CARE/PREVENTION COLLABORATIVE *planning*

HRSA AIDS Programs

Title I and Title II

Planning Bodies and

CDC HIV Prevention

Community

Planning Groups

U.S. Department of Health & Human Services

Health Resources & Services Administration

Section VII

Program Guidance

SECTION OVERVIEW

1 NEEDS ASSESSMENT

2 PRIORITY SETTING AND RESOURCE ALLOCATION

3 COMPREHENSIVE PLAN

4 EARLY INTERVENTION SERVICES

5 QUALITY MANAGEMENT

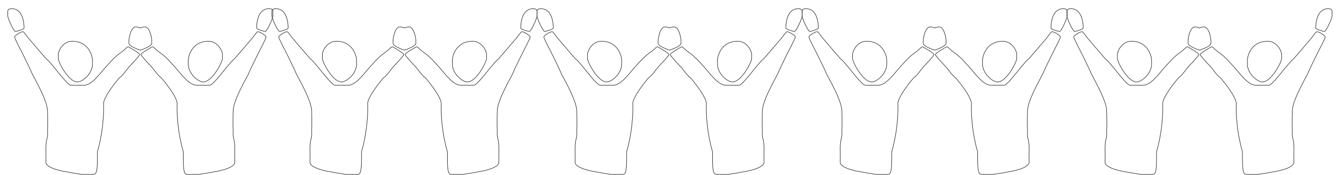
6 COORDINATION OF PAYERS AND PROGRAMS

7 TITLE I AND II COORDINATION

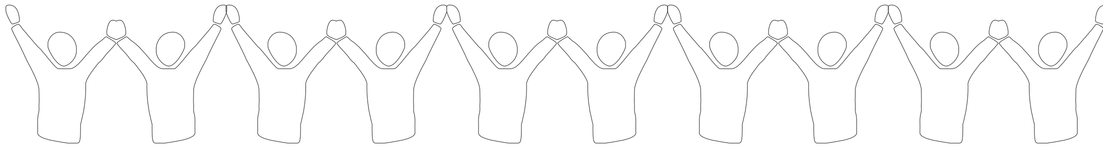
8 CARE/PREVENTION COLLABORATIVE PLANNING

9 STATEWIDE COORDINATED STATEMENT OF NEED

10 MANAGED CARE AND HIV DISEASE



8 Section VII
Care/Prevention Collaborative Planning



Introduction

Federally funded HIV/AIDS prevention and HIV/AIDS care both use planning—and planning groups—to assess needs in their respective realms and develop plans on how to respond. Hundreds of care and prevention planning bodies operate throughout the nation for this purpose. Most do so independently, in part because they are separately legislated. On the prevention side are Community Planning Groups (CPGs), which plan HIV prevention, for those at risk and already infected, to prevent infection and its further spread. They operate through State and local health departments and their communities, under guidance from the Centers for Disease Control and Prevention (CDC). On the care side, of course, planning is through CARE Act Title I and II planning bodies, funded through the Health Resource and Service Administration (HRSA), HIV/AIDS Bureau (HAB).

Although distinct, both care and prevention planning have common characteristics, providing a basis for collaboration. Adding to this interest are the CARE Act Amendments of 2000, which include provisions that seek to link PLWH into care by bringing prevention and care closer together. They include eligibility for Title I and II funding of early intervention services (EIS) (with HIV counseling and testing being part of EIS); outreach (to identify people who may need care); and requirements for better links across HIV/AIDS prevention and care systems. Coordination of care and prevention planning can help bridge gaps across prevention and care and thus help individuals learn their HIV status and enter care if infected. This need is evident given national surveillance data on the estimated 850,000 to 950,000 Americans who are thought to be living with HIV disease. Of these, about 670,000 Americans know they are infected, while another 180,000 to 280,000 have the virus but do not know it. About one-third of those who know their status (an estimated 233,000) are not receiving regular HIV-related health services.*

Shared features of care and prevention planning provide a solid foundation for coordination in planning. Both prevention and care planning are based on the principle of inclusive participation, and each conducts such planning tasks as preparation of epidemiologic profiles and needs assessments. Frequently, public agency staff and providers working in care and prevention serve on both planning bodies. Sometimes this membership overlap is the only direct connection between care and prevention planning.

* These statistics were presented by CDC officials at the Ninth Conference on Retroviruses and Opportunistic Infections in Seattle in February 2002, based on projections using national surveillance data.

Some communities have taken steps to more closely link their planning activities, either formally or informally. Efforts range from information sharing (often facilitated by people who serve on both planning bodies) to formal collaboration on planning tasks such as preparation of a single epidemiologic profile, combined resource inventory, or joint needs assessment activities. Some have merged their care and prevention planning bodies, in whole or in part through subcommittees. The benefits can include better use of planning resources (*e.g.,* compiling data at a single point in time, fewer planning meetings) and better services.

Legislative Background

The CARE Act requires Title I planning councils to work with HIV prevention under the following provisions. They include coordination in planning and service delivery—the latter being made possible through collaborative planning.

Planning Body Membership

Section 2602(b)(2)(L) requires "grantees under other Federal HIV programs, including but not limited to providers of HIV prevention services," to be represented on the Title I planning council.

Priority Setting and Resource Allocation

Section 2602(b)(4)(C) requires that planning council "priorities for the allocation of funds within the eligible area" be based on a number of factors, including: "coordination in the provision of services to such individuals with programs for HIV prevention…."

Comprehensive Planning

Section 2602(b)(4)(D) requires that the planning council's "comprehensive plan for the organization and delivery of health and support services" include "a strategy to coordinate the provision of such services with programs for HIV prevention (including outreach and early intervention)…."

Coordination of Services

Section 2602(b)(4)(H) requires that the planning council "coordinate with Federal grantees that provide HIV-related services within the eligible area," which includes prevention grantees.

Section 2604(b)(3) permits the use of Title I funds for "early intervention services" for individuals with HIV disease. It specifies entities "through which such services may be provided," one of which is "HIV disease counseling and testing sites." (Early intervention services include counseling, testing, and referral activities designed to bring HIV-positive individuals into care.)

Section 2605(a) requires that a Title I application include "assurances adequate to ensure—(3) that entities…that receive funds under a grant under this part will maintain appropriate relationships with entities in the eligible area served that constitute key points of access to the health care system for individuals with HIV disease." One of the listed points of access is "HIV disease counseling and testing sites."

Section 2604(b)(4) discusses ensuring services to women, infants, children, and youth and suggests coordination in calling for use of Title I funds for a specific type of prevention: treatment designed to prevent perinatal transmission of HIV. This provision requires the EMA to ensure the allocation of funds "for the purpose of providing health and support services to infants, children, youth, and women with HIV disease, including treatment measures to prevent the perinatal transmission of HIV." Such funds must total "not less than the percentage constituted by the ratio of the population involved [women, infants, children, youth in such area] with acquired immune deficiency syndrome to the general population in such area of individuals with such syndrome."

FEDERAL AGENCY COORDINATED PLANNING

The CARE Act requires coordination efforts at the Federal agency level designed to enhance the continuity of care and prevention services. Section 2675 specifies the following:

"(a) Requirement.—The Secretary shall ensure that the Health Resources and Services Administration, the Centers for Disease Control and Prevention, the Substance Abuse and Mental Health Services Administration, and the Health Care Financing Administration [now the Center for Medicare and Medicaid Services or CMS] coordinate the planning, funding, and implementation of Federal HIV programs to enhance the continuity of care and prevention services for individuals with HIV disease or those at risk of such disease. The Secretary shall consult with other Federal agencies, including the Department of Veterans Affairs, as needed and utilize planning information submitted to such agencies by the States and entities eligible for support."

"(b) Report—The Secretary shall biennially prepare and submit to the appropriate committees of the Congress a report concerning the coordination efforts at the Federal, State, and local levels described in this section, including a description of Federal barriers to HIV program integration and a strategy for eliminating such barriers and enhancing the continuity of care and prevention services for individuals with HIV disease or those at risk of such disease."

HAB/DSS Expectations

HAB/DSS expects Title I planning councils and EMAs to coordinate with prevention planning bodies and programs in the areas of planning body membership, conducting planning activities (*e.g.,* needs assessments), and service delivery coordination (*e.g.,* early intervention services, outreach), as follows.

Planning Body Membership

As called for in the CARE Act, HAB/DSS expects Title I planning councils to include Federally-funded HIV prevention programs as planning council members.

Planning Activities

HAB/DSS expects CARE Act Title I and Title II planning bodies to coordinate their needs assessment and priority setting activities with CDC's HIV prevention community planning groups.

Planning of Services

Points of Entry. HAB/DSS expects Title I programs and funded providers to establish and maintain formal, written relationships with points of entry into care—places where people with HIV who are not in care are likely to be found. Only through conscious and ongoing service coordination can Title I programs identify people who know their status but are not receiving care and provide reliable referral channels to get them into the HIV/AIDS service system. (See the EIS chapter for more information on points of entry.)

Outreach. Coordination between care and prevention should occur in the planning and delivery of local HIV outreach programs designed to identify people living with HIV disease and help them learn about their HIV status and enter care. HRSA/HAB requires that outreach programs funded through the CARE Act be planned and delivered in coordination with local HIV-prevention outreach programs and be targeted to populations known to be at disproportional risk for HIV infection. Outreach should be provided at times and in places where there is a high probability that HIV-infected individuals will be reached.

Early Intervention Services. If there is a shortage of early intervention services (EIS), including HIV counseling and testing and referral services, then the planning council may prioritize and allocate resources to such services. It should ensure that such funds supplement and do not supplant existing funds by doing an inventory of existing services as part of its planning process. Planning related to EIS will benefit greatly from communication and cooperation with the CPG.

Reducing HIV Perinatal Transmission. Coordinated planning should occur in developing outreach activities that target women of childbearing age in order to reduce HIV perinatal transmission rates. HAB/DSS expects planning councils to ensure that HIV-infected pregnant women have access to therapy that will reduce the likelihood of HIV transmission to newborns. There should be a coordinated effort to reach them through HIV education programs, counseling

and testing sites, and other community locations. Similarly, CPGs are expected to plan for HIV counseling and testing of pregnant women at risk for HIV and to arrange procedures to ensure that women found to be HIV-positive are referred immediately to appropriate care settings. Care programs need to work with prevention programs to ensure that women at risk have accurate information about the effectiveness of perinatal treatment and the importance of obtaining treatment early in their pregnancy.

CDC EXPECTATIONS FOR COLLABORATIVE PLANNING

Since guidance for HIV prevention community planning was issued in 1993, CDC has stated the need for collaboration and information sharing between prevention and care planning bodies. Prevention and care planning bodies are expected to be aware of each other's activities and identify opportunities for collaboration. CDC recognizes that collaboration can occur in many ways, including fully merged joint processes, shared membership, cooperative activities, and/or information sharing. CDC guidance suggests but does not require that, when appropriate, its grantees consider merging their prevention planning activities with those of other local planning bodies that are already in place. Subsequent CDC guidances have asked CPGs for descriptions of mechanisms they are using to coordinate HIV prevention planning with other planning activities, particularly CARE Act Title I and Title II, STD, and TB planning.*

Comparing CDC HIV Prevention and Title I/II Care Planning

Care and prevention planning have several common elements. Understanding them can help Title I planning councils identify potential areas for working together. Among these features (outlined in the chart below) is the use of community planning processes that emphasize inclusive planning body representation reflecting the demographics and trends of the local epidemic. Both also require needs assessments that involve epidemiologic profiles, identification of target populations, resource inventories of service providers, and estimates of the unmet need for particular types of services. Both use needs assessment results to establish service priorities that address identified needs, and both require comprehensive plans. In addition, both include provisions for evaluation.

* See CDC's HIV Prevention Community Planning Guidance: Essential Elements of a Comprehensive HIV Prevention Plan, available at http://www.cdc.gov.

Responsibility	Title I Planning Councils	HIV Prevention Community Planning Groups
Needs Assessment	Needs assessment must include determination of the size, demographics, and needs of the population living with HIV disease. This includes special attention to the following: determining the unmet needs of individuals who know their HIV status and are not in care; coordination with programs for HIV prevention and the prevention and treatment of substance abuse; links with outreach and Early Intervention Services; and determination of capacity development needs. The needs assessment requires obtaining input on community needs through methods such as public meetings, focus groups, and surveys.	Needs assessments examine the present and future HIV epidemic and existing community resources (*e.g.*, fiscal, personnel, and program resources from public, private, and volunteer sources).
Priority Setting	Planning councils establish priorities for the allocation of funds, including how best to meet each priority and additional factors the grantee should consider, based on documented needs, available cost and outcome effectiveness data, priorities of HIV-infected communities for whom services are intended, coordination with programs for HIV prevention and the prevention and treatment of substance abuse, and availability of other governmental and non-governmental resources.	Planning groups identify HIV prevention needs and identify specific high priority interventions & strategies to address needs by defined populations.
Comprehensive Plan	Planning councils develop comprehensive plans for the organization and delivery of health and support services. Plans must include a strategy for identifying individuals who know their HIV status and are not in care and helping them enter care. The plan must be compatible with existing state or local plans regarding HIV services.	Planning groups develop a comprehensive HIV prevention plan.
Evaluation	Planning councils are required to assess the efficiency of the administrative mechanism in terms of rapidly allocating funds to areas of greatest need within the eligible area. At their discretion, they may also assess the effectiveness of services offered to meet identified needs. Planning councils should also evaluate the effectiveness of the planning process as part of the evaluation of the administrative mechanism.	Planning groups evaluate the effectiveness of the planning process.

Care and prevention planning groups also differ in their duties. For prevention, CPGs set program priorities through their comprehensive HIV prevention plans, while health departments have sole responsibility for allocating resources to identified priorities. Under the CARE Act, Title I planning councils not only set priorities but also allocate resources across defined service priorities (although they are not permitted to become involved in procurement or contracting with service providers). Title I grantees have responsibility for procurement (soliciting proposals and awarding contracts for service provision), which must be consistent with priorities set by the planning council.

ABOUT CDC'S HIV PREVENTION COMMUNITY PLANNING

A total of 65 State, local, and territorial health departments have cooperative agreements from the CDC for HIV prevention planning and service delivery. CDC requires each grantee to convene at least one HIV Prevention Community Planning Group (CPG). CPGs are responsible for comprehensive HIV prevention planning, including the following:

- Assessing the epidemic in their jurisdiction
- Identifying HIV prevention needs
- Identifying interventions and strategies to address priority needs, and
- Developing comprehensive HIV prevention plans.

Each CPG's membership must be representative of the HIV epidemic and reflect epidemiologic trends in its area. CDC allows grantees flexibility to determine the most appropriate structure for conducting prevention planning. Some have formed regional planning groups in addition to, or instead of, a single statewide planning group. Over 200 local and regional CPGs conduct comprehensive HIV prevention planning to guide prevention funding in their areas.

To learn more, see CDC's Guidance on HIV Prevention Community Planning on the CDC website at http://www.cdc.gov/hiv/pubs/hiv-cp.htm.

Examples of Coordination

Coordination may occur in planning (such as membership and planning tasks like needs assessments) and in service delivery. When care and prevention planning bodies agree to work together, they typically benefit from the development of a memorandum of agreement (MOA) or other written document describing what and how collaboration will occur. The MOA should identify specific areas for collaborative planning, call for regular meetings of leaders and/or staff from prevention and care planning bodies, specify other communications as appropriate, establish links between counseling and testing sites and care services, and detail other areas of cooperation. Expectations for both groups should be clearly stated.

Following are examples of coordination.

Planning Body Membership

Communication between care and prevention planning groups often occurs through overlapping membership. Such shared membership is common. Membership categories likely to bring background in both areas include PLWH, staff of AIDS service providers, and health department representatives (including epidemiologists).

Planning groups have formally structured overlapping membership by designating membership slots for representatives of the other planning body. Some encourage leaders of each planning body to serve as *ex officio* (non-voting) members of the other body.

Since the CARE Act requires the planning council membership to include "grantees under other Federal programs, including but not limited to providers of HIV prevention services," a representative from the CPG might serve this role. HAB/DSS encourages planning councils to consider having direct CPG representation on the planning body. In addition, CPG members can join planning council committees or task forces. Similarly, one or two active planning council members might serve on the CPG and/or its committees, particularly those that address areas of common concern such as needs assessment and HIV counseling and testing.

Joint Meetings

Joint meetings (regularly scheduled or special sessions) between prevention and care planning representatives can provide a forum for enhanced collaborative planning. They can take several forms:

- **Regular Meetings.** Ongoing leadership dialogue and collaborative thinking can occur through monthly meetings between the co-chairs of the planning council and the co-chairs of the CPG. Agendas for meetings might include issues such as the continuum of care, planning outreach activities, funding and policy issues, and preparation of joint epidemiologic profiles and other needs assessment tasks.
- **Coordinated Meetings.** In some places, the two planning bodies are separate entities but share meeting dates and locations. Monthly meetings might have one group meeting in the morning and the other after lunch. This often works well given overlapping membership and lessened travel time, particularly in geographically large EMAs.

- **Subcommittees or Task Forces.** A number of planning groups have convened subcommittees, task forces, or ad hoc groups to address specific planning issues or coordinate joint efforts. For example, a planning council might develop an HIV prevention subcommittee to help ensure that its plan adequately addresses coordination between care and prevention services.
- **Special Forums.** Sometimes conference sessions are for care and prevention representatives to meet, present their activities, and share successes/barriers.

Needs Assessment

Some aspects of needs assessment benefit from joint efforts, like resource inventories and epidemiologic profiles. Others are best done separately (*e.g.,* priority setting). Generally, where the needs assessment's target audiences and/or methodologies correspond, activities are more readily conducted jointly. If many providers in the community conduct both care and prevention activities, joint needs assessment work is more practical. At a minimum, groups can share data tools and ideas on how to do a needs assessment (*e.g.,* sampling, survey development).

Epidemiologic Profiles. Much of the data contained in an epidemiologic profile (*e.g.,* number of AIDS cases, HIV cases, transmission categories and demographics of HIV and AIDS cases, STD and TB data) are equally important to HIV prevention and care planning. Epidemiologic profiles are usually compiled by the same State or local health department staff and thus might be more efficiently prepared at one point in time.

Various States and EMAs have worked collaboratively on epidemiologic profiles. Among their insights:

- Certain epidemiologic data items are useful for both care and prevention. For example, STD data can serve as a measure for targeting both HIV counseling and testing and HIV care early intervention activities. Identifying common items is a basis for collaboration.
- Certain epidemiologic data items may be used only in prevention or care planning (*e.g.,* for care, estimates on the number of PLWH at various CD4 levels serve as a marker for service demand).
- Some State and local health departments take the initiative to develop a regional or local epidemiologic profile that is shared with both care and prevention planning bodies. The usefulness of such a profile can be enhanced by having a State or local epidemiologist provide technical assistance to both care and prevention planning bodies on the development and analysis of the profile.
- Jurisdictions differ in terms of data availability, public health infrastructures, and approaches to planning. This can complicate agreeing on how to develop a single care/prevention epidemiologic profile. This can be addressed by limiting the amount of data compiled and focusing on ensuring that all data are interpreted and presented in user-friendly charts and graphs.

- In regular meetings involving care and prevention planning bodies and health department officials, participants can establish a common language (*e.g.,* defining outreach and secondary prevention) and process, identify data useful to both groups, share data and methods of presentation, and discuss issues of common concern such as data availability.

Resource Inventories. Resource inventories help catalogue existing services in a community. In their basic format, they describe agency services, number and types of clients served, and funding. In such cases, it may be efficient to prepare the inventory jointly, particularly where many providers offer both prevention and care services. This might entail use of a single survey form or compilation from a State HIV/AIDS hotline directory. When the inventory becomes more specific and attempts to include information such as an assessment of service quality (*i.e.,* when it becomes a provider profile of capacity and capability), a joint effort may be harder to achieve. At the least, sharing of mailing lists and contact information can occur.

EPIDEMIOLOGIC PROFILES:
COMMON APPROACH FOR CARE AND PREVENTION

A joint epidemiologic profile format for use by CARE Act planning bodies and CPGs was developed in 2002 by HRSA and CDC. See *Integrated Guidelines for Developing Epidemiologic Profiles for HIV Prevention and Ryan White CARE Act Community Planning*, 2002.

In addition, CDC and HRSA work together on many data projects that support both care and prevention planning (see http://hab.hrsa.gov). HRSA provides CDC with data on grantee and contractor locations and characteristics. CDC provides HIV/AIDS prevalence data to EMAs and States to assist with their grant application processes and to inform Title I and II formula allocations. The two agencies jointly fund efforts to provide estimates of the number of persons with HIV in EMAs located in States that do not have HIV reporting. CDC is also working with HRSA to develop methods and technical assistance for estimating unmet need in EMAs and States.

Merged Planning Bodies

Some areas have merged their prevention and care planning bodies, which has enabled them to share membership recruitment and needs assessment activities and enhance coordination between care and prevention planning. Often, such mergers retain separate committees to address care and prevention planning in greater detail. Committees are typically responsible for priority setting in their care or prevention area, which is harder to merge.

Separate committees have been created when planning body members voiced concerns that prevention planning was not receiving an appropriate level of attention and commitment. Some feared that urgent care and treatment needs were overshadowing the planning body's focus on prevention planning.

Mergers between Title II planning bodies and CPGs have occurred in several States. Facilitating factors include the rural character of the State, the existence of a fairly limited number of AIDS service organizations, and a public health system that is State-coordinated under a regional structure.

Referral Arrangements

Planning can result in the establishment of referral arrangements to help move people from prevention to care. Examples include written "points of access" agreements and other arrangements that coordinate outreach and link them with primary care facilities. All EMAs must establish written agreements with entities that serve as key points of entry into HIV care. Many EMAs and individual providers have long had such arrangements. Among the most valuable types of arrangements are those that:

- Involve meetings and cross training between care and prevention staff so that they develop personal relationships and understand the scope of work of the other group
- Enhance attention to HIV prevention by agencies focused on other service issues (such as substance abuse treatment programs that provide HIV education) to ensure that all their clients are aware of treatment options and new advances in medications
- Provide model approaches and assistance to prevention entities so they can encourage individuals considered at high risk to get tested
- Ensure that staff at points of entry have specific information about available services and how to make referrals and follow-up on them, and
- Provide regular orientation, training, and written summary information so that new staff are aware of referral resources and can make appropriate referrals based on the characteristics of clients.

Technical Assistance

Since a number of planning activities are similar regardless of whether done for care or prevention planning, technical assistance (TA) can be delivered effectively in a standardized manner. However, some tailoring may still be necessary in responding, for example, to legislative requirements specific to care or prevention.

TA areas that may be addressed similarly include the following:

- Compiling and interpreting epidemiologic profiles
- Conflict resolution
- Grievance procedures, and
- Establishing the planning body.

Initiating Collaboration: Key Questions to Address

Planning bodies considering either beginning or expanding collaborative planning should start with the following questions, which can be addressed in initial meetings with representatives of both care and prevention planning bodies. Determine what needs to be accomplished, whether it seems feasible, what challenges can be expected, and how best to begin working together. Be realistic: recognize that effective coordinated planning requires time and effort.

1. What is care/prevention collaborative planning?

The continuum of collaborative planning ranges from basic information sharing to establishment of a single, integrated planning process (*i.e.,* merging of care and prevention groups into a joint planning body). Many other joint activities fall between these extremes, such as:

- Development of a single epidemiologic profile
- Preparation of a joint resource inventory
- Cooperation on other components of a needs assessment
- Development of formal linkages between prevention and care providers, and
- Development of plans for specific joint activities, such as collaborative outreach, a referral process linking HIV counseling and testing sites and primary health care facilities, or an initiative focusing on preventing perinatal transmission.

2. Why undertake collaborative planning—what are the benefits?

Collaborative planning can create multiple benefits related to savings in time, resources, and effort, and improved plans that contribute to a continuum of prevention and care that better meets community needs. If you are considering collaborative planning, decide what benefits are most important to you. For example, EMAs and States have found that collaborative planning can:

- Reduce meeting time for individuals who serve on both care and prevention planning bodies
- Lead to a single epidemiologic profile that is more comprehensive and also reduce the workload of health department staff who would otherwise have to prepare two different profiles
- Reduce time and costs for needs assessment by avoiding duplication of effort by planning body members, staff, and consultants

- Improve linkages between prevention and care so that the continuum of care—from primary prevention through services for people living with HIV disease—is fully developed and referral relationships are improved
- Help infected individuals learn their HIV status earlier and get them into care without delay, thus reducing unmet need for services and improving long-term health outcomes
- Improve secondary prevention efforts, including prevention of HIV perinatal transmission, and
- Encourage providers involved in one aspect of HIV to become involved in the other, thus increasing care and prevention capacity.

3. What are the obstacles to collaborative planning?

Many factors discourage collaborative planning. Some are initial barriers that can be quickly overcome. Some are more serious and may make some kinds of collaboration difficult. Collaboration is most likely to be successful if planning bodies identify and directly address potential barriers rather than ignoring or minimizing them. Among the barriers are:

- **Concerns about the time and effort required.** Planning body members often feel overburdened and unable to expand their work to adequately address both prevention and care issues. This is a particular concern for planning groups considering a merger into a single care/prevention entity.
- **Concern by planning body members that collaboration will be too broad and therefore not successful.** This concern tends to be reduced where initial collaboration addresses specific planning tasks. For example, rather than beginning with a total shared needs assessment, the two bodies might want to collaborate on a shared resource inventory.
- **Fear that prevention will receive reduced attention.** Some members of CPGs are concerned that, in collaborative planning, care might overshadow prevention because there are usually more care dollars to allocate and decision makers might focus more on care.
- **Different perspectives of planning bodies.** The two planning processes require many similar skills but also some different perspectives that may not “cross over” well. For example, primary care personnel typically focus on care, while educators may focus more on prevention issues. Establishing a merged planning body or joint needs assessment committee that provides the whole range of skills and experience can mean a large an unwieldy working group.

4. What factors encourage collaborative planning?

Certain characteristics of communities and planning bodies seem to create an environment that is especially supportive of collaborative planning. For example:

- A shared interest in making the planning process more efficient provides strong motivation for collaborative planning. Where many providers are involved in both prevention and care, the time required to support separate planning bodies and planning efforts seems particularly burdensome. Both prevention and care planning bodies find it difficult to engage members and maintain high levels of consumer participation. The desire to reduce meeting time and prevent member burnout leads to a willingness to make the effort needed for successful collaboration.

- Leadership and commitment from key individuals can help move collaboration forward. This includes leaders care and prevention planning bodies, health department officials, the chief elected official, and providers.
- Smaller EMAs, rural areas, and communities with fewer HIV/AIDS cases tend to have fewer agencies and less complicated HIV/AIDS care and prevention systems. With fewer providers to involve in community planning, collaboration is easier to arrange—particularly when the same providers are doing both care and prevention work.
- Collaboration is often easier where public health systems are well linked at the State and local levels (*e.g.,* in States where local public health departments are branches of State government). This can create a climate of support for coordinated planning because State and local health department staff may work on both prevention and care, are usually well connected to State as well as local entities, are used to working together, and/or work regularly with community agencies.

Consider what factors within your area are likely to encourage and contribute to the success of collaborative planning.

5. What action is needed to begin collaboration?

Following discussion of the above questions, decide whether collaborative planning makes sense and, if so, what you want to do. If you decide to undertake some form of collaborative planning, establish a mechanism—such as a committee or task group—to further develop ideas and set a plan of action. This should include a time frame for carrying out specific agreed-upon planning tasks. If the planning council decides not to proceed at this time, consider establishing a time to revisit the issue. Planning needs may change and the benefits of collaborative planning may become more apparent by the next discussion.

R E F E R E N C E S

Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB). *Care/Prevention Collaborative Planning: HRSA AIDS Programs Title I and Title II Planning Bodies and CDC HIV Prevention Community Planning Groups.* Rockville, MD: U.S. Department of Health and Human Services, 1998.

HRSA, HAB. Collaboration between Titles I and II and HIV Prevention Community Planning Groups." CARE Act National Technical Assistance Call Report. Rockville, MD: U.S. Department of Health and Human Services, September 1995.

HRSA, HAB. "Growing Impact of HIV/AIDS among Underserved Populations." CARE Act National Technical Assistance Call Report. Rockville, MD: U.S. Department of Health and Human Services, November 1998.

HRSA and CDC. *Guidelines for Developing Integrated Epidemiologic Profiles: HIV Prevention and Ryan White Care Act Community Planning.* 2002.

HRSA, HAB. "New Tools for HIV Care. STD Treatment." CARE Act National Technical Assistance Call Report. Rockville, MD: U.S. Department of Health and Human Services, February 1998.

HRSA, HAB. "Reaching HIV-Positive Youth: Models that Work." CARE Act National Technical Assistance Call Report. Rockville, MD: U.S. Department of Health and Human Services, June 2000.

HRSA, HAB. HAB Policy 02-01. Outreach. 2002.

CDC. "Guidance: HIV Prevention Community Planning." See the CDC website at http://www.cdc.gov/hiv/pubs-cp/10community.htm.

RESOURCES

HIV Counseling, Testing, Referral Guidelines. HRSA/HAB worked with CDC in revising existing guidelines to increase their focus on HIV-infected persons and linking them with HIV services. See them at the CDC website at http://www.cdc.gov.

CDC Guidelines for HIV Screening of Pregnant Women. Revisions of guidelines on HIV counseling and voluntary testing for pregnant women, they were developed with HRSA input and stress: (1) HIV testing as a routine part of prenatal care, (2) simplification of testing to eliminate barriers, (3) a more flexible consent process, (4) provider determination of patient reasons for refusal of testing, and (5) HIV testing and treatment at the time of delivery for women who have not received prenatal testing and treatment. See them at the CDC website at http://www.cdc.gov.

HRSA CARE/PREVENTION ACTIVITIES

HRSA has engaged in a number of care/prevention collaborative activities. Examples include the above guidelines (developed with both CDC and HRSA input), Special Projects of National Significance (SPNS) projects that are developing models of care, and initiatives (*e.g.*, integrated behavioral and biomedical intervention addressing prevention, access, and adherence to therapeutic regimens; models of prevention and care for HIV-infected individuals). An updated listing of prevention and care activities can be found at the HRSA/HAB website at http://hab.hrsa.gov.

Section VII

Coordination

SECTION OVERVIEW

1 COORDINATION OF PAYERS AND PROGRAMS

2 TITLE I AND TITLE II COORDINATION

3 CARE/PREVENTION COLLABORATIVE PLANNING

4 STATEWIDE COORDINATED STATEMENT OF NEED

3

Section VII

Care/Prevention Collaborative Planning

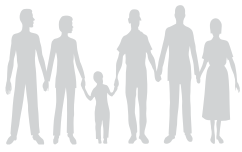
Introduction

Federally funded HIV/AIDS prevention and HIV/AIDS care both use planning—and planning groups—to assess needs in their respective realms and develop plans on how to respond. Hundreds of care and prevention planning bodies operate throughout the nation for this purpose. Most do so independently, in part because they are separately legislated. On the prevention side are Community Planning Groups (CPGs), which plan HIV prevention, for those at risk and already infected, to prevent infection and its further spread. They operate through State and local health departments and their communities, under guidance from the Centers for Disease Control and Prevention (CDC). On the care side, planning is through CARE Act Title I and II planning bodies, funded through the Health Resource and Service Administration (HRSA), HIV/AIDS Bureau (HAB).

Although distinct, both care and prevention planning have common characteristics, providing a basis for collaboration. Adding to this interest are the CARE Act Amendments of 2000, which includes provisions that seek to link PLWH into care by bringing prevention and care closer together. They include eligibility for Title I and Title II funding of early intervention services (EIS) (with HIV counseling and testing being part of EIS); outreach (to identify people who may need care); and requirements for better links across HIV/AIDS prevention and care systems. Coordination of care and prevention planning can help bridge gaps across prevention and care and thus help individuals learn their HIV status and enter care if infected. This need is evident given national surveillance data on the estimated 850,000 to 950,000 Americans who are thought to be living with HIV disease. Of these, about 670,000 Americans know they are infected, while another 180,000 to 280,000 have the virus but do not know it. About one-third of those who know their status (an estimated 233,000) are not receiving regular HIV-related health services.*

Shared features of care and prevention planning provide a solid foundation for coordination in planning. Both prevention and care planning are based on the principle of inclusive participation, and each conducts such planning tasks as preparation of epidemiologic profiles and needs assessments. Frequently, public agency staff and providers working in care and prevention serve on both planning bodies. Sometimes this membership overlap is the only direct connection between care and prevention planning.

* These statistics were presented by CDC officials at the Ninth Conference on Retroviruses and Opportunistic Infections in Seattle in February 2002, based on projections using national surveillance data.



Some communities have taken steps to more closely link their planning activities, either formally or informally. Efforts range from information sharing (often facilitated by people who serve on both planning bodies) to formal collaboration on planning tasks such as preparation of a single epidemiologic profile, combined resource inventory, or joint needs assessment activities. Some have merged their care and prevention planning bodies, in whole or in part through subcommittees. The benefits can include better use of planning resources (*e.g.*, compiling data at a single point in time, fewer planning meetings) and better services.

Legislative Background

The CARE Act requires Title II to work with HIV prevention under the following provisions. They include coordination in planning and service delivery—the latter being made possible through collaborative planning.

Planning Body Membership

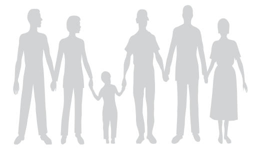
Planning body requirements for States are outlined in Section 2617(b)(6) require them to engage in "a public advisory planning process" to secure broad input in the development and implementation of the comprehensive plan from PLWH, providers, other CARE Act entities, and other agencies, similar to those outlined for Title I planning councils (*e.g.*, PLWH, health and social service providers, HIV prevention programs, other payers).

Title II planning body requirements are also outlined for consortia. Section 2613 requires the consortium membership to be inclusive in terms of (1) agencies with experience in HIV/AIDS service delivery and (2) populations and subpopulations of persons living with HIV disease (PLWH), who are reflective of the local incidence of HIV. Section 2613(c)(2) also provides for additional involvement by diverse perspectives by requiring consortia, in establishing their service plans, to demonstrate that they have consulted with PLWH, the public health agency or other entity(ies) providing HIV-related health care in the area, at least one community-based AIDS service provider, Title II grantee, Title IV grantees or organizations with a history of serving children, youth, women, and families with HIV, and entities such as those required to be represented on Title I planning councils (*e.g.*, PLWH, health and social service providers, HIV prevention programs, other payers).

Priority Setting and Resource Allocation

Section 2617(b)(4)(A) calls for States to "establish priorities for the allocation of funds within the State based on, in part:

"(ii) availability of other governmental and non-governmental resources, including the State medicaid plan under title XIX of the Social Security Act and the State Children's Health Insurance Program under title XXI of such Act to cover health care costs of eligible individuals and families with HIV disease;



Comprehensive Planning

Section 2617(B)(4)(c) requires States to “develop a comprehensive plan for the organization and delivery of health and support services” to be funded under Title II that, in part—

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

Coordination of Services

Section 2617(B)(4)(c) requires States to “develop a comprehensive plan for the organization and delivery of health and support services” to be funded under Title II that, in part—

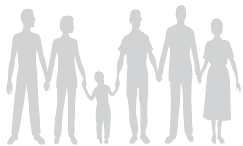
“(C) includes a strategy to coordinate the provision of such services with programs for HIV prevention (including outreach and early intervention) and for the prevention and treatment of substance abuse (including programs that provide comprehensive treatment services for such abuse);

(E) provides a description of the manner in which services funded with assistance provided under this part will be coordinated with other available related services for individuals with HIV disease; and

(F) provides a description of how the allocation and utilization of resources are consistent with the statewide coordinated statement of need (including traditionally underserved populations and subpopulations) developed in partnership with other grantees in the State that receive funding under this title….”

Section 2611(b) discusses the provision of funds “for the purpose of providing health and support services to infants, children, youth, and women with HIV disease, including treatment measures to prevent the perinatal transmission of HIV.” Such funds must total “not less than the percentage constituted by the ratio of the population involved (infants, children, youth, or women in such area) with acquired immune deficiency syndrome to the general population in the State of individuals with such syndrome.” Section 2611(b)(2) suggests coordination in determining use of Title II funds for these populations in allowing for a waiver of this requirement if “the population is receiving HIV-related health services through the State Medicaid program under title XIX of the Social Security Act, the State children’s health insurance program under title XXI of such Act, or other Federal or State programs.”

Section 2612(c) permits the use of Title II funds for “early intervention services” for individuals with HIV disease. It specifies entities “through which such services may be provided,” which include an array of substance abuse, mental health, homeless services, and other providers. Section 2617(b)(6)(G) requires that a Title II application include assurances that entities that receive funds under a Title II grant “will maintain appropriate relationships with entities in the eligible area served that constitute key points of access to the health care system for individuals with HIV disease.” These entities include an array of substance abuse, mental health, homeless services, and other providers.



FEDERAL AGENCY COORDINATED PLANNING

The CARE Act requires coordination efforts at the Federal agency level designed to enhance the continuity of care and prevention services. Section 2675 specifies the following:

"(a) Requirement.—The Secretary shall ensure that the Health Resources and Services Administration, the Centers for Disease Control and Prevention, the Substance Abuse and Mental Health Services Administration, and the Health Care Financing Administration [now the Center for Medicare and Medicaid Services or CMS] coordinate the planning, funding, and implementation of Federal HIV programs to enhance the continuity of care and prevention services for individuals with HIV disease or those at risk of such disease. The Secretary shall consult with other Federal agencies, including the Department of Veterans Affairs, as needed and utilize planning information submitted to such agencies by the States and entities eligible for support."

"(b) Report—The Secretary shall biennially prepare and submit to the appropriate committees of the Congress a report concerning the coordination efforts at the Federal, State, and local levels described in this section, including a description of Federal barriers to HIV program integration and a strategy for eliminating such barriers and enhancing the continuity of care and prevention services for individuals with HIV disease or those at risk of such disease."

HAB/DSS Expectations

HAB/DSS expects Title II to coordinate with prevention planning bodies and programs in the areas of planning body membership, conducting planning activities (*e.g.*, needs assessments), and service delivery coordination (*e.g.*, early intervention services, outreach), as follows.

Planning Body Membership

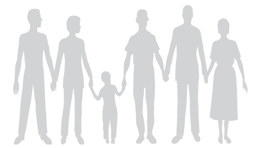
As called for in the CARE Act, HAB/DSS expects Title II planning bodies to include Federally-funded HIV prevention programs as members.

Planning Activities

HAB/DSS expects CARE Act Title I and Title II planning bodies to coordinate their needs assessment and priority setting activities with CDC's HIV prevention community planning groups.

Planning of Services

Points of Entry. HAB/DSS expects Title II programs and funded providers to establish and maintain formal, written relationships with points of entry into care—places where people with HIV who are not in care are likely to be found. Through proactive and ongoing service coordination can Title II programs identify people who know their status but are not receiving care and provide reliable referral channels to get them into the HIV/AIDS service system. (See the EIS chapter in this manual for more information on points of entry.)



Outreach. Coordination between care and prevention should occur in the planning and delivery of local HIV outreach programs designed to identify people with HIV disease and help them learn about their HIV status and enter care. HRSA/HAB requires that outreach programs funded through the CARE Act be planned and delivered in coordination with local HIV-prevention outreach programs and be targeted to populations known to be at disproportional risk for HIV infection. Outreach should be provided at times and in places where there is a high probability that HIV-infected individuals will be reached.

Early Intervention Services. If there is a shortage of early intervention services (EIS), including counseling and testing and referral services, then the planning body may prioritize and allocate resources to such services. It should ensure that such funds supplement and do not supplant existing funds by doing an inventory of existing services as part of its planning process. Planning related to EIS will benefit greatly from communication and cooperation with the CPG.

Reducing HIV Perinatal Transmission. Coordinated planning should occur in developing outreach activities that target women of childbearing age in order to reduce HIV perinatal transmission rates. HAB/DSS expects Title II to ensure that HIV-infected pregnant women have access to therapy that will reduce the likelihood of HIV transmission to newborns. There should be a coordinated effort to reach them through HIV education programs, counseling and testing sites, and other community locations. Similarly, CPGs are expected to plan for counseling and testing of pregnant women at risk for HIV and to arrange procedures to ensure that women found to be HIV-positive are referred immediately to appropriate care settings. Care programs need to work with prevention programs to ensure that women at risk have accurate information about the effectiveness of perinatal treatment and the importance of obtaining treatment early in their pregnancy.

CDC EXPECTATIONS FOR COLLABORATIVE PLANNING

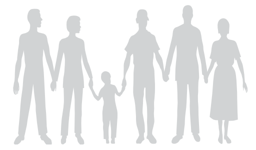
Since guidance for HIV prevention community planning was issued in 1993, CDC has stated the need for collaboration and information sharing between prevention and care planning bodies. Prevention and care planning bodies are expected to be aware of each other's activities and identify opportunities for collaboration. CDC recognizes that collaboration can occur in many ways, including fully merged joint processes, shared membership, cooperative activities, and/or information sharing. CDC guidance suggests but does not require that, when appropriate, its grantees consider merging their prevention planning activities with those of other local planning bodies that are already in place. Subsequent CDC guidances have asked CPGs for descriptions of mechanisms they are using to coordinate HIV prevention planning with other planning activities, particularly CARE Act Title I and Title II, STD, and TB planning.*

* See CDC's HIV Prevention Community Planning Guidance: Essential Elements of a Comprehensive HIV Prevention Plan, available at http://www.cdc.gov.

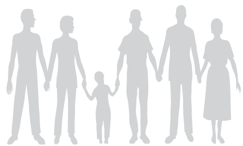
Comparing CDC HIV Prevention and Title I/II Care Planning

Care and prevention planning have several common elements. Understanding them can help Title II identify potential areas for working together. Among these features (outlined in the chart below) is the use of community planning processes that emphasize inclusive planning body representation reflecting the demographics and trends of the local epidemic. Both also require needs assessments that involve epidemiologic profiles, identification of target populations, resource inventories of service providers, and estimates of the unmet need for particular types of services. Both use needs assessment results to establish service priorities that address identified needs, and both require comprehensive plans. In addition, both include provisions for evaluation.

Care and prevention planning groups also differ in their duties. For prevention, CPGs set program priorities through their comprehensive HIV prevention plans, while health departments have sole responsibility for allocating resources to identified priorities. Under the CARE Act, States not only set priorities but also allocate resources across defined service priorities.



Responsibility	Title II	HIV Prevention Community Planning Groups
Needs Assessment	Needs assessment must include determination of the size, demographics, and needs of the population living with HIV disease. This includes special attention to the following: determining the unmet needs of individuals who know their HIV status and are not in care; coordination with programs for HIV prevention and the prevention and treatment of substance abuse; links with outreach and Early Intervention Services; and determination of capacity development needs. The needs assessment requires obtaining input on community needs through methods such as public meetings, focus groups, and surveys.	Needs assessments examine the present and future HIV epidemic and existing community resources (*e.g.*, fiscal, personnel, and program resources from public, private, and volunteer sources).
Priority Setting	States establish priorities for the allocation of funds with consideration to size and demographics of the population with HIV disease, availability of other governmental and non-governmental resources, capacity development needs resulting from disparities in the availability of HIV-related services in historically underserved communities and rural communities, and the efficiency of the administrative mechanism of the State for rapidly allocating funds to the areas of greatest need within the State.	Planning groups identify HIV prevention needs and identify specific high priority interventions and strategies to address needs by defined populations.
Comprehensive Plan	States develop comprehensive plans for the organization and delivery of health and support services. Plans must include a strategy for identifying individuals who know their HIV status and are not in care and helping them enter care, and a strategy to coordinate services with HIV prevention and substance abuse prevention and treatment.	Planning groups develop a comprehensive HIV prevention plan.
Evaluation	States are required to assess the efficiency of the administrative mechanism in terms of rapidly allocating funds to areas of greatest need within the State. At their discretion, they may also assess the effectiveness of services offered to meet identified needs. States and consortia should also evaluate the effectiveness of the planning process as part of the evaluation of the administrative mechanism.	Planning groups evaluate the effectiveness of the planning process.



ABOUT CDC'S HIV PREVENTION COMMUNITY PLANNING

A total of 65 State, local, and territorial health departments have cooperative agreements from the CDC for HIV prevention planning and service delivery. CDC requires each grantee to convene at least one HIV Prevention Community Planning Group (CPG). CPGs are responsible for comprehensive HIV prevention planning, including the following:

- Assessing the epidemic in their jurisdiction
- Identifying HIV prevention needs
- Identifying interventions and strategies to address priority needs, and
- Developing comprehensive HIV prevention plans.

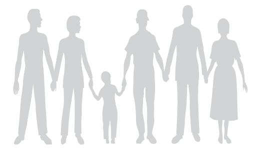
Each CPG's membership must be representative of the HIV epidemic and reflect epidemiologic trends in its area. CDC allows grantees flexibility to determine the most appropriate structure for conducting prevention planning. Some have formed regional planning groups in addition to, or instead of, a single statewide planning group. Over 200 local and regional CPGs conduct comprehensive HIV prevention planning to guide prevention funding in their areas.

To learn more, see CDC's Guidance on HIV Prevention Community Planning on the CDC website at http://www.cdc.gov/hiv/pubs/hiv-cp.htm.

Examples of Coordination

Coordination may occur in planning (such as membership and planning tasks like needs assessments) and in service delivery. When care and prevention planning bodies agree to work together, they typically benefit from the development of a memorandum of agreement (MOA) or other written document describing what and how collaboration will occur. The MOA should identify specific areas for collaborative planning, call for regular meetings of leaders and/or staff from prevention and care planning bodies, specify other communications as appropriate, establish links between counseling and testing sites and care services, and detail other areas of cooperation. Expectations for both groups should be clearly stated.

Following are examples of coordination.



Planning Body Membership

Communication between care and prevention planning groups often occurs through overlapping membership. Such shared membership is common. Membership categories likely to bring background in both areas include PLWH, staff of AIDS service providers, and health department representatives (including epidemiologists).

Planning groups have formally structured overlapping membership by designating membership slots for representatives of the other planning body. Some encourage leaders of each planning body to serve as ex officio (non-voting) members of the other body.

Since the CARE Act requires planning body membership to include "grantees under other Federal programs, including but not limited to providers of HIV prevention services," a representative from the CPG might serve this role. HAB/DSS encourages planning bodies to consider having direct CPG representation on the planning body. In addition, CPG members can join planning body committees or task forces. Similarly, one or two active planning body members might serve on the CPG and/or its committees, particularly those that address areas of common concern such as needs assessment and HIV counseling and testing.

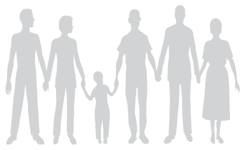
Joint Meetings

Joint meetings (regularly scheduled or special sessions) between prevention and care planning representatives can provide a forum for enhanced collaborative planning. They can take several forms:

- **Regular Meetings.** Ongoing leadership dialogue and collaborative thinking can occur through monthly meetings between chairs of the Title II planning group and co-chairs of the CPG. Agendas for meetings might include issues such as the continuum of care, planning outreach activities, funding and policy issues, and preparation of joint epidemiologic profiles and other needs assessment tasks.
- **Coordinated Meetings.** In some places, the two planning bodies are separate entities but share meeting dates and locations. Monthly meetings might have one group meeting in the morning and the other after lunch. This often works well given overlapping membership and lessened travel time, particularly in geographically large areas.
- **Subcommittees or Task Forces.** A number of planning groups have convened subcommittees, task forces, or ad hoc groups to address specific planning issues or coordinate joint efforts. For example, a CARE Act planning body might develop an HIV prevention subcommittee to help ensure that its plan adequately addresses coordination between care and prevention services.
- **Special Forums.** Sometimes conference sessions are for care and prevention representatives to meet, present their activities, and share successes/barriers.

Needs Assessment

Some aspects of needs assessment benefit from joint efforts, like resource inventories and epidemiologic profiles. Others are best done separately (*e.g.*, priority setting). Generally, where the needs assessment's target audiences and/or methodologies correspond, activities are more readily conducted jointly. If many providers in the community conduct both care and prevention activities, joint needs assessment work is more practical. At a minimum, groups can share data tools and ideas on how to do a needs assessment (*e.g.*, sampling, survey development).

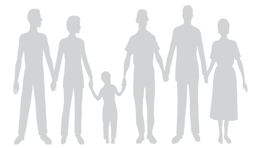


Epidemiologic Profiles. Much of the data contained in an epidemiologic profile (*e.g.*, number of AIDS cases, HIV infection cases, transmission categories and demographics of HIV and AIDS cases, STD and TB data) are equally important to HIV prevention and care planning. Epidemiologic profiles are usually compiled by the same State or local health department staff and thus might be more efficiently prepared at one point in time.

Various States and EMAs have worked collaboratively on epidemiologic profiles. Among their insights are the following:

- Certain epidemiologic data items are useful for both care and prevention. For example, STD data can serve as a measure for targeting both HIV counseling and testing and HIV care early intervention activities. Identifying common items is a basis for collaboration.
- Certain epidemiologic data items may be used only in prevention or care planning (*e.g.*, for care, estimates on the number of PLWH at various CD4 levels serve as a marker for service demand).
- Some State and local health departments take the initiative to develop a regional or local epidemiologic profile that is shared with both care and prevention planning bodies. The usefulness of such a profile can be enhanced by having a State or local epidemiologist provide technical assistance to both care and prevention planning bodies on the development and analysis of the profile.
- Jurisdictions differ in terms of data availability, public health infrastructures, and approaches to planning. This can complicate agreeing on how to develop a single care/prevention epidemiologic profile. This can be addressed by limiting the amount of data compiled and focusing on ensuring that all data are interpreted and presented in user-friendly charts and graphs.
- In regular meetings involving care and prevention planning bodies and health department officials, participants can establish a common language (*e.g.*, defining outreach and secondary prevention) and process, identify data useful to both groups, share data and methods of presentation, and discuss issues of common concern such as data availability.

Resource Inventories. Resource inventories help catalogue existing services in a community. In their basic format, they describe agency services, number and types of clients served, and funding. In such cases, it may be efficient to prepare the inventory jointly, particularly where many providers offer both prevention and care services. This might entail use of a single survey form or compilation from a State HIV/AIDS hotline directory. When the inventory becomes more specific and attempts to include information such as an assessment of service quality (*i.e.*, when it becomes a provider profile of capacity and capability), a joint effort may be harder to achieve. At the least, sharing of mailing lists and contact information can occur.



EPIDEMIOLOGIC PROFILES:
COMMON APPROACH FOR CARE AND PREVENTION

A joint epidemiologic profile format for use by CARE Act planning bodies and CPGs was developed in 2002 by HRSA and CDC. See *Integrated Guidelines for Developing Epidemiologic Profiles for HIV Prevention and Ryan White CARE Act Community Planning*, 2002.

In addition, CDC and HRSA work together on many data projects that support both care and prevention planning (see http://hab.hrsa.gov). HRSA provides CDC with data on grantee and contractor locations and characteristics. CDC provides HIV/AIDS prevalence data to EMAs and States to assist with their grant application processes and to inform Title I and II formula allocations. The two agencies jointly fund efforts to provide estimates of the number of persons with HIV in EMAs located in States that do not have HIV reporting. CDC is also working with HRSA to develop methods and technical assistance for estimating unmet need in EMAs and States.

Merged Planning Bodies

Some areas have merged their prevention and care planning bodies, which has enabled them to share membership recruitment and needs assessment activities and enhance coordination between care and prevention planning. Often, such mergers retain separate committees to address care and prevention planning in greater detail. Committees are typically responsible for priority setting in their care or prevention area, which is harder to merge.

Separate committees have been created when planning body members voiced concerns that prevention planning was not receiving an appropriate level of attention and commitment. Some feared that urgent care and treatment needs were overshadowing the planning body's focus on prevention planning.

Mergers between Title II planning bodies and CPGs have occurred in several States. Facilitating factors include the rural character of the State, the existence of a fairly limited number of AIDS service organizations, and a public health system that is State-coordinated under a regional structure.

Referral Arrangements

Planning can result in the establishment of referral arrangements to help move people from prevention to care. Examples include written "points of access" agreements and other arrangements that coordinate outreach and link them with primary care facilities. All States must establish written agreements with entities that serve as key points of entry into HIV care. Many States and individual providers have long had such arrangements. Among the most valuable types of arrangements are those that:

- Involve meetings and cross training between care and prevention staff so that they develop personal relationships and understand the scope of work of the other group
- Enhance attention to HIV prevention by agencies focused on other service issues (such as substance abuse treatment programs that provide HIV education) to ensure that all their clients are aware of treatment options and new advances in medications
- Provide model approaches and assistance to prevention entities so they can encourage individuals considered at high risk to get tested
- Ensure that staff at points of entry have specific information about available services and how to make referrals and follow-up on them, and
- Provide regular orientation, training, and written summary information so that new staff are aware of referral resources and can make appropriate referrals based on the characteristics of clients.

Technical Assistance

Since a number of planning activities are similar regardless of whether conducted for care or prevention planning, technical assistance (TA) can be delivered effectively in a standardized manner. However, some tailoring may still be necessary in responding, for example, to legislative requirements specific to care or prevention.

TA areas that may be addressed similarly include the following:

- Compiling and interpreting epidemiologic profiles
- Conflict resolution
- Grievance procedures, and
- Establishing the planning body.

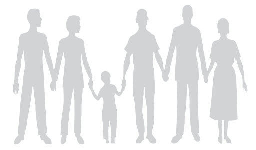
Initiating Collaboration: Key Questions to Address

Planning bodies considering either beginning or expanding collaborative planning should start with the following questions, which can be addressed in initial meetings with representatives of both care and prevention planning bodies. Determine what needs to be accomplished, whether it seems feasible, what challenges can be expected, and how best to begin working together. Be realistic: recognize that effective coordinated planning requires time and effort.

The following questions and answers are based on the experience of other groups.

1. What is care/prevention collaborative planning?

The continuum of collaborative planning ranges from basic information sharing to establishment of a single, integrated planning process (*i.e.*, merging of care and prevention groups into a joint planning body). Many other joint activities fall between these extremes, such as:



- Development of a single epidemiologic profile
- Preparation of a joint resource inventory
- Cooperation on other components of a needs assessment
- Development of formal linkages between prevention and care providers, and
- Development of plans for specific joint activities, such as collaborative outreach, a referral process linking HIV counseling and testing sites and primary health care facilities, or an initiative focusing on preventing perinatal transmission.

2. Why undertake collaborative planning—what are the benefits?

Collaborative planning can create multiple benefits related to savings in time, resources, and effort, and improved plans that contribute to a continuum of prevention and care that better meets community needs. If you are considering collaborative planning, decide what benefits are most important to you. For example, EMAs and States have found that collaborative planning can:

- Reduce meeting time for individuals who serve on both care and prevention planning bodies
- Lead to a single epidemiologic profile that is more comprehensive and also reduce the workload of health department staff who would otherwise have to prepare two different profiles
- Reduce time and costs for needs assessment by avoiding duplication of effort by planning body members, staff, and consultants
- Improve linkages between prevention and care so that the continuum of care—from primary prevention through services for people with HIV—is fully developed and referral relationships are improved
- Help infected individuals learn their HIV status earlier and get them into care without delay, thus reducing unmet need for services and improving long-term health outcomes
- Improve secondary prevention efforts, including prevention of HIV perinatal transmission, and
- Encourage providers involved in one aspect of HIV to become involved in the other, thus increasing care and prevention capacity.

3. What are the obstacles to collaborative planning?

Many factors discourage collaborative planning. Some are initial barriers that can be quickly overcome. Some are more serious and may make some kinds of collaboration difficult. Collaboration is most likely to be successful if planning bodies identify and directly address potential barriers rather than ignoring or minimizing them. Among the barriers are:

- **Concerns about the time and effort required.** Planning body members often feel overburdened and unable to expand their work to adequately address both prevention and care issues. This is a particular concern for planning groups considering a merger into a single care/prevention entity.

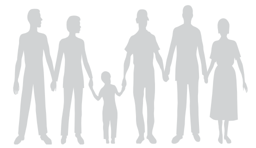
- **Concern by planning body members that collaboration will be too broad and therefore not successful.** This concern tends to be reduced where initial collaboration addresses specific planning tasks. For example, rather than beginning with a total shared needs assessment, the two bodies might want to collaborate on a shared resource inventory.
- **Fear that prevention will receive reduced attention.** Some members of CPGs are concerned that, in collaborative planning, care might overshadow prevention because there are usually more care dollars to allocate and decision makers might focus more on care.
- **Different perspectives of planning bodies.** The two planning processes require many similar skills but also some different perspectives that may not cross over well. For example, primary care personnel typically focus on care, while educators may focus more on prevention issues. Establishing a merged planning body or joint needs assessment committee that provides the whole range of skills and experience can mean a large an unwieldy working group.

4. What factors encourage collaborative planning?

Certain characteristics of communities and planning bodies seem to create an environment that is especially supportive of collaborative planning. For example:

- A shared interest in making the planning process more efficient provides strong motivation for collaborative planning. Where many providers are involved in both prevention and care, the time required to support separate planning bodies and planning efforts seems particularly burdensome. Both prevention and care planning bodies find it difficult to engage members and maintain high levels of consumer participation. The desire to reduce meeting time and prevent member burnout leads to a willingness to make the effort needed for successful collaboration.
- Leadership and commitment from key individuals can help move collaboration forward. This includes leaders care and prevention planning bodies, health department officials, the chief elected official, and providers.
- Less populous States, rural areas, and communities with fewer HIV/AIDS cases tend to have fewer agencies and less complicated HIV/AIDS care and prevention systems. With fewer providers to involve in community planning, collaboration is easier to arrange—particularly when the same providers are doing both care and prevention work.
- Collaboration is often easier where public health systems are well linked at the State and local levels (*e.g.*, in States where local public health departments are branches of State government). This can create a climate of support for coordinated planning because State and local health department staff may work on both prevention and care, are usually well connected to State as well as local entities, are used to working together, and/or work regularly with community agencies.

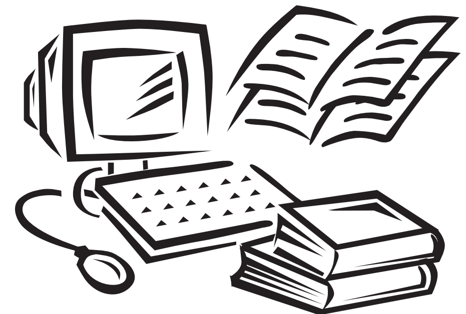
Consider what factors within your area are likely to encourage and contribute to the success of collaborative planning.



5. What action is needed to begin collaboration?

Following discussion of the above questions, decide whether collaborative planning makes sense and, if so, what you want to do. If you decide to undertake some form of collaborative planning, establish a mechanism—such as a committee or task group—to further develop ideas and set a plan of action. This should include a time frame for carrying out specific agreed-upon planning tasks. If the State/planning body decides not to proceed at this time, consider establishing a time to revisit the issue. Planning needs may change and the benefits of collaborative planning may become more apparent by the next discussion.

REFERENCES



Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB). *Care/Prevention Collaborative Planning: HRSA AIDS Programs Title I and Title II Planning Bodies and CDC HIV Prevention Community Planning Groups.* Rockville, MD: U.S. Department of Health and Human Services, 1998.

HRSA, HAB. "Collaboration between Titles I and II and HIV Prevention Community Planning Groups." CARE Act National Technical Assistance Call Report. Rockville, MD: U.S. Department of Health and Human Services, September 1995.

HRSA, HAB."Growing Impact of HIV/AIDS among Underserved Populations." CARE Act National Technical Assistance Call Report. Rockville, MD: U.S. Department of Health and Human Services, November 1998.

HRSA and CDC. *Guidelines for Developing Integrated Epidemiologic Profiles: HIV Prevention and Ryan White Care Act Community Planning.* 2002.

HRSA, HAB. "New Tools for HIV Care: STD Treatment." CARE Act National Technical Assistance Call Report. Rockville, MD: U.S. Department of Health and Human Services, February 1998.

HRSA, HAB. "Reaching HIV-Positive Youth: Models that Work." CARE Act National Technical Assistance Call Report. Rockville, MD: U.S. Department of Health and Human Services, June 2000.

HRSA, HAB. HAB Policy 02-01, Outreach. 2002.

"Guidance: HIV Prevention Community Planning." See the CDC website at http://www.cdc.gov.

RESOURCES

HIV Counseling, Testing, Referral Guidelines. HRSA/HAB worked with CDC in revising existing guidelines to increase their focus on HIV-infected persons and linking them with HIV services. See them at the CDC website at http://www.cdc.gov.

CDC Guidelines for HIV Screening of Pregnant Women. Revisions of guidelines on HIV counseling and voluntary testing for pregnant women, they were developed with HRSA input and stress: (1) HIV testing as a routine part of prenatal care, (2) simplification of testing to eliminate barriers, (3) a more flexible consent process, (4) provider determination of patient reasons for refusal of testing, and (5) HIV testing and treatment at the time of delivery for women who have not received prenatal testing and treatment. See them at the CDC website at http://www.cdc.gov.

HRSA CARE/PREVENTION ACTIVITIES

HRSA has engaged in a number of care/prevention collaborative activities. Examples include the above guidelines (developed with both CDC and HRSA input), Special Projects of National Significance (SPNS) projects that are developing models of care, and initiatives (*e.g.*, integrated behavioral and biomedical intervention addressing prevention, access, and adherence to therapeutic regimens; models of prevention and care for HIV-infected individuals). An updated listing of prevention and care activities can be found at the HRSA/HAB website at http://hab.hrsa.gov.