

FINAL REPORT

*Houston Area HIV Services
Ryan White Planning Council*



Perceptions and Evaluation of HIV/AIDS Care
and Prevention in Harris and Surrounding
Counties.

SUMA
PARTNERS

BACKGROUND

Houston Area HIV Services Ryan White Planning Council is a 38 member volunteer planning group made up of community members who have been appointed by the CEO, County Judge Robert Eckels, to serve a two-year term. The Houston Area HIV Services Ryan White Planning Council is responsible for activities under Title I of the Ryan White Comprehensive AIDS Resources Emergency Act.

Council members, in collaboration with consumers, service providers, and other Experts determine what services are most needed by people living with HIV in the Houston area. The Council then prioritizes those services and decides the best way to allocate Houston's Title I grant award to fund those services according to the approved priorities. The Council is also responsible for determining the Standards of Care for each of the funded service categories and for developing a plan to provide those services within the comprehensive plan. Comprehensive planning is the process used by the Ryan White Council in determining the organization and delivery of HIV services.

Opportunities and Challenges

The Ryan White Planning Council's Office of Support contracted SUMA Partners to carry out confidential, semi-structured interviews with key informants segmented into two groups (Key Leaders and Experts). Key Leaders were defined as Elected Officials (City Council members; County Judges; State Representatives and County Commissioners) who could be expected to vote on or exercise authority over broad level decisions relating to HIV/AIDS. Experts were envisioned as Administrators, Planners and Community Advocates who are more likely to be responsible for directing and/or implementing HIV/AIDS programs or decisions. The universe contacted consisted of 25 Key Leaders and 44 Experts. The research was designed to collect data on three major topics:

- Care financing/regulatory issues
- Jurisdictional/political factors
- Public health infrastructure constraints on the provision of HIV/AIDS care and prevention services.

The Office of Support outlined the following questions for the semi-structured interview process in the draft version of their Comprehensive Plan:

- *What can you tell us about the adequacy of financing for HIV/AIDS care and prevention in this geographical area? Please discuss how well the funds fit into the context of the available funding streams?*
- *How do you feel regarding the regulations that apply to the funding streams, including those related to HIV/AIDS care and prevention dollars? Do you find the regulations helpful or a hindrance to delivering needed services?*
- *What suggestions do you have related to the regulations that exist or should exist for funding HIV/AIDS care and prevention in this geographical region?*
- *What are the key political and jurisdictional factors that affect how HIV/AIDS care and prevention is delivered in this area?*
- *Would you want to modify these political and jurisdictional factors related to HIV/AIDS care and prevention? If so, how?*
- *What are the strengths of the public health system in this area with respect to the delivery of HIV/AIDS care and prevention?*
- *What are the weaknesses of the public health system in this area with respect to the delivery of HIV/AIDS care and prevention?*
- *What, if anything, do you think needs to be changed to help the public health system better provide HIV/AIDS care and prevention in this area?*

SUMA Partners worked closely with the Ryan White Planning Council to deliver accurate answers to these questions. The following **phased approach** was used.

- **The Ryan White Planning Council, Office of Support** revised the series of specific questions to be asked of key informants during Phase Two. Questions were structured to limit interviews to no more than thirty minutes.
- **The Ryan White Planning Council, Office of Support** developed a list of prospective interview targets.
- **SUMA Partners, Inc.** developed a standard letter for the Ryan White Planning Council to fax/mail/e-mail to prospective interview targets.
- **The Ryan White Planning Council, Office of Support** contacted the targets from the prospective interview list and asked them to participate in a completely confidential survey conducted by an independent market research organization.
- **SUMA Partners, Inc.** conducted one-on-one telephone interviews, approximately twenty-five to thirty minutes in length.

Interviewees were asked the same questions, in the same order. The interviewers probed for additional information, where appropriate.

- **SUMA Partners, Inc.** collected, organized and analyzed the interview information.

Interview Questionnaire

Hi, my name is _____. I'm with SUMA Partners. I'm calling on behalf of Judge Eckels' Office and the Ryan White Planning Council. We're scheduled to interview you. (Is this still a convenient time for an interview?)

SUMA Partners is an independent consulting firm contracted by Judge Eckels' Office and the Ryan White Planning Council to conduct the interviews. All of your responses will be kept completely confidential. Your responses will be compiled along with 74 other Key Leaders and Experts to develop a report. The Ryan White Planning Council will use our report to develop their Comprehensive Plan. Judge Eckels' Office intends to publish a copy of the Comprehensive Plan to all who participated in the interviews before the end of this year.

We would like to hear your opinions about eight questions, all relating to HIV/AIDS care and prevention. If you find any of the questions outside your scope or area of Expertise, just say so and we'll move on. You will hear pauses as I take notes during the interview.

1. What you can you tell us about the adequacy of funding for HIV/AIDS care and prevention in your geographical area?

The next two questions deal with regulations:

2. Tell me about the regulations that apply to the funding streams, including those related to HIV/AIDS care and prevention dollars: Do you find the regulations helpful or a hindrance to delivering needed services?
3. What suggestions do you have regarding regulations that currently exist or should exist for funding HIV/AIDS care and prevention in your area?

The next two questions deal with political and jurisdictional factors:

4. What would you identify as the key political and jurisdictional factors that affect how HIV/AIDS care and prevention is delivered in your area?

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5. Would you want to modify these political and jurisdictional factors related to HIV/AIDS care and prevention? If so, how?

The last three questions deal with the public health system:

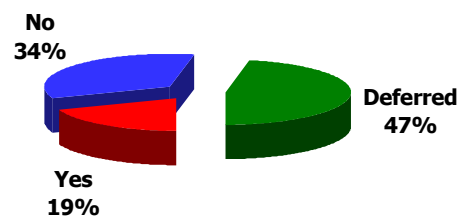
6. What would you identify as the strengths of the public health system with respect to the delivery of HIV/AIDS care and prevention?
7. What about the weaknesses of the public health system?
8. What, if anything, do you think needs to be changed to help the public health system better provide HIV/AIDS care and prevention in your area?

Interview Report

What can you tell us about the adequacy of funding for HIV/AIDS care and prevention in your geographical area?

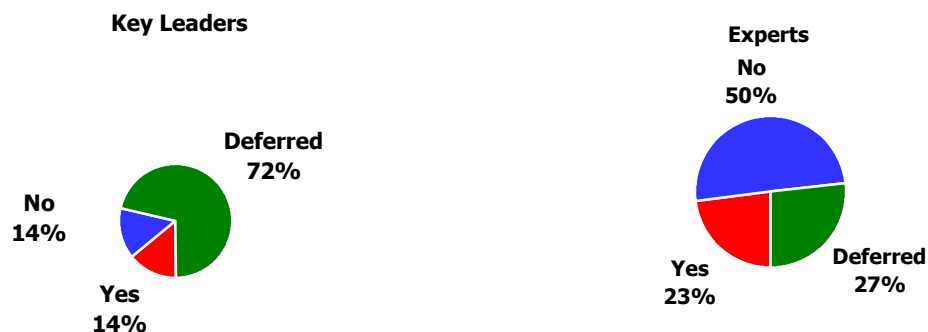
Responses were measured for both prevention and care. Thirty four percent (34%) of the respondents felt that prevention-related funding for HIV/AIDS was not adequate. Nineteen percent of the total respondents felt that funding for the prevention of HIV/AIDS was adequate. Significant in this question was the large number of total respondents that deferred by either saying that they did not know or that the adequacy of funding was the responsibility of another staff member.

Prevention (All informants)



When the responses were segmented between Key Leaders and Experts fourteen percent (14%) of Key Leaders responded that funding was adequate and fourteen percent (14%) responded that the funding for HIV/AIDS was not adequate. Significant was the large percentage (72%) of Key Leaders that **deferred** (See chart on page 8) indicating that the funding issues were delegated to staff or service providers and/or a lack of information on funding issues to form an opinion on funding adequacy.

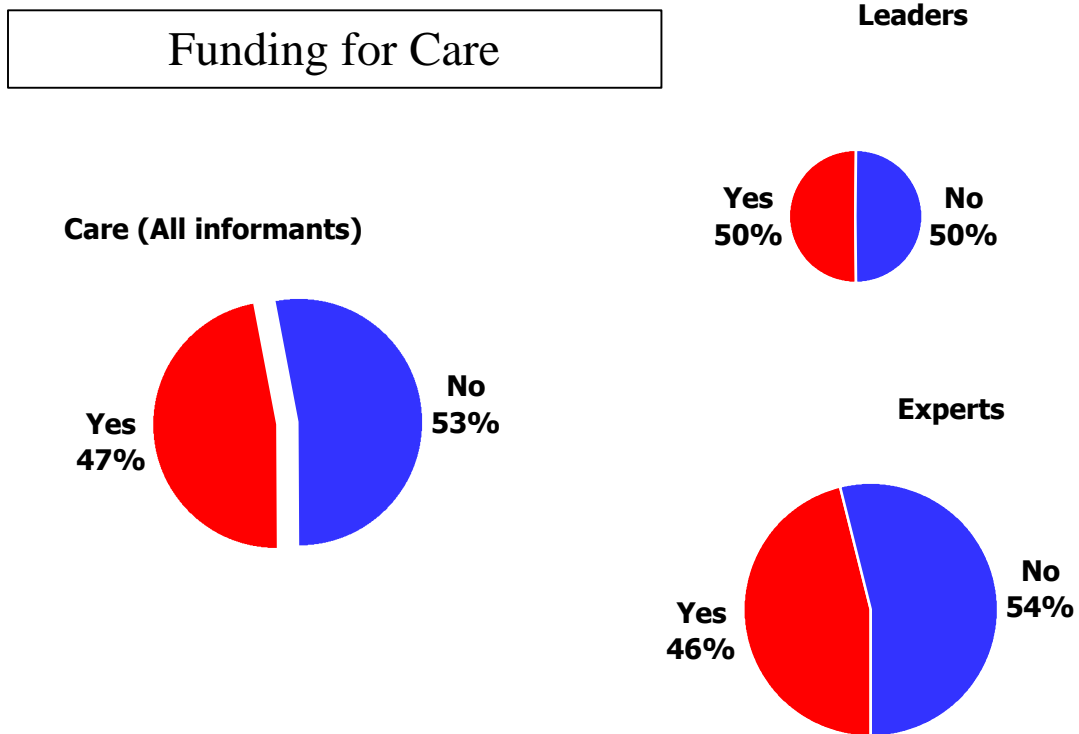
Funding for Prevention



Fifty percent (50%) of the Experts interviewed indicated that the funding for HIV/AIDS prevention was not adequate. Twenty three percent (23%) indicated that the funding for prevention was adequate and twenty seven percent (27%) deferred.

Funding for HIV/AIDS care as rated by the total respondents showed forty seven percent (47%) indicating that funding was adequate and fifty three percent (53%) indicated that funding was not adequate. Of the Key Leaders responding, fifty percent (50%) indicated that funding was adequate and fifty percent indicated that funding was not adequate.

Forty six percent (46%) of the Experts indicated that funding for care was adequate and fifty four percent (54%) indicated that funding for care was not adequate.



The following list of verbatim comments outlines the major themes related to prevention and care:

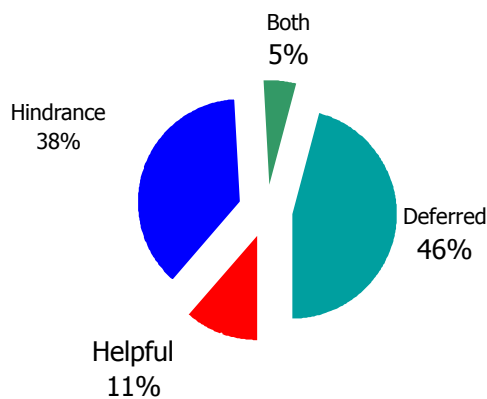
- *In terms of the funding of the "last resort" (populations that have no other means for paying for services) for the basic necessities, it seems to be adequate.*
- *We are meeting needs. But there have not been any real increases in funding to help develop new programs, yet we continue to get new clients.*
- *For HIV-infected people, those who are getting the services, the care and financing are adequate. However, if all the known and unknown existing HIV- positive people were to get treatment, there may be a problem --- a lack of funding.*
- *Whether it is adequate or not, I don't know, but it is probably as much money as most organizations can absorb.*

How about the regulations that apply to the funding streams, including those related to HIV/AIDS care and prevention dollars: Do you find the regulations helpful or a hindrance to delivering needed services?

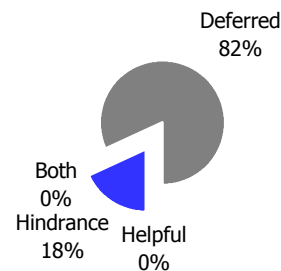
For the evaluation of whether the regulations were **helpful or a hindrance** to delivering the needed services, thirty eight percent (**38%**) of the total respondents indicated that the regulations were a hindrance. Eleven percent (**11%**) indicated that the regulations were helpful and five percent (**5%**) indicated that the regulations were **both** helpful and a hindrance. Forty six percent (**46%**) of the respondents **deferred** and did not answer the question.

Among the **leaders** interviewed, eighteen percent (**18%**) responded that the regulations were a hindrance to delivering the needed services and eighty-two (82%) deferred.

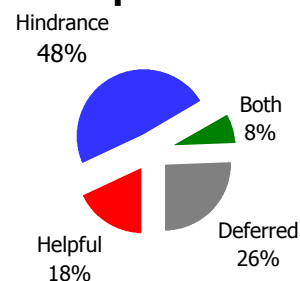
All Respondents



Leaders



Experts



For the **Experts** interviewed, forty eight percent (**48%**) responded that the regulations were a **hindrance** and eighteen percent (**18%**) responded that the **regulations** were helpful. Eight percent (8%) of the **Experts** responded that the regulations were both helpful and a hindrance and twenty six percent (**26%**) deferred.

Verbatim comments:

- *Regulations behind specific funding are a hindrance...they do not allow for emergencies.*
- *For the most part the regulations have a purpose, however some are antiquated. We need to update them and encompass the family.*
- *Title III grants are relatively easy to apply for, but Title I are a nightmare.*
- *For housing, regulations are a hindrance, for primary care they (the regulations) can be very helpful.*
- *I find regulations between different funding sources conflicting -- that is a problem. HUD -- their regulations say one thing. HRSA for housing say another thing. We deal a lot with families and a lot of the regulations prevent us from using funds to help families.*
- *Regulations are not a hindrance. The problem is the lack of technical assistance from the national level or adequate technical assistance to bring us up to speed with the latest techniques in research on what works and doesn't work in AIDS prevention.*
- *I think it's a hindrance because when people are writing regulations, probably they are written around people who lobby the hardest. You have both proponents and opponents who look for strict rules and regulations.*
- *There are barriers for some organizations especially to smaller-based agencies to apply for funding for HIV care services.*
- *Both, they are both helpful and a hindrance. Helpful because they require accountability; they are a hindrance because they slow the delivery process of services.*

What suggestions do you have in terms of the regulations that exist or should exist for funding HIV/AIDS care and prevention in your area?

Analysis of the suggestions provided by the respondents revealed the following themes. Sixty one percent (61%) of the Respondents offered suggestions indicating that **better coordination** was necessary. Other recommendations included:

- **standardization of forms**
- allowing for migration of care from rural to urban areas
- provisions for clear explanation of the proposed regulatory changes before the changes are put in place
- need for **regulatory flexibility** to meet specific needs
- consolidation on a federal level, more government input on accountability

Verbatim comments:

- *There should be more training and consultations on the regulations by bringing in people who implement the programs and have some discussion on the proposed regulation before they are actually approved.*
- *Providing technical assistance to start-up organizations that may not fit the bill that we have typically funded in the past.*
- *I think that the allocation formula might need to be modified since it hasn't been changed in over 8 years.*
- *In the area of assessment and facility control, there need to be standardized forms for people who fill out information and a plan to design a new computer system to intake data.*

What would you identify as the key political and jurisdictional factors that affect how HIV/AIDS care and prevention is delivered in your area?

Opinions related to key political and jurisdictional factors that affect how HIV/AIDS care and prevention is delivered in their area fell into several distinct categories among the 53% of total interviewees that responded to the question. Sixty-two percent (62%) of those that responded identified **coordination, communication, politics** and education were factors affecting delivery. Thirty percent (30%) were Leaders and seventy percent (70%) were Experts. Respondents' comments regarding politics included some discussion related to relationships and processes within cross-departmental jurisdictions. The term "education" was interpreted as the need to inform key influencers of the problems that exist as well as educating the public on care and prevention. Several respondents from both the Key Leader and Expert categories indicated that the issue of education related to prevention is politically controversial.

Verbatim comments:

- *It seems as though the larger areas seem to always get more money and can manage to get their voices heard.*
- *You have many jurisdictional and political entities trying to accomplish different parts of the same goal, but they don't complement each other.*
- *A conflict of interest that the City has is its dual role of both a funding source for HIV prevention as well as a provider of some of these services.*
- *... Harris County Hospital district is limited to Harris County and cannot use Harris County taxpayer money for servicing people that reside outside the County. Then people have to get service from other places such as UTMB. This makes it difficult for people to get services if they don't live in Harris County. Money comes into the area for prevention and goes directly to the city for Houston and then finally to the surrounding areas. On the other hand, prevention funds stop at the city limits. This makes coordination and planning very difficult.*

Would you want to modify these political and jurisdictional factors related to HIV/AIDS care and prevention? If so, how?

Interviewees who responded that they would like modification of the political and jurisdictional factors related to HIV/AIDS care and prevention proposed several suggested changes. Respondents recommended an **independent board** be established to administer both HIV/AIDS care and prevention funds. Emphasis was placed on jurisdictional areas such as county versus city administration. There was no specific mention of funding streams. Accountability rated high among respondents for program justification. In addition, the respondents suggested **stronger communication** between groups be provided through networking and close coordination to break down the boundaries and eliminate redundancies in service jurisdictions. The interviewees also recommended that multiple year funding was more effective way to ensure effective programming than single year funding.

Verbatim comments:

- *Increasing communication. I would modify by mandating that a cross-jurisdictional committee is developed to discuss common issue and concerns and to exchange information on who is doing what.*
- *I would like to see the political climate change and improve collaboration and coordination.*
- *Both federal and state governments need not be so rigid in their geographical boundaries for funds offered.*
- *In the area of HIV prevention, people tend to take into consideration social and political factors and give them more weight than the scientific studies that demonstrate how to effectively prevent HIV.*
- *Whoever is getting the funding should have to register with local authority (e.g., start with County Judge's Office). #1 Accountability #2 Tap into Networking Groups -- won't find resources on own.*

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- *Conflict of interest regarding its dual role, I would suggest along two lines: they should decide to completely contract out for these services and not have their own staff which do away with the conflict or if it is necessary because of location of these clinics and programs, they must have a portion of these funds for their programs, then they should set up administrative mechanisms that put their programs on the same competitive level as the other contractors other CBO's that have to compete against one another for the funding. The City Health Department clinic should also have to compete for with CBO's for funding. The second issue, CDC role, needs to expand its emphasis on quality, not quantity, and effectiveness on quality, and it increase its resources that are available to the local governments and CBO's to carry out these programs in an effective way. With regard to the competition with executive branch of the City government and the City Health Department, the City Council is presently being overly sensitive to program services aimed at reducing high-risk sexual and drug use behavior. It is a big detriment to these programs. They need to keep their authority at the level of policy and philosophy and principle, and let the city staff carry out the programs with some degree of autonomy.*
 - *When you start out with one pot of money and then try to split that pot up into many pots you end up with a lot of money wasted on administration salaries.*

What would you identify as the strengths of the public health system with respect to the delivery of HIV/AIDS care and prevention?

The respondents identified the major strengths of the public health system with respect to the delivery of HIV/AIDS care and prevention as:

1. the overall capabilities of the system, including a valuable database
2. the inherent knowledge available within the system
3. the **ability to track and document issues** involved with the care and prevention of HIV/AIDS system
4. the ability to provide **service to the indigent**
5. the strong track record in the area of **prevention.**

Most of the respondents referred to the public health system (medically indigent patients) in the generic sense, however, there were specific mentions of the Harris County Hospital District, CDC (as the ultimate public health system) and the Thomas Street Clinic.

Verbatim comments:

- *The public health system has good even world-renowned medical Expertise in the community.*
- *The strength I think comes from the coordination of care.*
- *Everybody who wants care can get it. I think that the system works very well. Bringing people into care involves the community and it is great. It can be cumbersome but it is a good model.*
- *The ability of the public health system to look at a situation scientifically with many different ethnicities and races in need and find some solutions that fit the need. Their technical Expertise is another invaluable tool for the public health system.*

What about the weaknesses of the public health system?

Respondents indicated that a major weakness of the public health system was the system was **not user friendly** to clients in terms of ease of access. They mentioned that the public health system is **not proactive** (outreach programs) and that people have to come to them using limited public transportation. Political issues related to funding affect both treatment and prevention, as does year-to-year **uncertainty about funding**. Also identified as a weakness of the public health system was the perceived lack of coordination, standardization and uniform quality control.

Verbatim comments:

- *On the whole, there is a lack of information.*
- *No outreach. People have to come to them.*
- *When funds are localized in the inner city and not spread around because then it might not reach the place where the greatest growth of HIV is occurring. An example of such is the aid not reaching the Hispanic population because they don't have Spanish-speaking counselors.*
- *The weaknesses are the ability to bring new clients into care- some of the paper work (eligibility as well as the new system the county has for co-pay).*
- *The weakness is the politics involved. We have a lot of competent and passionate people in this field, but I feel sometimes that their hands are tied.*
- *Lack of funding is the weakness. Funding is not available to reach the lower income minority population who tend to be more disenfranchised and don't take advantage of our services. Therefore, more resource is given to finding them.*
- *Not enough planning Experts and not enough people trained academically in Public Health.*
- *Weaknesses include the lack coordination even between the City Health Department and County Health Department. They duplicate services in some areas and then drop the ball in others.*

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- *It is too big. It gets caught up in itself trying to manage multiple funding streams. He thinks that they commission too much volunteer workers that don't have the proper training to be doing what they are doing. This usually results in special interest needs being addressed and not the main population of those in need. The Texas Dept. of Health has trouble making sure that all its needs are met through their councils and consortiums.*
 - *They don't pay enough attention to the individual needs of people and try to find a one size fits all solution.*
 - *Too early to tell. Ratio of HIV/AIDS seems to be rising among minorities. We need to look at that carefully. We need to explain to the public the importance of emphasizing prevention even though this disease is not the leading killer.*
 - *Weaknesses include the lack coordination even between the City Health Department and County Health Department. This concerns even the HIV services they provide. The prevention and care services should be a seamless continuum of services that's coordinated. The City Health Department and County Health Department hardly even communicate with one another, let alone coordinated with one another. They duplicate services in some areas and then drop the ball in others.*

What, if anything, do you think needs to be changed to help the public health system better provide HIV/AIDS care and prevention in your area?

Respondents indicated that the public health system should develop **proactive outreach programs** and strengthen prevention through education. Further, respondents suggested that the public health system should **break down the jurisdictional boundaries** and search out and stop overlapping functions to provide better HIV/AIDS care and prevention in their area. The respondents suggested that there be **stronger coordination** and unity among agencies (Texas Department of Health, HRSA and CDC) and that the public health system get away from politics and get to the people they service. Additionally, the respondents' felt that the public health system be **provided more and more consistent funding for care.**

Verbatim comments:

- *Better education to all the people involved in the delivery of services, those who vote on money, etc. We need to address these issues publicly.*
- *Need to do a better job on education, involve the parents more and impress upon kids about prevention. Education is the key.*
- *Increase of funding, more collaboration across jurisdiction communication and more community input.*
- *Outreach! Be proactive and educate. Prevention is always cheaper than damage control. Given dollars to fix; what about dollars to prevent.*
- *We need to remember that HIV is both a communicable and sexually transmitted disease. We should provide service and care to people without regard to their ability to pay.*
- *I think that we need to change the overlapping of functions. There are too many people doing the same things.*
- *Dollars to help people get information they need: 1. To obtain social work, 2. Teach & help people how to deal with their problems and disabilities, 3. Help people plan their future.*

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- *Need to have a mandate for patient care, not just for testing. Mission: To fund delivery of care -- Health Department should be involved. Ryan White should get involved in getting patients involved in clinical trials and make this a win/win situation. This is where the major disconnect occurs.*

SUMA Recommendations

- Respondents in the Key Leaders segment specifically mentioned their constituencies as sources of information including needs and successes of specific programs. Key Leaders indicated that they have not received information from their constituencies on HIV/AIDS prevention and treatment. Further, there were a significant number of Key Leaders that deferred (transferring responsibility to staff functions) on questions of funding adequacy. Therefore, SUMA recommends increased the **communication** to the Key Leaders across geo/political boundaries communicating both the successes and any unidentified needs, whether for funding and/or HIV/AIDS care and treatment within their individual jurisdictions.
- Respondents in both the Key Leader and Expert categories either alluded to, or made specific reference to, a lack of **coordination, collaboration and cooperation** among the various service providers. SUMA recommends a concerted effort be made among the various service providers to work together in order to maximize services without redundancies.
- SUMA recommends considering a systematic way to get information including the standardization of forms. Respondents identified general difficulty in getting **information**. Additionally, several respondents (Experts) suggested that **standardization** of forms would aid both administration and clients.
- Develop a system of **accountability** and quantify prevention and care successes and use of Title I and Title II funding. Experts' comments referred specifically to accountability as a method of providing quantitative information for political support and funding.
- **Survey** the HIV/AIDS community to identify unmet needs and barriers within the system. Respondents mentioned issues like the hours and/or days of operation of various services, outreach programs and other proactive programs that could be identified through frequent surveying of the client population. Both Experts and Key Leaders indicated a need for accountability and tailoring of services in both categories (care and prevention) to fit the needs of the community and neither indicated that

surveys were a tool currently used to gather information. Frequent surveying will provide a database that will quantify service and prevention knowledge and quality, as well as provide guidelines for future strategy development.

- SUMA recommends, because of the comments of several Experts and Key Leaders, an independent board that can de-politicize the funding and administrative process.
- Experts referred to the time and effort required by staff members in the funding effort. SUMA recommends efforts be directed toward multiple year funding with annual milestones and deliverables, to encourage long-term programs and shift staff resources from developing request for funding to proactive care and prevention activities
- The public health system should proactively position themselves as both the data resource and authority for care and prevention information – both Experts and Key Leaders commented on the various strengths of the public health system and its usefulness as a resource.
- Facilitate educational funding in the form of grants for designated institutions of higher learning to academically train people in public health issues related to HIV/AIDS. Comments by Experts provided the background for this recommendation.
- Aggressively target the lower income and minority population in the services available for care and treatment of HIV/AIDS. Additionally, comments from Experts concluded that a prevention strategy among lower income and minority populations should be pursued.