Community Involvement in HIV Planning and Administrative Structures

I. Introduction

Prevention and treatment of sexually transmitted disease (STD), including HIV/AIDS, is one of the most pressing health care needs in Texas. In 1994, the latest year for which estimates are available, between 49,000 and 71,000 people were living with HIV infection or AIDS in Texas. In 1997, the Texas Department of Health (TDH) received reports of 50,661 cases of Chlamydia, 26,617 cases of Gonorrhea, and 5,441 cases of Syphilis.

The Bureau of HIV and STD Prevention (Bureau) is charged with responding to the State's need for prevention and treatment of STDs by coordinating and funding HIV/STD prevention activities, HIV health and social services programs, HIV/STD disease surveillance activities, and the HIV/STD Medication Program, which provides STD medications to health departments, and HIV medications for low income Texans. All of these activities, except the Medication Program and HIV/STD surveillance, are carried out by community-based organizations and local health departments through contracts with TDH.[1] This arrangement is based on the philosophy that communities and local public health officials are in the best position to effectively implement programming and deliver services to their communities. In addition to service delivery and program implementation, the community has the function of assessing their HIV prevention and care needs, as well as conducting long and short term planning.

Thus, the administrative and current planning processes used by the Bureau rely heavily on the involvement and leadership of local communities. For both HIV services and HIV prevention, local planning and oversight is mandated by federal funding sources. Distinct mechanisms have been created over the past ten years to comply with these mandates. However, the current system in place for incorporating community input and for administering funds for HIV services is duplicative, inefficient, and short-sighted. The current system places an inordinate amount of strain on community and Bureau resources and makes it difficult for the Bureau to adequately perform its role: to assess, monitor and evaluate the quality of services, manage state and federal funds and provide outcome and cost measures. Additionally, meeting the requests from federal grantors and changes in the epidemiology of the disease have left the Bureau unprepared to adequately respond to these changes. The current system is difficult for the the community as well. Most communities do not have the capacity to conduct all of the complex activities related to planning. The current system is very resource intensive, intimidating and not conducive for broad community participation, especially from marginalized communities. Further, STD prevention and treatment issues are not sufficiently integrated into HIV planning activities.

[1]The Medication program is administered through the Bureau office in Austin. HIV/STD surveillance is carried out by public health staff at local, regional, and state health department offices, although the reporting system is driven primarily by the activity of staff at local health departments who contract with TDH.

The HIV epidemic has changed drastically since the current system for HIV planning and administrating services was developed. It was instituted in response to a devastating and quickly expanding epidemic, with the objective of rapidly identifying service providers and quickly distributing funds. However, advances in HIV treatment, the continued rise in HIV infection and the necessity of long term, sustainable processes have meant that the emergency systems developed early in the epidemic no longer effectively serve the Bureau, the community or the clients in this new environment, and make meeting the challenges even more difficult.

Also, it has become even more pressing that the Bureau further develop its oversight/evaluative role, as valid questions about effectiveness and benefit conferred by expenditure of HIV/STD funds are being asked at the national level by federal grantors. Communities, local and state health departments are increasingly being held accountable for documenting results for the large amount of funding allocated for HIV/AIDS programs. The Bureau and the community need to respond to the following questions:

- To what extent are programs providing services to the underserved minority and vulnerable populations?
- To what extent are programs providing clients with primary medical care whose quality meets or exceeds U.S. Public Health Service Standards and other care standards?
- To what extent are HIV prevention programs providing clients with high quality, effective interventions?
- To what extent are programs providing services that remove barriers to prevention services and primary medical care so that individuals can enter into and remain in care?
- To what extent are programs reducing HIV-related morbidity and mortality?
- To what extent are programs adapting to a changing service and cost environment?

The current method for planning and administrating HIV services has resulted in the Bureau performing dual roles: funding and monitoring HIV prevention and services as well as fulfilling the community's role in planning. This has meant that little or no leadership has been provided to determine the answers to the important questions above. Answers to these questions will require a critical evaluation of current HIV programs for cost and outcome efficiency. Given the current competition for funds, the Bureau and the community must be able to demonstrate clear evidence for continuing programs.

The purpose of this White Paper is to explore and re-evaluate the historic roles of community and government in the planning, implementation, and oversight of public health HIV/STD activities in Texas, to discuss problems within the current system, and to suggest recommendations for their resolution. This paper is intended to articulate the vision of accomplishing our public health goals.

Before embarking, we wish to define the values and beliefs that will drive the discussion:

- We believe that community and government must work in partnership to create systems that work.
- We believe in open processes accessible to all the stakeholders.
- We believe we are responsible for making the most of our limited resources.

The following are brief descriptions of current planning/oversight structures used for key program areas.

II. HIV Services

Although the State began providing HIV services in 1988, the driving force of health and social services for people with HIV disease was the Ryan White CARE Act of 1990 which established funding under four titles. Title I provides funding directly to high impact cities, which in Texas include Houston, Dallas, San Antonio, Fort Worth and Austin.

Title II funds, currently $35 million, go to the State and are allocated on a formula basis to 26 HIV Service Delivery Areas (HSDAs) primarily to fund those areas outside of the Metropolitan Statistical Areas covered by Title I. Title IIIb provides early intervention services to six sites in Texas, and Title IV funds four demonstration projects at University based hospitals to fund treatment for infants and children with HIV.

Current Structure

The current array of Title II HIV services programs has changed little since its inception. Today, the following components remain:

HIV/STD Medication Program. This program is administered directly by TDH. The program has responsibility for HIV medications, STD drugs and condom distribution to prevention programs, and resides within the Bureau of HIV and STD Prevention. HIV medications are purchased at Public Health Service prices through a single vendor who delivers the medications to a statewide network of community-based pharmacies. The Bureau of HIV and STD Prevention determines client eligibility based upon individual applications submitted, on a client specific basis, and maintains client data. The Medication Program works closely with Medicaid to maximize resources and client coverage. STD Medications are purchased by the Bureau and distributed by the Pharmacy Division to regional offices and local health departments statewide. These medications are utilized to treat gonorrhea, chlamydia, syphilis, and chancroid at no cost to the patient.

Early Intervention. Early Intervention (EI) is a strategy of service delivery to persons with HIV disease which focuses on ambulatory care. Services provided in EI include HIV-related clinical care, health maintenance activities, prevention of acute and chronic illness, and the integration of the client into a system that provides support services. Early health care and psychosocial intervention is most effective in delaying the onset of life-threatening symptoms and infections and in achieving and

maintaining the optimum level of health possible for each client. Early medical intervention, when combined with effective clinical case management strategies and psychosocial support, appears to slow disease progression and can enhance adherence with medical regimens. It also promotes healthy behaviors and may improve quality of life. This program is administered directly by the Bureau through nine contract sites located geographically around the state.

HIV Care Consortia. The Bureau developed a community-based planning process to identify priority HIV services needs in each of the twenty-six HSDAs. Local HIV Care Consortia create service plans specific to the needs of their area.

Funding is provided to the 26 HSDAs by TDH based on an allocation formula. Consortia provide planning for HIV health and social services based on a local needs assessment. Consortia are responsible for the following programs, with oversight by TDH:

> *Title II:* Title II of the Ryan White act enables funding for consortia activities including an array of health and social services defined by HRSA, such as outpatient medical care, treatment, dental care, screening and diagnostic tests, and support services.
> *State Services:* State appropriated funds are used as partial matching for the Title II grant and are used the same way as Title II.
> *Housing Opportunities for People with AIDS (HOPWA):* This grant program from the Department of Housing and Urban Development (HUD) is used to provide emergency and long-term rental assistance to low-income people with HIV disease. Emergency assistance may be provided to pay rent, mortgage and utilities on a temporary basis; and rental assistance may be provided as long as the need remains. This program is modeled after the HUD Section 8 program.

The TDH establishes a contract with one administrative agency recommended by the consortium in each of the 26 areas. The administrative agency administers the funding from Ryan White/Title II, state appropriation, and HOPWA. The administrative agency may be a local health department or a community-based organization. The administrative agency is charged with providing needed services, either directly or through sub-contracts. Currently, administrative agencies administer 391 contracts to provide health and social services for people with HIV disease. The planning for HIV services has changed very little since its inception in 1991.

The CARE Act sought to ensure a high level of local decision-making authority in meeting local priorities. However, the emergency structure created for this goal is not aging well: the experience in Texas indicates that the HIV services delivery system is structured in a way that reduces cooperation, increases administrative work, creates the perception of conflict of interest, fosters destructive competition, and leaves clients with a confusing, fragmented system that may not meet their greatest needs.

Planning, Implementation and Oversight Functions

The consortia concept relies on local control and local decision making. Planning for HIV services

takes place primarily at the local level, where consortia are required to allocate funds based on a client needs assessment.

A review of the 26 local consortia in Texas reveals that very few of these planning groups adequately conduct all of the processes related to the planning and allocating funds for HIV services. Three of the most important processes are: conducting a needs assessment, including community members and clients in the planning process and allocating funds for services.

Conducting the needs assessment is a very resource intensive process, requiring expertise in epidemiology, research methods and health planning. The quality and reliability of the needs assessment process vary among the different consortia. A review of these needs assessments conducted by the Bureau's Evaluation Branch in 1996 showed a wide variety of styles, methods, and tools used. Indeed, consortia with access to many community resources produced needs assessment findings that were very comprehensive, producing useful information for planning. However, other processes produced little meaningful information, and most smaller consortia do not have the resources to assess community needs.

Incorporating community and client participation in services planning is probably the most important task for consortia. Planning bodies located in the larger metropolitan areas have managed to cultivate true community interest and participation. However, consortia in the smaller HSDAs have constantly struggled to keep community members. In some areas, it is not uncommon to have only three or four HIV service providers regularly attend consortia meetings and little or no community representation at meetings. The resulting allocations, coupled with questions on the validity and authenticity of the needs assessment, can lead to infighting and allegations of conflict of interest within a community.

Another task for consortia is to choose an administrative agency to allocate funds. Through the administrative agency, consortia are responsible for implementing and managing all requirements of the services programs. After deciding how to allocate service dollars by evaluating the results of the needs assessment, consortia conduct a "request for proposals" (RFP) process to select contractors to perform the services. In smaller HSDAs, the administrative agency is usually the same agency providing HIV services. Additionally, many of the administrative agencies in smaller HSDAs do not have the capacity to competently administer funds, as well as provide services. Of the 26 service planning areas in Texas, over half contain administrative agencies that do not adequately perform their administrative role, such as collecting data on clients served. This results in Bureau staff completing much of the administrative work, and in some instances, Bureau staff has had to completely take over the role of administrative agency. Unfortunately, Bureau Staff spend an inordinate amount of time working with consortia and administrative agencies, and in many instances, actually conduct the needs assessment, allocate funds or complete other community planning duties.

There are limited Bureau staff available to conduct or even provide technical assistance on conducting the above processes. Available Bureau staff spend a disproportionate amount of their time guiding these community groups through this complex process. The result is that staff of the Bureau of HIV and STD Prevention find little time to complete the functions related to their role: developing policy,

managing funds, program monitoring to assure compliance, developing cost and outcome measures and assuring quality of services.

The larger HSDAs in Texas have developed consortia that have the capacity to conduct all of the complex processes related to planning and allocating funds for HIV services. These larger areas have located and developed many resources in their community to assist them in the processes, as well as community members and clients that actively participate in the process. Also, the administrative agencies in these successful areas perform only administrative functions and do not provide client services.

III. HIV Prevention

The HIV Prevention Program is built on a process primarily driven by community involvement. The community planning initiative mandated by Centers for Disease Control and Prevention (CDC) relies on local communities to provide representation, conduct planning activities and work in partnership with state health departments to establish HIV prevention funding priorities. The HIV prevention program receives approximately 11 million dollars in funding. The TDH funds 67 HIV prevention providers across the State to target populations and implement interventions identified in Regional Action Plans (RAPs) developed by the community planning groups (CPGs). HIV prevention providers are monitored by field staff of the TDH to insure prevention programs are implemented in accordance with the priorities identified in the RAPs. State health departments are held accountable to community planning groups and the CDC for complying with HIV program requirements. Local communities in Texas vary in their capacity to be a full partner in the planning process. The HIV Prevention Program in Texas requires intensive resources to plan, implement and monitor because of its size and diversity in population.

Current Structure

The CPG structure has evolved, and continues to evolve, in response to the changing HIV prevention environment. In Texas the CPGs are called HIV Prevention Regional Planning Coalitions (Coalitions). Community planning for HIV prevention began in Texas in 1993, with only one statewide CPG. In 1995 CPGs and TDH staff agreed that the state was too diverse to have only one planning group and created ten Coalitions representing the eleven public health regions in the State. Each develop a RAP specific to their geographic area.

In 1996 the TDH contracted with the Health Education Alliance Centers of Texas (HETCAT) to transition the role of direct technical assistance provider to the CPGs from the TDH Planning Staff to HETCAT. The twenty Coalition Co-chairs, TDH staff and HETCAT Consultants meet four to six times a year to make decisions regarding issues that effect the development of the State's Comprehensive HIV Prevention Plan and the structure of community planning.

In 1997 the TDH, in accordance with the bylaws adopted by the Coalitions, elected to redesign the structure of community planning. The re-structuring of HIV prevention planning groups is in response to the changing environment of the HIV epidemic. The proposed new structure will assist

many CPGs in the less populated public health regions who face the same problems with capacity that consortia in smaller HSDAs currently experience: few or limited resources in their small communities, over dependence on Bureau staff or outside sources to complete planning functions and little community representation. CPGs located in predominantly rural public health areas lacked the capacity to conduct all of the activities related to HIV prevention community planning. The result was scant community participation in a complex planning process, that led to high membership and leadership turnover. The new structure will result in fewer planning groups, but enhance local participation by creating a "community" friendly process, easier and less intimidating to access. This can be accomplished by encouraging frequent, informal, local meetings for information sharing and coordination and less frequent regional meetings for conducting business and planning. The regional meetings will include areas which have the resources to conduct planning activities.

The CPGs are moving forward with re-structuring by addressing any issues and impact it will have on their Coalitions. The proposed target date for completion of re-structuring is October of 1999.

Planning, Implementation and Oversight Functions

While there are many opportunities for community involvement in the HIV prevention program, they require a significant investment of volunteer time and a tolerance for working within a bureaucratic environment. The community has an extensive role in TDH's HIV prevention program: community planning is the foundation for HIV prevention programs and as such affects almost every branch within the Bureau. CPGs are charged with applying complex processes within their Coalition and accomplishing many tasks that result in the development of RAPs. CPG members are required to digest and apply to the planning process epidemiologic information that relies on reported AIDS cases. In addition, there have been no significant evaluation data collected to apply to the planning process. Developing RAPs, training Coalitions on the principles of the community planning process and insuring that they have current knowledge of changing trends in the epidemic are labor intensive tasks shared by volunteers and Bureau staff. It is particularly difficult for Coalitions to recruit individuals to participate in CPG activities who are representative of the HIV infected populations. Coalitions are in most need of individuals from disenfranchised populations whose first priority is satisfying basic survival needs. The inability to involve individuals from these populations is a barrier to complying with the principles of parity, inclusion and representation.

Staff resources to monitor CPGs, prevention providers and consultants are limited. The technical assistance needs of the CPGs and training needs of HETCAT result in Bureau Staff having insufficient time to thoroughly monitor Coalition expenditures and activities. Maintaining ten viable CPGs that are in compliance with CDC guidelines and the Bylaws is resource intensive and a constant challenge. In addition, prevention providers are monitored by regional and central office staff to assure compliance with contract provisions. Staff determine monitoring priorities by applying a risk assessment tool, along with desk top monitoring, to prevention providers to identify those who most need technical assistance. Those providers who are assessed as high risk are scheduled for regular site visits by regional and central office staff. Prevention providers are required to report quarterly on who they serve and what interventions are being implemented. Data collection requirements for reporting are currently being addressed by TDH staff. There has been significant community

involvement in the form of stakeholder meetings to determine what data elements should be collected by prevention providers.

IV. STD Prevention

While, there is a long history of TDH involvement in STD control and prevention, comparatively few fiscal and human resources have been devoted to these programs. This is especially true over the past decade when resources have remained static, while the need to address new and emerging infections has increased. During the past years, evidence has mounted indicating the significant link between STD and HIV transmission. It is now clear that STD infections increase the likelihood of HIV transmission and acquisition and that STD prevention is an essential component of a comprehensive HIV prevention program.

Current Structure

Currently, almost all STD prevention funds are funneled to local health departments, primarily for disease intervention services. Disease intervention is the process of interrupting the transmission of disease through the use of patient education, counseling and partner referral. Disease Intervention Specialists (DIS) counsel persons with selected STD diagnoses about their infection, and work with the client to ensure the identification, examination and treatment of at-risk sexual partners. DIS also perform surveillance functions including case follow-up, as well as laboratory and physician education. Most local health department STD programs also conduct screening programs for gonorrhea, chlamydia and syphilis, often in both clinical facilities and at non-traditional settings such as correctional facilities, bars, street corners and other venues where at-risk persons are likely to congregate. In the past few years, TDH has encouraged local STD programs to develop partnerships with funded HIV prevention and care providers to conduct joint HIV/STD education, outreach, testing and treatment programs. Many local programs have embraced this philosophy while others have been unable or unwilling to move in this direction.

The TDH has no funds to support clinical STD services: public STD clinics, a critical component of STD prevention efforts, are all locally funded in Texas. Many local health departments have decreased STD clinical services in recent years, citing funding issues as the primary reason for cuts. In addition, TDH regional clinics, once an important source for STD clinical care, have closed across the state as the TDH refocuses its efforts away from direct patient care.

Planning, Implementation and Oversight Functions

Currently, there is no system for community involvement in planning STD prevention and treatment programs. In the late 1980's, attempts were made in Houston and Dallas to create community advisory groups, but these efforts could not be sustained, partly because of a lack of resources, direction and support from the TDH, and partly because of the difficulty in recruiting community members sufficiently invested in STD issues to dedicate significant amounts of time and energy to planning efforts. Since that time, some STD program staff have become involved to varying degrees in regional HIV prevention planning efforts. The lack of a system for enlisting the involvement of affected communities seriously impairs the ability of Texas to adequately plan and implement a

response to this epidemic.

In the absence of community participation, planning activities remain largely the domain of local health departments and the TDH. These planning efforts tend to be episodic, unstructured and generally crisis motivated; little long range planning has occurred. The exception to this is the strategic planning process implemented by the Bureau in 1997: STD issues are prominent in the strategic plan adopted by the Bureau.

The TDH implements STD program activities through a variety of mechanisms. The TDH secures funding for the program through legislative appropriation requests, applications for federal assistance to the CDC, and through partnerships with other TDH programs. Family planning and maternity care programs contribute resources to gonorrhea and chlamydia screening efforts, as does the TDH laboratory. The vast majority of TDH resources fund DIS activities in two areas: TDH regional offices which serve areas of the state without local health departments; or local health departments which provide DIS services. The state provides direct assistance in the form of medications to treat selected STDs as well as laboratory services and supplies to test for bacterial STDs (gonorrhea, chlamydia and syphilis.)

The TDH staff in Austin develops program goals and objectives in partnership with local and regional staff, develops program policy, guidance and procedures, and develops contracts with local health departments. Staff then monitor those contracts to assure compliance with contract provisions. The role of regional staff in monitoring these contracts is variable and poorly defined. Central office staff conduct program reviews in regional offices to assure quality in the direct program services provided by TDH public health regions.

V. Observation of the Symptoms and Causes

A close look at the history (see Appendix A) and current structure (above) of community involvement and delivery of HIV care services reveals symptoms of underlying structural problems and suspected causative agents. The origin or cause of these problems, while appearing somewhat anecdotal, nonetheless, are based on program experiences. Note that certain agents may work to cause multiple symptoms.

A. **Symptom:** Community/consumer participation in planning, implementation, and oversight are extremely underdeveloped in many areas of the State. Sufficient consumer participation is often missing in community-based planning[2] and oversight work.
Causes: Many factors mitigate against building and sustaining effective community presence in the planning and delivery of HIV & STD services:
1) Persons with HIV disease may not be well enough to participate or at liberty to share their HIV status.

[2]Community Planning in this context refers to planning by the larger community as opposed to the CDC Community Planning Program.

2) Persons at risk for HIV often do not recognize a need to participate.
3) Extremely marginalized individuals may not view participation as a priority in the demands for their daily energy and focus.
4) Consumers may not possess the knowledge and sophistication about service delivery systems and funding issues as do professionals in the fields of HIV/STD. This lack of knowledge acts as a substantial barrier to participation as consumers may be unwilling to deal with the discomfort and embarrassment of not being able to understand or communicate in the "proper" jargon and esoteric language.
5) There are large workloads and complex activities to be carried out by community volunteers with little or no support staff.
6) Current planning structures are not "client friendly", and place more emphasis on the complex planning process rather than community inclusion.
7) Consumers are intimidated by a process that requires participants have a working knowledge of epidemiology, health planning and health care delivery.

B. **Symptom:** Communities are not uniformly able to conduct sound needs assessments and other technical planning processes, This may lead to shallow or uneven assessment of needs and lack of focus on outcome. Community groups focus on narrow areas of responsibility or funding (e.g., HIV services only , HIV prevention only, STD only), which leads to duplication of effort or plans and interventions which do not acknowledge the connections between diseases or services.

Causes:
1) Communities do not have uniform capacity and support to use data in decision making and evaluation. Because of this, these models can be frustrating for community members who are not interested in mechanistic decision making, and in some cases, this frustration has resulted in local use of decision making processes which are neither data-based nor defensible.
2) Communities lack of understanding of and training on roles and responsibilities.
3) There is a lack of strong, positive leadership in many communities.
4) Due to resource limitations, there is uneven or insufficient technical assistance.
5) There is a lack of awareness of connections between STD and HIV.
6) The planning and decision making models required by Federal grantors require the use of very sophisticated and time-consuming decision-making and planning models which exacerbate these problems. These models require community members to manipulate epidemiologic data, conduct and evaluate the results of needs assessments, and justify the prioritization of community interventions using guidelines which are perceived as being either too loose to be instructive, or so controlling as to be restrictive.
7) No funds have been allocated for consortia development.

C. **Symptom:** Duplication of effort, especially in planning and administrating HIV care funds.

Causes:
1) Many areas in the State contain multiple, uncoordinated planning processes and several

local planning groups. Some groups are only focusing on prevention, others with Ryan White services. These groups are sometimes conducting different needs assessment processes for the same community.

2) Currently, all administrative agencies are performing the same management and allocation process.

D. **Symptom:** Real or perceived conflict of interest exists.

Causes: Since community participation in planning is difficult to maintain, the result is that generally only a few community participants, usually service providers who need planning functions completed in order to receive funds, participate in HIV planning. They are then perceived to be using the planning process to further their own interests.

E. **Symptom:** Disjointed service systems, and community tensions and upheaval. The Bureau experiences constant rounds of "hot spots" in the State that require heavy investments of staff time to address. While a certain level of tension is inevitable concerning funding and program responsibilities, communities that are in turmoil frequently remain in that state for months or even years. Eventually the focus of the community-led efforts revolves around the tension and competition rather than around client needs and services.

The delivery of HIV/STD program activities lacks the cohesiveness/ connectedness needed to fully address client needs and facilitate client flow through the system. Though the Bureau has been programmatically integrated since 1994, this has occurred only minimally at the local level. Communities are still disjointed along the lines of their different funding streams. We cannot continue to support the current stressed system. While some efforts have been made to integrate programs locally, such as HERR and PCPE, much work needs to be done.

Causes:

1) Competition for funds limits ability to build effective coalitions, collaborations, or planning efforts.

2) Separate funding streams with different contractual, administrative, and regulatory requirements creates divisive and duplicative processes.

3) Regulations are disjointed, understanding of common issues is minimal, and program priorities and philosophies are diverse.

F. **Symptom:** There is no community support, advocacy or interested constituency to provide community input for STD services, which has resulted in no new resources to control STDs.

Causes:

1) There is no statutorial or funding entity mandate for community involvement in STD

activities.
2) There is an artificial line between HIV and STD in the Bureau and in the community.
3) Communities need to educated regarding the link between STDs and HIV.
4) No sense of community that can lead to participation exists for consumers of STD services.

G. **Symptom:** The Bureau experiences substantial limitations in its ability to effectively organize and develop local planning and oversight efforts.

Causes: The most obvious causes of these limitations include:
1) The large geographic size of the State leads to constant and expensive travel by Bureau Staff.
2) The diversity of the populations within the State and the HIV epidemic (race/ethnicity, economic, marginalized communities.) mean that extensive time must be spent in these communities to solicit participation.
3) There is a lack of staff capacity to provide individualized technical assistance and training to community groups, as well as a lack of technical assistance and training materials.
4) There is confusion about roles and responsibilities of Bureau staff regarding assisting community groups.
5) There is a lack of guidance from some funding sources about the community's role in the planning process.
6) There is a lack of knowledge of local dynamics, key players, and history of community group interactions.
7) There are institutional barriers, such as FLSA limitations, travel restrictions, and administrative caps.

VI. Strengths and Weaknesses

Another useful way to look at current structures for planning and oversight is to analyze perceived strengths and weaknesses. By looking at these more global issues, we can make recommendations for system changes that build on existing strengths.

A. HIV Services

Strengths:
1) Treatment improvements are forcing a new dialogue about what services are needed and should be funded.
2) Community members and provider staff at the local level have a great desire to participate in the process.
3) Needs assessment, priority setting, and allocations are mandated to have a community driven process with a client focus.

Weaknesses:
1) The Ryan White Comprehensive AIDS Resources Emergency Act (CARE Act) was

enacted by Congress in 1990 as a short-term response to the AIDS crisis. The resulting structures that were developed are not effective as long-term solutions.
2) There are too few available and capable volunteers (particularly HIV-infected individuals) for the large number of consortia. Consortia volunteers frequently have no background in needs assessment, priority setting, planning and other core consortia roles.
3) There is significant confusion over consortia responsibilities.
4) There are limited accountability and limited consequences for poor performance.
5) There is limited Bureau staff capacity to provide technical assistance and monitoring for the large number of consortia.
6) Competitive procedures require Administrative Agencies to compete for service dollars, then to be responsible for contracting with and monitoring their competitors.
7) Administrative Agencies frequently lack capacity and skill in monitoring subcontracted services.
8) Conflicts of interest are exceedingly difficult to manage.

B. HIV Prevention

Strengths:
1) In general, there is fairly high buy-in from local communities on prevention priorities because the priority setting process is community driven.
2) The community planning groups (CPGs) include limited, but broad and diverse representation from across the State.
3) The community planning process has forced more narrowly targeted prevention efforts.
4) Active partnerships with the community have resulted in the development of creative and mutually beneficial processes and reinforced a customer oriented focus.
5) Community planning process has increased awareness of HIV issues at the local level.
6) CDC and TDH have made funding available to support the planning process.
7) Prevention evaluation projects have included community participation.
8) TDH and many local providers employ knowledgeable and experienced staff.

Weaknesses:
1) CPGs have uneven capacity to conduct planning activities.
2) Many CPGs are unable to maintain the CDC requirement for Parity, Inclusion, and Representation from the affected and infected communities.
3) There is limited staff capacity to provide technical assistance and monitoring for the number of CPGs.
4) Many communities do not have enough identified and available local leadership to support CPGs.
5) There are insufficient behavioral science resources to participate in the planning process.
6) Most CPGs lack STD expertise and knowledge of STD prevention.
7) Many CPGs experience too little consumer participation and too much contractor influence.
8) Until recently, there has been a lack of policies for holding CPGs & co-chairs accountable.

9) Inadequate technology exists in many local areas to produce highly technical planning documents and effectively communicate with prevention partners.

C. STD Prevention

Strengths:

1) The Bureau Strategic Plan offers a good framework for improving STD program planning and implementation activities.
2) Dedicated staff within TDH and local and regional health departments are eager to work toward improvement.
3) CDC is supportive of comprehensive STD planning activities.
4) CDC is supportive of customizing STD program activities at the state and local level.
5) The 1997 IOM report on STDs has provided momentum for increasing public education and awareness and for strengthening all aspects of STD screening, diagnosis, treatment, and disease intervention.
6) The focus of the Bureau's strategic plan strengthens the integration of HIV and STD programs.

Weaknesses:

1) The lack of community (including significant institutional partners) participation weakens our ability to address STD issues.
2)There is a need for a process to assess needs and establish priorities for STD program resources at the local level.
3) There is no history of community involvement in STD program planning.
4) Some STD program staff may fear loss of program control with greater community involvement.
5) There are little to no fiscal or human resources to assist/encourage community involvement.

VII. Principles

The basic premise of this document is that we need to plan more efficiently due to limited resources. The processes created in the Bureau do not create a relationship between the community and the government which capitalize on the strengths of each. Because we believe that community and government must work together to create a response to the public health problems of HIV and STD,

we seek to recreate ourselves into a system which works. In doing so, the Bureau holds the following principles as a guide:

A. Planning and administrative jurisdictions and structures must be guided by differences in disease morbidity, service utilization, and community capacity.
B. A continuum of HIV/STD care, including prevention, must be available in each jurisdiction in Texas. However, this continuum is not license for duplication of programs and processes.
C. Roles must be matched with capacity. All participants must play to their natural strengths.
D. Planning efforts should be integrated, addressing HIV prevention, HIV care services, and STD issues.
E. Communities are complex and multifaceted. Broad-based community participation (including local health departments, clients, local universities, interest groups, business communities and others) in planning and program implementation is vital and will create more effective programs.
F. TDH cannot improve the system until we decrease or eliminate the impediments to those improvements.
G. Programs and processes must be data driven and scientifically supportable.

Based on these principles and the foregoing problem and cause statements, the following recommendations have been developed:

VIII. Recommendations

A. The TDH should integrate planning processes for HIV services, HIV prevention, and STD prevention, broaden the charge given to planners from their funding stream or specific scopes of interest, and simplify the planning processes to minimize the learning curves of participants and remove barriers to community participation.

B. The TDH should reduce the number of administrative agencies, in order to capitalize on existing strengths. This restructuring and integration process should not reduce the amount of money available for HIV and STD Services.

C. Ideally, the administrative agency should focus solely on the tasks related to administering services. When this is not possible, TDH should set a system in place that reinforces the administrative function of administrative agencies in order to minimize conflict of interest.

Clearly, TDH will need to work collaboratively and in partnership with the community to achieve successful outcomes. Successful implementation of the recommendations will result in Bureau staff fully executing their role in the provision of HIV and STD services. Staff will have the opportunity to produce clear and simple standards of practice and guidelines for administration of programs. Bureau staff will also have the opportunity to build infrastructure and capacity for community development with fewer jurisdictions.

APPENDIX A

Background on STD and HIV in Texas

The TDH has been involved in controlling the spread of STDs in Texas since before World War II. Initially, TDH activities centered around the use of public information and education campaigns. In

the **1940's**, TDH participated in the operation and management of "rapid treatment" centers in Texas. STD prevention efforts languished through the **1950's** and early **1960's**, until increases in early syphilis prompted a renewed interest in controlling this preventable infection. During this period, in partnership with the Centers for Disease Control (CDC), the TDH began to focus on early detection and treatment of infected persons and the prompt referral of their sex partners for evaluation and treatment. This strategy has been used extensively and is an important component of STD prevention programs.

An infusion of federal funds in the early **1970's** was intended to address rising rates of gonorrhea in Texas. The gonorrhea screening program was created to test at-risk women in a variety of health care settings, to assure treatment for those infected, and to refer their sexual partners for examination and treatment. Syphilis epidemics in the mid and late 1970's and early **1980's** led to the last infusion of state funding for STD programs in 1982. No new significant resources have been allocated to STD efforts since.

The TDH Bureau of Epidemiology began monitoring what is now called AIDS after it was first described by the Centers for Disease Control (CDC) in June 1981. The Bureau published a case definition in its newsletter and asked physicians to report cases to the CDC. This passive surveillance was TDH's first involvement with the epidemic.

Active surveillance of AIDS began in **1982**, with the publication of a refined clinically-based definition of AIDS by the CDC. A person could be diagnosed with AIDS if he/she was diagnosed with a disease at least moderately predictive of a defect in cell-mediated immunity if there was no known cause for diminished resistance to that disease. In other words, AIDS was diagnosed because of the presence of a recognized opportunistic infection (OI). As part of the definition, it was noted that in the absence of a reliable, inexpensive, widely available test for what was then only clinically recognized as AIDS, the working case definition was the best available tool for incidence monitoring. A uniformly conducted national reporting system was put in place as all areas of the United States rapidly adopted the CDC surveillance case definition. In Texas, AIDS case reporting began in **1983,** when the Texas Board of Health added AIDS to the list of reportable conditions. In late **1983**, the human immunodeficiency virus (HIV) was identified as the cause of AIDS.

In **1984,** a serum antibody test was developed to screen for HIV infection. Beginning in early **1985**, this antibody test was made commercially available to screen donated blood and plasma for the presence of HIV. The addition of laboratory-based evidence of HIV infection was added to the definition.

The seeds of HIV prevention programming were sown in **1985** through the availability of new CDC funds to provide HIV counseling and testing. Twenty-six counseling and testing sites (called "alternate sites") were set up across the state and educational components were added in some cities.

In **1986** the Commissioner of Health formed a Task Force on AIDS to discuss public health issues and to suggest a possible legislative response. The following year the 70th Legislature revised the

Communicable Disease Prevention and Control Act and added AIDS and HIV infection to the statute. That legislature appropriated $3.4 million for FY 1988 grants to community-based programs for HIV education and services. To administer the program, TDH identified a small number of staff to form the Bureau of HIV and STD Control in **1987.** The Bureau had two divisions, the AIDS Division (including surveillance) and the STD Division. The mission given to the AIDS Division was to: 1) provide education and prevention services (Prevention); 2) collect data on the prevalence of HIV and AIDS (Surveillance); and, 3) assist community organizations in providing medical and social services to lower the costs of care (Services).

Chlamydia became a reportable infection in **1987**, and limited federal funds were secured to begin a screening program for this STD based on the successful gonorrhea screening program model. Currently, gonorrhea morbidity is significantly lower than during peak years in the 1970's and early 1980's, and reported early syphilis is at an all-time post World War II low. Chlamydia is now the most commonly reported STD in Texas, and as expected, the number of reported Chlamydia cases continues to rise as our screening efforts are expanded.

The first federal funds in Texas for HIV Services were for the HIV Medication Program, which began in December **1987** with the drug AZT. The first state funds for services for people with HIV were appropriated in **1987** for the 1988-89 biennium. Fifteen contractors were identified through an RFP process to provide services.

In **1987**, HIV infection was made a reportable condition in Texas. Between 1987 and 1994, HIV infections were reported in Texas *anonymously*, meaning that only limited demographic information was reported for confirmed HIV infections.

In **1989**, the State HIV/AIDS Services Program was created by the legislature. Over $2 million were allocated to continue existing services and to identify new service providers. To implement the program, a program manager, two consultants, and a secretary were hired. Rules were written and an advisory committee was solicited.

In order to accomplish effective delivery of services equitably across the regions of the state as required by the legislature, the state was divided into 27 HIV Service Delivery Areas (HSDAs) in **1990**.

The Ryan White Care Act was passed in **1990** and TDH received its first Title II federal grant in April, **1991**. The Title II monies were used to establish and/or supplement: 1) HIV Care Consortia activities, 2) Home and Community-based Services, 3) Continuation of Insurance; and 2) the HIV Medication Program. Public input was solicited at the PHS Region VI Summit Conference held in New Orleans in 1991, attended by approximately 150 Texas providers.

The service delivery plan was then presented to the HIV Services Advisory Committee. The Advisory Committee, established in 1989 had service providers and consumers as committee members. At the recommendation of the Advisory Committee, a funding allocation formula would be utilized to

determine the funding level of each HSDA. Application of the formula was meant to insure that the needs of cities and rural areas were met. Title I programs were also consulted.

In the 1990 RFP, TDH actively encouraged HIV service providers in each HSDA to develop local consortia. The consortium concept put the responsibility for determination of needs and allocation of resources at the local community level, it allowed local service providers to coordinate services and prevent duplication, and put Texas in line with Ryan White Act requirements. In 1991, HSDAs were reduced to 26 and a single application was required from each HSDA. However, these consortia had to write three applications for the different funding areas, and not all consortia had administrative agencies to do so. The Medication Program continued to be administered directly by TDH.

Initially, written guidance consisted of financial management documents from Grants Management Division, and four "recommendation" documents created by the Bureau in partnership with consortia and administrative agencies in 1992. In **1994**, TDH published its first consortia policy dealing with subcontractor selection, and four other consortia policies followed in 1996. Official oversight was provided by the HIV Services Advisory Committee until 1995, when it was abolished by the Board of Health in response to state legislation.

Over the next few years, the Insurance Program and the Home and Community Based Program were combined into one program within consortia--easing the administrative and planning burden of the administrative agencies.

In **1992**, the TDH issued an RFP for HIV Early Intervention Services, allocating $500,000 in state funds for the services program. These funds were not allocated to consortia, but were competed to areas not being served by the Ryan White/Title IIIb Early Intervention programs. The program was designed to provide early medical assistance for people with HIV disease to prevent the onset of AIDS.

In **1993**, TDH received its first funds to provide housing assistance to people with HIV and AIDS through Housing Opportunities for Persons with AIDS (HOPWA), a HUD program. These funds were also contracted to consortia, using the same formula as Title II.

As experts gained a greater understanding of the underlying mechanisms of disease development, the AIDS case definition and focus of disease surveillance shifted. Rather than tracking diagnoses of OIs, the CDC case definition for AIDS adopted in **1993** focused on using laboratory evidence of severe immunosuppression (CD4+ T cell count below 200 microliters per decaliter of blood or below 14%) as a marker of AIDS. Laboratory reporting of names of patients whose CD4+ T cell counts met the new definition of AIDS began in Texas in **1994**. In Texas, as in other states, AIDS has been reportable by the name of the individual diagnosed with the condition since reporting was initiated in 1982.

In **1994**, reporting of HIV infection in Texas by unique identifier (UI) began. The Texas Board of Health amended reporting rules to require laboratories and other providers to report a UI for each

confirmed HIV infection in individuals 13 years of age or older. The 12-digit UI was made up of the last four digits of the social security number; month, day, and year of birth; sex; and race/ethnicity of the patient. HIV infections in individuals younger than 13 years of age became reportable by name.

A major reorganization of the Bureau of HIV and STD Control in 1994 lead to the formation of the Planning and Policy Branch. This created three new functions within the Bureau: planning, grant writing/RFP process, and policy development. Most other resources of the Bureau were placed into functional branches and units for the purposes of monitoring, contract management, data management, and evaluation.

In **1993** the CDC mandated that states implement the community planning initiative. This initiative required states to create a community planning group (CPG) consisting of individuals who mirrored the epidemic in the state. The first CPG in Texas was a statewide group whose members were chosen from regional coalitions to form the HIV Prevention Partnership. Both the regional Coalitions and the statewide group were composed of volunteers with varying levels of experience and skill in group process. The charge to the CPG was to determine target populations at highest risk for HIV infection and reinfection and the interventions most likely to reduce their risk of HIV transmission. Unlike consortia, the CPG in Texas was not given the responsibility to allocate funds. However, the CPG was required to assign a priority to the populations and interventions which had to be based on evidence of HIV disease. The TDH provided an epidemiologic profile and developed a needs assessment process that the CPG implemented in the eleven regions of the State to collect data on the target populations and interventions. The development of the Comprehensive HIV Prevention Plan provided a link between the priorities determined by the CPG and allocation of funds. In partnership with the TDH staff, the CPG developed a plan that specified which populations and interventions should be targeted for HIV prevention funding. The Comprehensive HIV Prevention Plan was the basis for the RFP issued in 1994 for funding prevention programs in 1995.

This new paradigm of conducting HIV prevention was received with mixed acceptance by HIV prevention providers, the TDH staff and consumers of HIV prevention services. The guidelines for the community planning program issued by CDC required the CPG to implement several complex processes in order to carry out its charge. There was an extensive amount of work the CPG had to accomplish in a short time frame to develop the first Comprehensive HIV Prevention Plan. The tasks required to complete these processes were labor intensive for volunteers and TDH staff who were responsible for providing technical assistance and leadership to the CPG. After the completion of the 1995 Comprehensive HIV Prevention Plan, regional coalitions expressed their dissatisfaction with the representation on the statewide group. In January of 1995, the statewide group was abolished and ten regional coalitions each with a community co-chair and TDH designated co-chair were created. In November of 1997, the Bureau proposed that CPGs be reduced in number and restructured geographically. Restructuring is currently being addressed by CPGs, TDH staff and the CPG technical assistance provider.

The Texas Board of Health has adopted HIV reporting by name. This change will be effective January 1, 1999. Starting on this date, all providers and laboratories will be required to report

confirmed HIV infections with test dates on or after January 1, 1999 to the local surveillance authority. The new surveillance system should provide CPGs with more accurate data on HIV infections in the State of Texas.