shopping." The family stays in the same examination room while the physicians rotate visits, and child care is provided while the mother is being seen. Two of these projects are located in children's hospitals which have expanded the

traditional definition of service population from children to children and their mothers. Both have arranged for the adult physicians from affiliated hospitals to attend the clinic. To accomplish this, these projects had to address logistical issues such as scheduling across institutions and billing and record-keeping procedures. Project staff indicated that once they had agreement on the concept, these issues were fairly easy to resolve.

Coordinating medical appointments for several family members so that they are scheduled for the same day at convenient times is another way Title IV projects have improved access to medical services. Of the projects that responded to the self-study, 46 percent indicated that they offer concurrent medical services or coordinated same-day appointments at all of their medical care locations. However, some project staff cautioned that some families prefer spreading out medical appointments over several days to avoid a long day with back-to-back appointments. In response to client complaints about long appointment days, one site that previously offered concurrent appointments has reverted back to separate appointment schedules.

For projects that only provide medical services for infected children, infected adult family members must seek care elsewhere. Strong referral relationships and information sharing between the child and adult medical providers have helped enhance access to services for adults at the few project sites which have adopted this approach. Medical information pertinent to the health of the family as a whole is coordinated, and clients get a strong message that the health of each family member is of concern to providers. The majority of the site-visited projects that provide medical care directly only to children had established referral relationships with adult medical care providers, but few had established strong linkages that included routine exchange of information.

Other approaches to easing access identified by Title IV project staff included locating project sites in areas where public transportation is within walking distance, sharing clinic space with other medical departments or

"...teens do not like to travel all the way to [Manhattan]...so the good thing about the [project] is that it brought cl. inic to where young people are."
Adolescent focus group participant

projects to expand the number of available clinic rooms, and establishing satellite clinics in different locations across a city or state to reach clients who cannot travel to the main clinic site.

Scheduling Policies and Practices

The ability to arrange medical appointments within a few days helps convey to clients the importance of their health. The ability to respond quickly to clients' requests for appointments is even more critical, given the ambivalence that often follows a diagnosis of HIV/AIDS. Denial, fear of disclosure, and other issues can easily translate into missed appointments, especially if clients have a long time to think about these issues before the appointment. On the self-study, 58 percent of the projects indicated that they were able to arrange medical appointments within 6 days and another 33 percent were able to arrange appointments within 1 to 2 weeks.

Similarly, the ability to provide medical services in a timely manner that minimizes waiting conveys respect to clients. Most projects (54 percent) indicated on their self-studies that they schedule medical appointments for a specific time rather than for an appointment block. This scheduling method has resulted in shorter waits than appointment block scheduling. Thirty-three percent of the projects indicated that they were able to keep clinic waiting times to less than 15 minutes, and another 29 percent indicated that they were able to keep this time to between 15 and 30 minutes.

Transportation Assistance

In an effort to further improve client physical access to medical and social services, Title IV projects also focus on clients' transportation needs. Many Title IV clients do not have cars and have difficulty keeping appointments with both medical and social service agencies; they may be too sick to take public transportation or live in areas where public transportation is poor or does not exist.

Most common types of transportation assistance offered by Title IV projects:

- cards or tokens for public transportation
- taxi vouchers
- emergency transportation
- van/shuttle service

Parents or guardians with several children in their care also have difficulties with transportation. Public transportation is often difficult to maneuver with several children in tow and Medicaid transportation will only transport those family members with medical appointments. Thus, Title IV projects have developed a number of

"I spend hours in the car with my clients driving them around. It's an opportunity to really talk with them, so I've taken to calling them 'car visits'—just like home visits."

Case manager

different strategies to address transportation issues. Ninety-nine percent of Title IV projects reported that they provide clients with tokens or passes for public transportation. In cases of emergency, a number of the hospital-based projects have arrangements with their affiliated medical institutions to provide van or shuttle service to clients in need. Projects located in outlying areas have had to rely on Medicaid transportation as public transportation is either non-existent or limited. Thus, these projects provide taxi vouchers, have established formal cooperative agreements with Medicaid transportation agencies, or directly provide transportation through staff.

b. Family-Centered Care

The concept of family-centered care encompasses a broad range of activities and attitudes that together ensure that services are focused on the needs of the family. The Institute for Family Centered Care describes family-centered care as “a system-wide approach to pediatric care based on the assumptions that the family is a child’s primary source of strength and support.”¹⁵ In family-centered care, families and providers are partners in program and policy development.

Five Guiding Principles of Family-Centered Care

Respect--for client’s values, beliefs, and cultural background
Information sharing--to ensure that families get complete and accurate information in a form that suits their learning styles and preferences

Collaboration--to ensure that the family’s expertise is melded with medical and other technical expertise

Family-to-family support--to help families with similar needs find strength and comfort and work together to identify strategies for coping and participating more effectively in health care

Confidence building--to help families augment their skills to become more effective caregivers and participators in care at whatever levels they choose

Source: Hanson, et. al. 1994. *Hospitals: moving forward with family-centered care*. Institute for Family Centered Care. Bethesda, MD

¹⁵ Hanson, et al. 1994. *Hospitals: moving forward with family-centered care*. Institute for Family Centered Care. Bethesda, MD

Families as Colleagues and Collaborators

Including families on advisory boards and governing bodies is one mechanism for involving clients in project planning and oversight activities. Title IV clients were most often represented on interagency task forces (75 percent) or advisory committees (68 percent). Site visits illustrated a range of involvement including clients holding several seats on groups that have voting responsibilities and active subcommittees, to a single client holding a position on a group that meets infrequently and has no planning or policy-setting authority.

At one Title IV project, a group of families and the project administrator co-founded a state registered non-profit organization. The group addresses family issues, coordinates family outings and support groups and has a 24 hour "on call" service to respond to family crises. Members of the family support group serve on the Title IV project's advisory committee, and the Title IV project director and administrator sit on the family support group advisory and executive boards.

Many projects also involve clients as volunteer or paid peer educators and mentors. Projects that have developed such roles emphasized their importance in providing clients and families with an easily accessible source of information, education, and support. Employing clients as staff or volunteers also gives other project staff insights into the needs of families living with HIV. These clients' perspectives have helped projects identify ways to make their services more responsive to family needs.

In various advisory, planning, and staffing roles, clients have established and organized fundraisers, have helped projects institute child care during clinic visits, and have started family support groups. In addition, several clients have participated in national meetings and training sessions sponsored by agencies such as the Family Leadership Conference sponsored by the Institute for Family Centered Care, to increase both the type and quality of input clients can provide to their respective projects.

Title IV projects that have been successful in achieving client involvement emphasized the importance of providing clients with the tools to adopt a meaningful role in the project. Sixty-four percent of Title IV projects indicated that they provide families with training in personal advocacy. These trainings focus on educating clients about the types of services available to persons and families living with HIV as well as their legal rights. In addition, projects train clients in local, state, and federal HIV/AIDS policy, public speaking, and rules for conducting formal meetings of advisory boards and executive committees on which clients might serve. Through personal advocacy training, clients have an opportunity to expand their roles within systems of care from consumer to educator, advocate, and leader.

Above all, however, project staff consistently stressed the importance of relying on clients to determine when they want to take on more responsibility. Circumstances that prevent involvement at one point can change; at another time, a client may feel more comfortable or have more time to take on a more involved role.

"My case manager wants me to be a peer educator....she thinks that I would be good at it, but I don't want to do it...she told me to let her know if I change my mind..."

Focus group participant

Client involvement in Title IV project activities provides not only an opportunity for the projects but an opportunity for the clients. A number of the clients who serve as peer-educators, advisors, or volunteers consistently stated that by helping

"Seeing people you teach get enlightened--it's a great feeling."

&d&scent peer educator

others they have helped themselves. The sense of accomplishment and pride that clients have received from serving others has, for many, renewed their belief and faith in themselves and has provided project staff with an added level of insight into current and changing client needs. More importantly, however, such volunteer, advisory, and staffing opportunities have allowed many clients to, in their own personal way, make a difference and a lasting impression. In the memories of staff and other clients, client volunteers have the chance to be remembered as more than just a client receiving services, a person with HIV, or a person in need, but rather, as a friend, a provider, a mentor, and a colleague.

Creating an Environment That is Responsive to Family Needs

An equally important element in family-centered care is that services are provided in an environment which is warm, welcome, and responsive to families. The vast majority of Title IV projects have incorporated into the intake

One project developed a checklist of service/information needs for families to complete at the beginning of every clinic visit. This allows families to set their own priorities and helps providers focus their discussions on topics most important to clients.

and case management process a client/family-identified needs assessment which provides clients with an opportunity to identify their service needs as a family and tailor their case management plan accordingly. As a result, the Title IV projects can be more responsive by addressing those issues of more pressing concern to clients and their families.

Title IV projects have also gone to great lengths to design and create clinics with a bright and cheery atmosphere conducive to families. The majority of site-visited projects provide children with toys, games, and recreational activities to occupy

"I like to get together with people who know what it's like to be HIV-positive, but we don't have to talk about it all of the time."

Adolescent focus group participant

their time while waiting for clinic appointments. These activities serve the dual purposes of keeping children preoccupied so that they do not focus on being sick or become nervous about the doctor's appointment, and giving parents/caregivers a chance to relax and focus on information being provided by project staff. In addition, Title IV projects frequently sponsor luncheons, picnics, or "pot luck" dinners to provide clients with an opportunity to socialize and get together with other clients. These family social events not only foster and support client relationships, but demonstrate the projects' commitment to families and family-to-family support. Projects that have been successful at developing and maintaining family support groups also emphasized the importance of having participants determine the focus and agenda of the gatherings so that clients' and families' issues are specifically addressed.

Staff Training

Creating an environment which is responsive to families' needs also requires staff orientation and training in the various philosophies and dimensions of family-centered care. Sixty-one percent of Title IV projects indicated that they provide staff training in developing collaborative relationships with families. These trainings focus on family systems theory, recognizing the needs of both the family as a unit and individual family members, and working to preserve families and assist them with becoming more self-sufficient.

Issues

Title IV project staff cautioned that numerous issues influence their ability to involve clients and families as partners. In some projects these issues represented barriers that prevent family involvement, while in others they represented issues to

In an effort to address transportation as well as other issues such as confidentiality and disclosure, one Title IV project has started to convene client "brown bag" lunches or client parties on clinic days. In this more informal atmosphere, staff elicit client input in a more relaxed setting. In addition, clients do not have to make extra (often uncompensated) trips to the Title IV project on non-clinic days to participate in advisory committee meetings or client focus groups.

be sensitive to in developing successful approaches.

Disclosure Issues. Projects identified clients' varying levels of disclosure about their HIV status as a potential barrier to participation on advisory boards, advocacy groups, and support groups. Clients who are uncomfortable discussing their HIV status may not be motivated or ready to participate in a group setting. Project staff emphasized two important points: disclosure needs to be approached cautiously and clients need help in assessing their readiness to disclose their HIV status as well as the likely reception of the person or persons to whom they plan to disclose.

Confidentiality Issues. Project staff expressed concern over the inherent difficulty in ensuring client confidentiality outside of project-provided services. As a result, participation in advocacy groups, interagency committees, or even support groups sponsored by outside agencies represents a potential threat to client confidentiality as a client's HIV status is disclosed to more individuals through participation in such meetings.

Lack of transportation and child care assistance. Transportation and child care assistance is rarely available for non-medical appointments such as support groups and advisory group meetings. Project transportation funds are limited and are reserved for emergencies and assistance with social service appointments. Thus, clients, the majority of whom lack cars or transportation resources, cannot participate in support groups or advisory group meetings. Focus group participants reiterated the importance of transportation and child care assistance to increase client participation in project activities outside of clinic and social service appointments.

Client discomfort. Project staff at several sites commented that clients are often reluctant to attend advisory meetings or to become client advocates because they feel uncomfortable speaking about HIV outside of the clinic setting. Staff at these sites reported that clients also feel overwhelmed at the idea of participating in a meeting with "professionals" such as doctors, nurses, case managers, or administrators.

c. **Cultural Competency**

Project settings and services that are reflective and respectful of clients' cultural and ethnic backgrounds are also an integral part of the design and development of a comfortable project environment. Ensuring that a project and its services are culturally competent involves formal efforts such as recruiting culturally competent staff; offering staff training in cultural competency; minority input in decision-making; developing appropriate educational materials; and

*"They treat me with respect
... they don't judge me..."*

Focus group participant

developing and institutionalizing policies and procedures that address cultural competency. Other less tangible aspects of providing services include creating an atmosphere of respect and acceptance and an environment that feels welcoming and comfortable to clients of different cultural backgrounds.

Recruiting Culturally Competent Staff

Title IV projects identified several strategies they have used to ensure cultural diversity among staff. One project recruited staff from client communities or from ethnically and culturally diverse universities or organizations. Several projects incorporate into their hiring process routine questions about experience and level of comfort with people of various ethnic and cultural backgrounds; they also asked candidates to respond to various scenarios with cultural themes. While project administrators indicated that they work very hard to recruit culturally competent staff, they often must compete with other medical and social service providers from a sometimes limited pool of applicants.

Project staff also emphasized that to ensure cultural competency of staff and services requires not only attention to hiring practices, but also to promotion practices and levels in the organization at which minority staff are placed. Staffing configurations that include staff who mirror the predominant culture being served in administrative and decision-making roles convey cultural respect to clients. Sixty-four percent of projects indicated that they have minority staff in decision-making roles.

Project staff also indicated that the use of clients as paid staff and peer educators effectively responds to clients' needs as well as conveys respect for their views and beliefs. Forty percent of the projects reported the use of clients/peers on staff.

Staff Training in Cultural Competency

Recruiting staff who share the same ethnic or racial backgrounds of the client population cannot alone ensure cultural competency. Nor should it be assumed that a staff person from a different ethnic/racial background cannot be culturally competent in their approach to providing care. Similar to maintaining a family-centered care approach, ensuring culturally competent care is an ongoing process. Periodic staff training in cultural competency is one way to ensure that the process continues. Sixty-seven percent of projects reported that they have provided cultural sensitivity in-service sessions to staff. However, it was clear from interviews with staff that many projects view such training as a one-time effort and have not built in ongoing training in cultural competency.

Creating an Atmosphere That Respects Cultural Diversity

Projects have also implemented additional strategies to create an atmosphere of respect for various beliefs and cultures, including:

- celebrating cultural holidays in the service setting
- active staff participation in community cultural events
- decorating clinic rooms and waiting areas with art, posters, and literature reflective of the client population served
- developing partnerships with minority and culturally diverse organizations

Developing Appropriate Materials/Communicating in the Client's Language

The availability of culturally and linguistically appropriate materials is another aspect of cultural competency.

Title IV projects have developed a variety of approaches to assure that communication with clients is appropriate. Projects have purchased or

developed educational materials and posters that represent clients' languages as well as their ethnicity and culture. In addition, projects reported that they have geared their educational and reading materials to reflect clients' reading levels. Over half of the projects reported that their reading materials are geared to a 6th grade reading level or lower and another 25 percent of projects have materials geared to 7th through 9th grade reading levels.

Communicating with Clients	
Title IV projects reported that they use the following strategies to improve the quality of communication with clients: (N=32)	
translators/interpreters	91%
assistance explaining/reviewing of materials	81%
multilingual instructions/forms	72%
multilingual posters/signs	60%
non-technical instructions/materials	60%

Policies and Procedures

More formal efforts to creating and maintaining a culturally competent project, services, and staff include the adoption and institutionalization of policies and procedures regarding cultural competency and cultural sensitivity. Forty percent of Title IV projects reported that they have developed cultural competency policy statements. However, when asked to describe or provide copies of cultural competency statements, in many cases projects cited their Equal Employment

Opportunity (EEO) regulations. This could indicate that projects are mistakenly assuming that minority staff representation is synonymous with cultural competency.

With regards to hiring practices, more than half of the site-visited projects (10/18) have formally incorporated cultural competency requirements into their job descriptions. Of those projects that do not include cultural competency requirements in job descriptions, again, Affirmative Action or Equal Employment Opportunity regulations were most frequently cited as the official cultural competency statement.

2. **Key Findings**

- Title IV projects have organized staff and service schedules to be convenient and timely; 58 percent of Title IV projects arrange client medical appointments within 6 days and another 33 percent arrange appointments within 1 to 2 weeks.
- One way projects facilitate physical accessibility is by addressing transportation issues. Forty-nine percent of Title IV projects provide public transportation passes or tokens to all clients while the remaining projects (51 percent) provide passes or tokens to some clients (based upon various eligibility criteria).
- To address other client needs and as a result of expanding catchment areas, Title IV projects use multiple approaches, often simultaneously, to increase client access to services. These approaches include:
 - expansion of project service capacity by offering more services on-site
 - coordination of service schedules and client appointments with other service providers
 - establishment of referral relationships and information exchange between adult and child medical providers
 - establishment of flexible appointment scheduling policies
 - establishment of satellite clinics to reach less accessible clients such as adolescents or persons who live in outlying areas
 - concurrent clinics for adults and children
- The level and depth of client involvement in task forces and advisory committees varies greatly across Title IV projects. While in many Title IV projects clients are active participants in task forces and advisory committees, there are a few projects in which client involvement remains somewhat *pro forma*. Although clients may hold a position on a task force or advisory committee, their role is minimal.
- Projects that have had difficulty recruiting new clients to fill staff, advisory, or volunteer roles attribute this to client reluctance or disclosure and confidentiality issues. The same client often serves multiple roles (advisory committee member,

peer educator, and volunteer). In such instances, projects may not be receiving an adequate representation of client views and concerns if new clients are not being successfully recruited.

- Title IV projects that have been successful in recruiting clients as staff, volunteers, or advisors have developed a number of strategies to improve the quality and quantity of client involvement. These strategies include:
 - open, individual discussions with clients to assess their readiness to adopt more active roles within the project
 - client and family training in personal advocacy, HIV/AIDS policy, leadership skills, and public speaking (provided by 64 percent of Title IV projects)
 - use of more informal settings such as lunches or parties to elicit client perspectives and opinions about project staff and services
 - providing clients with the opportunity to decide when and how they wish to participate in project activities
 - hiring clients as staff (offered by 42 percent of Title IV projects)
- Sixty-one percent of Title IV projects provide staff training in developing collaborative relationships with families.
- Sixty-seven percent of Title IV projects provide cultural sensitivity training and in-service sessions to staff. However, these trainings are generally offered only once and without any follow-up or educational reinforcement. Therefore, cultural competency must be incorporated into service delivery, project setting, and project administration if it is to be reinforced and effective.
- In projects where client support groups have thrived, they have been client initiated and/or led and have persevered despite periodic lapses in attendance. Project staff and clients have worked together to maintain support groups throughout the groups' various stages of development.

F. **Services**

Are clients receiving the array of comprehensive medical and social services that they need?
--

1. **Discussion**

Women, children, and adolescents, despite their unique medical and social service needs, share a need for a comprehensive range of services. This spectrum of services ranges from HIV prevention/education and outreach to medical care and ancillary services. As described in the previous section, Title IV projects not only provide these services, but have improved the ways in which these services are delivered by addressing issues of accessibility, acceptability, coordination of services, and collaboration with outside service agencies.

There are individual service needs however, that cannot be addressed with a universal or broad approach. Rather, a more specific delivery approach is required which addresses the accessibility, acceptability, coordination, and collaboration issues specific to the individual service need. Title IV projects have developed a number of creative approaches to address the obstacles presented by individual services. These approaches take into account client needs, characteristics of the individual service, and the system and environment in which the service must be delivered.

Yet, despite even the best efforts, there remain specific challenges related to individual service needs that cannot be addressed within the scope of Title IV projects. Some services may be hard for clients to access without transportation assistance, while other services may not be culturally appropriate. And in some cases, some services may simply not be available. Thus, it becomes imperative to highlight the challenges that remain in providing these services so that future efforts, program developments, and policy changes can address these issues.

This section describes each of the key service needs of Title IV clients, along with the common approaches and successful strategies used by projects to improve these services. Additionally, the remaining issues and challenges specifically related to each service are described as well.

a. HIV Outreach, Education, Counseling and Testing

In the absence of a vaccine or cure, HIV/AIDS has highlighted the importance of prevention, education, early intervention, and outreach efforts as our only methods of controlling the spread of the disease. These efforts encompass individual counseling sessions and peer-to-peer outreach, as well as group education sessions and mass media campaigns. Early intervention efforts involve identification of persons with HIV infection early in the stages of the disease so that both treatment can be initiated and so that these individuals can learn ways to reduce further transmission of the illness. Title IV projects have incorporated HIV outreach, education, counseling, and testing into systems of care through strong linkages to existing HIV prevention efforts or by launching their own new and innovative prevention programs where they are needed.

Approaches

Community education. To enhance community understanding about HIV/AIDS and build collaborative relationships with community agencies, Title IV projects, including clients, have engaged in broad-based community education. Such educational efforts include seminars and workshops, lectures, special presentations, radio and television public service announcements, and even call-in television talk shows.

Staff participation in "Speakers' Bureaus." Speakers' bureaus, roundtables, and other public speaking forums provide Title IV projects with an opportunity to raise awareness among community groups (especially those outside of the health/social services professional community) about the many issues surrounding HIV. These forums highlight the efforts of individual projects, provide opportunities for future collaboration with community agencies, expand possibilities for volunteers, and inform communities about the various services that projects provide.

Outreach/case finding. Outreach/case finding includes numerous strategies such as HIV testing and counseling of runaway youth, injection drug users (IDUs), and the homeless in their neighborhoods. Collectively, 32 of the Title IV projects, either directly or through agreements with local HIV/AIDS outreach agencies, have provided education, counseling, and referral services to 17,732 enrolled clients and 54,677 individuals between January and June of 1994. Through group encounters/educational sessions, these projects also reached 115,820 individuals, approximately one-third of whom were adolescents (Lewin-VHI, Inc.).

Title IV projects and collaborating agencies have provided education, counseling, and testing in substance abuse treatment centers, emergency rooms, and other arenas where high-risk populations might be found. Individuals who have agreed to be tested and have tested HIV-positive have been referred to Title IV projects and other

AIDS service organizations for assistance in accessing and coordinating the medical and social services they need.

Peer education. Peer education efforts employed by Title IV projects generally describe one-on-one education and counseling services provided to clients once they have been enrolled into the project. Such efforts usually emphasize transmission prevention, healthy lifestyles, and personal support and education and are usually offered by a trained client already enrolled in the project. Half of the Title IV projects that were visited (9/18) currently use peer educators as a method of client education, outreach/case finding, and community education. The use of clients or “peers” as educators offers several advantages. Peers can serve as role models and a source of social support to new clients. Peers also can more readily relate to the many issues new clients face, since they share common concerns. Peer education was a key feature of projects serving adolescents.

Early intervention and the WIN initiative. As a result of the findings from the ACTG 076 clinical trials, it has become increasingly important that women who are HIV-infected and are either pregnant or are thinking about pregnancy have access to ZDV during pregnancy and labor and for their newborns. Thus, 61 percent (11/18) of the site-visited Title IV projects have taken formal, proactive steps in reducing perinatal transmission of HIV. These projects provide HIV testing, counseling, and referrals for ZDV treatment to pregnant women in emergency rooms, family planning clinics, public health clinics, and pre-natal clinics. Several projects also described community-wide strategic planning processes they have initiated to establish guidelines for testing and counseling of pregnant women as well as educating women and the surrounding community about the importance of early ZDV treatment during pregnancy.

Professional education. To raise awareness about medical treatment of HIV and the importance of HIV education, testing, and counseling as standard medical care, Title IV projects are providing training and education to both inpatient and outside-agency medical staff.

Participants in Title IV professional education activities:

Outreach workers	Nurses
Child welfare professionals	Physicians
Substance abuse professionals	Educators
Mental health professionals	Case managers

Topics of professional education sessions:

HIV education/prevention	substance abuse
HIV treatment and care	child development
cultural competency	HIV research
tuberculosis testing/treatment	cultural competency
psychosocial issues (family and individual)	clinical practice updates

(source: *Lewin-VHI, Inc.*)

Additionally, Title IV projects provide educational opportunities to allied health professionals such as case managers, substance abuse counselors, and outreach workers. According to data collated by Lewin-VHI, Inc., between January and June of 1994, 32,406 health and social service professionals received HIV/AIDS education and training across 32 of the Title IV projects. Approximately one of every four participants was a nurse.

Professionals received training in the form of seminars, site visits to Title IV clinics, training courses, and grand rounds. The topics of these training sessions covered not only HIV education and prevention, but psychosocial issues of individuals and families, child development, tuberculosis testing and treatment, and current research findings.

Issues

Reluctance to provide HIV education. Title IV project staff have consistently reported that certain local organizations, particularly local schools, are reluctant to provide students with HIV/AIDS prevention and education information. Controversies center on the type of education that children and youth should receive and who should provide this education. These controversies have galvanized communities along religious and political lines and have hampered projects' efforts to educate young people about HIV/AIDS and how to protect themselves.

Lack of routine HIV testing and counseling in the private medical community. Title IV medical and outreach staff frequently raised concerns that private providers, especially obstetricians and gynecologists, are not routinely offering HIV testing and counseling services to their patients. They worry that private medical providers perceive "high-risk" individuals as poor and minority and thus do not consider their own patients as being at risk. As a result, this segment of the population does not have adequate access to HIV education, testing, counseling, and early intervention. Furthermore, physicians are missing opportunities to identify cases of HIV infection earlier in the course of the disease.

Lack of universal HIV testing of pregnant women in hospitals. Several Title IV medical and outreach staff have expressed concern regarding a common hospital practice of only offering HIV testing and counseling to women perceived to be "high risk" and not to ***all women***. This practice has led women to feel singled out and has unfairly excluded other women from receiving information about HIV/AIDS, ACTG 076 results, and other available treatment and service options. Project staff also emphatically cautioned that outreach and testing strategies related to ACTG 076 be carefully considered and that providers have clear guidelines on how to counsel women on this issue.

b. Coordination of Medical Services

Regardless of their age, gender, or extent of disease progression, people with HIV/AIDS need a combination of routine and specialized medical care. Unfortunately, they often lack access even to basic primary care. Title IV projects have responded to the need for access to both primary and specialty medical care by providing clients with a range of services, emphasizing

quality outpatient care and the reduction of hospitalizations and emergency room visits. Title IV projects have also designed outpatient and ambulatory care services to emphasize health maintenance by providing clients with prophylactic care such as bacrim to prevent pneumocystis pneumonia, immunizations for children, and isoniazid (INH) to prevent tuberculosis. Guidelines and support for proper nutrition, exercise, and general healthy living are also offered to clients in the outpatient clinic settings.

In addition to delivering medical services, Title IV projects have participated in the design and development of services and models of service delivery. As a result of their vast experience in providing medical services to women, children, and adolescents, Title IV projects have provided leadership, direction, and insight and in many cases have pioneered efforts to establish state and national guidelines for the care of persons living with HIV.

Approaches

Adult and pediatric HIV care. Sixty-one percent (11/18) of projects visited provide adult *and* pediatric medical care either in the same clinical space or in the same general location. Pediatric medical services include immunizations, well baby care, and developmental assessments. Adult HIV care provided by Title IV projects commonly consists of primary care, including gynecological care, HIV care such as preventive therapies for tuberculosis and pneumonia, immunological treatments, and HIV treatment.

Medical services provided by Title IV projects

- primary care
- prenatal/obstetric
- gynecology/family planning
- HIV testing
- outpatient specialty care
- other outpatient care
- developmental assessments
- nutritional support
- inpatient care
- TB screening, counseling, and treatment

Establishment of referral linkages with local health care providers for HIV specialty care. Referral linkages with local health care providers assist Title IV projects in increasing client access to needed medical services that cannot be directly provided. Persons living with HIV/AIDS require not only basic primary medical care, but at times, specialized HIV-related care that is not always available at Title IV project sites.

Linking HIV counseling and testing with medical care. Sixty-one percent of the site-visited Title IV projects (1 1/18) have established collaborative relationships with outside agency medical staff to facilitate the integration of HIV testing and counseling into medical standards of care, particularly obstetric care. Such efforts provide opportunities for early intervention and treatment for persons who may not come into contact with Title IV projects until much later in disease progression. Subsequently, in this population, access to ZDV during pregnancy may reduce the risk of perinatal transmission of HIV.

Joint case conferences. In an effort to bridge the gap between adult and pediatric HIV care, increasing numbers of Title IV medical staff have begun to coordinate adult and pediatric care through joint case conferences. Some projects have established formal case conferences to share adult and pediatric medical care information, while other projects maintain frequent but informal contact with adult care providers on an as-needed basis. This strategy not only has implications for the improvement of family health and well-being, but bridges the sometimes wide gaps between adult and pediatric HIV care.

Inquiries about the health of adult caregivers. Pediatric care providers across Title IV projects are more frequently inquiring about the health of the parents and caregivers of pediatric clients. Even the most informal inquiries about the health of the entire family can help alert health care providers to possible crisis medical situations that will ultimately affect the health of the family, including the children.

Internships and medical rotations through Title IV clinics for primary care providers. Increasing numbers of Title IV projects located within academic medical centers have formally established clinic rotations and internships through their Title IV clinics. Approximately 40 percent of Title IV projects are based in academic medical centers, which gives them potential access to a constant pool of primary care medical staff and residents. Projects have numerous opportunities to add to a resident's or intern's cadre of medical knowledge, thereby increasing awareness and understanding of the many medical and social aspects of HIV throughout the medical community.

Shared and donated nurse and physician staff with other clinical programs. Across Title IV project sites, medical resources in the form of nursing or physician staff are either donated or shared with other programs in the same clinical setting or

system of care. These shared and/or donated resources increase client access to needed medical services and reduce financial strain on project budgets.

Development of adolescent-focused service components. Several project sites have focused attention in recent years on enhancing adolescent services. Approaches varied and included:

- Establishing linkages with the adolescent department within the project clinical/hospital setting
- Developing an adolescent HIV clinic that is separate from the adult and pediatric clinic and staffed by a specialist in adolescent medicine
- Providing services to adolescent women within the adult clinic but with specialized, youth-focused outreach efforts and a focus on adolescent issues.

Issues

Lack of concurrent or co-located services. Providing services for adults and children in the same clinic space or even the same building can ease a family's access to medical care. Due to financial and staffing constraints, concurrent clinics or co-located medical services for adults and children cannot be offered at most Title IV projects. While the scope and quality of medical services available for children may be quite exceptional, medical staff at these sites frequently expressed frustration that they are not able to provide such care to HIV-infected parents. Adult focus group participants in several sites also expressed their frustration in trying to obtain needed medical services for themselves at other service locations.

Lack of pediatric and ob/gyn linkages. Four of the sites visited have established formal linkages and coordination with ob/gyn and pediatrics, and one project is attempting to forge stronger linkages. However, most projects reflect the historical split between the two professions and had only ***ad hoc*** relationships. This schism has implications for effective application of the PHS recommendations for perinatal ZDV therapy since HIV counseling, testing, and ZDV treatment for pregnant women and their newborns require staff coordination on behalf of both obstetricians/gynecologists and pediatricians.

Insensitive staff at outside medical agencies. Focus group participants commonly reported that medical staff at outside agencies, particularly inpatient and emergency room staff, tended to be insensitive to their situation. This insensitivity intimidates many clients and they are reluctant to seek medical assistance from agencies outside the project. This situation hinders coordination with outside medical agencies and impedes client care.

Lack of services for the uninsured. Clients who do not meet the financial eligibility criteria for entitlement programs are also not eligible for entitlement-funded services. In the first half of 1994, 11 percent (2,240) of the clients served by 27 of the Title IV projects were uninsured. This lack of financial coverage for needed services greatly impedes access to needed medical and social services. Clients must either pay for services themselves or rely on project staff to try to arrange for access to *pro bono* medical and social services from local agencies or provide the services themselves.

Lack of services focused on adolescents. Two of the eighteen visited projects are entirely youth-focused and include on-staff specialists in adolescent medicine. However, several staff in other project sites have expressed concern about the lack of services specifically for youth. Staff emphasized that adolescent service needs and issues are substantially different than adults and pediatric clients because of the convergence of developmental and physical changes that require specialized medical approaches.

c. Case Management Services

Case management has long been used by social service providers to help link clients to the services they need. There is no single definition or approach to case management, but in general it is a process to help individual clients and families identify their service needs, determine how these needs can be met, and to help assure that services are delivered.

Case management services are a particularly critical component of the Title IV projects because of the array of medical and

social services needed by persons with HIV/AIDS. Typically these services are provided by multiple service agencies, each with its own eligibility requirements, administrative protocols, and funding streams. Navigating through these various systems of care often requires more skill, time, and resources than many individuals and families have. The challenge is even more daunting for clients served by the Title IV projects, given the chronic and debilitating nature of HIV/AIDS and its impact on multiple family members. Further, many non-HIV community agencies have been slow to accept their responsibility to serve the HIV-infected population.

Case Management Components
<ul style="list-style-type: none">• Client/family identification and eligibility determination• Comprehensive client/family needs assessment• Development of a service plan• Implementation of the service plan: linkage and coordination• Monitoring of service delivery• Advocacy/individualizing services• Evaluation• Termination/case closure• Empowering the family• Service system networking and capacity building

Approximately 60 percent of Title IV projects reported that they assign case managers to *all clients*. Another 10 percent assign case managers to at least 75 percent of their clients. The remaining projects assign clients to case managers based

Outside agencies most likely to provide Title IV clients with additional case management include:

- Child welfare agencies
- Adult HIV care programs
- Title V agencies

on various criteria, including level of client need, client-to-case manager ratios, and the availability of outside case management services. Project staff in one of the sites visited pointed out that not all clients accept case management and it is not a requirement for receiving other services provided directly by the project. Projects also reported in their self-studies that clients are likely to have at least one other case manager from an outside agency in addition to the Title IV case manager (reported by 75 percent of the projects), and sometimes as many as two case managers (reported by 21 percent) or even three (reported by one project). These outside case managers rarely address the breadth of issues that HIV-affected families bring, but represent an additional coordination challenge for the Title IV case managers, who typically assume the lead role.

Approaches

Because Title IV projects bring different orientations to case management and have varying goals and objectives, the range of activities involved in case management vary widely across projects. Also, the level of service integration in a community,

“My approach ‘to case management is to-give myclients hope...”

Case manager

the range of services that are available and part of an integrated network, and the goals and objectives of a particular Title IV project impact the roles and activities required of case managers. In addition, the setting in which the case management services are based and the intensity of services required by clients impact the ultimate design and shape of case management models currently in use by the Title IV projects.

Setting

Clinical or hospital-based case management. Within this approach, clients are assigned to a clinical social worker or a nurse case manager for coordination of medical services within the clinical setting. Client medical referrals, appointments, inpatient care, home health care, and other needed medical services are coordinated

by this staff person. Clients are referred to community-based organizations and other social service agencies for assistance with social support needs.

Community-based case management. In a community-based approach to case management, clients are assigned to a social worker or case manager within the community or outside of the clinical setting for coordination of social services needs. This approach emphasizes coordinating services with community-based social support agencies in the clients' communities. Community-based case managers also serve as liaisons between Title IV projects and community-based agencies, thus improving collaboration between the two entities.

Clinical trials case management. Clients enrolled in clinical trials may be assigned to a specific case manager who coordinates trial visits and any services that clients require related to their participation in the trials as well as their own health needs. In conjunction with other clinical trial staff, these case managers educate clients about trial requirements, benefits, and disadvantages, and address any concerns clients have about participating. They also help ease the burden of other case management staff by addressing client needs specifically related to the clinical trial, such as transportation or child care during trial visits.

Level of Intensity

High-intensity case management.

Many clients and families are in crisis when they enter a Title IV project and as HIV disease progresses. They require such basic services such as food, housing, money, and emergency medical care as well as assistance with mental health and substance abuse problems. Often, clients

and their families have multiple problems which each require immediate attention. And, in addition, the urgency with which clients require these services is often exacerbated by their HIV infection. After initial and recurring needs assessments, those clients/families who are found to be in crisis often are assigned to a "high intensity" case manager or "family case manager." This staff person helps stabilize the family by coordinating immediately required services such as food, shelter, or emergency mental health. In the first half of 1994, 63.9 percent (6,473) of Title IV clients were assigned to high-intensity case management as a result of such intense and complex service needs (Lewin-VHI, Inc.).

The community-based organization, that provides case management services for one project recently developed- an intensive case management component patterned after the family preservation model. Families -in crisis are assigned to a case manager who makes frequent home visits for a period of about 6 weeks. Once the family is stabilized they are then transitioned back to the regular case management services.

Low intensity case management. Clients or families who, after initial and recurring needs assessments, are not found to be in crisis, are assigned to “low-intensity” or “adjunctive” case management. Between January and June 1994, only 11.5 percent (1,168) were assigned to low intensity or limited case management (Lewin-VHI, Inc.). Clients receiving this level of case management receive help in obtaining less urgently needed services, and case managers emphasize coordinating HIV medical services and helping families become more independent and self-sufficient in obtaining services.

Project staff also identified a range of **mechanisms to incorporate a broad range of input into the service planning** and implementation to ensure that clients’ multiple needs are addressed and multiple agency/staff perspectives are coordinated:

Client-specific case conference meetings. Client-specific case conferences, either within the project or with outside agencies, provide a forum to address unique client issues that a case manager may face in coordinating services for a particular client. These conferences also bring various agency staff together in a collaborative manner as participants contribute their personal expertise or knowledge. Participants also have the opportunity to learn about the different resources that are offered by other staff and/or agencies.

Case management committees. Several issues, such as the lack of certain services, transportation issues, or duplication of services, require system-wide efforts to address. Title IV projects participate in case management committee meetings to address such issues. Case managers from within the projects and from outside agencies address collaborative approaches to provide services that are absent, improve the way in which services are coordinated, or reduce duplication of services across agencies.

Project staff also described **approaches that served multiple purposes** of assessing accessibility and acceptability of services, helping clients learn their way around the service system through staff efforts as well as through peers, and augmenting their own services and efforts.

Client accompaniment to initial referral appointments. In an effort to ease client concerns about outside referral services and reduce the number of missed referral appointments, case managers frequently accompany clients to initial referral appointments. This practice provides case managers with an opportunity to teach clients how to access and negotiate needed services for themselves, thus fostering independence and self-sufficiency. In addition, case management staff are able to directly observe how clients are treated when they access referral services and immediately address any problems that arise.

Case management support staff. Many Title IV projects have incorporated various features to reduce the physical and emotional burdens on case management staff. Support groups, mentors, and trained volunteer “buddies” can help expand the encouragement, support, and practical assistance that are typically provided by case managers. Also, these staff assist with the multitudes of paperwork and data collection required by entitlement agencies and funding sources.

issues

Case managers across Title IV projects are extremely dedicated and gifted in working the system to coordinate the services clients need. However, despite the talent, dedication, and perseverance of individual staff, several issues related to service coordination remain. Case managers identified numerous obstacles they frequently encounter while coordinating client services.

Overwhelming caseloads of multi-problem clients.

Regardless of the specific approach to case management, many case managers are faced with steadily increasing caseloads of clients with numerous and complex service needs. Meeting all

of these service needs leaves little time for the intensive needs assessment and frequent follow-up most case managers feel are required. The number of primary clients per case manager ranged widely from 10 to 176 (median = 35) and the number of family members followed by case managers ranged from 18 to 680 (median = 102). The size of the caseload has implications for the approach that case managers take and the range of functions they are able to fulfill. Several projects indicated that the numbers of new clients and the lack of resources for additional case management staff force them to transition families who no longer have an HIV-positive child (because of seroconversion or death) to other adult-focused agencies for case management services. Most expressed concern that these other agencies usually carried even larger caseloads and provided only minimal case management services.

Clients often have multiple and complex service needs: . . .

- acute medical problems (endstage of illness)
- mental health problems
- acute substance abuse problems
- homelessness
- domestic violence

Services are not available.

The best case management efforts and skills cannot obtain services that are not available. This requires more systemic efforts such as the development of collaborative relationships, funding opportunities, or advocacy. The lack of needed services is one of the biggest obstacles case managers face.

Percentage of Title IV projects reporting gaps in needed client services (N=18)

mental health services	83%
housing assistance	83%
transportation	78%
substance abuse treatment	67%
child care services	61%
respite and hospice care	44%

Lack of services for adolescents. Case management staff from 44.4 percent (8/18) of site-visited Title IV projects reported an increase in the number of adolescents infected with HIV and other STDs and reported that available services are not sufficient to meet the demand. Projects also indicated that available HIV medical and social services are either child-oriented or adult-oriented. Adolescents do not seem to “fit in” anywhere and thus have difficulty finding services that they need in a setting where they feel comfortable.

Lack of familiarity with HIV at referral agencies.

Focus group participants across Title IV projects indicated that they have at one time or another encountered insensitivity, ignorance, or discrimination from staff at outside agencies. As a result, clients do not want to return to agencies where they have had a bad experience and they inform other clients and friends about the manner in which they have been treated.

“I have many problems with staff at other agencies... other agencies are not as nice and understanding as the project staff are.”

Focus group participant

Clients fail to keep referral appointments. Clients may not keep referral appointments for a number of reasons: they may not feel comfortable discussing their HIV status with staff at other agencies, they may fear being seen by family or friends at an “AIDS” agency, or they may not be ready to accept that they are HIV-infected. Sometimes the effects of active drug use or other personal challenges get in the way. As Title IV clients become known for missing appointments, referral agencies may become less inclined to assist future Title IV clients.

Stigma and fear in the community about HIV. Despite national campaigns and local project efforts to educate the public about HIV and to raise awareness and sensitivity around the issue of HIV infection, there still exists widespread fear and distrust about HIV and those living with the illness. Many clients still face

discrimination and bad treatment when attempting to access such services as child care, housing, or even medical services.

d. Substance Abuse Treatment Services

Access to substance abuse treatment services is limited in general, but the shortage of treatment slots, particularly inpatient, is extremely acute for women with children. In the course of addiction, many women who abuse drugs express a desire to quit using drugs and many will try. However, relapse is common and many give up, particularly those who do not receive help. The window of opportunity for entering treatment--when a woman is motivated to do so--is often fleeting. Thus, the immediate availability of a treatment slot can mean the difference between treatment and continued substance abuse. But the lack of alternative child care and fear of losing their children prevent many women from entering drug treatment programs.¹⁶ In addition, long waiting lists and lack of immediate access to treatment services further hinder women who are seeking help.

Recognizing both the lack of treatment services in their areas and the negative impact that substance abuse has on physical and emotional well-being, projects have begun to look for alternative approaches to meeting the support and treatment needs of women who abuse drugs. These various approaches address not only issues of access to treatment services but also issues around social support and education about substance abuse and HIV infection.

Approaches

Incorporating substance abuse treatment into project services. On-site substance abuse counselors, substance abuse screening at intake, and subsequent treatment describe examples of efforts that two of the eighteen site-visited projects have implemented to meet the treatment needs of clients who abuse drugs.¹⁷ Clients can receive substance abuse-related services along with HIV-related services, thus

¹⁶ Jessup, M. 1990. The treatment of perinatal addiction: identification, intervention, and advocacy. *Addiction Medicine* [special issue] *Western Journal of Medicine*; May (152): 553-558.

¹⁷ According to data collected by Lewin-VHI, Inc. between January and June of 1994, 58 percent of Title IV project service entities (N=81) provided substance abuse treatment services to pregnant women and mothers under the age of 22 and 59 percent provided treatment to pregnant women and mothers over the age of 22. Additionally, 50 percent of the reporting entities provided substance abuse counseling and education to pregnant women and mothers under the age of 22 and 78 percent provided counseling and education to pregnant women and mothers over the age of 22. Similarly, 70 percent of the projects provided substance abuse support groups to pregnant women and mothers of all ages.

maintaining a continuity of care. In addition, clients can receive services in an environment in which they are comfortable and are familiar with the staff and the philosophy of care.

Cross-training staff. Although substance abuse (particularly injection drug use) has been closely linked with the HIV epidemic for at least a decade, cross-training and collaboration between HIV and chemical dependency staff are not always routine. Chemical dependency counselors are naturally focused on their clients' sobriety, and legitimately fear that learning one's HIV status may jeopardize a fragile and hard-won sobriety. HIV care providers, on the other hand, are not always trained in the nuances of chemical dependency--the fits and starts of relapses, the fleeting opportunity to enter treatment, the temptations that old neighborhoods and old friends may pose. Because of the overlap in chemical dependency and HIV, cross-training and other means of understanding each others' perspectives can help individual providers, as well as the services they provide for their clients.

Establishment of direct referral linkages with local substance abuse treatment agencies. A direct referral linkage with local substance abuse treatment agencies has allowed almost one-third of the visited Title IV projects to reserve treatment slots for clients, especially women with children and pregnant women. In the event that a client has expressed a desire to get help with her addiction, this window of opportunity can be utilized immediately and the client can be placed into treatment right away.

On-site support groups. Access to support groups for clients who abuse drugs or who are in recovery can be an excellent support mechanism and help prevent relapse. Clients in recovery can offer mutual support to each other, discuss issues of recovery, and provide support during crises, the most vulnerable period for recovering addicts.

Issues

Title IV projects and their clients encounter numerous roadblocks when trying to obtain substance abuse treatment services. Thirteen of the eighteen visited Title IV projects reported a lack of substance abuse treatment services in their catchment areas, particularly for women with children. Other issues impeding accessing to substance abuse treatment include:

Long waiting lists for treatment services. Every year nearly a million substance abusers who seek treatment cannot find an available space in a treatment facility.*

¹⁸Stang, L. and Miner, K. Drug Use Prevention: Health Facts. ETR Associates. California: 1994. p.73.

This lack of available treatment slots, as noted earlier, is an even larger problem for women with children.

Fear of losing children. Child protection legislation has become increasingly punitive against mothers who abuse drugs, especially pregnant women and women with small children. As a result, many women fear losing their children if they admit to substance abuse by seeking treatment. Instead, many women will try to quit on their own and many will fail.

Complexity of the problem. Substance abuse is an extremely difficult problem to address, requiring long-term, intensive intervention beyond the scope of most Title IV programs. Relapse is common and there is no guarantee that a person will accept and benefit from treatment at a particular point in her life. Abusers also vacillate between periods when they wish to quit using drugs and periods when they do not. Drug abuse also generally wreaks havoc with clients' daily lives. Instability can make clients who abuse drugs difficult to work with. At times they can be hard to locate, may fail to keep appointments, or are simply unreliable.

e. **Mental Health Services**

People living with HIV/AIDS face a multitude of physical and mental stresses. They may face hostility and fear from neighbors, friends, colleagues, school systems, and in some cases, even medical providers. Women may feel guilt about having transmitted the virus to their children and may suffer anguish over the prospect of leaving their children behind to an uncertain future. Youth with HIV/AIDS are forced to face their own mortality decades before they should have to. Young children may face temporary separation from their parents, frequent doctor visits, hospitalizations, or the permanent loss of a parent or sibling. In addition, the many issues surrounding disclosure of HIV status cause an added level of emotional duress. Thus, access to a variety of mental health services can help alleviate the stress, despair, and mental anguish that many experience as they face their illness and its grim prognosis.

Projects reported that there is a great need for supportive and therapeutic mental health services, especially for families and children. In an effort to meet these needs, Title IV projects have developed several different approaches to provide various types of mental health services to clients in need.

Approaches

On-site mental health services. The lack of appropriate mental health services for persons living with HIV/AIDS has led 23 Title IV projects to expand their current program components to include on-site mental health services. Counselors,

psychologists, and psychiatrists provide either part-time, volunteer, or full-time mental health support in an environment that is accessible, familiar, and tailored to the needs of persons living with HIV.

Referral linkages with local mental health providers. One-third of the site-visited projects (6/18) indicated that they have established formal referral linkages with local mental health agencies to improve client access to needed mental health services. Families face numerous crises in their struggle to live with HIV disease. In the course of HIV diagnoses and disease progression, there are many points at which families need additional support. The onset of a crisis often requires more professional mental and emotional support than can be provided by project staff.

Support groups. Seventy-one percent of Title IV projects offer client support groups in all of their service locations (22/31). Support groups can be an excellent mental health resource for individuals and families living with HIV/AIDS. The sense of helplessness and isolation that many infected individuals and families face can be overwhelming. People have an opportunity to discuss issues and concerns with others who share similar experiences. They also have the opportunity to build supportive relationships with each other, relationships that are otherwise absent in their personal lives.

Pastoral care. Focus group participants frequently stressed the importance of religion and/or spirituality in their lives and ways it has helped them face their illness. Through either referral or on-site volunteer pastoral care staff, 18 percent (6/33) of the projects have helped clients draw on spiritual support services such as church support groups, bereavement counseling sessions with religious leaders, or assistance with funeral arrangements.

Family counseling services. Through mental health counselors, family psychologists, or other mental health specialists, Title IV projects have begun to offer an array of family counseling services. These services include assistance with permanency planning for children, parenting skills training for caregivers, and information about safety precautions in the home, in addition to family counseling. Family counseling also plays a key role in helping families cope with both the illness and the loss of a loved one. The illness of a family member disrupts all aspects of family life, including role, responsibilities, and relationships between family members. Family counseling is essential in helping a family cope with and survive an HIV diagnosis.

Art therapy for children. Forty-three percent of the Title IV projects (14/33) have staff or volunteers working with infected children and their siblings during clinic visits. While working with children, staff help them work through their different feelings through the art that they create. The effectiveness of art therapy as a therapeutic intervention for children with chronic or terminal illness is well

documented in the literature. Art therapy provides an outlet for children to informally and creatively express their feelings and emotions about being sick without verbalization.

Issues

Eighty-three percent (15/18) of the site-visited projects reported a dearth of mental health services for clients. Further, they reported several concerns related to the quality and appropriateness of mental health services that are available.

Lack of culturally appropriate mental health services. Across all projects that were site-visited, staff reported a lack of culturally appropriate mental health services. In some cases, the services are not appropriate or helpful in addressing the mental and emotional needs of persons diagnosed with a terminal illness such as HIV/AIDS. In other cases, clients of color are uncomfortable with mental health providers of different ethnic backgrounds. Additionally, there are few mental health services for non-English speaking clients.

Lack of mental health services for families as a whole. Project staff across the sites that we visited also reported a lack of *family-centered* mental health services. Services provided by outside agencies were described as either adult-focused or child-focused with few services available for families. Families living with HIV have unique emotional issues such as learning to cope with the illness, dealing with the death of a family member, and simply learning how to function as family during periods of crisis,

Lack of mental health services for adolescents. The mental health needs of adolescents infected with HIV can be particularly acute. Besides dealing with the diagnosis of HIV infection, these youth also must face the issues surrounding normal adolescence--puberty, self-identification, and maturity. Mental health services for adolescents must address all of these issues and their inter-relationship. Unfortunately, mental health services for these adolescents are scarce.

f. Family Support Services

Families living with HIV/AIDS require a broad range of services to cope with both daily life stresses and the added burden of living with HIV/AIDS. In some cases families may need help with

“If you can care for the parents, they can care for the children, and the child can do better.”
Focus group participant

overdue rent, late utility bills, household chores, or other finite, crisis-driven types of assistance. Everyday needs may include assistance with transportation, child care, housing, or legal advocacy. Projects have developed approaches to providing various types of support services.

Approaches

Child care services. Access to child care services during both medical and social service appointments is imperative. Parents or caregivers may require assistance with child care while other children have appointments or during their own appointments. In an effort to meet this need, projects have developed on-site child care services using staff or volunteers or have established cooperative agreements and/or referral linkages with local child care providers.

Services	Offered by all entities	Not offered
Child care during adult visits	64 percent (21)	12 percent (4)
Child care for other purposes	49 percent (16)	24 percent (8)
Home visits	74 percent (23)	3 percent (1)
Support groups	71 percent (22)	7 percent (2)

* Percentages do not add to 100 percent. Projects who reported variances across entities are not reported.

Home visits. When either children or adults become too sick to travel to medical or social service appointments, home visits and home health care become essential. Home visits allow project staff the opportunity to assess family needs in their own environments. Home health care provides sick children and/or parents with the medical care they need to survive without having to travel to medical appointments. Home visits also provide invaluable insights into a family's overall living situation, which may not be apparent in the clinic setting. Referral linkages with the local Visiting Nurses Association and other home health care agencies have allowed projects to provide home health care services to families who are too sick to come to clinic.

Support groups for family members. Support groups for family members infected or affected by HIV provide the chance to talk with others about common experiences, whether HIV-related or not. Support groups also offer support for

Bay Positives was started by young people for young people and continues to reach out to Bay Area youth of different racial and ethnic backgrounds and different sexual orientations.

Another project, has been successful in establishing youth groups for sexual minorities in area high schools.

parents. As in any family, parents often sacrifice their own needs for the needs of their children. Support groups give parents and other adult caregivers an opportunity to address their own needs. Similarly, support groups for adolescents play a key role in helping young people work through feelings of alienation and the struggle for independence, normal adolescent developmental issues which are exacerbated by HIV/AIDS. Currently, projects offer groups for foster parents, siblings, grandparents and other caregivers, for biological parents, and for adolescents,

Transportation assistance.

Transportation remains a barrier for families who do not own their own cars, cannot afford taxi service, or for whom public transportation is either scarce or difficult to manage. For mothers with small children, public transportation can prove either too time-consuming or exhausting, particularly if illness is a factor. All Title IV projects reported that they offer some type of transportation assistance to help clients get to medical and social services.

The following percentage of projects (N=33) reported that they offer transportation assistance:	
public transportation cards or tokens	100%
emergency transportation	99%
taxi vouchers	91%
van shuttle service	75%

Project staff also described a range of other approaches they have taken in an effort to meet families' support service needs:

- Referral linkages with family support and advocacy agencies help families with crisis situations such as emergency housing, food, clothing, and respite care.
- Donations and private grants have enabled some projects to provide such support services as emergency transportation, food, clothing, and gifts for children during holidays.
- Volunteer staff, graduate students, and designated "assistant staff" have enabled projects to provide such services as home health care, transportation, child care, and *pro bono* legal aid services.
- Twenty-two projects reported in self-study data that they hire clients and family members as paid or volunteer staff. With training, peer staff have served as administrative assistants, support group leaders, client advocates, child care assistants, and health educators.

Issues

Despite the creative efforts and approaches Title IV projects have developed to meet the social and logistical support needs of families living with HIV, numerous challenges to providing these services remain. Many of these challenges are more systemic in nature, such as a lack of certain services, long waiting lists, or legal requirements.

Child and respite care. Licensing requirements for child care facilities, lack of space, and difficulties recruiting appropriately trained staff were the main barriers project staff cited to providing or coordinating child and respite care services for clients. In site visit interviews, 61 percent (11/18) of projects reported a lack of child care services in their catchment areas.

Home visits. This useful but time-intensive activity requires staff time that is in short supply. In some cases, staff feel unsafe visiting clients' neighborhoods and in other cases, projects lack the resources to provide staff transportation to client homes. In addition, as caseloads increase over time, staff have less time to make home visits to all clients. Currently, case management staff have indicated in site visit interviews that they already have begun to limit the number of home visits to initial and emergency visits only.

Transportation. Services such as Medicaid-funded transportation often are not sufficient to meet the needs of families. Medicaid transportation services do not allow for the transport of siblings, some contracted taxi services do not provide child safety-seats, and most provide transportation for medical appointments only. Lack of transportation for social support services such as support groups, mental health services, or legal services greatly restricts families' access to these services.

Legal services. Legal services are typically offered by volunteer lawyers through a community agency, but often they are only available in the evenings. This can restrict access for clients, particularly those with young children. Also, clients without transportation have difficulty getting these services.

Support groups. Staff and clients noted that it is difficult to start and maintain support groups, especially when participants are uncomfortable or unfamiliar with discussing their personal feelings in a group setting. Support groups are also subject to the same transportation and other access barriers as other appointments. Both Title IV clients and project staff also expressed concern over the lack of support group services for specific family members such as groups for biological parents, foster care parents, adolescents, or grandparents. Focus group participants also expressed concern over mixing support groups for biological parents and other caregivers.

g. Housing Assistance

The lack of affordable and safe housing, especially in urban areas, has forced many families into crowded or substandard housing, or into homelessness. As their resources are further depleted by medical costs and forced unemployment, many people living with HIV have extreme difficulty finding and maintaining housing. Homelessness exacerbates physical and mental health problems; contributes to family break-up, substance abuse, child abuse, and neglect; disrupts education for children; and hinders child development. Homelessness also hinders access to needed services, thereby impeding efforts to coordinate needed medical and social services. Clients and families who are homeless or in unstable living arrangements are often difficult for projects to locate and therefore assist.

In an effort to address the above-noted issues, projects have developed approaches to secure safe and affordable housing for families. In some cases, projects have located housing for clients. And in some other cases, staff have worked with public and private housing agencies to improve client access to safe and affordable housing.

Approaches

Establishment of referral Linkages and collaborative relationships with housing agencies. Referral linkages and collaborative relationships offer an opportunity for Title IV projects to combine their efforts with those of housing agencies to locate suitable living arrangements for clients and families. Projects have assisted housing and shelter agencies in grant applications, fundraising activities, renovations, and advocacy.

Establishment of relationships with local realtors and landlords.

Discrimination, ignorance, and fear often prevent families living with HIV from finding safe and affordable housing. There have been countless cases of discrimination in renting and leasing practices, despite state and federal laws to prevent such discrimination. To address these issues on a local level, Title IV projects have begun to establish relationships with local landlords, realty associations, and other private housing groups.

“My case manager helped me find a place to live...and-when that didn't work out, she was able to find me another place.”
Adolescent focus group participant

Establishment of key contacts within local housing agencies. Title IV projects reported that establishing key contacts and liaisons within referral agencies is very effective in the timely and successful coordination of services for clients. Liaisons

and key contacts within local housing agencies quickly provide case managers with information on available housing and help reduce the paperwork and bureaucracy that often slows down the referral process, particularly for housing. Case managers can also personally negotiate housing arrangements for clients in crisis and can help establish housing priorities for families living with HIV.

Roommates/shared housing situations. Title IV projects have helped families locate housing they could afford by pairing up families or clients so that they can share housing. In many cases, Title IV clients often lack the financial resources necessary to secure appropriate housing. As a result, they are forced to live in unsafe, overcrowded housing arrangements which are not conducive to physical and emotional well-being, particularly for family members who are ill. Shared housing arrangements offer families social support as well as provide affordable, more suitable living conditions.

Issues

Fifteen of the eighteen site-visited Title IV projects reported a lack of clean, affordable housing for clients who require housing, especially those with families. Safe housing, especially for families with small children, and housing large enough for families with several children are special needs. Project staff identified other issues associated with housing needs for clients:

Long waiting lists and lack of funds for housing. As the number of homeless families increases, the demand for housing has exceeded the supply. In many cities, local funding for housing has been depleted and there are simply no more public housing units available. Thus, there are long waiting lists extending into months and years for local public housing. Unfortunately, families living with HIV/AIDS are among the many families awaiting housing assistance.

Community hostility and discrimination. Project staff have reported that landlords often refuse to rent to persons infected with HIV and that communities have reacted with hostility towards clients who move in. As a result of such hostility, families are forced to hide the fact that they are HIV-infected.

h. **Child Welfare Services**

Local child welfare agencies often become involved when parents are no longer able to care for children because of their own illness or death, or when substance abuse or domestic violence threaten the safety and well-being of children with AIDS.

In addition, runaway and homeless youth infected with HIV may be placed in foster homes or transitional living situations. As the number of children orphaned by HIV increases, the role of child welfare agencies in the care and placement of these children also will increase greatly. Thus, as the medical and social service providers for children with HIV, all Title IV projects have reported that they are in constant contact with the child welfare agency in their local area.

Approaches

While Title IV projects have encountered difficulties working with local child welfare agencies, they also have developed strategies to address these issues. Expanding collaborative relationships and formalizing referral arrangements are the chief ways that Title IV projects attempted to improve both project and client relations with child welfare agencies.

Shared staff with child welfare agencies. As local child welfare agencies become more involved in coordinating services for children with HIV, Title IV projects have had opportunities to combine their efforts. Child welfare staff may be detailed to a Title IV project on a part-time or as-needed basis to assist with coordinating social support services for children in custody.

Subcontracts or cooperative agreements with child welfare agencies. As the local provider of pediatric HIV services, Title IV projects have been called upon to provide HIV testing, counseling, and, if necessary, medical services to children in custody. In some cases, projects have been asked to provide HIV education, testing, and counseling in group homes and residential centers, and, in other cases, foster parents of HIV-infected children have been referred to Title IV projects to receive social and medical services.

Establishment of referral linkages with child welfare agencies. All projects reported in site visit interviews that they have established referral networks with the child welfare agency in their catchment area. As a last resort, in cases of medical neglect of children, Title IV projects reported that they have had to seek the assistance of the local child welfare agency. More commonly, however, Title IV agencies serve as the medical and social service providers for children in foster care or child welfare custody.

Case managers as family advocates. Project case managers are often the only support families have. Case managers not only facilitate access to needed services, but also provide emotional support and in many cases become confidantes and friends. Given their close relationship to families and awareness of the families' different emotional and physical strains, case managers are well poised to advocate on behalf of the family as a whole. Case managers have negotiated temporary care for children, advocated on behalf of mothers who seek to regain custody of their children, and assisted in permanency planning and adoptions.

Issues

The development of referral and collaborative relationships between child welfare agencies and Title IV projects has brought to the surface a number of issues related to delivering services for women and children infected with HIV/AIDS.

Child welfare regulations are often too punitive. Across the 18 projects we visited, both case managers and focus group participants expressed concern about the punitive nature of child welfare regulations. There was even greater concern expressed about the treatment of mothers who abuse drugs or fail to bring their children in for medical treatment. Staff and focus group participants indicated that child welfare agencies do not give mothers and families the opportunity to improve their situations through substance abuse treatment, parenting skills training, or other social support services. Instead, children are immediately removed from their homes and placed in foster care. It also has been more difficult for mothers who have had their children taken away to regain custody.

Child welfare agencies are child-focused, not family-focused. Focus group participants and project staff also have expressed concern that child welfare agencies are too child-focused. To many mothers or adult caregivers, it appears that such agencies are more concerned about the welfare of the child and not the welfare of the whole family. There are little or no social support services offered for families and not enough efforts are made to help families stay together. Project case managers have encountered difficulties in advocating for family preservation.

2. Key Findings and Policy Implications

Findings

- Projects are providing HIV outreach, education, counseling and testing services by linking with existing community efforts or by developing their own efforts when none exist. Over 17,000 clients and 54,000 other persons have been reached through individual counseling sessions. Over 115,000 people were reached through group sessions.
- Peer educators are used by half of the projects for outreach/casefinding, client education, and community education.
- Most projects are providing HIV testing, counseling, and referrals for ZDV treatment for pregnant women and many have initiated community-wide planning efforts to address counseling and testing issues. However, the traditional split between pediatrics and ob/gyn remains in most project sites, which could have implications for the effectiveness of such efforts.
- Title IV projects have provided training to more than 32,000 health and social service professionals including medical staff, case managers, substances abuse counselors, and outreach workers.
- The majority of projects provide pediatric medical care in the same clinic space or in the same general location.
- The majority of projects have linked with outside medical care providers to facilitate the integration of HIV testing and counseling into standards of care. Clinic rotations and internships increasingly are being used as mechanisms to accomplish this.
- Project directors across Title IV sites described case management as the heart of the projects and a focal point of project coordination and collaboration efforts.
- Nearly two-thirds of project clients are assigned to high-intensity case management services because of the complexity of their service needs. Case managers report steadily increasing caseloads that are beginning to require more staff time and project resources than many projects can spare.
- Faced with steadily increasing caseloads, Title IV projects are beginning to consider (or have already implemented) more rigid limits on eligibility for case management services. In addition, projects also may be forced to limit the intensity of case management services provided to clients and reduce the number of home visits and personal contacts.

- Some of the services Title IV clients require are either not available or are culturally inappropriate or do not address the specific needs of adolescents or women with children. The services most frequently described as unavailable or inappropriate are:

Mental health services
Substance abuse treatment services
Child care services
Transportation assistance
Child welfare services

- In response to these gaps, projects are expanding their own array of services. Twenty-three projects have added on-site mental health services to their mix of direct services. Other mental health-related services provided by many projects include client support groups, family counseling, and art therapy.
- In response to the increasing numbers of adolescents with HIV, Title IV projects have developed services specific to the adolescent population. Projects treat adolescents as a unique population with unique service needs rather than as additional clients for existing services.

G. **Clinical Trials**

Has the program had an impact on increasing participation in clinical drug trials?

1. **Discussion**

One of the major goals of the Title IV HIV program has been to link comprehensive systems of care with HIV/AIDS clinical research trials and other research activities to increase access for children, youth, women, and their families. Clinical trials are viewed as an opportunity to provide additional treatment options to individuals living with HIV, enhance client roles in their own treatment, provide clients with an opportunity to benefit themselves as well as others with HIV, and provide clients with the sense that they are combating the disease, now and in the future. Additionally, clinical trials are viewed as beneficial to service providers by offering state-of-the-art information about research results and procedures.

Title IV programs facilitate participation in clinical trials by addressing many of the barriers that have historically limited the ability of women and children (especially minorities) to participate, such as lack of access to care; lack of transportation, child care, or other support;

and protocols that are not designed to accommodate the special needs of children, youth, women, and families.

In the first half of 1994, a total of 996 clients were enrolled in clinical trials.¹⁹ This included 713 infants and children, 99 youth (including 38 adolescent women and mothers), and 184 pregnant women and mothers 22 and over. Of the total, 321 clients were newly enrolled in a research trial during this reporting period. Title IV projects are continuously working to improve access to research trials through the identification of eligible clients and by increasing the availability of research trials.

Approaches

AIDS clinical trials are established under a model that assumes a certain level of resources, motivation, familiarity, and comfort with medical environments among potential research subjects. None of these qualities comes easily for families with HIV. Typically, they represent a population that has had little or no interaction with the health care system prior to their HIV and are dealing with numerous complex issues in addition to their HIV. Title IV staff can play a key role in helping clinical trial staff understand the implications of the trial protocol for their clients. Similarly, they are uniquely positioned to help identify potential candidates for research trials and can play a key role in helping their clients understand the terms and expectations of the trials.

Strategies to ensure client access to clinical trials have included:

- providing on-site access by applying to be a primary research site funded by NIH
- collaborating as an approved sub-unit of another site
- arranging for research staff from other research sites to conduct trials in Title IV community sites
- referring patients to research sites, providing education about trials, and logistical support to facilitate their participation.

Title IV projects have worked to enhance client education strategies to help clients understand research protocols and their potential benefits and risks. Approaches to supporting client participation include intensive, one-on-one, client education with the trial director or a clinical trials case manager; designating a client advocate to discuss issues around clinical trials; providing transportation assistance; providing child care during clinical trial visits; and designating a clinical trial case manager to address specific client issues regarding the clinical trial.

¹⁹ Source: Lewin-VHI Tables 3A, 3B, and 4 data, 1995.

Many of the current Title IV projects are using innovative approaches to overcome barriers and increase the link between comprehensive systems of care and research activities. These approaches aim to identify client eligibility and increase client participation in research activities.

In one project, most care associated with clinical trial protocols is carried out in a community-based site. Primary-tertiary partnerships permit collection of blood and specimens and other aspects of protocol implementation during regular clinic appointments. Families accept and understand the protocol requirements better because the physicians and nurses who conduct the protocol are the same providers who see patients at the community clinics.

Another Title IV project uses a network outreach educator (NOE) in conjunction with the adult research team. The NOE provides education to families on the full range of research initiatives available to them. Research initiatives include HIV/AIDS clinical trials as well as research studies on the effect of HIV/AIDS on parenting, depression, death anxiety, and hope among female caregivers of children with HIV/AIDS.

Another project uses a clinical trials liaison (CTL) to inform women of available research within the medical setting as well as in the community for themselves and/or their family members. The CTL attends regular meetings in the community to disseminate and collect important information for clients.

Still another project has two pharmacists dedicated to working with clinical trial clients during clinic visits to answer any questions. Additionally, the pharmacists carefully monitor dosages and refills to be alert to adherence problems.

Currently, 155 AIDS clinical trials are open at multiple sites, nationwide. Fifty-five of these clinical trials focus on studying primary HIV infection. Of these, 44 are adult-focused and 11 are child and adolescent-focused clinical trials. Adult clinical trials are available in 35 Title IV-funded program communities.

Examples of AIDS Clinical Trials	
Sponsor	Trial Type
National Institute of Health	Drug/vaccine Perinatal transmission Behavioral and natural history
Centers for Disease Control and Prevention	Perinatal transmission seroprevalence (natural history studies)
American Foundation for AIDS Research	Perinatal transmission Behavioral interventions
Bristol Myers	Drug/vaccine
American Heart Association	Drug/vaccine
Serona Roche	Drug/vaccine
Burroughs-Wellcome	Drug/vaccine

Child/ adolescent clinical trials are available in 32 Title IV-funded program communities.²⁰

Issues

Title IV projects face multiple issues in ensuring client access to clinical trials. Key among these are clients' fear or suspicion of medical settings and professionals. The lack of trust among African-American clients can be traced back, in part, to the legacy of the Tuskegee study of

	Is an Issue	Not an Issue*
Fear or suspicion of medical professionals/clinical trials	66.7%	18.2%
Fear of medical settings/procedures	48.5%	30.3%
Release/consent issues	18.2%	66.7%
Distance/transit time to clinical trial site	51.5%	21.2%
Lack of transportation	45.5%	27.3%
Frequency/duration of visits (N=32)	59.4%	15.6%
Eligibility criteria	36.4 %	39.4%
Protocol requirements	42.4 %	33.3%

* Percentages do not add to 100 percent. Projects who reported variances across entities are not reported.

untreated syphilis, which was perceived as a racist experiment. The unethical nature of this experiment, as well as a widespread, general distrust of governmental agencies, has left many African-Americans very distrustful of federal research, trials, and experiments. Two-thirds of the Title IV projects report that issues of distrust were major barriers to trial participation for their client populations.

Additional issues that impede client participation in clinical trials identified by project staff include geographic distance, lack of transportation, and stringent eligibility and participation requirements.

Title IV project staff emphasized the important role that clinical trials play in the provision of care for HIV-infected women and children. However, they also noted that the eligibility requirements and the regimen that clients must follow once involved in the trials are sometimes exceptionally challenging for participants.

²⁰ Data acquired from the National Library of Medicine AIDS TRIALS on-line data system.

The specificity of requirements also narrows the potential population from which they can recruit. For example, for the ACTG 076 trial, women were eligible only during a certain stage in their pregnancies. Women who participated in the trial were seen once every 4 weeks up to 32 weeks gestation, and then weekly until delivery. Infants were seen at weeks 1, 2, 6, 12, and then every 12 weeks up to 78 weeks.

ACTG 076: A Phase-III Randomized, Placebo-Controlled Trial to Evaluate the Efficacy, Safety and Tolerance of Zidovudine for the Prevention of Maternal-Fetal Transmission

Eligibility:

- HIV-infected pregnant women (14 to 34 weeks gestation)
- No anti-retroviral treatment during current pregnancy
- CD4+ T- lymphocyte counts greater than 200
- No clinical indications for maternal antepartum ZDV therapy

Duration:

- Women from pregnancy to 6 months postpartum
- Infants from birth to 78 weeks of age

Methods:

- 477 pregnant women enrolled
- Randomized to receive ZDV or placebo
- Newborn infants received ZDV or placebo for 6-8 weeks
- Women seen frequently during pregnancy, through delivery, and for six months postpartum
- Assessed for evidence of drug toxicity, HIV disease progression, and fetal well-being

Number of Study Sites:

- 72 (50 US primary sites; 13 subsites; 9 sites in France)

2. **Key Findings**

- Title IV projects have been successful in enrolling nearly 1,000 children, youth, and women in clinical trials.
- Title IV projects provide a bridge between service delivery and research through a range of approaches including conducting the trials on-site at the Title IV project location, implementing the research in community-based settings, and providing staff who have a linkage and educational role.
- Efforts to enroll and retain low-income, medically underserved families in clinical trials are enhanced when the research is conducted within an established comprehensive system of outpatient and family support services, such as those developed through the Title IV program.

- Rigorous protocol requirements, coupled with clients' prevailing fears or suspicions of medical settings and medical providers, emphasize the importance of establishing trusting relationships for increased clinical trial participation. Title IV projects are uniquely positioned to fulfill this role and have done so through client and community education, client advocacy, and coordination of client needs and clinical trial requirements.

Chapter IV. Conclusion

It is clear from this evaluation study that the Title IV projects have increased access of children, youth, women, and families to comprehensive care. The programs served 17,732 enrolled clients during the first half of 1994, representing a 17 percent increase over the enrollment in the previous 6 months. The projects have been responsive to the growth and trends of the HIV epidemic, evolving and expanding to serve new and emerging HIV-affected populations, such as adolescents and women.

Title IV projects have enhanced access to clinical trials for children, youth, and women living with HIV, populations which traditionally have had limited access to research. A wide range of strategies has been employed to facilitate client participation in research, including shared research and care staff, new linkages with research sites, and provision of family and logistical support services. As a result of these strategies, nearly 1,000 clients participated in research during the first six months of 1994, including over 300 clients who were newly enrolled in a trial during this period.

From a client perspective, Title IV projects have had a tremendous impact. They have improved access to an array of needed services, meeting the immediate medical and social service needs of children, youth, women, and families. Beyond these services, Title IV grantees have fulfilled their mandate of making a difference in clients' lives by demonstrating that project staff care about their clients' overall well-being. Clients continually praised the compassion and dedication of staff. The combination of services and emotional support makes Title IV programs distinctive, and underlies the comment clients made repeatedly:

"Where would I be without them?"

Interagency collaboration, new linkages among diverse medical, social service, and family support providers; and innovations in service delivery among Title IV programs created new and improved services for the populations served by Title IV. In addition, training and professional education conducted by Title IV for community providers has resulted in more qualified personnel to deliver services to HIV-affected populations. New approaches to the organization of services, such as co-location of pediatric and adult care, have improved services to families.

Projects have involved families in the development and implementation of programs, with youth and family members as family liaisons, educators, and other support roles. Family involvement has been enhanced through training opportunities and leadership development sessions.

While this evaluation study has highlighted many project successes, it also provides insights into future policy challenges at the national and local levels. As the program as a whole and the individual grantees continue to grow and change to meet the evolving needs of their client populations within the context of their communities, they will need to be attentive to training and technical assistance needs, program priorities and future directions, and opportunities for forging new relationships.

Findings from this evaluation suggest areas for focus in the immediate future, including:

- **Training and technical assistance** in such areas as cultural competency staff training and policy development; administrative roles, relationships, and authority related to reporting, data collection, and overall service delivery policies of multiple entities participating in funded networks of care; incorporating and maintaining meaningful client participation in program development and implementation; service provision to substance abusing populations; service provision to adolescents; and outreach to women of childbearing age.
- **Program goal and priority setting** as demand exceeds resources, particularly related to relative emphasis on outreach versus direct services; definitions of client eligibility for services in general and especially for case management services, and policies and procedures for transferring care to other service systems when clients no longer meet defined eligibility criteria; and strategic planning to address issues such as financial viability, service capabilities, and needs assessments.
- **Identifying and developing opportunities to forge new collaborative relationships** with such service arenas as housing, education, substance abuse treatment, mental health, research, other components of the Ryan White CARE Act, and managed care health care systems.

Addressing these issues requires complementary efforts at the local, state, and national levels since the expertise, responsibility, and resources rest at all three levels. Perhaps the greatest challenge is to continue to build on evaluation and research findings such as those presented in this report and to link system-level evaluation findings to client outcomes to ensure that the evaluation feedback loop can continue to guide future directions.

APPENDIX A

RYAN WHITE TITLE IV GRANTEES
FY 1995

GRANTEE/ADDRESS	(YR. 1ST FUNDED) PROJECT PERIOD	CONTACT
Comprehensive Care/Research Grantees:		
<u>REGION I</u>		
Boston Pediatric AIDS Project Dimock Community Health Center 55 Dimock Street Roxbury, MA 02119	(1988) 8/1/94-7/31/97	Ruth J. Liberman 617-442-6758 617-445-0091 (fax)
Family AIDS Center for Treatment and Support (FACTS) 18 Parkis Avenue Providence, RI 02907	(1991) 8/1/94-7/31/97	Paul Fitzgerald 401-521-3603 401-861-2981 (fax)
◆Division for Children with Special Health Care Needs Massachusetts Dept. of Public Health 150 Tremont St., 7th Floor Boston, MA 02111	(1991) 8/1/94-7/31/97	Deborah Allen 617-727-6941 6 17-727-6 108 (fax)
Connecticut Primary Care Association 30 Arbor Street North Hartford, CT 06106	(1990) 8/1/95-7/31/96	Richard J. Jacobsen, PhD 203-232-3319 203-236-0618 (fax)
<u>REGION II</u>		
Dominican Sisters Family Health Service 279 Alexander Avenue Bronx, NY 10454	(1993) 8/1/93-7/31/96	Margaret Sweeney, 718-665-6557 718-292-9113 (fax)
◆New Jersey DOH Special Child Health Services CN 364 Trenton. NJ 08625-0364	(1988) 8/1/94-7/31/97	Diane DiDonato 609-292-1078 609-292-3580 (fax)

New York University Medical Center 550 First Avenue New York, NY 10016	(1993) 8/1/93-7/31/96	Keith Krasinski, MD 212-263-6427
N. Manhattan Women and Children HIV Demonstration Project Columbia School of Public Health 600 W. 168th St., 7th Floor New York, NY 10032	(1988) 8/1/95-7/31/97	Cheryl Heaton, Dr. PH 212-305-3616 212-305-6832 (fax)
◆Puerto Rico Pediatric AIDS Project Puerto Rico Dept. of Public Health P.O. Box 71423 GPO San Juan, PR 00936	(1988) 8/1/95-7/31/97	Rolando Jimenez Mercado 809-721-2000 x208 809-723-3565 (fax)
Bronx Pediatric AIDS Consortium Albert Einstein College of Medicine 1300 Morris Park Avenue Bronx, NY 10461	(1989) 8/1/95-7/31/98	William Caspe, MD 718-518-5764 718-518-5124 (fax)
The Family Center Medical and Health Research Association, Inc. 56 Reade Street New York, NY 10007	(1991) 10/1/95-9/30/98	Barbara Draimin, DSW 212-766-4522 212-766-1696 (fax)
Adolescent AIDS Program Montefiore Medical Center 111 East 210th Street Bronx, NY 10467-2490	(1989) 8/1/95-7/31/98	Donna Futterman, MD 718-882-0322 718-882-0432 (fax)
Brooklyn Pediatric AIDS Network SUNY-HSCB 450 Clarkson St., Box 49 Brooklyn, NY 11203	(1989) 8/1/95-7/31/98	Hermann Mendez, MD 718-270-3825/3826 718-270-3824 (fax)
Pediatric/Adolescent/Family Comprehensive Center AIDS Institute (NY DPH) Corning Tower, Room 321 Empire State Plaza Albany, NY 12237	(1995) 9/1/95-8/31/96	Gloria Maki 518-473-7542 518-474-0419 (fax)

<u>REGION III</u>		
D . C. Pediatric AIDS Health Care Demonstration Project Dept. of Human Services 1600 L St., NW, Suite 907 Washington, DC 20036	(1990) 8/1/95-7/31/96	Linda Jenstrom 202-673-6724 202-727-9021 (fax)
◆AIDS Administration Maryland Dept. of Health and Mental Hygiene 201 West Preston Street Baltimore, MD 21201	(1990) 8/1/93-7/31/96	Julia Hidalgo, ScD 410-767-5087 410-333-6333 (fax)
Circle of Care Project Family Planning of Southeastern Pennsylvania 260 S. Broad St., Suite 1510 Philadelphia, PA 19102	(1990) 8/1/95-6/30/96	Alicia Beatty-Tee 215-985-2657 215-732-1252 (fax)
<u>REGION IV</u>		
Georgia Dept. of Human Resources Division of Public Health 2 Peachtree St, NE, 8th Fl. Atlanta, GA 30303	(1988) 8/1/94-7/31/97	Virginia Floyd, MD, MPH 404-657-2850 404-657-2910 (fax)
Comprehensive Pediatric AIDS Project N. Broward Hosp. District 417 South Andrews Avenue Ft. Lauderdale, FL 33301	(1990) 8/1/94-7/31/97	Susan M. Widmayer, PhD 305-779-1955 305-779-1957 (fax)
S. Carolina Children's AIDS Care System S. Carolina Dept. of Health and Environmental Control 2600 Bull Street Columbia, SC 29201	(1993) 8/1/93-7/31/96	JoAnn Lafontaine 803-737-4016 803-734-3255 (fax)
Pediatric HIV/AIDS Health Care Demonstration Program U. Alabama @ Birmingham 751 Children's Hosp. Tower Suite 751 Birmingham, AL 35222	(1990) 8/1/95-7/31/96	Marilyn Crain, MPH, MD 205-934-7883 205-934-8658 (fax)

U. of Miami School of Medicine Dept. of Pediatrics (D4-4) P.O. Box 016960 Miami, FL 33101	(1994) 8/1/94-7/31/97	Gwendolyn B. Scott, MD 305-547-6676 305-547-5562 (fax)
Tampa Bay Pediatric AIDS Project U. of South Florida 13201 Bruce B. Downs Blvd. MDC 56 Tampa, FL 33612-3805	(1992) 8/1/95-7/31/98	Jay Wolfson, Dr. PH, JD 813-974-6643 813-974-6642 (fax)
<u>REGION V</u>		
Family AIDS Clinic & Educational Services (FACES) Columbus Children's Hospital 700 Children's Drive, Rm. 6072 Columbus, OH 43205-2696	(1991) 8/1/95-7/31/97	Michael T. Brady, MD 614-722-4451 614-722-4458 (fax)
Women & Children's HIV Program @ Cook County Hospital [a.k.a. Hektoen Institute] 1835 West Harrison Street CCSN, Room 912 Chicago, IL 60612	(1991) 8/1/94-7/31/97	Mardge Cohen, MD 312-633-5080 312-633-4902 (fax)
Youth & AIDS Projects U. of Minnesota 428 Oak Grove Street Minneapolis, MN 55403	(1990) 10/1/95-9/30/96	Gary Remafedi, MD, MPH 612-626-2855 612-627-6819 (fax)
◆Great Lakes Hemophilia Foundation 8739 Watertown Plank Rd. P.O. Box 13127 Wauwatosa, WI 53213-0127	(1994) 8/1/95-7/31/98	Janice R. Hand 414-257-0200 414-257-1225 (fax)
Bureau of Child & Family Services Michigan Dept. of Public Health P.O. Box 30195 3423 N. Martin Luther King Blvd. Lansing, MI 48909	(1989) 1995-1996	Terri D. Wright, MPH 517-335-8969 517-335-9222 (fax)

<u>REGION VI</u>		
Tarrant Co. Pediatric AIDS Demonstration Project (a.k.a. Catholic Charities) Fort Worth, TX 76105	(1991) 8/1/94-7/31/97	Sue Smith, LMSW-ACP 817-536-1160 817-536-4671 (fax)
Pediatric AIDS Program Children's Hospital - New Orleans Kingsley House, 2nd Floor 914 Richards Street New Orleans, LA 70130	(1988) 8/1/94-7/31/97	Michael Kaiser, MD Beth Scalco, BCSW 504-524-4611 504-523-2084 (fax)
Houston Regional HIV/AIDS Resource Group 811 Westheimer, Suite 201 Houston, TX 77006	(1993) 8/1/94-7/31/97	Michael J. Springer 713-526-1016 713-526-2369 (fax)
U. of Texas Hlth. Science Center @ San Antonio 7703 Floyd Curl Drive San Antonio, TX 78284-7811	(1988) 8/1/95-7/31/97	Victor German, MD, PhD 210-692-3641 210-567-6921 (fax)
Pediatric AIDS Network of Dallas (PANDA) JT Southwestern Medical Center 1935 Motor Street Dallas, TX 75235	(1989) 8/1/95-7/31/98	Janet Squires, MD 214-640-2871 214-640-5702 (fax)
<u>REGION VII</u>		
Nashington University Research Office 724 S. Euclid Avenue St. Louis, MO 63110	(1995) 8/1/95-7/31/98	Gregory A. Storch, MD 314-454-6079 314-367-3765 (fax)
<u>REGION VIII</u>		
◆U. of Colorado Health Sciences Center 4200 E. Ninth Avenue, Box A081 Denver, CO 80262	(1995) 8/1/95-7/31/98	Myron J. Levin, MD 303-270-8501 303-270-7909 (fax)

<u>REGION IX</u>		
Alameda Co. Hlth. Care Services Agency Office of AIDS Administration 1970 Broadway, Suite 1130 Oakland, CA 94612	(1994) 8/1/94-7/31/97	Ivy Wagner 5 10-873-6500
Los Angeles Pediatric AIDS Network (LAPAN) Children's Hospital of Los Angeles 6430 Sunset Blvd., Suite 1003 Los Angeles, CA 90028	(1988) 8/1/95-7/31/97	Marcy Kaplan 213-699-5616 213-461-1394 (fax)
Project AHEAD San Francisco Dept. of Public Health 1242 Market Street, 3rd Floor San Francisco, CA 94102	(1990) 8/1/93-7/31/96	Janet Shalwitz, MD 415-487-5777 415-487-5771 (fax)
<u>REGION X</u>		
Seattle - King Co. Pediatric AIDS Demonstration Project Northwest Family Center 1001 Broadway, Suite 210 Seattle, WA 98122	(1988) 8/1/94-7/31/97	Julia Sarkissian 206-720-43 19 206-720-4302 (fax)
Cooperative Agreements:		
Institute for Family-Centered Care (<i>Reg. III</i>) 7900 Wisconsin Ave., Ste. 405 Bethesda, MD 20814	(1993) 8/1/93-7/31/96	Elizabeth S. Jeppson 301-652-0281 301-652-0186 (fax)
National Pediatric & Family HIV Resource Center (<i>Reg. II</i>) 15 South 9th Street Newark, NJ 07107	(1993) 8/1/93-7/31/96	Carolyn Burr 201-268-8251 201-485-2752 (fax)
Hemophilia Special Initiative:		
Dartmouth-Hitchcock Hemophilia Center (<i>Reg. I</i>) One Medical Center Drive, 4B Lebanon, NH 03756	(1993) 10/1/94-9/30/96	Kathy Parsonnet, RN, MPH 603-650-5454 603-650-7791 (fax)

Planning/Initial Development:		
Maricopa County DPH (Reg. IX) 1845 East Roosevelt Street Phoenix, AZ 85006	8/1/95-7/31/96	Toby Urvater, CMSW 602-506-6853 602-506-6855 (fax)
Ventura County Public Health (Reg. IX) 3147 Loma Vista Road Ventura, CA 93003	8/1/95-7/31/96	Diane Seyl 805-652-65 12 805-652-6617 (fax)
Orlando Regional Health Care Systems, Inc. (Reg. III) 1414 Kuhl Avenue Orlando, Fl 32806	8/1/95-7/31/96	Gidget Ruscetta, RN, BSN 407-841-5143 407-649-6824 (fax)
Metrolina AIDS Project (Reg. III) 1415 South Church Street Charlotte, NC 28202	8/ 1/95-7/31/96	Barbara Rein 704-333-1435 704-376-8794 (fax)
Houston Institute for the Protection of Youth (HIPY) (Reg. VI) 811 Westheimer, Suite 102 Houston, TX 77006	(1994) 11/1/94-10/31/96	Tracy Brown 713-942-9884
University Medical Center of Southern Nevada (Reg. IX) HIV Wellness Center 1800 W. Charleston Blvd. Las Vegas, NV 89102	(1994) 11/1/94-10/31/96	Ann Occhi, RN, MSN 702-3 83-2203
Research Foundation of SUNY (Reg. II) Office of Research Services State University of New York Stony Brook, NY 11794-3366	(1994) 11/1/94- 10/31/96	Sharon Nachman, MD 5 16-444-7692 5 16-632-6963 (fax)
Women's Initiative for HIV Care and Reduction of Perinatal HIV Transmission:		
Maryland Dept. of Health and Mental Hygiene S/A (Reg. III)	(1995) 1995-1998	Julia Hidalgo, ScD/ Alina Savat-Wright 410-767-5087 410-333-6333 (fax)
Univ. of Texas Southwestern Medical Center S/A (Reg. VI)	(1995) 1995-1998	Pam Newton 214-640-5897 214-640-5702 (fax)

Massachusetts Dept. of Public Health S/A (Reg. I)	(1995) 1995-1998	Gail Merriam 617-727-6941 617-727-6108 (fax)
N. Broward Hospital District S/A (Reg. IV)	(1995) 1995-1998	Gail "Stormy" Schevis 305-799-1970 305-799-1957 (fax)
Children's Hospital - New Orleans S/A (Reg. VI)	(1995) 1995-1998	Beth Scalco 504-524-4611 504-523-2084 (fax)
New Jersey Dept. of Health S/A (Reg. II)	(1995) 1995-1998	Beverly Kupiec 609-292-1078 609-292-3580 (fax)
Family Planning Council of Southeastern Pennsylvania S/A (Reg. III)	(1995) 1995-1998	Alicia Beatty-Tee 215-985-2657 215-732-1252 (fax)
NIH Adolescent Medicine HIV/AIDS Research Network Sites:		
Children's Hospital of Los Angeles Division of Adolescent Medicine P.O. Box 54700 Mail Stop 2 Los Angeles, CA 90054-0700		Marvin Belzer, MD 213-669-2390 213-913-3614 (fax)
Children's Hospital National Medical Center 111 Michigan Avenue Washington, D.C. 20010		Lawrence D'Angelo, MD 202-884-3066 202-884-5685 (fax)
New York University Medical Center 550 1st Avenue New York, NY 10016		Keith Krasinski, MD 212-263-6427 212-263-7806 (fax)

◆ Denotes projects with state-wide service areas.

APPENDIX B

**Ryan White Title IV Evaluation
Advisory Committee Members**

Sylvia Trent-Adams
Hemophilia and AIDS Program Branch
Maternal and Child Health Bureau, HRSA

Deborah Allen
Division for Children with Special Health Care Needs
Bureau of Family and Community Health
Boston Department of Public Health

Mary Boland, R.N., M.S.N.
National Pediatric AIDS Resource Center

Pernell W. Crockett
Hemophilia and AIDS Program Branch
Maternal and Child Health Bureau, HRSA

Sheila Catherine Fuoco
Consumer Representative

Christine Hager, Ph.D.
Office of Science and Epidemiology
Bureau of Health Resources Development, HRSA

Julia Hidalgo, Ph.D.
Maryland Department of Health
AIDS Administration

Linda Horton
Johns Hopkins University
Health Policy and Management

Rudolph Jackson, M.D.
AIDS Research Consortium
Morehouse School of Medicine

Ibby Jeppson, Ph.D.
Institute for Family-Centered Care

David Maglott
Office of Program Development
Maternal and Child Health Bureau, HRSA

Gloria Maki, Ph.D.
N.Y. State Dept. of Health AIDS Institute

Xandra Negron
Director, Massachusetts CARE
Bureau of Family and Community Health
Department of Public Health

Moses Pounds, Ph.D.
Office of Science and Epidemiology
Bureau of Health Resources Development, HRSA

Beth Roy
Hemophilia and AIDS Program Branch
Maternal and Child Health Bureau, HRSA

Jean Setzer, Ph.D.
University of Texas Health Sciences Center
Department of Pediatrics

Mildred Williamson, M.S.W.
Women and Children HIV Program
Cook County Hospital

Arnette Wright, R.N., B.S.N., M.A.
Division of Programs for Special Populations
Bureau of Primary Health Care, HRSA

Macro Staff

Lela Baughman, Project Director
Mary McCormack, Ph.D.
Tom Chapel

APPENDIX C

Title IV Program Evaluation Study Questions and Indicators

1. Have systems of care been established, improved, maintained, or expanded?

A. Are the appropriate entities participating in the demonstration in a collaborative way?

- Shared vision, goals, and objectives among agencies
- Exchange of resources such as staff, planning, and funds
- Participation of grantee and level of participation in:
 - Collaborative/interagency task forces
 - Ryan White planning process
 - Collaborative efforts with Title V agency(ies); Healthy Start
- Formal links with advocacy groups/coalitions
- Leadership roles in advocacy groups and coalitions
- Joint staff training/staff meetings
- Community training or educational sessions
- Joint data/information systems

B. Are the appropriate services being offered either directly or by referral?

- Existence of key services in following categories:
 - Prevention
 - Outreach and education
 - Medical
 - Social services
 - Support services
- Documentation of priority of services
- Documentation of referral links for services not provided directly

2. Do the systems have the desired attributes?

A. Are services accessible?

- Penetration rates (project cases as percent of area projection):
 - AIDS cases: pediatric, women, and adolescent
 - HIV cases: pediatric, women, and adolescent
- Location of project services relative to residence of clients
- Hours and days of operation
- Physical accessibility for persons with disabilities
- Location relative to parking lots and public transit

- Transportation assistance or van services
- Provider and client perceptions of physical accessibility
- Availability of Medicaid
- Availability of funding sources for uninsured, non-Medicaid clients
- Provider and client perceptions of financial accessibility

B. Are services available and care comprehensive?

- Existence of key prevention services directly pr by referral:
 - A. HIV group outreach/education
 - Street outreach
 - HIV individual education
 - HIV ongoing education
 - Bleach kit distribution
 - Condom distribution
 - B. Other counseling and education
 - Preconception
 - Alcohol and substance abuse
 - STD
 - Family planning
- Existence-of key medical, social, and support services directly or by referral:
 - Outreach
 - Core medical services
 - Supplemental medical services
 - Health support services
 - Mental health services
 - Other psychosocial services
 - Case management services
 - Education services
 - Housing services
 - Child welfare services
 - Family services
 - Logistical support services
- Evidence of client utilization of key services
- Provider and client perception of availability and comprehensiveness

C. Is care family-centered?

- Broad and inclusive definition of family
- Family care in-service sessions for staff
- Evidence of family members receiving services
- Participation in family support groups
- Family involvement in planning and service delivery through:
 - Clients/family members on governing body
 - Family participation in service planning
 - Use of clients/peers as staff or counselors
- Family empowerment/personal advocacy training
- Mechanisms for family-centered service delivery:
 - Co-located services
 - Concurrent clinics
 - Child care during adult appointments
- Client perception of level of involvement in service planning and delivery

D. Is care culturally-competent?

- Demographic/cultural breakdown of staff
- Multilingual/cultural signage, materials, and forms
- Use of clients/peers as staff or counselors
- Project has cultural competency vision, such as:
 - Policy statements related to cultural competency
 - Activities to identify barriers
 - Cultural sensitivity in-service sessions
- Client perception of staff-client relationships
- Client perception of intelligibility and sensitivity of:
 - Treatment plans
 - Instruction
 - Educational efforts

E. Is care high quality?

- Provision or strong referral links to tertiary care
- Provision of strong referral links to home care
- Existence of guidelines for pediatric care
- Existence of guidelines for womens' care
- Existence of quality assurance process
- Client perception of quality of care

F. Is care coordinated?

- Number of clients and families receiving case management
- Case manager/client ratios
- Ability to link files of clients and family members
- Mechanisms of coordination such as:
 - Standardized intake process
 - Lead case manager or single point of contact across agencies
 - Common information reporting format/tracking system across agencies
 - Multidisciplinary service planning
 - Service plan monitoring and updating
- Provider and client perception of coordination

3. Is the system reaching and serving intended unserved or underserved target populations?

A. Is the project serving women, children, and youth with HIV infection?

- Demographics of catchment area
- Projected AIDS prevalence by gender, race, age
- Projected HIV prevalence by gender, race, age
- Client descriptions:
 - Number of clients
 - Age/birth date
 - Gender
 - Race/ethnicity
 - HIV status
 - HIV exposure category
 - Living arrangement
 - Primary care giver
 - Funding source
 - People in household
- Service utilization by age and gender for key services

B. Is the project serving families?

- Evidence of services directed at families
- Evidence of families using or being referred to services

C. Is the project addressing people at risk [through prevention and education]?

- Evidence of prevention and education activities

- Description of prevention and education participants

4. **Are providers accessible and available that are multidisciplinary and trained to serve the target population?**

A. Are providers accessible and available?

- Number of staff by position
- Staff turnover
- Average length of stay of staff
- Number, type, and duration of staff vacancies
- Salaries for selected positions and competitiveness of salaries

B. Are providers multidisciplinary?

- Number of staff by discipline
- Staff input to decision making
- Mix of certification/degrees
- Cross-training of staffs for women's and children's services

C. Are providers trained appropriately?

- In-service training sessions
- CEUs completed by staff
- Appropriate certification/degrees
- Prior experience with HIV/AIDS
- Prior experience with service populations

5. **Are clients receiving the array of medical and social services that they need?**

A. Is the array of services comprehensive?

- Existence of broad array of services per question 2B
- Evidence of client utilization of broad array of services

B. Is the array of services coordinated into an individualized service package?

- Multidisciplinary service planning
- Service plan monitoring and updating
- Provider and client perception of coordination and individualization

6. Has the program had an impact on increasing participation in clinical drug trials?

- Number of clients referred to clinical trials
- Number of clients enrolled in clinical trials
- Location of trial site in relation to project and residence of clients
- Activities to identify/reduce barriers
- Staff and client perception of accessibility to clinical trials

7. Has the program has an impact on maintaining family structure intact?

- Distribution of client living arrangements
- Client perception of level of support
- Client perception of level of empowerment
- Client perception of maintenance/improvement in family structure

8. Has the program had a positive impact on client and family life satisfaction?

A. Client satisfaction

- Client perception of maintenance/improvement in:
 - Life satisfaction/quality of life
 - Participation in leisure activities
 - Educational/vocational activities
 - Activities of daily living
- Client report of changes in risk behaviors

B. Family satisfaction

- Family perception of maintenance/improvement in:
 - Life satisfaction/quality of life
 - Participation in leisure activities
 - Educational/vocational activities

APPENDIX D

**RYAN WHITE TITLE IV
HIV DEMONSTRATION PROGRAM
FOR CHILDREN; ADOLESCENTS, AND FAMILIES**

SELF-STUDY QUESTIONNAIRE

*Form Approved
OMB NO. 09150177
Exp. Date 09/95*

Public reporting burden for this collection of information is estimated to average 4 hours per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to:

*PHS Reports Clearance Officer; ATTN: PRA
Hubert H. Humphrey Bldg, Room 721-B
200 Independence Ave.
SW; Washington, DC 20201*

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*The Office of Management and Budget
Paperwork Reduction Project (0915-0177)
Washington, DC 20503*

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*The self-study questionnaire should be completed by the project director, with input from other project staff as needed. It is important that the responses reflect the overall perspective of staff throughout the project.**

Once you have completed the self-study questionnaire, please return it in the enclosed envelope to:

Macro International Inc.
3 Corporate Square
Suite 370
Atlanta, Georgia 30329
Attn: Erika Reed

Please complete the questionnaire by **[self study due date]**. Feel free to call Nicole Lezin or Erika Reed at Macro with questions at 404-321-3211.

*You may fill in the answers by hand; they do not need to be typewritten.

Thank you for your time and effort in completing this guide.

A. ACCESSIBILITY

In this section, we want to explore the physical accessibility and convenience of your program and facilities.

- In the chart below, indicate the following for each of the major service components of your program (see definition of service component on page 2). Please use a check mark (✓), except where days/hours or length of time is requested.

Service Component	DAYS AND HOURS OF OPERATION			APPROX. LENGTH OF TIME (MINUTES) TO:		FACILITY ACCESSIBLE TO PERSONS WITH HANDICAPS (Y/N)	SCHEDULING POLICY			APPROXIMATE WAITING TIMES	
	Weekday	Weekend	On-call or after-hours provisions (Y/N)	Parking lots	Transit stop		By appointment	Appointment block	First-come, first-served	How many days/weeks to get an appointment	How many minutes/hours after arrival at clinic, if on-time

2. What types of transportation assistance are available to your clients?

TYPES OF ASSISTANCE	AVAILABLE TO		IF SOME, SPECIFY SELECTION CRITERIA
	ALL	SOME	
Public transportation cards or tokens (paid for by the program, Medicaid, or through donations)			
Taxi vouchers			
Regular van or shuttle transportation between service locations and/or service locations and client's home			
Staff transport clients			
Emergency assistance			
Other (specify)			

3. Does available assistance meet client needs?

4. What are your program's biggest problems or concerns with accessibility of services?

B. FAMILY -CENTERED CARE

In this section, we want to explore the ways in which you are able to give families opportunities to be involved in planning and delivering services, and provide them with the support to do so. We would also like to know about your philosophy of care, as it relates to families.

1. Which of the following do you offer directly or by referral:

- Family care training sessions for **staff**
- Staff training in developing collaborative relationships with families
- Family support groups
- Family/personal advocacy training for clients

2a. Which of the following do you offer:

- Co-located services for child and family member
- Concurrent medical clinics for child and family members
- Coordinated same-day appointments for child and family members
- Child care during adult appointments
- Child care for other purposes (e.g., drop-in, respite, support groups)
- Support groups
- Home visits

2b. If not, what barriers or obstacles (including physical plant) have prevented your program from offering:

Co-located services:

Concurrent clinics:

Same-day appointments:

Child care during appointments:

Child care for other purposes:

Support groups:

Home visits:

3a. Does your program have a governing body?

Yes

No

3b. If yes, do clients/family members serve on the governing body of the program?

Yes (How many:) _____

No

4a. Does your program have an advisory committee?

Yes

No

4b. If yes, do clients/family members serve on the advisory committee?

Yes (How many:) _____

No

5a. Does your program participate in interagency task forces?

Yes

No

5b. If yes, do clients/family member serve on any task forces?

Yes (How many:) _____

No

6. In which of the following additional ways are clients/family members involved in service planning and delivery?

Use of clients/family members/peers as paid or volunteer staff, counselors, or support group leaders
(How many:)_____

Family member serves on the team that develops the service plan for the child

Family member participates in own and child's treatment

Clients/families as spokespersons/advocates

Other (describe): _____

7. Does your project have a written philosophy of care statement?

Yes (please attach a copy)

No

8. Describe any other activities that **you** offer to support, train or otherwise assist families to increase their involvement in policy making and/or service delivery.

4. For each of the major service delivery components of your program, please list the breakdown of the staff, as follows. If staff members represent a particular culture or nationality within these categories that corresponds to the race/ethnicity of clients being served, please note this as well (e.g., Haitian/Creole, Puerto Rican, Laotian).

SERVICE COMPONENT	NUMBER OF STAFF BY GENDER		NUMBER OF STAFF BY RACE/ETHNICITY				
	MALE	FEMALE	WHITE	AFRICAN-AMERICAN/BLACK (non-Hispanic)	HISPANIC/LATINO	ASIAN/PACIFIC ISLANDER	AMERICAN INDIAN

White: Including Canadian, East European, European, Middle Eastern, Russian

African-American/Black (non-Hispanic): Including African-American, African, and persons having origins in any of the black racial groups of Africa

Hispanic/Latino: Including Cape Verdean, Central American, Cuban, Mexican/Mexican American, Portuguese, Puerto Rican, South American, Spanish

Asian/Pacific Islander: Including East Asian (Chinese, Japanese, Korean, Taiwanese), Pacific Islander (Hawaiian), South Asian (Bangladeshi Indian, Pakistani), Southeast Asian (Hmong, Kampuchean, Laotian, Vietnamese)

American Indian: Including Native American, Aleutian, Native Alaskan, Eskimo

5. Do staff represent any other cultures or subcultures that you find relevant to effective service delivery for your clients (e.g., culture of

drug use)?

6. Please indicate any of the following ways in which your program has addressed cultural competency in service delivery (check all that apply):

- Availability of translators or interpreters
(Which languages: _____)
- Availability of sign language interpreters
- Multilingual signs/posters in facility or reception area
(Which languages: _____)
- Multilingual instructions, forms, or educational materials
(Which languages: _____)
- Non-technical instructions or educational materials oriented to specific *cultures* (not necessarily multilingual)
(Which cultures: _____)
- Visual materials for non- or low-literate clients
(Describe: _____)
- Assistance explaining and reviewing materials/instructions
- Use of clients/peers as staff or counselors
(How many:) _____
- Other efforts (describe): _____

7. What *grade level* are your materials for clients geared to? _____

D. QUALITY ASSURANCE

In this section, we are interested in the ways in which your program assures a full spectrum of *medical care* and provides that care in accordance with some set of recognized standards.

1. Do you have a formal protocol or set of guidelines for pediatric care? If so, what is its source? (Please attach a copy).
2. Which of the following HIV diagnostic tests do you perform for pediatric patients?

Type of diagnostic test	Diagnostic test performed (check all that apply)	Diagnostic test used most often (check all that apply)
HIV culture		
PCR (polymerase chain reaction)		
ELISA (w/ Western Blot confirmation)		

3. Do you have a formal protocol or set of guidelines for women's ob/gyn care? If so, what is its source? (Please attach a copy).

4. For each service delivery component, indicate the following in terms of medical chart review procedures:

SERVICE LOCATION	CHARTS ROUTINELY REVIEWED (Y/N)	CHARTS SELECTED FOR REVIEW		FREQUENCY OF REVIEWS	WHO IS RESPONSIBLE FOR REVIEWS?
		ALL CHARTS	SOME CHARTS (SPECIFY CRITERIA)		

5. If chart reviews are conducted, what do you do with the results of the review? What are the key follow up activities?

6. Do you use any other mechanisms to monitor staff adherence to care protocols? If yes, please describe:

7. What procedures are used to safeguard client confidentiality?

8. Are there particular factors that influence your approach to quality assurance?
(e.g., institutional guidelines/requirements, other grants)

Please describe :

E. COORDINATION OF CARE

In this section, we are interested in the ways in which you are able to integrate and coordinate the care provided to an individual client or family by multiple providers.

1. How many case managers within the demonstration program is the typical client likely to have? How many do families usually have? If more than one for individual clients or for families, describe their various roles.

2. How many other case managers outside of the demonstration project is the typical client or family likely to be involved with? What agencies/systems do these case managers represent?

3. Which of the following mechanisms for coordinating client care are you currently employing? Rank order the top three mechanisms with 1 as the most common mechanism.

- _____ Central intake process across agencies or joint intake process
- _____ Lead case manager or single point of contact across agencies
- _____ Common reporting format across agencies
- _____ Common or joint information system across agencies
- _____ Routine telephone contact
- _____ Participation in case management/care coordination committees
- _____ Participation in client specific case conferences
- _____ Other (describe): _____

4. For each service location/program component, what are the typical case manager caseloads?

Service location/component	Total number of case management FTEs	Average number of index clients per case manager	Average number of individuals per case manager including family members

5. What percentage of clients are assigned a case manager?

6. What are the criteria for determining whether clients are assigned a case manager?

7. How many FTEs throughout your program are engaged in performing each of the following in your program?
(e.g., if 3 people each spend a quarter of their time on initial intake, $3 \times .25 = .75$ FTEs)

Initial intake
Assessment
Service plan development
Service plan implementation (sum of i and ii)

i. Direct service
ii. Referral to other agencies

___ Monitoring/follow-up
___ Reassessment
___ Crisis intervention
___ Supervisory review
___ Multidisciplinary case conferencing
___ Discharge/exit planning
___ Interagency coordination/system development
___ Other (specify) _____

8. How are case management services paid for? If more than one source indicate approximate percentage covered by each one.

	Percent
Title IV grant	
Other grant funding	___
Medicaid	
Sponsoring institution	
Other (specify)	___
Total	100%

9. Are individualized service plans developed for clients?

Yes

No [Go to Question 16]

10. How often is the plan updated? What prompts updating?

11. How is the plan updated?

Case manager updates

Multidisciplinary team update meeting

Other (Specify): _____

12. Do family members have access to the plan?

Yes

No

13. Do you conduct routine case plan reviews?

Yes

No (Go to Question 16)

14. If yes, provide the following information on case plan review procedures. If procedures differ for each service component, please use a separate line for each component.

SERVICE COMPONENT	CASE PLANS ROUTINELY REVIEWED (Y/N)	CASE PLANS SELECTED FOR REVIEW		FREQUENCY OF REVIEWS	WHO IS RESPONSIBLE FOR REVIEWS
		ALL CHARTS	SOME CHARTS (SPECIFY CRITERIA)		

15. What do you do with the results of the case plan review? What are the key follow up activities?

16. Do you have any other mechanisms for monitoring case planning? If so, please describe:

17. How is the input of the following staff/professions (as relevant) elicited? Check all that apply. If input is regularly sought from other staff/professions not listed, please specify.

STAFF/PROFESSION	ROUTINE TEAM MEETINGS ¹	AD-HOC TEAM MEETINGS ²	ROUTINE CONSULTATION ³	CONSULTATION AS NEEDED ⁴	THIS TYPE OF STAFF INPUT IS NEEDED BUT NOT AVAILABLE	THIS TYPE OF STAFF INPUT IS <u>NOT</u> NEEDED
Physician staff						
Nursing staff						
Social services staff						
Child welfare staff						
Mental health professionals						
Education/school personnel						
Housing personnel						
Parents/guardians						
Other (specify):						
Other (specify):						
Other (specify):						

¹ Regularly scheduled meetings held for most/all clients

² Team meetings called on an ad-hoc basis, not regularly scheduled

³ Usually consulted for most/all clients

⁴ Available for consultation when needed, not routinely consulted

18. Do you have protocols for sharing information among project staff? If so, please attach or describe:

Yes (Describe or attach)

No

19. Do you have protocols for sharing information with staff from other agencies/systems? If so please attach or describe:

Yes (Describe or attach)

No

20. Here are some outcomes that may be goals for your program. For each one, please : a) indicate how important the outcome is to your program as an indicator of success b) indicate how often your project has been successful in meeting the outcome, and c) describe factors that have influenced your ability to be successful

OUTCOMES	IMPORTANCE			SUCCESS			FACTORS THAT INFLUENCE OUR SUCCESS
	CRUCIAL 1	NOT IMPORTANT 2	3	ALWAYS 1	2	RARELY 3	
Access to clinical trials							
Meeting basic medical needs							
Avoiding unnecessary hospitalization							
Avoiding unnecessary visits to the emergency room							
Patients keeping appointments							
Keeping biological family together							
Transitioning legal custody of children before mother becomes critically ill							
Meeting social service needs most of the time							
Other (specify)							
Other (specify)							

21. What are the key barriers that you encounter in trying to coordinate services?

22. What strategies have you found to be effective in addressing barriers to coordination?

F. **CLINICAL TRIALS**

In this section, we are interested in exploring factors that make it easy to enroll clients in clinical trials and factors that make it more difficult.

1. Which of the following factors make it difficult to enroll clients in clinical trials? **(Check all that apply.)**

- Fear or suspicion of medical profession/clinical trials
- Fear of medical settings/procedures
- Release/consent issues
- Distance/transit time to clinical trial site
- Lack of transportation
- Frequency/duration of visits
- Eligibility criteria
- Protocol requirements
- Other (specify): _____

2. What factors have facilitated enrollment in clinical trials?

3. Are there specific barriers related to age, gender, or race/ethnicity (e.g. competition for pediatric patients)?

4. Describe project activities/efforts to reduce barriers to access to clinical trials:

G. STAFFING

In this section, we explore the characteristics and background of your staff who routinely provide services to your project clients.

- For each staff category: a) indicate the total number of full time equivalents (FTEs) who routinely provide services to demonstration project clients, whether or not their salaries are supported by the grant, b) indicate the number of FTE staff who are funded by the grant (include salaried and subcontracted staff for a and b), and c) indicate the number of volunteers--i.e., unpaid staff.

STAFF CATEGORY	TOTAL NUMBER OF FTEs	TOTAL NUMBER OF FTEs FUNDED BY THE GRANT	NUMBER OF VOLUNTEERS
Nurses			
Aides			
Therapists			
Technicians			
Physician assistants			
Nurse practitioners			
Physicians			
Dentists			
Pharmacists			
Case managers/social workers			
Health educators/outreach workers			
Mental health professionals and licensed counselors			
Other staff (specify:) _____			
Other staff (specify:) _____			

2a. How many of your staff bring prior experience or training in HIV/AIDS?

Paid/in-kind _____
Volunteer _____

2b. How many of your staff bring prior experience or training in the substance abuse prevention/treatment field:

Paid/in-kind _____
Volunteer _____

3. How many staff have left the program during the past 12 months?

3a. What job titles did these staff hold?

4. In your experience, which job titles are the hardest to fill?

4a. For up to the three most difficult job titles to fill, which of the following factors make them hard to fill? **(Check all that apply.)**

Factors	Job Title: (specify) _____	Job Title: (specify) _____	Job Title: (specify) _____
Salary			
Benefits			
Hours			
Complexity of client care			
Lack of supply in this profession			
Burnout			
Fear of infection			
Lack of expertise in HIV			
Lack of experience with client population			
Other (Specify):			
Other (Specify):			

5. In your experience, in which job titles is it hardest to retain staff!

5a. For up to the three most difficult job titles to retain, which of the following factors make them hard to retain?
(Check all that apply.)

Factors	Job Title: (specify) _____	Job Title: (specify) _____	Job Title: (specify) _____
Salary			
Benefits			
Hours			
Complexity of client care			
Burnout			
Fear of infection			
Other (Specify):			
Other (Specify):			

6. What factors make it easiest to retain staff?

7. Which of the following aspects of staff training are included in your program? (Check all that apply.)

- Cross-training of staff for women's and children's services
- In-service training sessions
- Monetary support for continuing education/conference attendance
- Release time for continuing education/conference attendance
- Other (specify): _____

8. What other opportunities for advancement are available in your program or institution?

9. How are staff involved in decision making for your program?

10. What other staff support does your program offer? (Check all that apply.)

- Mental health, psychiatric, counseling services
- Staff support groups
- Other(specify): _____

11. What methods of staff support have you found to be most effective?

H. CLIENT SATISFACTION

1. Do you have any mechanisms in place to gauge clients' satisfaction with **medical** services? Please describe the mechanism and how frequently you use it:
2. Do you have any mechanisms in place to gauge clients' satisfaction with **non-medical** services? Please describe the mechanism and how frequently you use it:
3. If clients are not satisfied, what actions are taken?
4. What are some examples of ways in which client feedback has affected program policies or procedures?

I. CALL FOR EVALUATION/RESEARCH FINDINGS

The current evaluation is primarily limited to collecting and analyzing outcome data about systems of care. However, HRSA is interested in broader evaluation questions and studies and would like to know the results of any evaluation efforts your project has conducted, particularly those related to *client* outcomes. Please attach copies of any such studies that you have conducted including a description of the methodology and the findings.

This completes the self-study. Thank you for your time and efforts!

APPENDIX E

**RYAN WHITE TITLE IV
HIV DEMONSTRATION PROGRAM
FOR CHILDREN, ADOLESCENTS, AND FAMILIES**

SITE VISIT PROTOCOL

*Form Approved
OMB NO. 0915-0177
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Public reporting burden for this collection of information is estimated to average 3 hours per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to:

*PHS Reports Clearance Officer; ATTN: PRA
Hubert H. Humphrey Bldg, Room 721-B
200 Independence Ave.
SW; Washington, DC 20201*

and to:

*The Office of Management and Budget
Paperwork Reduction Project (0915-0177)
Washington, DC 20503*

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A. AVAILABILITY

Purpose: To explore the priority of services, availability of key services, and referral links

Methods: Interviews with key staff

Target: Case management staff and administrative staff

In reference to the completed Table 2--Service Mix Profile--site visitors will explore the following issues:

1. Which of the services listed do you consider of highest priority or most central to the mission of your project? Does this differ across service populations?
2. Which services are the hardest to access or have the longest waiting list?
3. For the boxes that are left blank:
 - 3a. Are these services not available or not accessible?
 - 3b. Are they needed?
 - 3c. For those services that are not accessible, what are the issues?
4. For those services that are delivered by a network member or through referral outside of the network (marked B and C respectively), please describe the nature of your referral links:
 - Active--the demonstration project has allocated or reserved spaces or accompanies the client to the referred agency and follows up with and gets feedback from the agency.
 - Somewhat strong--the demonstration project has a relationship and can ease the process, but has no ability to reserve spaces or capacity for its clients (no follow up or feedback is involved)
 - Passive referral--the agency refers the client, but does not follow up to ensure the service is available, nor is feedback given.
5. What are the key issues or barriers that you encounter in making referrals?
6. What strategies have you found to be effective in addressing barriers?

7. Does your project have an outreach program to promote early anti-retroviral therapy (e.g. AZT/ZDV) for pregnant women?

If yes, describe this outreach program:

If no, what are the barriers to implementing such a program?

How many pregnant clients are currently on AZT/ZDV?

B. COLLABORATION

Purpose: To determine the degree to which the demonstration project is creating or participating in a system of care that includes major entities.
Methods: Interviews
Target: Demonstration project directors, case management staff, and directors of key collaborating agencies

We are interested in exploring the breadth and depth of your collaboration with active project participants and other agencies and organizations. We already have information on your *referral* relationships through the data tables. Here we want to focus on other collaborative mechanisms and relationships in which you are involved and explore further the collaborations you described in Table B of your grant application.

For the collaborative relationships identified in the grant application, site visitors will probe the following issues:

1. How well do the collaborations with these agencies work? How often do these entities meet? About how much total staff time per month is spent in collaborative activities?
2. Which collaborations are most important? What percentage of staff time is spent on these major collaborations?
3. To what degree do you believe that the mission and desired outcomes are shared among agencies involved with your clients?
4. To what extent is information exchanged between the demonstration project and collaborating agency?
5. Are there ways in which financial resources are shared? If so how?
6. Are there overlapping staff appointments? If so how many and what are the titles?
7. Are there joint activities (other than referrals) between the demonstration project and collaborating organization? What are these activities? How frequently do they occur? Who takes the lead on sponsoring them?
8. [Asked of other agencies] How active is the grantee in these efforts? Are they serving in a leadership role or member role only?
9. Is there a joint planning or policy committee? Who (titles) sit on this committee?

10. Are there formalized relationships between the demonstration project and collaborating agency? How is the relationship formalized?
11. How knowledgeable is the demonstration project about collaborating agency's functions?
12. How well coordinated are the responsibilities of the various professional disciplines?
13. Is there a clear procedure for communication between collaborators and the demonstration project?
14. For each of the Ryan White programs, how does the process work in your catchment area? How well does it work? How were pediatric concerns handled in the allocation process? Do HIV/AIDS community organizations see themselves as fractionalized or united? If fractionalized, along what lines? If united, describe how.
15. For collaborations that do not exist or are still in the planning stages, what have been the barriers? (e.g., non existent in community, demonstration program excluded, etc.)
16. How feasible are the various mechanisms for collaboration? What are the obstacles to implementing them?
 - planning/needs assessment
 - shared financing
 - Joint data or information systems
 - Joint staff training
17. What strategies have you found to be successful in addressing barriers?

18. *Asked of collaborating agencies (each)*

Please answer the following questions:

- a. What agency do you represent in local interagency activities?

- b. What is your job title?

On a scale of 1 to 5, with 1 being the lowest possible rating and 5 the highest, please answer the following questions:

- c. How would you rate the level of coordination among pediatric care providers in your area?

1 2 3 4 5

- d. To what extent do pediatric care providers make effective joint decisions through collaborative interagency mechanisms?

1 2 3 4 5

- e. To what degree are the agencies who serve children with HIV and their families able to function together as a unit to achieve common goals?

1 2 3 4 5

- f. How often has your agency had conflict with other agencies over a policy, funding, or service issue?

1 2 3 4 5

C. ACCESSIBILITY

Purpose: To determine the physical accessibility and convenience of the program's services
Methods: Interviews with service staff and observation of the service setting
Target: Facilities

1. How did you decide on your current hours/days of operation? Have you made any changes in these hours (e.g., night/weekend hours)? If so, why?
2. How did you decide on your program's scheduling policy (appointment vs. first-come, first-served)?
3. In your self-study guide, you noted that you offer the following types of assistance with transportation:

- *[This section will list information from the self study guide.]*
-
-

What kinds of barriers have you experienced to providing this type of assistance? What has worked well?

4. In your self-study the following problems or concerns with accessibility of services were noted:

- *[This section will list information from the self study guide.]*
-
-

Can you elaborate? *(Site visitors will tailor probes based on the self-study responses)*

Confirm/observe checklist

- Confirm through observation accessibility of major service locations to persons with handicaps.
- Confirm through observation the location of parking lots, ease of parking, and location of public transit stops.
- Confirm through observation the physical environment and "ambiance."

D. FAMILY-CENTERED CARE

Purpose: To explore ways in which the project involves families in project decision making and in their own service plans
Methods: Interviews with staff and observation of process
Target: Case management staff

1. Do you have a written policy on who is eligible for services?

How feasible is this policy, in your opinion? (That is, although you would like to serve more than the client, in actuality, are you able to? Where are the gaps?)

2. What are your guidelines for stopping or ending services?

3. In your self-study, the following barriers or obstacles were identified:

- co-located services--
- 0 concurrent clinics--
- same-day appointments--
- 0 child care during appointments--
- child care for other purposes (support groups, respite care)--
- support groups--
- 0 home visits--

Can you elaborate?

(Site visitors Will tailorprobes based on the self-study responses)

4. *If project has a support group for clients:*

When did support group(s) first get started?

How did support groups first get started?
(e.g., client-initiated or project initiated)

Were there any barriers/issues to starting the support groups?

When and where are support groups held?

How are they staffed?

What is the focus of the support groups?
(e.g., education, social activities, counseling)

5. *If home visiting services are offered:*

Who is responsible for making home visits? (e.g., staff or referral agencies)

How often are home visits made?

What is the nature/purpose of these visits? (e.g., case management, home health care, help with household chores and other activities of daily living)

6. Do you have any printed materials on family care training for staff?
7. What do staff do to involve families in service planning?
8. What have been some of the barriers to including family members in advisory committees, task forces, or other planning groups? How have you overcome these barriers?

Confirm/observe checklist

- Confirm through observation existence of files for family member other than the child
- Confirm through observation of schedules or actual sessions, existence of
 - Co-located services
 - Concurrent clinics
 - Child care during adult appointments
- Confirm through reading agendas or observing actual sessions, existence of
 - Family care in-service sessions for staff
 - Family empowerment/personal advocacy training
 - Participation in family support groups
- Confirm through reading agendas, minutes, or observation, family involvement in planning

and service delivery through:

- Clients/family members on governing body

- Family participation in service planning

- Use of clients/peers as staff or counselors

E. CULTURAL COMPETENCY

Purpose: To explore how the project addresses the cultural diversity of its clientele and the cultural differences between clients and staff
Methods: Interviews with key staff and observation
Target: Medical, social services, and case management staff

1. Does your program have a policy statement related to cultural competency?
2. Data from Table 3A (Person based demographic and clinical status summary) indicates that the key cultural groups that you serve include:

- *[This section will list information from the self study guide.]*
-
-

How does this affect your approach to service delivery? Have you found the need to take a different approach for any particular subcultures (e.g., substance abuse, homelessness, etc.)?

3. Is cultural competency an element of staff job descriptions?
4. What kinds of activities do program staff undertake to identify program barriers to cultural competence (e.g., client surveys, utilization data)?
5. What types of training in cultural competence skills are offered to staff?
6. How do the program's cultural competence activities relate to those of the larger institution (if applicable)?
7. Have you had any problems developing or obtaining multilingual materials (if applicable)?
8. *(For projects that have multilingual materials)* What materials are available in which languages?
9. How did you decide which grade level to target your materials to?

Confirm/observe checklist

- Confirm through observation demographic/cultural breakdown of staff versus predominant clientele
- Confirm through observation multilingual/cultural signage, materials, and forms
- Confirm through observation use of clients/peers as staff or counselors

F. QUALITY CARE

Purpose: To examine quality assurance mechanisms as a proxy for quality of care
Methods: Review of documents and interviews
Target: Medical staff

Before going on site, site visitors will review protocols and guidelines for pediatric care and women's ob/gyn care provided as part of the self study.

Particular areas for follow up and clarification will be noted and asked of medical staff. In addition, the following questions will be asked:

1. In your self-study guide, you indicated that you use the following HIV diagnostic tests:

- *[This section will list information from the self study guide]*
-
-

And you indicated that you use the following HIV test(s) most often:

- *[this section will list information from self study guide]*
-

Under what circumstances do you use which tests?

What factors influence your choice of tests?

2. Do you make any exceptions/adaptations to guidelines and protocols?
(e.g., point at which clinical therapy is initiated) If so, please describe.

3. Are alternative therapies available for your adult and pediatric patients? Who provides this care? Please describe your referral and information feedback processes.

4a. What mechanisms do you have in place to identify primary care providers for pediatric patients? Adult patients?

4b. Is medical information for pediatric clients shared between tertiary care, primary care, and other service providers? If so, how? How frequently? What is the typical turn-around time?

4c. Is medical information for adult clients shared between tertiary care, primary care, and other service providers? If so, how?

- 4d. Is medical information from the mother's prenatal/obstetric records shared with the child's pediatric medical care provider? If so, how? How frequently? What is the typical turn-around time?
- 5a. Is home health care information for pediatric clients shared between home health care, primary care and other service providers? If so, how? How frequently? What is the typical turn-around time?
- 5b. Is home health care information for adult clients shared between home health care, primary care and other service providers? If so, how? How frequently? What is the typical turn-around time?
- 6a. Is mental health information for pediatric clients shared between home health care, primary care and other service providers? If so, how? How frequently? What is the typical turn-around time?
- 6b. Is mental health information for adult clients shared between home health care, primary care and other service providers? If so, how? How frequently? What is the typical turn-around time?
7. Is substance abuse treatment information for adult clients shared between home health care, primary care and other service providers? If so, how? How frequently? What is the typical turn-around time?

G. COORDINATION

Purpose: To explore how the project integrates multiple efforts directed at the same client of family and further elaborate mechanisms of collaboration and approaches to case management

Methods: Interviews and observation

Target: Case management staff

1. When clients come into the system for the first time, what is the process for linking them with case management services? How are clients assigned to case managers? How is the lead case manager determined?
2. Are there any project clients who do not receive case management services? If not, who and why?
3. What factors influence your approach to case management?
4. In your self-study the following mechanisms for coordination were identified:

- *[This section will list information from the self study guide.]*
-
-

Do these work well for you? Why or why not?
What factors influence your approach to coordination?

5. In your self-study the following client service needs were identified as the most time-intensive:

- *[This section will list information from the self study guide.]*
-
-

What influences the case managers ability to link clients with these services? Why are they so time consuming?

7. What major changes have you experienced in your client population that have had implications for case management since the project's inception? In the last year?

8. In your self-study the following barriers to coordination were identified:

- *[This section will list information from the self study guide.]*
-
-

Can you elaborate? *(Site visitors will tailor probes based on the self-study responses)*

9. What efforts have you found to be effective in addressing barriers?

Confirm/observe checklist

- Confirm through observation of files, ability to link files of clients and family members
- Confirm through observation of selected files, existence of mechanisms of coordination such as:
 - Multidisciplinary service planning
 - Service plan monitoring and updating
 - Standardized intake process

H. CLINICAL TRIALS

Purpose: To explore access to and participation in clinical trials for adult and pediatric clients

Methods: Interviews, document review

In your self-study you noted the following barriers to participation in clinical trials:

- *[This section will list information from the self study guide.]*

-

-

Could you elaborate on these and on strategies for overcoming these barriers?

I. STAFFING

Purpose: To explore staff availability, multidisciplinary nature of staff, and staff training and support
Methods: Interviews, document review, and observation when feasible
Target: Administrative staff (Q. 1-5), medical and social services staff (Q. 6-11)

1. What has been your experience with staff turnover over the length of the project?
 2. What is the average length of stay of staff?
 3. When you have had turn over in staff, what has been the average duration of staff vacancies?
 4. Do you feel that you are able to offer competitive salaries?
 5. In the self study you indicated that the following staff support activities have been most effective for you:
 - *[This section will list information from the self study guide.]*
 -
 -
- Have they made a difference in staff retention? Why do you think they have been so effective?
6. Are there particular staff supports that make a difference in your attitude about staying with this project?
 7. How involved are you in program decision-making? Do you feel that your level of involvement is appropriate?
 8. Are there particular staff roles or disciplines that you feel are not adequately represented on your staff? Why or why not?
 9. What types of training have you participated in since joining the project?
 10. Are you given monetary support and leave time to attend continuing education?
 11. Do you have training needs that are unmet?

Confirm/observe checklist

- Confirm through review of policy, minutes, or actual observation of staff meeting, staff input to decisionmaking
- Confirm through observation of agendas or actual sessions, cross-training of staffs for women's and children's services
- Confirm through observation of agendas or actual sessions, in-service training sessions
- Confirm through review of selected personnel files:
 - CEUs completed by staff
 - Appropriate certification/degrees
 - Prior experience with HIV/AIDS

APPENDIX F

**RYAN WHITE TITLE IV
HIV DEMONSTRATION PROGRAM
FOR CHILDREN, ADOLESCENTS, AND FAMILIES**

FOCUS GROUP DISCUSSION GUIDE

*Form Approved
OMB NO. 0915-0177
Exp. Date 09/95*

Public reporting burden for this collection of information is estimated to average 2 hours per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to:

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200 Independence Ave. SW;
Washington, DC 20201*

and to:

*The Office of Management and Budget
Paperwork Reduction Project (0915-0177)
Washington, DC 20503*

INTRODUCTION

Thank you very much for being here today. This is an informal discussion, so please just relax and make yourselves comfortable.

This group discussion is part of a study of a national government program that gives funding to organizations that provide medical and social services for families affected by HIV and AIDS. It's important for the national program to look at how the funding is being used by the projects and how their services are helping families. **[Project]** is one of the sites that gets this type of funding. We're here to find out about your experiences at the **[project]** and to discuss how you feel about their services. The purpose of our discussion is to understand how these services work from your point of view, and to help improve them if that's appropriate. We are also talking to project staff. Your opinions about these services are important too, and that's why we want to hear what you think.

We know that the issue of HIV/AIDS is a sensitive one. Sometimes it may be painful or uncomfortable to talk about how the disease has affected you and your family. I want to stress how much we appreciate your talking about these things with us. We're interested in your true, honest opinions. Everything you say here is completely confidential. When we write a report about the discussion, we will never associate a particular comment with any individual. The project staff will not know who said what today, but we'll let them know in general what we discuss.

The discussion should last about 2 hours and will cover five main topics:

- Accessibility--how easy or hard it is for you to get here and get the services you need
- Cultural Competency--ways that the project help you feel welcome
- Family Centered Care--how your family's needs are met and how your family is treated here
- Family and Individual Outcomes--how the project has affected your life, your child's life, and your family's life
- Prevention Outcomes--how the project has affected your own behavior

We are also interested in getting your suggestions for how the project can improve in these areas.

I'd like to introduce **[notetaker]**, who will be taking notes while we talk. Please try to speak clearly and one at a time so that she can follow our conversation.

Do you have any questions before we get started? Let's get started by introducing ourselves. Let's take a few minutes to go around the table and have each person say his or her name and a little about themselves--your family, work, school, or hobbies.

ACCESSIBILITY

1. How did you first find out about the [project]?
Probes: case manager, friend, social service agency, doctor...
2. What types of services do you get through the project?
Probes: medical care, case management, housing, transportation...
3. What types of services are easy to get through the project?
4. What types of services are hard to get?
5. What makes it hard to get these services?
Probes: transportation, hours, child care, physical access, other?
6. Are there other services that you need that you are not able to get here?
7. Are you usually able to make appointments for the services you need?
8. When you schedule an appointment, how long do you have to wait?
9. Do you have to wait a long time after you get here?
10. What kinds of arrangements do you have to make to keep appointments?
Probes: babysitter, ride, someone to take care of parent...
11. Is the location convenient for you?
12. How do you get here?
13. How long does it take?
14. Are the clinic hours convenient for you?
15. What hours would be more convenient?
16. Have you had any problems with how services are paid for?

17. Is there a case manager or someone else who helps keep track of all the services you need and are getting? Is that person at this agency or somewhere else?

Probe: Do the various providers seem to work well together and share information?

18. If there were no case managers, how do you think this would change the way you get services?

SERVICES

1. When you or your child started taking medicine, did you feel that it was the right time to start? How did staff help you with this?
2. Have you ever disagreed with what the staff here recommended for you or your child? How did you deal with this? What happened?
3. Have you ever wanted to look at your medical records? Was this possible? Did staff help you do this?
4. Have you ever considered any alternative treatments? Did staff help you with this?
5. Are any of you or your families enrolled in clinical trials? How has this worked out for you?

CULTURAL COMPETENCY

1. What kinds of things have staff done or said to make you feel comfortable--that is, welcome and at-ease?
2. What kinds of things would help you feel more comfortable?
3. What kinds of things would help other clients feel more comfortable?
4. Do you understand the information you get about services and medical care?
5. What kinds of things would help you understand better?
6. Do you feel comfortable asking questions?
7. Is there anyone here who speaks your language and understands where you're coming from?
8. How do you feel about the staff here and the way they treat you?

FAMILY CENTERED CARE

1. Do other members or your household receive services here?

2. If not, why not?

Probes: no services available, eligibility issues, inconvenient hours, ties to other providers, other...

3. What kinds of things could the staff do to make it easier for you to receive services as a family?

4. If your children or other family members receive services here--how are you involved in their care? Would you like to be more or less involved?

5. Are you invited to team (i.e. treatment team) meetings?

Probes: 1. Are meetings scheduled at times when you can attend?

2. Are you encouraged to express your concerns, ideas, priorities?

3. Are you given enough information?

6. Do project staff do anything in particular to help you be more involved?

7. Do you or any families that you know of serve on any planning groups or committees?

8. Are there other ways that you give staff your ideas about services and programs?

9. Would you like to be more involved in planning the projects and services?

10. Does the project help you get in touch with other families dealing with the same problems?

FAMILY AND INDIVIDUAL OUTCOMES

1. How do you feel physically now, compared to a few months ago? How about compared to a year ago?
2. What kinds of activities are you less/more able to do now, compared to a few months ago? How about compared to a year ago?
3. Does this project help take care of things that are harder to do? How?
4. Are you more or less concerned about your family than a few months ago?
5. What are you worried about? (your health, family members' health, \$, other?)
6. What kinds of things is this project doing to help you and your family?
7. In what other ways could the people here help you?
8. In general, what difference has the program made for you and your family?

PREVENTION OUTCOMES

1. What kinds of things do project staff do to help you stay safe--that is, take care of yourself and avoid things that are unhealthy for you?

Probes: support groups, referrals to drug treatment, supplying condoms, counseling partners.. .

2. What other activities or information would be helpful?