

PJ-ABY-615
ISN 99379

PROCEEDINGS
of the Roundtable Working Group Sessions
at the
USAID 3RD HIV/AIDS
PREVENTION CONFERENCE

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U.S. Agency for International Development
Washington, D.C.

May 1996

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The Proceedings of the Roundtable Working Group Sessions
at the USAID 3rd HIV/AIDS Prevention Conference
was written and produced by the Health Technical Services Project,
(Project No. 936-5974.10, Contract No. HRN-5974-C-00-3001-00) of
TvT Associates and the Pragma Corporation, under the auspices of the
HIV-AIDS Division, Office of Health and Nutrition,
Bureau for Global Programs, Field Support and Research,
United States Agency for International Development.

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Definition of Terms

behavior change: usually refers to changes in how an individual responds or reacts to a particular stimulus or condition

benchmarks: measurable achievements that are used to mark progress toward identified objectives

care: activities that enhance the well-being of individuals, families, or communities

cultural sensitivity: an awareness that each community has unique characteristics that differentiate it from other communities, and the ability to relate to each community in terms of its own perspective rather than one's own perspective

empowerment: enhancement of an individual's or community's sense of control over his/her/its own situation

HIV/AIDS programming: organized activities that promote the prevention of HIV transmission or the care of people living with HIV/AIDS

integration: utilization of a single program structure to accomplish two or more sets of objectives

intermediary: an agent or agency that intervenes between the donor and the community-based recipient of funds, either to facilitate the interaction of the two or to provide technical assistance to the recipient in complying with donor requirements

outcome evaluation: an evaluation that measures the effects or results of a program

performance indicators: quantifiable objectives that can be used to measure the relative improvement of a program

stakeholders: those individuals who have an interest in the activity under consideration, as contributors, benefactors, or opponents

stigmatization: the rejection or disdain of an individual or community because of some assumed characteristic or behavior of that person or persons

sustainability: the capacity of a program to maintain itself without external assistance

I. Overview

A. GOALS AND OBJECTIVES

The goal of the Roundtable/Working Group (RT/WG) Sessions was to provide USAID with guidance in designing the next decade of HIV prevention and care programming. To achieve this goal, the eight most critical HIV/AIDS policy and program questions were articulated and examined in depth.

B. PROCESS

USAID addressed eight of the most critical questions regarding HIV/AIDS prevention in the Roundtable/Working Group (RT/WG) Sessions of the Third HIV/AIDS Prevention Conference. The eight HIV-related issues, which continue to be hotly debated, nevertheless are fundamental to the success of the next decade of HIV/AIDS prevention and care. The process for the RT/WGs brought together a broad range of thinking on each issue and produced a joint analysis which specifically focused on identifying areas of emerging consensus, as well as areas in which regional, technical, and community differences may lead HIV/STD service providers in different directions. This analysis will thus provide USAID with a kick-start to the design process for the next decade of HIV prevention and care programming.

For each of the eight issues, a background paper was developed representing the best summative thinking of one selected expert who was asked to provide a preliminary road map to the current status of the issue. Then, a pre-conference workshop of selected professional and community experts from the field distilled the background paper into a set of key questions and emerging themes.

The key questions were then posed to a larger group consisting of self-selected participants in each HIV/AIDS Prevention Conference Working Group. Through in-depth discussion, participants in the Working Group examined the questions, discussed the range of perspectives regarding the issues at hand, and articulated any emerging consensus that is developing among experts in the field. A summary of the proceedings of each of the RT/WG Sessions was

presented in the final plenary session of the Prevention Conference to share the lessons from all eight RT/WGs with the entire audience.

The most significant outcomes of the meeting were a resounding endorsement of certain outstanding principles that have come to be the primary underpinnings of HIV/AIDS policy and programming, and nearly unanimous enthusiasm for the RT/WG process itself. In addition, issues germane to each of the eight topics were elaborated and examined for dissemination to provide a technical update to the field.

C. OVERARCHING THEMES

1. Community Participation

A number of overarching themes manifested throughout the RT/WG discussions. One of the strongest themes was the importance of community participation in HIV/AIDS policy and programming. Community participation becomes a fundamental goal in and of itself, not only because it is a desirable goal for the altruistic reason that it enhances self esteem and increases community empowerment, but also because other goals cannot be achieved without accomplishing community participation.

Community participation underlies the success of programming in a number of ways. Community participation is key to the integration of HIV/AIDS programming with other services, the sustainability of HIV/AIDS programming, the cultural appropriateness of messages, acceptance by the community of programming and its evaluation, the involvement of all stakeholders, and the reduction of stigmatization of people living with HIV/AIDS.

2. Sustainability

Achieving program sustainability was another overarching theme of the RT/WGs. The principle of sustainability was seen particularly in the context of the limited external resources for resolving the problems of HIV/AIDS. In addition, however, self-sufficient programming was defined as being an important aspect of achieving genuine cultural relevance of programming, of achieving complete program integration, and of engaging all stakeholders in the process of programming.

3. Involvement of People Living with HIV/AIDS

The importance of involving people living with HIV/AIDS (consumers) in HIV/AIDS programming was a theme that emerged throughout the RT/WG discussions. The scope of this involvement encompassed having the consumers of HIV prevention messages and of HIV-related

services participate directly in all aspects of policy development and of program design, implementation, and evaluation.

The involvement of people living with HIV/AIDS achieves a number of objectives: assuring that education and services address the appropriate target audience; addressing the identified needs of consumers; assuring cultural sensitivity toward consumers among all relevant parties (stakeholders) in program planning, implementation and evaluation; and, reducing discrimination against people living with HIV/AIDS.

4. Combining HIV/AIDS Prevention and HIV/AIDS Care

A persistent theme was the importance of no longer separating HIV/AIDS prevention from HIV/AIDS care. The phrase "HIV prevention and care" was frequently used in the RT/WGs. The integration of HIV/AIDS prevention programming with HIV/AIDS-related care has several advantages: utilizing the health service infrastructure for HIV prevention (for example, for HIV counseling); enabling cross-training and skills development across a wide range of sectors; sensitizing the community and its leadership that HIV is an important issue by making HIV care visible.

5. Integration of HIV/AIDS Programming With Other Primary Health Care Services

Throughout the RT/WGs, the assumption was made that HIV/AIDS programming should be integrated with other primary health care services wherever possible. Integration has the advantages of utilizing an existing infrastructure (including personnel) for HIV prevention and care. Using the existing infrastructure has the advantages of achieving more widespread coverage than would otherwise be possible; creating a wider range of stakeholders (including communities at risk) in HIV prevention and care; and, targeting a diversity of audiences and communities for HIV prevention.

6. Focus on the Socioeconomic Dimensions of HIV/AIDS

Many discussions included concern that the social and economic dimensions of HIV/AIDS must be addressed both for successful prevention and for effective care. Poverty and social marginalization are factors that contribute to increased risk for HIV and to lack of access to care services.

Socioeconomic factors were of concern for a number of reasons: they help to determine which communication models are appropriate in various communities; in some communities, participation in HIV prevention rests on meeting essential needs such as food, shelter, and personal safety; discrimination based on socioeconomic factors is often linked to discrimination

based on real or perceived HIV serostatus for many people at risk for HIV; and, lack of economic resources necessitates that HIV prevention and care services be built into other existing services.

7. Prevention of Stigmatization and Discrimination

The impact of fear and discrimination on the lives of those who are infected and affected by HIV cuts across all dimensions of the epidemic. A number of the RT/WGs emphasized that discrimination is a barrier to achieving other HIV/AIDS-related objectives, including: access for high-risk communities to both prevention and care services; conducting needs assessment as well as evaluation; achieving broad-based community participation in HIV/AIDS programming; obtaining the commitment of all stakeholders.

8. Complexity of Components

RT/WG participants expressed concern that the complexity of the issues they were addressing not be lost in generalizations or broad categories. HIV/AIDS is a complex problem with not only multiple affected communities and sectors of impact, but also multiple responses and solutions. Each component (community, sector, response, and solution) in turn contains an intricate network of differing elements which should not be lumped together into a single abstraction (e.g., gender).

It is important to disaggregate each of the components into its discrete parts in order to analyze the subtle interrelationships and make appropriate decisions regarding activities or interventions. This is as true of counseling as it is of evaluation, as true of urban communities of gay men as it is of rural villages, workplaces, or populations defined by age and sex.

There are many stakeholders, each of whom sees the problem from a perspective that does not necessarily take into account the issues or needs of even other closely aligned stakeholders. Careful definition and analysis must occur in order to determine the necessary and sufficient degree of disaggregation required to avoid compromising results by resorting to the least common denominator.

D. SUMMARY OF FINDINGS

1. Roundtable Working Group I: Prevention and Care

Participants in the Prevention and Care RT/WG felt that although prevention and care programs have usually been funded and implemented separately, this separation contradicts a historically sound public health model. Furthermore, the two have never actually been separated at the community level.

At the outset, the Prevention and Care RT/WG described the basic components of prevention and care and established the premise that prevention and care are both important components of HIV programming. Three of the rationales for expanding HIV programming beyond prevention were identified as: 1) care is essential in addressing the adverse effects of the HIV epidemic on societies; 2) seeing people living with HIV/AIDS being cared for helps address the fear and stigma by making AIDS visible in the community; 3) limited resources make it critical to utilize existing health service infrastructure for prevention.

An important issue was the role people living with HIV have to play in both prevention and care, and the challenges associated with promoting their increased role. Among the lessons learned are that a continuum, or package, of care is needed that includes not simply medical care and HIV prevention, but a range of activities including attention to the human rights of the infected.

Given the exciting innovations that have resulted from AIDS services, such as comprehensive care, attention was given to transferring successful and effective models of care to newly affected communities.

2. Roundtable Working Group 2: Behavior Change Communication Strategies: Finding the Right Models for Specific Audiences and Settings

An important finding of the RT/WG Session on Communication for Behavior Change was that communication always occurs within a specific context, and that it is unreasonable to expect that communication alone can bring about far-reaching social change. Because of the complex social context, it is necessary to redefine the criteria for "success" of communication interventions and to monitor and evaluate communication strategies with a focus on intermediate and process indicators as well as outcome variables such as behavior change.

The group acknowledged the importance of targeting gatekeepers and opinion leaders and of ensuring that vulnerable and marginalized communities, including people living with

HIV/AIDS, be intimately involved in the design, implementation and evaluation of communication programs. While there was consensus around these principles, the group found it challenging to define how to implement them. One significant question was how not to impose a prevention agenda on a community from the outside, but to allow each community to determine its own prevention priorities, and to develop a process for individuals to explore risks and solutions in their own life contexts.

3. Roundtable Working Group 3: Community Participation and Sustainability

A key concept of this RT/WG was that participation of communities should be viewed not only as a strategy but also as a goal of HIV/AIDS programs. Community participation seeks to democratize decision making which will enhance community empowerment. It requires the allocation of resources, including time, to enable communities to fully participate in the elaboration and implementation of policies and programs. However, governments should not see community participation as a strategy for replacing their legitimate role in health and social services or as a response to resource scarcity.

Participants suggested that community participation as a concept refers to a transition stage in community work. The use of the word *participation* implies that there is an organization (e.g., a donor) with which a community is working. *Community ownership* was proposed as the term for the final stage in community work, which connotes program sustainability, since the community would have accepted full responsibility for the program rather than merely being a partner in its implementation.

When working toward community participation, the context of the community must be considered because the nature and starting point of community participation will vary according to the capacity and capability of the communities involved. In addition, the inherent imbalance of power between NGOs and donors must be considered, and measures must be taken to strengthen the capacity of NGOs to relate to donors.

The RT/WG participants defined the sustainability of NGOs in broader terms than just achievement of financial and programmatic self-sufficiency. Their definition includes sustaining community action on HIV/AIDS issues, which incorporates factors such as community and organizational development, establishment of linkages to other community participation experiences, and building of national and international networks.

Numerous challenges in achieving community participation and sustainability were discussed, including competing political agendas among community members and lack of experience in community organization.

4. Roundtable Working Group 4: Protecting and Strengthening Human Rights: Facilitating a Participatory Process

According to the RT/WG on Protecting and Strengthening Human Rights, respect for human rights is a necessary precondition for optimal and sustainable HIV/AIDS prevention and care. The integration of human rights into HIV/AIDS programming and the serious examination of all ethical considerations are critical to the development and implementation of HIV/AIDS programs and policies. The challenge is to ensure that processes and mechanisms which facilitate this integration are developed, disseminated, and implemented.

There was agreement that locally appropriate application of ethical theory, principles, and rules requires a process that allows a full discussion by the diversity of stakeholders. Ethical dilemmas are not static; therefore, interim solutions and iterative debates are inherent in the process of conflict resolution. The group felt that USAID should facilitate the development of a common framework for approaching ethical dilemmas in the HIV/AIDS epidemic.

5. Roundtable Working Group 5: Benchmarks, Performance Indicators, and Evaluation

The Benchmarks RT/WG identified a number of advances in evaluation of HIV/AIDS prevention that have occurred in recent years, including: a growing acceptance of the need for qualitative data; the use of mathematical modeling for examining trends and patterns at the national level; and the use of multiple evaluation strategies, which makes evaluation findings more credible. The democratization process is pushing participatory evaluation, which enhances the process of ownership of evaluation findings.

On the other hand, donors are impatient to demonstrate results, making the required time frame for achieving outcomes unrealistic. There is still little funding for baseline studies, which would assist in project design, define the context of a program, and increase the ability to conduct true impact evaluation. The participants recommended that mechanisms be developed to improve networking among projects as a means to share field experience in evaluation and to disseminate findings from both successful and unsuccessful projects.

6. Roundtable Working Group 6: Integrating HIV/STD Prevention, Family Planning and Other Programs: What, Where, When, How, and Why?

This RT/WG specified that while integration of HIV/STD with family planning and other services is often beneficial, it must be carefully assessed prior to implementation because it is not always the best solution to problems. One of the numerous factors that must be taken into

consideration is whether it will serve the greatest good for the greatest number of people. The advantages of integration include the fact that integration may achieve multiple objectives in a single service setting. On the other hand, disadvantages include the fact that policy makers and donors may prefer vertical funding mechanisms and very specific indicators of success for individual programs, to enhance accountability. The challenge in each situation is to know whether, how, and what to integrate. Successful integration must occur simultaneously at multiple levels (policy, programmatic, operations, ideological, and societal).

Integration requires policy development on a number of levels. First, a national policy is needed in order to set priorities, organize administrative work, and to allocate resources. Second, a policy is needed to harmonize the objectives of family planning and the control of HIV/STDs. Third, a policy on professional practices needs to be developed.

7. Roundtable Working Group 7: HIV Counseling and Behavior Change

The RT/WG on HIV Counseling and Behavior Change determined that counseling is a broader topic than counseling and testing, that behavior change involves more than risk reduction, and that counseling should be included in any comprehensive HIV/AIDS program. The purposes and goals of counseling should be determined prior to designing a counseling program. Design issues to be considered include possible program integration (to increase accessibility and decrease cost) and the importance of program flexibility (to adapt to the specific structural limitations of the environment, or the context).

Outcome evaluation is difficult with counseling interventions, in that there are numerous beneficiaries, possible outcomes, and levels of change that can result from counseling. In addition, attribution of behavior change to counseling interventions is difficult given the complex context of other factors experienced by individuals who are counseled. The group did not reach consensus about the relative importance in outcome evaluation of meeting the client's needs versus influencing the client's behavior. Two unanswered questions were, "Why is outcome evaluation necessary?" and, "Is it possible to demonstrate that counseling causes behavior change?"

8. Roundtable Working Group 8: Creating a Common Purpose and Bridging Differences Among Stakeholders (Communities, Researchers, Industry and Government) in Providing New STD/HIV/AIDS Products

Participants in the RT/WG on Building Bridges Among Stakeholders to Provide New HIV/STD Products felt that in order to establish partnerships, the power differential among the stakeholders must be recognized. For collaboration to take place, differential interests must be minimized while creating a common ground among the stakeholders. On the other hand,

participants must retain their separate identities and not coopt each other. Safe and honest communication is vital.

Participants felt that product development should involve building consensus across stakeholders, agreeing on an agenda, and including communication in all the steps related to development and distribution of the product. In addition, evaluation must take collaboration into consideration: whether each stakeholder is being heard adequately, and if, in fact, they continue to be committed and involved in the process.

II. Roundtable Working Group Session Summaries

A. ROUNDTABLE 1:

Prevention and Care: Implications for Program Improvement and Sustainability

1. Introduction

a. Background

During the first ten years of the HIV/AIDS pandemic, most national AIDS control programs focused primarily on prevention. Care, while considered worthy, was not accorded the resources and priority assigned to preventive efforts to combat the pandemic.

Despite the importance of prevention efforts, the fact that the number of infections continues to increase pushes the need for care into increasing prominence in countries throughout the world. WHO estimates there are now approximately 19.5 million people with HIV. Illness and death resulting from AIDS are placing an additional burden on health care systems.

In addition, AIDS is having adverse social and economic impacts on families, communities, and countries throughout the world. As AIDS takes its toll, care must be considered an increasingly important component of efforts to combat the effects of the pandemic. This raises critical issues linking prevention and care.

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Care is not only an issue requiring increasing attention of countries. It is a critical component of any effort to prevent the spread of HIV. Communities continue to be afraid and stigmatize people living with HIV. Only when communities experience HIV in their midst by acknowledging and participating in the care of the ill will they be able to embrace HIV prevention.

Constituencies involved in the issues of prevention and care, include, but are not limited to:

- affected and infected communities
- donors
- governments (ministries of health, development, social welfare, labor, finance)
- workplace/business
- the military
- religious institutions
- private/public health sectors
- traditional care institutions.

b. Components of Care

Care for people living with HIV and people affected by HIV involve a wide range of services providers who meet a broad spectrum of HIV-related needs, including:

- medical care, including appropriate diagnosis, rational treatment, and planning for follow-up;
- traditional care, including local healing practices and alternative/complementary therapies;
- nursing care, including the provision of health care, health maintenance, and palliative care, the promotion of hygiene and nutrition, the counseling and education of family members on prevention, as well as on how to care for the afflicted family member;
- counseling, including facilitation of informed decision making (e.g., whether to get tested), reduction of stress and anxiety, promotion of positive living and planning for the future, and facilitation of behavior change;
- social support services, including provision of information, referral to support groups, welfare services, and legal advice;
- self-care practices, including the care people provide for themselves when they make healthy lifestyle choices.

c. Components of Prevention

HIV prevention involves numerous sectors that are all engaged in improving the quality of life of individuals and the capacity of communities, including:

- health education that occurs outside health services (e.g., in schools, work places);
- teaching of social or life skills leading to empowerment and enabling people to care for themselves;
- provision of information enabling people to make informed decisions; and,
- activities that provide people with the tools, resources, capacities, and empowerment to prevent disease.

d. Prevention as Part of the Continuum of Care

Prevention education is a vital aspect of caring for people's well being. Conversely, care can be an entry point for discussing prevention. The separation between the two, which is artificial at the community level, makes implementation of either activity difficult.

A range of prevention tools can be used by health workers depending on a person's needs for care. As an example, treating a STD, which is care, prevents it from getting worse and is an entree for teaching about HIV/STD transmission; immunizing children prevents them from getting sick and is an entree for teaching about hygiene and use of sterile injection equipment.

The appropriate approach to prevention depends upon the target group. For example, people living with HIV/AIDS have different prevention as well as care needs than uninfected youth.

2. Issues in Linking Prevention and Care

a. Integration

The limited discussion among experts and in the literature about the integration of prevention and care has been primarily among health care economists and planners. Otherwise, care and prevention are viewed as having separate objectives, areas of service, target populations, and resources. While the separation helps resolve the problem of evaluating the outcomes of care versus prevention, the distinction is artificial at the level of implementation.

The provision of care has been primarily interpreted as meeting the biomedical needs of infected individuals. In response to the limitations of this interpretation, CBOs/NGOs have taken the initiative of filling the gaps that remain, such as meeting the psychosocial needs, basic physical needs, and the prevention needs of people within affected communities.

To achieve the integration of prevention and care, the various sectors of society each have special responsibilities, and they must collaborate (not just providers, but also family, donor, government, and community members). All levels of society need to be involved to accomplish integration.

b. Fear and Stigma

Awareness of the increasing number of HIV infections often leads to fear of the magnitude of care needs. Fear regarding the enormous task of caring for the infected has been used as a justification for a singular focus on HIV prevention and an avoidance of addressing care at all.

Negative images of HIV/AIDS have contributed to the proliferation of a different but more alarming kind of fear and stigmatization. Moral judgments and negative attitudes toward people living with HIV have created resistance to providing care to them. In addition, the stigma experienced by people living with HIV has caused other people to deny that HIV affects them, and to not take HIV prevention seriously in their own lives.

c. Limited Resources

The resources directed to HIV prevention activities are inadequate to the task. Therefore, many HIV experts make a distinction between prevention and care in an effort to keep the limited prevention funding from being eroded by the equally acute need for HIV care (for which resources are also entirely inadequate). Thus, scarcity of resources is used as an argument against integrating care and prevention. In addition, donors tend not to support integration of services with the limited resources, because it is simpler to fund programs with discrete objectives rather than comprehensive sets of objectives (i.e., integrated prevention and care services).

Given the reality of limited resources, communities must address both prevention and care needs within existing programming. The work of individuals who conduct STD, family planning, and HIV/AIDS education is already integrated, full-time work.

The immense needs for care and prevention indicate that despite the limited resources, more people need to be trained. Organizations and communities need training in capacity-building to become self-sufficient. Communities need to generate both their own income and additional resources to meet the growing demands of both prevention and care.

d. Evaluation

Evaluation is a critical aspect of HIV programming that should be ongoing, to identify gaps in programs and ensure that programs are having the desired impact. However, it is often not conducted within a time period that enables programs to utilize the results to modify and improve their programs. Communities sometimes feel that evaluation goes on and on with no results and no useful answers. "When can we expect from results?" is a frequent complaint. Communities need to be trained to develop and use performance indicators for monitoring and evaluation, to enable them to work with donors to conduct evaluation, rather than resisting the process.

The distinction between measuring social objectives and medical/clinical objectives is difficult and not clear cut. A conflict often arises between the donor and the community regarding the value of the identified outcomes. For example, a community may reach their objective for care without having prevented illness, which may have been the donor's objective.

e. Community Versus Provider/Donor Control

The community defines care according to its own pressing needs, and is concerned primarily with the problems it has today. Because of this, HIV prevention probably would not be a priority problem for many communities. As a result, health care providers and donors often feel that decisions about HIV priorities should not be left to the community. They resist the basic principle that programs should be community-driven rather than donor-driven.

The demands of the community do not necessarily overlap with HIV prevention needs identified by donors or providers. Therefore, HIV prevention programming should begin with some overlap with community demands in order to achieve community commitment.

f. The Role of People Living with HIV/AIDS

People living with HIV have an important role to play in HIV-related care. Psychological and social problems arise from people finding that they are HIV positive, especially when they are asymptomatic. The most effective way of overcoming these problems is to have productive, asymptomatic people who are living with HIV introduced to the community as well as to people who are newly diagnosed. However, the fear and stigma associated with HIV make it a difficult and challenging task to arrange for people living with HIV to identify themselves to others. In fact, there is concern that if programs are encouraged to use people living with HIV for support or educational purposes, some programs may force people to disclose their status without their consent.

Involving people living with HIV/AIDS in HIV prevention is also difficult to arrange. On one hand, people living with HIV/AIDS are powerful messengers for prevention education, and programs are often encouraged to have people living with HIV to speak in the community. On the other hand, people all over the world are stigmatized for being identified as HIV positive. Disclosure of HIV status has resulted in loss of jobs, housing, insurance, and in abandonment by family and community.

HIV-infected peer educators have an important role to play in HIV prevention education, but are challenging to organize. In Kenya, people living with HIV formed organizations and came together to form a movement to provide help and counseling to people living with HIV and also to provide prevention information to those who are not infected. However, the process takes time and cannot be forced: it is important to allow people and communities to develop at their own pace.

The idea that there is always value in voicing issues or opinions aloud is a western way of thinking, and one that not all cultures agree with. In some cultures, it would be even more difficult than in others for people living with HIV to self-identify within the community. An overriding principle should be to respect cultural values, traditions, and beliefs, even at the expense of having less impact.

g. Key Contributions and Limitations of HIV Care and Prevention

HIV prevention programs have been successful in generating resources, developing innovative approaches, and improving access to under served populations. However, in the process there has been little integration with existing services; increased access has resulted in an overwhelming caseload on the public sector; and generation of local resources has resulted in a reduction in donor funding.

Capacity building has resulted in an emphasis on increased responsibility by local NGOs in both HIV-related prevention and care. On the other hand, the NGOs have been hard-pressed to meet the growing problems due to their essential lack of skills, resources, and training.

The issues of self-care and community empowerment put forth by AIDS service organizations has had an impact on community control within the broader arena of health care systems. However, the impact has been limited as well as geographically sporadic.

A unique characteristic of HIV/AIDS programming has been the involvement of people living with HIV/AIDS in providing advocacy and guidance and in highlighting programming inadequacies. However, this involvement has decreased with the shift from empowered to disempowered populations as the epidemic has evolved.

3. Lessons Learned

Cross-training is needed to broaden and improve HIV prevention and care skills.

Cross-training is the most effective way to improve many of the skills needed to provide both HIV-related prevention and care. The range of people and agencies who require training includes: all staff in health facilities, including administrators; NGO staff; community people (school/church groups, youth workers, volunteers, traditional healers, retired people).

The subject areas for skills-building and training in the community include clarification of misinformations, practice of skills for HIV prevention (condom negotiation, communication, role playing), and HIV prevention strategies for youth. Parents need information and skills in communicating with their children. Family care givers need training in providing care. NGO staff needs training in planning for sustainability (which includes cost recovery measures, utilization of seed money, entrepreneurial and fundraising skills, and networking), and training in personnel management (which includes providing support for staff as well as dealing with staff turnover).

The health care workers need training in all these subject areas as well as information about standards of care, information about existing resources and services in the community, and skills in discharge planning (before the person is discharged) and in basic counseling. A very important but an intangible factor that must be promoted is the value of having a sensitive and humane approach to caring for people living with HIV/AIDS: "People don't care how much you know, they want to know how much you care."

Community self-sufficiency is needed to assure sustainability.

HIV/AIDS is not the most important issue for most people. Programming should begin by addressing a community's basic unmet needs, which may be for food and adequate shelter. Ultimately, communities must be able to sustain themselves in order to maintain HIV/AIDS programming with little or no external support.

People should be hand picked for leadership roles. Those who are recruited and trained should be motivated and are in a position to implement prevention and/or to provide care.

Networking and sharing information is critical to self-sufficiency. South-to-south collaboration enables neighboring countries to share HIV-related information and resources.

Integration of HIV prevention and care is crucial.

Prevention and care cannot be isolated from each other. The operational linkages of prevention and care must be reinforced, and governments must be involved in the linkages.

Although HIV prevention and care services are usually separate now, they should be provided either within a single program or with a good level of coordination between services. In addition, coordination and linkages should occur between services provided in communities and services provided in health facilities. Otherwise, communities will be unresponsive.

A package of care is needed.

A package of care, or continuum of care, is needed. This package should address the needs of all affected persons and include the concerns of everyone in the community. The sociocultural dimensions of HIV/AIDS should be addressed, such as the impact of gender and culture on behavior, the need for advocacy, and the protection of human rights including confidentiality.

The structure established for prevention should be utilized for provision of care (e.g., outreach efforts, grass-roots activities, and mobilization of resources at the community level).

Comprehensive care should be provided within a single service agency. For example, instead of a health center providing pretest and post-test counseling and referring a person elsewhere for ongoing counseling, one person at the health center should do all the counseling and provide ongoing support.

People living with, and affected by, HIV/AIDS must be involved in all decisions affecting their care.

People with HIV/AIDS should be involved in the planning, implementation, and evaluation of HIV prevention and care services. In addition, they should be informed about their situation and their treatment, and involved in decisions affecting their individual care if they wish.

The image of HIV/AIDS must be changed.

Many communities are reluctant to provide care and support. To counteract this reluctance, the negative images of HIV/AIDS and people living with HIV/AIDS need to be destigmatized. Both community education and a change of health care provider attitudes

would contribute to these changes. People living with HIV/AIDS also have an important role to play in transforming the negative image of HIV/AIDS.

At the same time, there is a concomitant need to promote a positive image of living with HIV/AIDS and to convey the message that people infected with HIV can continue to lead fulfilling lives. Education is needed at all levels: the community, churches and other religious institutions, the family, the workplace, and among health care providers and policy makers.

Change in attitudes about HIV/AIDS needs to occur even at the family level. This can be achieved by taking advantage of all available opportunities for education (health service visits, women's associations, churches/religious institutions). Families affected by HIV/AIDS have a potential role in changing attitudes and beliefs of other families in the community.

Identifying and transferring models of care.

There is a natural process of response to the HIV epidemic through which each country or community must mature, beginning with denial, and moving through recognition of the problem, to finally addressing the problem. In order to address the problem, the community must identify resources, establish priorities, structures, roles, and responsibilities. If this process of responding must occur, how can successful strategies be transferred from later stages of the maturation process to earlier stages, and from culture to culture? What can be done to catalyze this process? Transferring successful models of prevention and care is important. Given the considerable lessons learned from a wide range of models, communities and countries should not have to "reinvent the wheel."

Common characteristics of viable models include effectiveness, affordability, acceptability and feasibility. The ingredients for a successful project include an acute understanding of the problem, commitment, openness, leadership, respect/trust, and community design and ownership.

The stages for the transfer of identified models to other communities are:

- learning about or observing the model in its original context;
- reflecting on the components that make the model viable;
- attempting to adapt the model to the new context; and,
- fine-tuning the model to the conditions of the new context.

Some mechanisms for the diffusion of effective models include:

- translating research and evaluation results into a format easily understood by non-specialists;
- forging local, national, and international linkages (networking);
- channeling emotions through creative means (e.g., the Names Project, theatrical expression, art exhibitions, music);
- appealing to the spiritual and ethical values of a community; and,
- tapping existing channels of communication (the media, the grapevine).

Successful transfer, expansion, and sustainability of a given model depend upon the model's attractiveness to three key constituencies: 1) those who will implement it (providers, community leaders, PWAs); 2) those who will benefit from it (PWAs, families, communities); 3) those who will pay for it (government, donors, communities, PWAs, society at large).

4. Recommendations

Health care providers should be trained to provide appropriate care to people who are affected by HIV as well as appropriate HIV prevention services to everyone in the community.

- Health care providers should be educated so that they can provide their HIV-positive patients with a full range of alternatives for treatment. Education should teach the importance of a human approach to care, not just the technical provision of treatments and services.
- Protocols for HIV/AIDS care should be developed and disseminated to primary health care providers. These protocols should also be readily available to people living with HIV/AIDS and their families.
- The protocols should be comprehensive. They should cover not only medical treatment but mechanisms to promote health behaviors such as proper nutrition and alternative therapies.
- Training of health educators and health promoters should include HIV/AIDS counseling.

- Providers of HIV/AIDS prevention and care services should be taught to respect cultural values, traditions and beliefs, even at the expense of having less impact, especially in communities where disclosure creates fear and isolation.

People living with and affected by HIV should be involved in all aspects of HIV prevention education.

- People living with HIV/AIDS can have an important role to play as counselors and health prevention communicators in a community. However, in order for this to happen, the community must support people living with HIV/AIDS to take on the responsibility.
- AIDS in the workplace educational programs should target employees and employers alike so that people living with HIV/AIDS can continue working.
- Popular sports figures and artists who are living with HIV/AIDS can effectively communicate HIV messages (also leaders/business people respected by the community).

People living with HIV should be involved in all aspects of their care.

- Primary health care services should be trained to achieve a *partnership in care*, with providers, patients, and their families.
- Donors should conduct needs assessments as perceived by care recipients and care providers *before* designing projects.
- Policy dialogue could explore options such as government policies and tax breaks to support families who are providing home-based care to family members with HIV/AIDS.
- Policy dialogue could support micro enterprise for village banking/credit scheme models to provide loans and savings schemes to groups of people living with HIV (small businesses, etc.).

Community capacity should be strengthened to enable HIV prevention and care services to become self-supporting and sustainable.

- Because the burden of care often occurs at the community level, there is a need to develop the capacity of communities: by training more people to provide prevention and care; and, by training community-based organizations in management and fund raising.

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- Partnerships should be formed between communities and funding agencies to prioritize needs and services. This will ensure a sense of ownership at the community level, which will then contribute to program/project sustainability.
- South-to-South collaboration should be promoted, through: development and support of centers of excellence in developing countries/regions; strategic dissemination of evaluation results; and, support of study tours/workshops at the regional level.

B. ROUNDTABLE 2:

Behavior Change Communication Strategies: Finding the Right Models for Specific Audiences and Settings

1. Introduction

Since early in the AIDS epidemic, communication has been central to HIV-related health promotion efforts. Initially it was thought that once people were provided with the facts about HIV, substantial behavior change to reduce sexual- and injection-related risks would follow.

In the past 12 years, we have learned a great deal about effective interventions to promote HIV-related risk reduction, and about which interventions are most appropriate for use with various communities. There is growing recognition that communication programs are but one component in any comprehensive HIV prevention strategy. Usually, the elements of communication strategies should be integrated with other program elements, including services, policy making and structural factors. Realistic, usually scaled-down, objectives must be established when communication strategies are implemented in isolation.

A broader debate relates to how best to link HIV/AIDS risk reduction messages with the often conflicting messages of other health programs, such as STD, MCH, tuberculosis control, and reproductive health, as well as to both formal and informal, institutional, and local structures of leadership and authority.

A realistic appreciation of what communication strategies can achieve acknowledges the fact that communication always occurs within a specific context. It is unreasonable to expect that communication alone can bring about far-reaching social change. When this is taken into account, it is possible to redefine the criteria for success of communication interventions. Ongoing monitoring and evaluation of communication interventions must focus on intermediate and process indicators as well as outcome variables such as behavior change.

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There are no definitive practice guidelines regarding implementation of communication strategies to effect behavior change. Each community is different, requiring communication strategies to vary from situation-to-situation. However, seven principles have been identified that are consistently present within each situation. These principles, combined with our knowledge of effective interventions, will set the stage for developing more concrete guidelines for HIV/AIDS communication strategies. In addition, there are several considerations that are critical to build into communication strategies for behavior change:

- The approach must stress reduction of risk, rather than complete, immediate change of risky behavior; reduction of harm rather than total elimination of risky behavior.
- The approach must address not only an individual's behavior, but also the larger context of the cultural norms of that individual's society.
- All relevant communities must be involved in the design, implementation, and evaluation of communication programs.
- Communication interventions must focus on behaviors rather than on groups of people.

2. Targeting Gatekeepers and Opinion Leaders About HIV-Related Prevention and Care

Gatekeepers and opinion leaders must be targeted for the success of any HIV prevention strategy, as they have a critical role to play in community mobilization. Ensuring that their influence is tapped and used wisely involves three fundamental factors: 1) use of multiple levels of gatekeepers; 2) use of culturally appropriate language; and, 3) implementation of appropriate research.

a. Multiple Levels of Gatekeepers

Multiple levels of influential gatekeepers and opinion leaders should be identified and utilized. These may be church leaders, chief executive officers, politicians, health workers, media personalities, or teachers within the community, all of whom may have status and some degree of persuasiveness in that community. Whatever the case may be, the challenge is to identify the appropriate levels of leadership for the selected intervention.

There is strong evidence that intervention efforts will fail without the political will to act and the concomitant mobilization of community resources for prevention. The leaders, who are also potential funders for programs, require education regarding the concept of community-

organized interventions, the need for continual evaluation, and the need for bottom-up community participation.

To the extent that business leaders are considered to be community leaders, or at least opinion leaders and gatekeepers, public health professionals must adopt their language in order to communicate with them about AIDS prevention and care.

b. Culturally Appropriate Language

Communication should utilize culturally appropriate language with which the people are familiar and comfortable (e.g., program content that may not be appropriate under the title "Family Life Education" in one community may be accepted in the same community under the title "wellness program"—the exact opposite may be true in another community). Often, an ongoing debate within the community can be used to publicize or simply discuss certain views.

c. Research

One step in the development of behavior change strategies is to understand the community by becoming familiar with the demographic, economic, political, and cultural environments that influence and constrain the gatekeepers and their constituents. Identifying the factors that influence the leaders in that community may take into consideration issues such as political events, ambition, social pressures, and money. The data collected can be used to carefully plan how to encourage, enlist and visibly promote the gatekeepers' positive views.

Research must be: 1) the basis upon which to build communication strategies; and 2) the tool to reality check throughout the process of design, implementation, monitoring, and evaluation.

3. Involvement of Communities in the Design, Implementation, and Evaluation of Risk Reduction Communication Programs

Communities must be involved in the design, implementation, and evaluation of all communication programs. The importance of this principle cannot be underestimated.

Formative and baseline inquiry to provide insight into community needs is essential for the design of relevant and sustainable interventions. Such an approach requires the early involvement of intended beneficiaries and is likely to ensure that interventions will be acceptable and appropriate to their social context. This in turn increases the likelihood of achieving successful program outcomes. By the same token, it is essential that participants have input into pretesting communication materials in order to achieve a good product.

In order to involve people in risk reduction communication programs, the community and its constituents must be identified. A community may be defined as the people who live in a specific geographic area, an age-defined cohort, or a group of individuals who share a common occupation or interest, such as injecting drug users or commercial sex workers (CSWs). In that respect, attention must be paid to adolescents and young adults, who often comprise the majority of the target population within a community. A special effort must be made to involve them and identify with them their needs and problems as well as the solutions they think will make a difference. The value of peer education should not be overlooked.

Once the community has been identified, it is important to define the sub-communities or sub-populations of individuals who may simultaneously have many social identities, and who may or may not identify as part of the larger community. For example, in the case of a community of men who have sex with other men, most may identify themselves as gay men, but there may be some who do not. Among women who exchange sex for money, there may be some who do not define themselves as commercial sex workers. The challenge for communication specialists is to pick communication strategies at a level that accommodates the complexity of human nature.

Incentives may need to be provided as a way of attracting individuals to participate in the design, implementation and evaluation of communication programs.

The more channels of communication that are utilized, the better the chance of effectively reaching target audiences. Existing local and traditional networks can be used extensively to introduce and reinforce messages. The mutual reinforcement of using both interpersonal and multimedia communication strategies is effective and should be encouraged and expanded.

4. Ensuring the Full and Active Participation of People Living with HIV/AIDS in the Design, Implementation, and Evaluation of Risk Reduction Programs

Including people living with HIV/AIDS fully and actively in the design, implementation, and evaluation of risk reduction programs is of paramount importance in ensuring the appropriateness and success of those programs. While people living with HIV/AIDS are frequently invited to be educators for primary prevention purposes, they are less frequently included from the beginning in the development of HIV risk reduction programming.

There have been varying degrees of success with involvement of people living with HIV/AIDS in programming. A number of barriers impede the objective of ensuring that a project is developed and designed with the inclusion of people living with HIV/AIDS.

Experience thus far indicates the following:

- Program implementors often utilize people living with HIV/AIDS in educational capacities without actually involving them in design or consulting them about their perspectives or issues.
- People living with HIV/AIDS may prefer to focus their sometimes limited energy primarily on care rather than on prevention.
- A specific person living with HIV/AIDS may not have the programmatic communication skills that are important for AIDS prevention programs.
- Program implementors may fear that the inclusion of people living with HIV/AIDS will create a negative reaction from their community members and have a negative impact on their program's success.
- Physicians may be resistant to having their patients involved in the design, implementation, and evaluation of programs perceived to belong to the medical community.

The cultural context of the country or community in which people reside must be considered when involving people living with HIV/AIDS in programming. People living with HIV/AIDS may be part of societies in which a great deal of stigmatization and discrimination occur, causing people living with HIV to be unwilling to disclose their serostatus in the community. For this reason, confidentiality continues to be vitally important. Most societies still have many barriers to involving people living with HIV/AIDS in programming, including lack of legal protection and negative community values.

In order to encourage the full and active participation of people living with HIV/AIDS, program planners should understand the following:

- People living with HIV may need social, moral, and financial support.
- Programs that offer incentives are more likely to ensure the active participation of people living with HIV/AIDS.
- Family understanding and support are crucial for giving people living with HIV/AIDS the confidence to be publicly involved in AIDS communication activities.
- People who would like to contribute often require training in communication and teaching skills.

- It may be easier to involve people who have a group identity, such as gay men or HIV positive women.

Many difficulties in involving people living with HIV/AIDS can be attributed to the fact that stigmatization continues to pose a danger to them. The challenge is reaching vulnerable groups without stigmatizing them. Factors contributing to persistent stigmatization include:

- health care workers not disclosing the HIV status to the individual and the family;
- communication messages that imply that "bad behavior" causes HIV transmission (messages such as: Don't go to prostitutes; children are innocent victims);
- denial by governments of the existence of HIV/AIDS in their countries; and,
- the belief that people living with HIV/AIDS chose to engage in the behaviors by which they became infected, and thus it is their "fault."

5. Development of Communication Programs to Bring About Changes in Broad-Based Community Norms and Values

Ultimately, in order to be successful, a prevention program must be consistent with the community's value system. Instead, communication specialists often find themselves doing the following:

- imposing their own values on the community;
- asking communities to define their own needs when they may not be aware of what those needs are;
- utilizing behavior and communication theories that are not applicable to other communities;
- making assumptions about what the community wants;
- supporting what exists, rather than supporting the change inherent in risk reduction; and,
- deciding that risk reduction messages shortchange the prevention message.

Defining the correct approach to helping people to change risky behaviors is a challenge, particularly because behaviors are deeply rooted in cultural traditions. The communication expert must fulfill multiple roles. The primary role is a *facilitator* of change, rather than as a *creator* of change. The expert should adhere to several principles:

- provision of clear messages that are appropriate to each different community;
- willingness to be honest about not having all the answers;
- working from a healthy sexuality model;
- knowing the target community;
- being persistent;
- continually assessing whether messages are being received accurately;
- addressing his or her own perceptions and issues before talking about risk reduction to others.

6. Using Communication to Substitute Safer Sexual and Drug-Related Behaviors for Risky Behavior

Suggesting that people substitute safer behaviors for those that are risky is more effective than suggesting that they eliminate all risky behaviors. Behavior change generally occurs in gradual phases rather than in a single instance.

Knowledge alone is not sufficient to ensure or sustain substantial risk reduction. For knowledge to be translated into practice, environmental and structural conditions must be supportive and favorable. This can be achieved by modifying economic, legal, regulatory and environmental factors so as to enable individuals to adopt and maintain safer behaviors.

Specific strategies to emphasize safer behavior vary by culture, values and communities. Whatever the case may be, interventions need to both persuade and enable individuals to adopt and maintain safer behaviors. This principle is grounded in theory as well as in practice and experience from around the world.

7. Building and Sustaining Capacity and In-Country Ownership of Risk Reduction Communication Programs

Investment on the part of the country or community will ensure that programs can continue indefinitely. Steps in building and sustaining capacity and in-country ownership include:

- acknowledging the different types of groups that exist within a country (NGOs, local/district/federal government, experts, and groups of HIV-infected people);
- respecting the needs and perspectives of the local people and involving them wherever possible;
- orienting funders and institutions to the program and educating them to the realities of the situation;
- understanding multi-sectoral linkages and levels of networks and gatekeepers;
- coordinating between relevant partners to avoid duplication and cross-over;
- building partnerships, linkages, networks and coalitions among different groups, decision makers and local and technical experts;
- being sensitive to the culture and the language, and understanding and validating community values.

8. Achieving Linkages Between Programs (e.g., HIV/AIDS and STDS, Family Planning, Tuberculosis)

In the absence of appropriate resources and services, even the most persuasive communication strategies are likely to fail. For example, efforts to promote safer sex or STD care-seeking behavior in circumstances in which condoms are unavailable or where STD services are inaccessible, will not achieve their goals.

HIV/AIDS services should be linked into the larger framework of health services. It is the quality of reproductive health services, not just HIV/AIDS services, that must be improved. Strong leadership must create a vision of how the issues can be addressed through linkage. Resources and services must be available and dependable. Joint planning must occur among linked organizations, services, and the population, and the development of services must be driven by the needs of the population. For example, clients may demand availability of condoms within STD control units.

The challenge for communication specialists is to understand the strengths and limitations of other sectors on the one hand, and to guide them in appreciating the realities and complexities of AIDS on the other hand. The objective is for other sectors to incorporate "international best practices" in AIDS prevention into their own operations. By the same token, creating a supportive framework and a mechanism for linkage among donors, ministries, and NGOs will reduce duplication and increase quality and access to services.

**C. ROUNDTABLE 3:
Community Participation and Sustainability**

1. Introduction

a. Definition

Participation of beneficiary communities in HIV/AIDS includes their involvement in the conceptualization, design, implementation, and evaluation of HIV/AIDS policies and programs. It involves community participation at every step and at every level of decision making: local, national, and global.

The participation of communities needs to be viewed not only as a strategy but also as a goal of HIV/AIDS programs. As a strategy, it ensures that community needs and interests define and shape HIV/AIDS programs and policies. As a goal, community participation seeks to democratize decision making which will help promote and strengthen the role of civil society (community empowerment).

Whether as a strategy or goal, community participation requires the allocation of resources (including time) to enable communities to fully participate in the elaboration and implementation of policies and programs.

Communities comprise more than "grass roots organizations." Communities exist at all levels. They are complex entities with evolving leadership, institutional dynamics, purposes, and approaches to problem-solving. In defining communities, it is important to rely on self-identification, not external, predetermined identification by others.

The concept of "community participation" can be seen as one of a series of phases in community work. "Participation" implies that there is an organization (e.g., a donor) with which a community is working. Community *ownership* is the final phase, when the community would have accepted full responsibility for the program rather than being a partner in its implementation. At this point, the program has the greatest chance of achieving full sustainability.

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The increasing pressures on public resources, both in developing and developed economies, require communities to assume greater responsibility for social programs. However, community participation should not be the result of an abrogation of the legitimate responsibility by other appropriate entities, nor should resource scarcity be the primary impetus for seeking community participation. Rather, it should be as an important expansion of the response to HIV/AIDS.

b. Rationale for Community Participation

Although community participation is widely acknowledged as a valid principle, its concrete value and vital role in addressing HIV/AIDS is not adequately appreciated or understood. Key arguments supporting community participation include:

- Experience demonstrates that all partners, government, communities, and the private sector, must work cooperatively and in partnership to increase the chances of success for interventions.
- Better problem definition and analysis result from involving communities from the onset.
- Participation enables affected communities to have an increased awareness and ownership of the issues, and a base from which to build a common agenda and approach toward the more difficult stages of design, implementation, and evaluation.
- The involvement of communities in the process increases their capacity for community action.
- Many governments and their agencies are ill equipped to work with the HIV-affected communities. Irrespective of their level of economic development, governments are constrained from working effectively with communities by virtue of their bureaucratic structure and governing role. Governments need an intermediary to be able to effectively interface with communities, especially those already marginal to government and bureaucratic processes.
- Community participation helps to democratize decision making, building capacity of communities to deal with other issues affecting the community and ensuring community mobilization regarding social vulnerabilities that impact on HIV/AIDS.
- Lessons from AIDS program organizing can be transferred to other development areas.

c. Community Participation as a Goal

Community participation is not simply a strategy of HIV/AIDS programming; it is an essential goal. Communities are strengthened in the process of their organizing and mobilization, and better able to address long standing social vulnerabilities. Only when community participation is a goal can sustainability be achieved.

Having community participation as a goal provides an appropriate emphasis on capacity building and organizational development, which assists the community in setting priorities and addressing other important issues.

In order for community participation to be realized through HIV/AIDS programming, certain key components must be addressed:

- Individuals representing diverse communities must be motivated to accept HIV/AIDS as a community issue and these communities must be mobilized to take action.
- The skills, resources, and capacity of community organizations must be strengthened and supported so that they can participate as full partners.
- An environment that enables and encourages participation must be established.

d. Community Participation as a Strategy

Community participation is a process by which groups of individuals identify and perceive HIV/AIDS as both an immediate- and long-term threat to their communities, and subsequently become agents of change in response to this perceived threat.

In order for a partnership approach in HIV/AIDS programming to be successful, it is essential that communities, through their organizations, participate in every step of programming:

- Conceptualization: defining the causes and consequences of HIV/AIDS, and defining the priorities for action in the community;
- Design of interventions: defining the roles and responsibilities; determining the methodologies, strategies, and approaches to be used; determining funding requirements and time frames;
- Implementation: the mobilization of key actors to carry out the agreed upon work;

- **Evaluation:** defining the measures of success; conducting the assessment, analyzing the results and sharing them with all members of the community; and elaborating the next steps.

Community ownership, collaboration, and partnership are important for effective programming at each phase of the programming cycle.

2. Issues Related to Achieving Community Participation

a. The Importance of Considering Context

There is no blueprint for creating full community participation since it depends upon factors such as history, culture, and political environment. Furthermore, the nature and starting point of the participation will vary according to the capacity and capability of the communities involved. Although these factors may create obstacles, they may also present opportunities for a dynamic and creative approach to the process of community participation. Imported methodologies or theories for community development cannot work in every society/culture.

It is important to consider the history of social movements in a community, and whether they have succeeded or failed, since there may be resistance or hesitance on the part of a community without successful experiences in community participation in their past. Communities will (and do) act in the absence of, and sometimes in spite of, external assistance.

Communities are not monolithic entities but represent often fragile, changing coalitions of interested individuals which can easily lose their linkages to community bases as a result of rapid growth, or alternatively, loss of funding. They suffer from a lack of information about the experiences of other community programs, and sometimes face internal competing political agendas.

b. Intermediaries

Donors often do not deal directly with NGOs but rather they relate to them through intermediaries (groups that receive funding from donors to work with community groups).

Intermediaries are necessary from the donor's perspective in that they provide technical and management support which the donor could not otherwise provide. They are necessary from the NGO's perspective in that they provide a buffer to interpret the requirements of the donor organization. The role of intermediaries should be as collaborative and transparent as possible to reduce the possibility of misunderstanding.

c. Identifying and Strengthening Community Capacity

In the conceptualization/design phases of project development, special emphasis should be placed on identifying the existing mobilization and coping mechanisms of communities in order to build on indigenous current strengths.

Methods to mobilize communities can include providing training in needs assessment and in participatory research methods, and providing opportunities for communities to articulate their needs.

Increasing the number of NGOs in AIDS work does not necessarily translate into *better* work by NGOs. The skills of existing AIDS-related organizations must be developed in addition to encouraging more NGOs to participate in AIDS work.

The inherent imbalance of power between NGOs and donors makes it critical for efforts to be undertaken to strengthen the capacity of NGOs to deal with donors.

There is a need to differentiate between reaction and response in order to promote real *response* from the community, not simply a reaction to outside ideas.

d. Strategies for Low Prevalence Countries

The "readiness" of the community to examine HIV/AIDS as a community priority differs by level of prevalence, which translates into the degree to which AIDS is visible within the community. Strategies for promoting community participation in the conceptualization phase for low prevalence countries are particularly important given the lag time between infection and appearance of symptoms of illness. Mobilization strategies include:

- building sensitization programs into existing primary health care and community education programs, based on data from the community;
- sensitizing local government officials and religious leaders to assume leadership in development of HIV/AIDS programming;
- staging community events such as dramas, which allow culturally appropriate treatment of otherwise taboo/sensitive subjects.

e. Sustainability

Sustainability is often conceptualized in its narrow form as financial and programmatic self-sufficiency. In this context, as donor funding ends, communities are expected to find their own or other resources for continuing program activities.

However, sustainability should be defined in broader terms, as sustaining community action on HIV/AIDS issues. This definition goes beyond the financial level to incorporate issues such as community and organizational development, establishing linkages to other community participation experiences, and building national and international networks.

f. Difficulties of Community Participation

Potential hazards of growth for community-based organizations include the loss of linkages to community bases and the sometimes overwhelming burden of responding to bureaucratic requirements.

Programs tend to disseminate success stories, but to not talk about failures, which can lead to the duplication of unsuccessful programs.

Other difficulties that arise in promoting community participation are competing political agendas among community members and lack of experience in community organizing. Common dynamics among community members are either to resist taking on more responsibility or to refuse to share responsibility.

Some of the organizational difficulties CBOs and NGOs face as they develop include conflicting agendas, and competition among organizations for scarce donor funds, leading to divisiveness rather than coalition-building.

g. Participation of People Living with HIV/AIDS

There is value in asking people living with HIV, who are members of the community, to speak openly about their serostatus, as "every community has its own experts on this subject." However, the potential for stigmatization and infraction of human rights often makes it difficult for HIV positive individuals to comfortably "reveal their expertise."

3. Relationship of CBOs, NGOs, Intermediaries, and Donors

There are inherent power imbalances and unavoidably different perspectives in the relationship of CBOs, intermediaries, and donors. Nonetheless, through conscious effort, these organizations can minimize their differences and strengthen the possibility for achieving

mutually-shared goals. The core features of the relationship between NGOs, intermediaries, and donors which can promote success should include:

- Flexibility: Donors should develop guidelines, not prescriptions that are unchangeable; requirements must be not only understandable but useable at the community level.
- Dynamism: Ongoing consultations are needed to ensure accurate articulation of mutual and evolving roles and responsibilities of all parties.
- Transparency: There must be opportunities and space for constructive critical feedback from CBOs to donors; e.g., monthly meetings or biannual in-country workshops for assessing processes and progress openly and carefully.
- Mutual Learning: Donors need to be sensitized to the needs of communities through constant exposure to these groups.
- Creativity: Creativity is crucial, especially in articulating to constituencies the value that community participation adds to programming.
- Time-Intensity: Community participation requires attention to the pace at which communities work; full implementation requires time.
- Pragmatism: There must be an acknowledgment that communities have their cleavages, politics, and problems and that these need to be addressed if the project is to eventually be sustained.

D. ROUNDTABLE 4:

Protecting and Strengthening Human Rights: Facilitating a Participatory Process

1. Introduction

This paper provides a summary of the purpose, process and outcome of the Roundtable/Working Group (RT/WG) on human rights.

The original focus of the RT/WG was on ethical issues in clinical practice. However, the participants in the pre-conference workshop were uncomfortable with this focus on clinical practice. Through the pre-conference workshop process, the focus of this RT/WG was expanded to address the protection of human rights within HIV/AIDS programs, and simultaneously narrowed to focus specifically on developing an understanding of the necessary process. The desired outcome was a tool which could assist a broad range of individuals and organizations to protect and promote human rights within the context of HIV/AIDS prevention and care.

2. Definition of Human Rights

The starting point was the development of a common understanding and use of the terms *human rights* and *ethics*.

It is important to consider human rights in relation to HIV/AIDS prevention and care, and the process by which policies and programs that respect human rights can be developed, implemented, and sustained.

Human rights are internationally recognized principles that are set out in the Universal Declaration and international human rights treaties. While the specific application of these

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principles may vary across countries and cultures, human rights are universal and indivisible, as was affirmed at the Vienna World Conference on Human Rights (December 10, 1948). They place firm obligations on the State to protect and ensure quality of life for people within its domain.

3. Linkages between Human Rights and HIV/AIDS

From the definition of terms, the group moved to define the linkages between human rights and HIV/AIDS by identifying circumstances in which the absence of human rights and ethical thinking can jeopardize the well-being of people living with HIV or AIDS, or thwart otherwise effective prevention strategies. The group accepted the notion that respect for human rights is a necessary precondition for optimal and sustainable HIV/AIDS prevention and care. From here, linkages were identified and illustrated by sample scenarios.

Three key areas of human rights directly affect the implementation of policies and programs supporting the control of the HIV/AIDS epidemic.

a. Freedom of Speech and Association

Open expression, communication, and community participation are necessary for successful HIV policies, strategies, and programs.

The development of a strong community-based response to HIV/AIDS is essential for effective HIV prevention and care. In situations in which the non-governmental (civil society) sector is constrained, perhaps due to war, civil strife, or dictatorship, the potential for an effective community-based response will be diminished.

- *For example*, in societies where public meetings are prohibited, community mobilization for HIV prevention and care is severely impaired. In countries where mass media is censored, effective health communication messages cannot be achieved.

b. Self-Determination and Provision for Basic Needs

Issues of power and vulnerability must be addressed, recognizing the diversity of cultural beliefs and values, if identified risk factors for HIV are to be eliminated.

Social and economic vulnerability contribute to vulnerability to HIV infection. The human rights of marginalized and subordinated groups (such as women, indigenous peoples, and street children) must be respected if prevention programs are to succeed.

- *For example*, when children and youth are forced to exchange sex for shelter and food, they are at increased risk for HIV infection.
- *For example*, in communities in which cultural norms and power relations inhibit women from negotiating safe sex, they are at risk for HIV infection.

c. Prevention of Discrimination and Stigmatization

Discrimination and stigmatization of people living with HIV and AIDS must be removed to ensure their access to services. The respect of the rights of people living with HIV/AIDS is essential, not only for their well-being, but to enable them to fully participate in all stages of policy and program development and implementation. The involvement of people living with HIV/AIDS is necessary to assure that HIV-related programming is appropriate and effective in communities at risk.

- *For example*, people living with HIV are in danger of being denied health care services and dismissed from employment in situations in which: being HIV infected is a notifiable medical condition; confidentiality cannot be assured; and, institutions are legally able to deny services or employment on the basis of HIV status.
- *For example*, people living with HIV cannot participate in policy- and program-influencing forums in situations in which they are denied freedom of movement because of their HIV status.

4. Application of Ethical Reasoning

In considering the process of resolving the issues presented, the group developed an understanding that human rights issues are often about conflict between the perceived rights of individuals or communities at risk for, or infected with, HIV, on one hand, and the rights of other individuals or the broader community, on the other hand. One process that can be used to analyze and resolve these conflicts is appropriately applied ethical reasoning.

Human rights often are discussed using the framework provided by ethical reasoning. Ethical reasoning provides guidelines for ethical conduct by applying theory, principles, and rules to a situation. Ethical reasoning can be applied to a wide range of political or philosophical orientations. For example, a feminist orientation utilizes ethical principles in justifying women's interests in self-determination, taking into consideration women's perspectives and experiences.

Traditionally, four principles are used in the ethical review of health situations. These principles are: 1) autonomy (respect for peoples); 2) beneficence (the intervention should do

good); 3) non-maleficence (the intervention should do no harm); and, 4) justice (equality of opportunity).

Locally appropriate application of ethical theory, principles, and rules requires a process that allows a full discussion of the diversity of interests concerned. The development of a locally appropriate application may include the need to create a new common language. Ethical dilemmas are not static; therefore *interim* solutions and *iterative* debates are inherent to the process of conflict resolution.

5. The Process of Developing Sustainable Policies and Programs

The RT/WG began to identify steps and principles required to protect and strengthen human rights in the context of HIV/AIDS prevention and care. The list developed was familiar to the participants. In essence, the list comprised key components in the development and implementation of a *participatory process*.

The following are some principles essential to the protection and strengthening of human rights in the interest of HIV/AIDS prevention and care:

- Analyze, from a human rights perspective, existing barriers to successful policy and program development and implementation.
- Acknowledge and understand the basis of ethical principles that guide us at personal and organizational levels.
- Incorporate human rights components into all prevention and care activities.
- Involve individuals and communities at risk for, and affected by, HIV/AIDS in the development, implementation, and evaluation of HIV/AIDS policies and programs.
- Acknowledge and share the diversity of viewpoints and the areas of "non-formal" expertise among the stakeholders.
- Build bridges with mainstream human rights organizations (e.g., Amnesty International, Human Rights Watch, Save the Children) and movements, including women's organizations.
- Facilitate an understanding among all stakeholders of the implications of protecting human rights.

- Develop strategies and mechanisms for conflict resolution including attention to consensus-building processes.
- Share and draw upon previous experiences.
- Evaluate and revisit the barriers and catalysts to this process. Take into consideration the perspectives of people living with HIV/AIDS, the media, parliamentarians, medical institutions, government bureaucracies, political status quo, the church/religious communities, public perceptions/opinion, the private sector, non-governmental organizations, including community-based and private voluntary organizations, health care workers, military, and other law enforcement agents.

The group attempted to classify the items listed above as either principles or steps in a process and then to define the order of that process. Through this exercise, participants discovered that the approach or process of developing and implementing a participatory process begins and develops differently for different individuals and organizations. The participants were interested in exploring the basis for these differences, but were constrained by time.

6. Conclusions

The RT/WG concluded that protecting and strengthening human rights is critical to the development and implementation of sustainable HIV/AIDS programs and policies for both HIV prevention and care. The challenge is to develop and maintain a participatory process that, through ethical reasoning, can successfully resolve conflicts between individual and community rights. Therefore, it is necessary for individuals, organizations, communities and governments to develop an *ethical capacity*. This ethical capacity includes the following:

- definition of starting point;
- definition of circumstances and biases of individuals and organizations;
- development of a common framework;
- identification of stakeholders;
- facilitation of communication;
- development of strategies;
- education programs;
- accountability.

In moving toward this process, it is important to remember that the process is dynamic and is the shared responsibility of every individual and organization that is concerned. Roles will differ based upon local circumstances, but the success of this approach requires that all parties accept and fulfill their particular roles.

In this regard, the group made the following recommendations related to the roles and responsibilities of the United States Agency for International Development (USAID):

- The principle of participation of affected communities must underpin all phases of USAID activities and supported programs.
- USAID should support programs that facilitate the development of a common framework for approaching ethical dilemmas in the epidemic.
- USAID should actively seek to identify and engage all stakeholders in ongoing participation in, and dynamic review of, policies and programs.
- USAID should utilize mechanisms that ensure appropriate consideration of ethical and human rights issues during the design, implementation, and evaluation of HIV/AIDS programs.
- USAID should be accountable for protecting human rights within its HIV/AIDS activities and programs.
- USAID should support the development of mechanisms to promote human rights accountability.

The inability of individuals and organizations around the world to successfully implement participatory processes indicates that there are barriers to this process. Barriers will differ from community to community, which will require the development of a common language and process for each community. However, the principle of human rights and its critical importance to HIV/AIDS prevention and care are universal.

E. ROUNDTABLE 5: Benchmarks, Performance Indicators, and Evaluation

1. Introduction

Evaluation, the systematic assessment of the degree to which services or their components fulfill stated goals, is vital to the design and maintenance of effective interventions for HIV prevention, care, and support. It enables service providers to learn from experience and to monitor, improve, and provide stakeholders with an account of their activities; it assists planners and implementers to identify the consequences of their actions and provides an empirical foundation for decisions about how to allocate resources. Members of the RT/WG on Benchmarks, Performance Indicators and Evaluation noted a widespread increase in interest recently in evaluation activities and skills. They identified numerous areas of change and success, as well as some outstanding concerns and problems in the evaluation of HIV/STD activities, and recommended follow-on processes to address them.

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a. Types of Evaluation

Evaluation is usually divided into various types:

Formative: To assist in design and definition of the context of a program.

Process: To determine quality and nature of intervention delivery.

Outcome: To measure results or effects of the intervention.

Outcome evaluation may assess *efficacy* (whether interventions under ideal circumstances can produce the desired outcomes) and *effectiveness* (whether interventions provide results under

usual practice conditions). The demands of data collection and analysis can vary greatly by type of evaluation, from routine weekly or monthly reports of numbers and types of services and clients, to costly, dedicated cohort studies in intervention and control sites, in which special biologic and behavioral data are collected to measure and explain intervention effects. Confusion about the different goals and demands (including costs) of varied forms of evaluation was seen as a prime cause of evaluation problems at all levels of HIV/STD programming.

b. What is Working Well in HIV/AIDS Evaluation?

The very nature of HIV, its long asymptomatic latency period, modes of transmission, and the stigma often associated with the disease and behaviors linked to it, make the evaluation and implementation of HIV programs very challenging. We frequently must rely upon indirect measures of effect based on reported, rather than observed, behavior. The epidemic presents a different profile in each setting, therefore limiting the application of a single intervention or evaluation instrument in different settings. Despite these complexities, RT/WG participants noted a number of strengths and successes in HIV/STD program evaluation, including:

- Recognition of a broader array of evaluation approaches and tools: There has been an increased interest in, and use of, qualitative data, in baseline descriptions, formative research, ongoing monitoring, final evaluations of service quality, and interpretation of quantitative measures of service effects. Planners more frequently conduct formative research in the field, where they can better appreciate the conditions and constraints service providers are, or will be, facing.

RT/WG participants endorsed diverse data collection approaches, such as small group discussions and focus group exercises, periodic structured surveys at the service site, and on-site use of mathematical models to illustrate and project the effects of service statistics. The selection of methods depends on the evaluation purpose, and on the nature of the service or project itself.

Linking evaluation methods to an explicit theoretical model of the program's effects was a promising success story reported by some RT/WG participants. It was agreed, however, that no single tool was sufficient for all purposes, whereas *triangulation* of data from several, complementary methods permits service providers and other stakeholders to capture the range of information required.

- Increased participation in evaluation: This theme resounded throughout the RT/WG in several forms. First, participants stressed that including project staff and managers in evaluation processes increases the absorption of lessons learned, and increases staff commitment to the process and faith in its results and recommendations. Participatory evaluation is itself a mechanism for promoting rapid feedback of results

to the people involved, which was stressed as an important feature of useful evaluations. This was often mentioned as a benefit of *internal* evaluations, in which service or project members systematically review and assess their own work. But it should be noted that *external evaluations* can also use a participatory design. In either case, it is not just funders and staff who need to be included, but also service recipients and the communities served. RT/WG members stressed the success of community participation in creating a sense of ownership and in strengthening service relevance and quality.

- **Capacity building:** Closely linked to the benefits of increased participation in evaluation was the benefit of training project staff, community, and especially mid-level project managers, in evaluation skills. RT/WG participants reported various successes in building internal capacity for evaluation in private and public sector HIV/STD programs. Local evaluation personnel have a broader understanding of the context, have lower travel costs, and often have more enduring commitment to the project and accountability for the evaluation's consequences.
- **Creative uses of failure:** While evaluation is routinely associated with *lessons learned*, RT/WG participants stressed that it is not only successes that can improve HIV/STD services. The idea that projects can learn from *failures* and make good use of unintended directions or events in a project's history, was a promising approach to countering the common image that errors in project strategy or implementation are invariably *bad*.
- **Increased dialogue with donors:** More consultation between donors and project participants, early in the process and on an ongoing basis, helps improve cooperation for project success. Donor flexibility and willingness to review and discuss evaluation constraints with the project staff have led to more realistic and useful evaluations. Coordination through consultation helps avoid overlap and wasted time and effort. (The image of "the Germans are leaving today and the Swiss (evaluators) arrive tomorrow," clearly struck a cord with the group.) RT/WG participants agreed that evaluation plans should be *negotiated with* donors, so that the purposes of the project itself can be achieved.

2. Current Measures of Performance and Success

Since by definition program evaluation involves the *systematic* assessment of performance and achievements, yardsticks for measuring performance must be explicit. While criteria of good performance are not always explicit, they are usually operationalized in a set of *indicators*—markers or measures of project performance. Indicators are often thought of as continuous variables (e.g., proportions; scores from -10 to +10, or tallies, such as number of attenders).

They can also be operationalized as a sequence of critical achievements or milestones, or as items that are true/false, present/absent.

Good indicators are phrased to define results in terms of three dimensions: 1) quality; 2) quantity; and, 3) a time frame. Measures of quantity should make the denominator explicit, and the quality dimension should be translated into concrete terms that can be recorded reliably. For example, an indicator for a "safer sex negotiation skills training workshop for women at a family planning clinic" might be: quarterly percent of women served at the clinic who report having spoken with their spouse about STDs in the previous three months. The measure of success might be the ratio of successes among respondents, who did receive the training, divided by the number of successes among respondents who did not receive the training. While the result may not reflect all the subtle skills and changes that the workshop sought to convey, it has the advantage of being a *reliable* measure that is meaningful *per se* and applicable across a wide variety of cultural and socioeconomic settings.

Indicators and milestones should operationalize project goals. Wherever possible, they also should be understandable to people outside the project, and comparable with measures from other projects with similar objectives and activities. This facilitates valid comparisons across projects that enable us to learn from one another. Indicators of program or project performance should be identified during the design of the project so that the systems for data collection, analysis, and reporting are built in from the start. RT/WG participants noted that this confronts projects with the dilemma of whether to spend the time required to develop and test indicators *from the ground up*; to select and apply indicators and measures that have been developed and tested by others; or, to attempt some combination of these strategies.

To promote comparability among programs and to save time and resources, there are several current sets of indicators in use or under development for evaluating HIV/STD projects and programs. These include:

- Core Prevention Indicators (PIs). The World Health Organization Global Programme on AIDS (GPA) PIs were specifically developed for national/regional-level users. They are focused on the long-term view and are focused on national populations.
- Care and Support Indicators (CSIs). The new GPA CSIs attempt to address some crucial features of health systems and the social environment relevant to HIV/AIDS care and support that were not included in the original set of PIs.
- Reproductive Health Evaluation Project (EP) Manuals. The USAID Office of Population Evaluation Project has drafted a series of manuals for programs in the area of reproductive health, including one for HIV/STD programs. Unlike the WHO/GPA PIs, the EP manuals are intended to offer indicators suitable for users at the project

level. They include measures of program inputs (resources invested); process (activities or services provided); outputs (results at the program level); and outcomes (effects and impacts at the population level). No single project would use all the indicators (75 are under consideration!). Rather, program developers can review the list and select indicators appropriate to their planned goals and activities. The EP indicators are now undergoing technical review and comment, and will be available for field testing in the near future.

- USAID Bureau and Mission Strategic Objectives Indicators. As part of the agency-wide reengineering process, USAID is implementing strategic planning at the agency, bureau, and mission levels. USAID operating units at each of these levels have a framework of strategic objectives and strategies that will achieve those objectives. Development of performance indicators to show progress and success toward the objectives is an integral part of the planning process.

RT/WG members noted the cost advantages of *prepackaged* indicators, but also noted problems with adopting and using measures that were derived outside the context of particular projects. Available sets of indicators may not adequately capture or reflect all of a project's important outcomes, or issues relating to program accessibility, quality, and other process-level, programmatic concerns. None of the available sets replace the need for individual project-level planning, to define the measurable objectives of the project, and to define the necessary and sufficient set of indicators required to see if, when, and how well those objectives are being met. As noted below, the RT/WG made several suggestions as to how to resolve the inevitable tradeoffs between completeness, local appropriateness, and cost of development of these essential evaluation tools.

3. Concerns and Issues in HIV/STD Evaluation

a. Costs Involved in Evaluation

A primary concern that arises persistently is the cost of evaluation in terms of money and other resources, including staff time.

- Programs often set targets that cannot be achieved with the available resources in the available time.
- Duration of funding is often too short to enable evaluators to determine program impact.
- Collecting evaluation data costs time and money—often more than people expect.

b. Diverse Purposes and Needs Among Users of Evaluation

Individuals and organizations at many different levels are consumers of evaluation data. These levels can range from: the communities that require and rely on effective interventions; to grassroots agencies providing a service; to district and national bodies that are responsible for projecting service needs, effects, and costs; to government and private agencies that provide the funding and must justify their funding actions to constituents and other stakeholders.

The interests and information needs of the various parties can vary at each level. For example, a community-level service agency will most likely find specific and detailed implementation data most useful in order to document and improve their services; a funding agency may require an accounting of the services supported by their funds, but may also seek answers about longer-term intervention effects to help determine the kinds of programs to fund in the future. Identifying and meeting these diverse needs in a timely and efficient manner is the challenge that evaluation of HIV, or any health program, continually faces.

c. Attribution of Effects to Interventions

Direct attribution of a planned result to a specific program intervention is difficult. Program interventions must be analyzed within the context of all the factors influencing individuals in the community, including other HIV prevention interventions initiated by local, regional, and national governments, and private organizations. The multiple actors involved in HIV/AIDS prevention, such as local, regional, and national governments, as well as external donors, make such attributions dubious, at best. Attempting to prove causal links is time-consuming, expensive, and methodologically fraught with difficulties.

d. Lack of Clear Linkages Across Sectors, Levels, and Technical Specialties

Often evaluation needs and results are not shared from one level to the next (i.e., national to local). This can produce duplication of effort or gaps in data collection, which can leave policy makers and program managers with incomplete or incompatible information on which to base decisions.

e. Need for Additional Types of Indicators

RT/WG participants identified a wide range of needs for additional types of indicators.

- A wider range of indicators. The most familiar and widely used performance indicators (PIs) come from WHO/GPA, and are not intended to capture all aspects of all programs.

- A means to capture unexpected outcomes. Unanticipated or adverse outcomes may emerge from a program. Currently, no indicators or guidelines exist to detect and record these outcomes in a timely manner.
- A means to measure the context. Factors beyond the level of the individual (e.g., contextual factors) greatly affect programs but are often overlooked.
- A means to measure intermediate outcomes. A need exists to be able to measure intermediate outcomes (e.g., attitude change) and to develop legitimate process indicators during program implementation, to help refine programs while underway.
- A means to measure community, behavioral and psychosocial factors. Factors such as steps in behavior change and measures of empowerment are critical to HIV prevention and care. Better ways are needed to document and/or measure them.
- A means to capture and interpret linked, interdependent outcomes. Related factors such as condom distribution and condom use must be better analyzed interdependently.
- A means to assess project structures and operational issues. In addition to evaluating the effectiveness of available technical strategies and program content, there is a need to learn about the effects of different management designs and project structures on effectiveness, cost, and sustainability. For example, current evaluation methods do not lend themselves to systematic comparison of centralized vs. decentralized management structures. In the absence of indicators or guidelines, evaluation of important structural choices, such as giving power to a community advisory board, may thus be left to anecdotal and impressionistic assessments.

f. Need for an Improved, Comprehensive Understanding of the Value and Usefulness of Evaluation

Programs need a strategic framework in order to proceed in an orderly manner. Evaluation is one component of the larger process of program design and implementation. Having to specify concrete indicators of program outcomes helps to focus on desired results and how they are to be achieved. One must ask: What outcomes are sought? What change or impact is expected from this program and how will it be achieved? How will we know when we have achieved it? When developed along these lines, the evaluation and monitoring process will not be alien to the project but integral to it.

- Evaluation is often perceived as a process of grading *how good* a project is, or *how effective* its staff is. This generates anxiety and resistance among project staff.

- Even when comprehensive evaluation plans are incorporated during the planning stage, the costs in both human and financial resources are frequently diverted to other program areas, as evaluation is often seen as less important than, for example, service delivery.
- External evaluations are usually seen as impositions inflicted upon program managers and staff, demanding their time and effort.
- Internal evaluations may be viewed with suspicion by external observers such as donors. On the other hand, evaluation may not be undertaken by in-house staff with the objectivity or seriousness that is required.
- With inappropriate indicators, programs may generate unfulfilled expectations, frustration, and even disillusionment due to lack of feedback on the impact of the work carried out.
- In turn, unfulfilled objectives can result in dissatisfied donors, imperil future funding, and potentially alienate intended beneficiaries, who have been given inflated expectations.

4. Solutions/Recommendations

a. Shift the Paradigm

Too often in the health and social sciences, evaluation is approached as an external activity imposed or inflicted from the outside, and is associated with painful, negative results. In contrast, many other professions consider basic evaluation to be a routine obligation of conducting high-quality work. A paradigm shift is needed in the health and social sciences in order to put evaluation skills and processes in their proper perspective. Evaluation is a *practical* endeavor that provides accountability, allows programs to learn from experience, and demonstrates progress to beneficiaries, donors, and other stakeholders. To achieve this shift, evaluation must be demystified (so that anyone can learn and participate) and normalized (made an essential part of high-quality work). Evaluation must not be used as a punitive process, but rather as a useful component of professional work.

b. Be Realistic and Open About the Costs and Benefits

- More realistic objectives should be set.
- More effort should be made by donors to effectively use qualitative evaluation research and to integrate qualitative and quantitative research.

- More funding and more time should be allowed for formative or qualitative assessment research at the baseline and at identified milestones. Project design should include adequate time and staff for internal monitoring.

c. Promote Participation

- Communities should have access to an in-country or regional documentation center, or access to resources through means such as a newsletter, meetings, E-mail users groups, and other modes of communication.
- Common goals and objectives should be sought and highlighted.

d. Inform and Educate All Stakeholders

To bring about the needed *paradigm shift*, the various stakeholders must be informed and convinced of their right and need to be part of the evaluation process.

- At the community level, members of a community can be taught to systematically record and tabulate conditions and events that document program activity and impact, and to use the results themselves.
- Decision-makers need to learn about different kinds and uses of evaluation, what they cost and how to perform and use them. They need to examine activity and project management structures and to learn how evaluation may be operationalized in a positive (not punitive) way.
- The implementing agencies should understand the need for evaluation, should have, or be able to, achieve the capacity to implement it, and should have the ability and process to utilize it.
- Donors need to understand the need to provide resources and guidelines. They should provide evaluation guidelines: What are the minimal reporting requirements and in what forms?
- USAID should host an ATSP project development workshop of one week's duration, with the implementing agencies as participants.
- In some cases, demystifying evaluation implies a significant change in approaching the project or service activity. Defining specific objectives and outcomes in advance is a prerequisite for evaluation, and this is an orientation that cannot be taken for granted.

- Norms of service, commitment, and sacrifice may conflict with the professional culture that routinely accepts self-justification, accountability, and quality control. This conflict can be overcome by showing how evaluation can help everyone make better use of precious HIV service resources.
- Finally, to sustain staff and community enthusiasm for evaluation, information on program process and outcomes must be fed back to the people who need it in a timely way. Better ways to communicate program results can be developed in the process of educating the stakeholders about evaluation.

e. Provide Guidelines for Development and Implementation of Appropriate Evaluation Indicators

Available evaluation systems, such as the GPA PIs, stress the need for contextual data and the need for projects and programs to develop their own context-specific indicators. In order to develop context-specific indicators and to collect contextual data, clear guidelines are needed and clear criteria for what should be recorded. Otherwise, it is not clear to decision makers how to interpret the additional data. The needed guidelines should clarify and promote consensus on:

- the kinds of context data required, in what units and intervals, and methods for data collection;
- constructs that are *expected* to vary across social and cultural program settings, and how to locate and use them;
- data collection and analysis methods available and what they require and cost;
- explicit instructions on how the additional data will be used and how to ensure timely delivery to users.

National-level evaluation plans are needed, developed with the participation of CA's and communities that spell out the roles and relationships contributing to the commonweal.

Guidelines need to be provided for developing and designing the following:

- performance indicators for/at the project level;
- standards, rationale, and methodology for identifying and recording essential contextual data.

f. Build Capacity and Provide Technical Support for Community-Level Project Evaluation

In order for organizations to be involved in HIV/STD prevention and care, they should:

- develop ways to institutionalize capacity for each type of evaluation at national/organizational levels;
- focus on capacity to assist communities to evaluate their own programs for internal purposes;
- work on building understanding of, and thus demand for, evaluation at the community level;
- ensure that evaluation results are provided to program staff, community and donors, quickly and in understandable and usable form;
- establish the mechanism for project staff and community to provide feedback to donors (i.e., evaluation of donors).

g. Clarify Linkages Across Levels, Time Frames, Projects, and Stakeholders

Evaluation will meet different needs and goals for various stakeholders and at each level for which there are performance indicators. New ideas and approaches are needed, however, to share insights and lessons from one level to another (e.g., national to local). An evaluation network might be one approach to consider. Donors should decrease incentives for programs to skimp on evaluation, for example, by not exerting pressure programs to be implemented too rapidly. Policy makers and donors should educate partners and the public about the purpose of evaluation (e.g., uses for management).

h. Simplify and Systematize the Evaluation Process

- Evaluation should measure only what stakeholders really need to know. The problem here is that there are many stakeholders. Therefore, costs and success must be taken into consideration for the various levels of evaluation.
- Research should be identified and conducted to simplify and strengthen evaluation. For example, STD markers are predictive of other trends.
- The donor/external evaluation processes should be streamlined and coordinated.
- Approaches should be developed to evaluate effectiveness and sustainability of project structures.

**F. ROUNDTABLE 6:
Integrating HIV/STD Prevention, Family Planning, and other Programs:
What, Where, When, How, and Why?**

1. Introduction

a. Background

Integration can be broadly defined as the combining of activities to achieve shared goals. Moving from this broad conceptual definition of integration, the working group focused their discussions on integration of HIV/STD prevention activities with family planning and other programs.

Integration can occur in various settings, such as in the policy arena, within mass media/communications, and in community outreach programs.

Integration should not be seen as a goal in itself. Rather, it is a means to a goal. Efforts to assess the indications for integration need to be situation-specific. The challenge in each situation is to determine whether, how, why, when, where, and what to integrate in order to enhance HIV/STD prevention efforts and also to enhance the objectives of the programs with which HIV/STD is to be integrated.

b. Assumptions

In order to discuss aspects of integration, the working group has made the following assumptions. While these have not been validated, they are nonetheless principles that should be considered when integrating activities and programs:

- Integration should be undertaken when it will serve the greatest good for the greatest number of people.

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Proceedings of the Roundtable Working Group Sessions

- Recognizing that men and women need different approaches, it is necessary to integrate a gender perspective into all activities and programs.
- The objectives of all programs involved, not only those of STD/HIV prevention, need to drive integration efforts.
- In order to increase effectiveness of HIV/STD prevention, the issue of sexuality needs to be addressed in multiple facets of society.
- An assessment of the community and provider staff needs should precede design and implementation of integrated programs.
- When integrating activities, one should strive for maximizing cost benefit, cost-effectiveness and quality of life.
- It is neither necessary nor possible to reach everybody for every service.
- Interventions that focus on individuals and on populations should occur simultaneously.
- Services should serve those who need them, not those who provide them.
- The design and implementation of integrated programs is enhanced by ongoing assessment of community and provider needs and resources.
- Evaluation of integration should begin by addressing quality of services and client satisfaction, proceed in the medium term to include cost benefit and cost effectiveness, and then, in the long term, to assess its relationship to quality of life

c. Pros and Cons

Decisions about what activities to integrate should be made on technical grounds, not ideologic ones. As part of this technical analysis, the potential advantages and disadvantages of integration must be considered. In many cases, a perceived advantage can conversely be seen as a disadvantage.

POTENTIAL DISADVANTAGES	POTENTIAL ADVANTAGES
Policy makers and donors prefer vertical funding mechanisms and very specific indicators of success	May achieve multiple objectives. Provides opportunities for dialogue: opposing views can be brought together
May stigmatize other programs (e.g., family planning clients may shy away from facilities where STD services are delivered)	May destigmatize sensitive interventions (e.g., people can gain HIV/STD prevention messages and services without fear of being identified as belonging to a "high risk group")
May raise cost-effectiveness concerns (e.g., start-up costs for renovating facilities, procurement of equipment and drugs, etc.)	May provide cost advantages derived from sharing facilities, staff, etc. May provide opportunities for cost sharing/cost recovery
May create provider dissatisfaction (e.g., increased workload, responsibility, and time with each patient)	May create provider satisfaction (e.g., increased skills; being better able to respond to client demands)
May dilute efforts, (e.g., increased workload, increased time with each patient, domination of curative over communication interactions)	May enhance quality/utilization/ access/ impact of all services. A positive synergy can be achieved (e.g., family planning programs would benefit by adding discussions of sexuality and accessing men, whereas HIV/STD prevention programs would gain by being better able to access women)
Supervision and accountability may be difficult	May create a more balanced view and a less fragmented approach when supervisors are trained in multiple areas
Evaluation of integrated programs may be difficult (lack of indicators and lack of focus on a specific health issue)	May bring attention to evaluation of peoples' broader problems/needs
There may be a perception that vertical programs are desired by the persons they serve	More holistic approach to client and has been repeatedly requested by clients

2. Implementing Integration

a. Definition

When considering the process of integration, there are multiple settings in which integrated activities could occur. In the discussion that follows, "settings" are defined either by the site in which they take place (interventions in facilities, communities, schools, or the workplace) or by the channels through which implementation occurs (e.g., cultural/folk/mass media, policy).

- Integration is situation-specific. What makes sense at one point in time or in one place might not make sense later. Changing disease patterns, resources, and social situations require ongoing assessment. Data and information are needed, not assumptions.
- Integration is a dynamic process that requires ongoing assessment and decision-making. Services may benefit from being integrated at one time, and then need to be shifted back to vertical programming at a later time.

b. Key Policy Needs for Integration

Certain policy dialogues are of primary importance in the process of achieving integration:

- It is important to have a national policy on integration of HIV/STD/FP and other programs in order to set priorities, organize administrative work, and allocate resources.
- There is a need for a policy to harmonize the objectives of family planning and the control of STDs/HIV. This is particularly relevant in Ministry of Health recommendations for family planning policy, which can conflict or coincide with what is recommended for HIV/STD prevention policy (e.g., dual method vs. IUDs).
- A policy on professional practices related to these services is critical for health care workers to function effectively. One example is the need in many countries for a policy that allows nurses to prescribe treatment for STDs according to national guidelines. This would increase the access of clients to care, especially if STD services were integrated into family planning services staffed by nurses.

There are specific areas in which policy development is important:

- provision for sex education and sexuality in the context of family life education;

- assured access for adolescents to integrated FP/HIV/STD services;
- assurance of gender equity (integration should assure that education and counseling services and messages are appropriate for both women and men);
- interventions to prevent and reduce injecting drug use should be integrated into appropriate settings;
- clear guidance is needed to assure privacy and confidentiality in all integrated as well as vertical programs.

Questions that could initiate a discussion of the key policy issues include:

- What are the key policy issues (at the national and programmatic levels)?
- What are possible steps for integration at the policy level?
- What support do countries and programs need to integrate activities and programs?

c. Interventions in Facilities

Integration needs to occur at multiple levels: national, regional, district, and community. At each level, assessment should include the following components:

- potential impact upon the community and its members;
- synergistic relationship of services: Will integration strengthen what exists? and, How can it best do this?;
- the burden of disease (not just the prevalence of a problem);
- potential public health impact;
- administration of the facilities;
- ability of the facilities to accommodate the proposed change in terms of space, confidentiality, and staff competencies, attitudes, workload, and training needs;
- cost and financial feasibility:
 - because there may be upfront costs that pay off over time, it is important to think in both the short and the long term—this point must be stressed with donors

- What are the opportunities for cost recovery? What can clients afford?
What are the community's desires, needs, and level of involvement?

The key questions that should be asked when integrating services in facilities include:

- What are the steps necessary to integrate STD/HIV management and screening into:
a) family planning settings; b) other health settings?
- Are men accommodated in the family planning process? Are women accommodated in HIV/STD services? If not, how can this be achieved?
- What are the steps needed to integrate primary HIV/STD prevention? Where should this service be provided?
- How are sexuality and a gender perspective best addressed in family planning and STD/HIV programs?
- How are the principles of targeting and segmentation maintained in the integrated setting?
- What support do countries/programs need in order to integrate?
- How can the advantages be capitalized on and the disadvantages be surmounted?

d. Interventions in Communities

By their very nature, community needs demand the integration of STDs/HIV and family planning. True community integration has the following characteristics:

- Community integration is a "bottom up" approach that utilizes participatory decision making about the types of interventions desired. Key questions are how to make the integrated services acceptable, and how to increase the community input into the design of programs and services.
- Ideally, the approach selected empowers the community to select the most pragmatic interventions. It is important to note that community members have been willing to pay user fees when the result would be an improvement in their reproductive health services available (e.g., Kenya's FLPS clinic).

- Community integration addresses people's needs and uses opportunities that already exist. The approach utilizes two-way feedback mechanisms including monitoring and evaluation. Examples include:
 - In an income generation project in Honduras, women took time from income-generating activities to learn about HIV, and when they held a fair to sell their wares, they also disseminated HIV/AIDS information.
 - In the Bahamas, women used a church as a meeting place for HIV and family planning question and answer sessions.
 - In one Kenya clinic offering family planning and HIV/STD services, exit interviews are conducted to assess the quality and content of the patient visit.

Adherence to the above criteria truly defines an activity as an *integrated community intervention*. Thus, a community activity is defined by the processes that occur, not by the physical location of an intervention or the home base of the provider staff person. For example, a health worker who was sent from the Ministry of Health to give an HIV/AIDS prevention lecture in a town meeting room would not necessarily be considered engaging in a community intervention.

Steps are needed to determine whether and how to integrate primary HIV prevention. Some questions communities need to consider:

- Should condoms be free or be sold?
- Can people living with HIV be utilized to teach in the community?
- What media best suit the needs of the community—pictures, role plays?
- How can men become involved? (In Honduras, drivers for the family planning program became very enthusiastic HIV educators. In Kenya, men were effectively trained as community-based distribution workers (CBDs).)

Key questions that need to be asked in considering the integration of primary HIV prevention with other primary care services include:

- How can integrated services be made acceptable to the community?
- How can community input be increased before designing services?
- How can the advantages be capitalized on and the disadvantages be surmounted?

- How can integrated programs be evaluated?
- How can principles of targeting and segmentation be maintained in the integrated setting?

e. Outstanding Concerns in Other Settings

Primary HIV prevention can be integrated into many other potentially valuable settings, including folk/mass media, schools, and workplaces. In addition to the above questions, certain key questions can be asked to guide the discussion regarding whether integration is appropriate and how integration can occur.

- Cultural/Folk/Mass Media:

How can sexuality best be addressed in prevention messages?

- Schools:

How are sexuality and a gender perspective best addressed in a school setting?

What are the steps needed to integrate primary HIV/STD prevention, and where should it be done within a school setting?

- Workplaces and Other Institutions:

What are the steps needed to integrate primary HIV/STD prevention and where should it be done in a workplace setting?

How are sexuality and a gender perspective best addressed in the workplace?

How are decisions made regarding the most cost-effective and cost-beneficial interventions?

G. ROUNDTABLE 7: HIV Counseling and Behavior Change

1. Areas of Consensus

a. Definition of Counseling

HIV counseling is the development of a relationship between a counselor and a client for the purpose of: 1) assessing the risk of HIV infection; 2) developing a plan to reduce risk, or to seek care and support; and, 3) coping with psychological (emotional) and interpersonal reactions to HIV-related issues.

The lines between counseling and health education are sometimes unclear. For example, community counseling is the term used by some experts for the discussion of HIV issues within a community, with the goal of making the community aware of the problems and of addressing the problems.

b. Working Premises

- HIV counseling is useful for prevention as well as for care and support of affected individuals and families.
- Counseling can be provided to both the infected and the affected.
- Counseling and testing is a subset of HIV counseling, and counseling is an essential component of testing.
- There is some consensus that HIV antibody testing is a more effective agent of behavior change when it is conducted in conjunction with counseling.
- However, there is still controversy about the effectiveness of HIV counseling, how best to deliver the service, and its role within particular HIV/AIDS control programs.

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2. Designing and Implementing Effective HIV Counseling Interventions

a. Selecting Interventions

In choosing counseling methods, it is important to consider a number of factors that impact on the design of interventions:

- the goal of the intervention (e.g., behavior change, change in behavioral intentions, care and support);
- the actual counseling techniques used (e.g., discussion, education, skill-building);
- who participates in the intervention (e.g., individual, groups, couples, families?); and,
- who conducts the intervention (e.g., peers versus professionals).

Determining the best modality for providing counseling depends on the definition of counseling, the target group, the demand for services, available resources, and other factors such as the rate of seroprevalence in the community.

b. Considering Context

Counseling should be modified according to the structural limitations posed by the environment in which it is being provided, including the community and the program in which the intervention is to be implemented. The context shapes the nature of the service that can be provided as well as the effect that counseling can have on the individual. It is unreasonable to expect clients to change behavior without addressing the limitations they may face. For example, it would be inappropriate to counsel people to use condoms in a setting in which condoms are not available or are not acceptable.

Programs planners and counselors alike need to take into account existing structural limitations. Programmatic recommendations, as well as options presented to clients, should recognize limitations presented by the environment. These include social discrimination based on HIV status, gender inequality, access to appropriate information, and the availability of materials (condoms/syringes, testing), and services (trained counselors).

c. The Role of HIV Counseling

Counseling involves the development of a trusting relationship between the provider and the client to enable the client to disclose personal issues and problems. Through the process of

counseling, an individual develops insight about his or her own situation, and then can begin to make decisions about changing that situation. Insight should enable him\her to recognize and put into perspective his\her reality—to feel like a protagonist of his\her own destiny. This contributes to a person's self esteem and sense of empowerment, which in turn will lead to making choices that are healthy and protective.

Counseling services should not be used to encourage affected/infected people to become advocates or to disclose their serostatus. This is a natural process that will happen as people are given adequate care and support and as their personal need requires.

It is not possible to develop one model of counseling. There is a need for multiple types of counseling that vary by population and context and respond to resources, cultural context, and so on. Service providers need to develop their goals, remain flexible, and do the best they can!

d. Integrating HIV Counseling Interventions

HIV counseling can be one essential part of a comprehensive program, in which counseling is integrated with other ongoing HIV prevention activities. The procedures for integration need to be carefully defined. One example is the inclusion of HIV counseling and testing activities in STD diagnosis and treatment.

If HIV counseling for prevention as well as for care and support is part of a comprehensive plan for HIV/AIDS services, the question arises, "What percentage of limited resources should be dedicated to counseling activities?" Decisions about when and whether to use counseling should *not* be completely determined by outcome measures or cost effectiveness alone.

HIV counseling may occur in several sites in a community. The counseling in these different sites needs to be coordinated. Information about the services that are offered needs to be shared, both with other sites providing counseling and with sites providing other services.

e. Targeting HIV Counseling Interventions

An important but unanswered question is whether HIV counseling interventions are more effective as well as more cost effective when they are targeted to specific individuals within a population? Targeting may be particularly relevant to counseling programs because of the relative cost and the intensive, individualized nature of the intervention.

Two issues should be considered when making the decision whether to target: 1) HIV seroprevalence and; 2) the most common mode of transmission. If HIV counseling interventions are targeted, it is necessary to define a process to decide *who* the target group should be. For example, would it be those with the greatest *need* or those expected to be most likely to *use* the

service? Would it be possible to increase the *accessibility* of the services to the groups who most need them?

3. Evaluating HIV Counseling

a. Evaluating the Effectiveness of HIV Counseling

What are the best ways to effectively and appropriately measure the impact of HIV counseling interventions? The specific procedures and content of counseling interventions are rarely described. It is difficult to determine efficacy and/or to compare across studies without this information. Researchers and program planners should explicitly describe: procedures of the intervention; the expected outcomes/goals; the actual outcomes of the program, including negative outcomes; and structural limitations, such as access to condoms, stigma, and economic constraints.

Counseling is a service, not a form of health education. Its objectives involve individuals, not society. It must therefore be evaluated as a service, not as an IEC program.

Determining the effectiveness of HIV counseling interventions is complex. Outcomes should include more than the client's behavior change. Effectiveness should be measured for various beneficiaries (individual, couple, family), for various expected outcomes (risk reduction, increased care, increased support, improved quality of life), and at different levels of change (cognitive and behavioral). It is also important to monitor and plan for both the immediate- and long-term positive and negative impacts of the counseling experience. Outcome evaluation must also address human rights and cost-effectiveness issues.

b. Issues to Consider Regarding Evaluation Research

- Process versus impact evaluation: Process evaluation should be required for most counseling programs, to assure that projects are functioning effectively. On the other hand, some meeting participants felt that impact evaluation should be conducted in discrete, well-planned, and well-funded research projects in which it is possible to evaluate the outcome effectiveness of specific counseling interventions, or counseling under specific circumstances.
- Proxy measures: In measuring the effectiveness of HIV counseling, changes in behavior are measured, under the assumption that behavior change will lead to decreased morbidity (evidenced by decreased incidence of HIV or other STDs) at the community level. A review of the literature reveals that the relationship between behavior and HIV/STD incidence is not clear or straightforward. Therefore, proxy measures are not an ideal method to determine the effectiveness of counseling:

behavior is considered to be a proxy for HIV incidence; behavioral intentions are used as a proxy for behavior. Using proxy measures may not necessarily find the same results as measuring the actual disease incidence variables.

- Variation in human response: Researchers attempt to achieve universal conclusions in the face of great variation among individuals who are exposed to counseling interventions. As a result, the conclusions contain a necessarily wide margin of error. For example, for some individuals, testing itself may result in behavior change, while others may require four years of intensive counseling for behavior change to occur.
- Confounding counseling with testing: Most studies of HIV counseling are conducted within the context of counseling and testing. Thus, it is not possible to discuss the effectiveness of counseling without the effect of the client also having recently acquired knowledge of his/her HIV serostatus. Moreover, most studies are conducted in communities with a high incidence of HIV, where HIV counseling and testing is only one of numerous interventions. Thus, it is impossible to divorce the effect of the counseling intervention from the effect of the other interventions that are being implemented.
- Selection bias: Issues of selection bias pose problems in the interpretation and generalization of study results.
 - Who comes to the study to be involved in the counseling?
 - Who receives which type of treatment? How do those who receive counseling only differ from those who receive medical treatment only? How do those who receive pretest and post-test counseling differ from those who receive post-test counseling only? It is difficult to standardize the intervention or make it independent of the type of person receiving the counseling.
 - It is desirable to look at the sustained effect of counseling, but there can be selection bias related to follow-up. There may be a difference between those who drop out of the study and those who do not.

To resolve these problems, it is critical to include randomization in all study designs.

- Goals of counseling: Counseling can be seen as a service with the goal of providing individuals with different coping strategies, rather than with the goal of achieving behavior change aimed at decreasing HIV incidence. With this revised goal, the measures of success might be different, and perhaps easier to obtain. This leads to the observation that the reasons agencies provide counseling may be different from the reasons that individuals seek counseling. Does the counseling intervention emanate from the recognized needs of the community, or from the needs that the planner

identifies? Another way to look at this is to ask whether evaluation is to justify the program to the funding source or to provide effective services to the client?

- The effects of mandatory testing: Mandatory HIV testing exists and is increasing. It is conducted for a variety of reasons, including immigration, employment, and insurance. Mandatory testing, conducted for the economic benefit of employers and insurers, is unlikely to be completely eliminated.

Providing HIV counseling might limit the harmful effects of mandatory testing. This might be compared to the concept of "harm reduction" as it is implemented in syringe exchange programs to intravenous drug users. However, is it possible to reduce the harmful effects of mandatory testing without, at the same time, supporting its existence?

Mandatory testing exists not for the benefit of the person who is tested but for the benefit of those doing the testing. Can and/or should counseling make mandatory testing also benefit those who are being tested?

c. Questions That Still Need to be Examined

- What should be the role of HIV counseling in an HIV/AIDS control program?
- What is the relative importance in the outcome evaluation of meeting the clients needs vs. influencing behavior?
- Why is it necessary, and is it possible, to show whether counseling causes behavior change?

H. ROUNDTABLE 8:

Creating a Common Purpose and Bridging Differences Among Stakeholders (Communities, Researchers, Industry, and Government) in Providing STD/HIV/AIDS Products

1. Objective

The differing interests of stakeholders should be recognized even while working toward the common objective: to prevent the spread and reduce the incidence of STDs/HIV/AIDS, and improve the lives of those affected by STDs/HIV/AIDS.

a. Identifying the Stakeholders

The stakeholders are all those individuals and groups concerned with the common objective. The list below identifies some of the stakeholders. The outline in Section VII lists special concerns held by each category of stakeholder.

- People groups (includes people living with and affected by HIV/AIDS/STDs, especially women; residents/potential users; advocates; community representatives, formal and informal; local NGOs/voluntary groups; traditional healers)
- Health care providers (includes family planning; leaders and personnel at every level)
- Industry
- Research
- Government (includes regulatory agencies and ministries)
- Bilateral and multilateral development agencies
- International NGOs
- Media

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2. Building Bridges Among Stakeholders to Achieve a Common Purpose

Very often key encounters take place between individuals prior to a broader meeting. The outline of steps below assumes that there will be a moderate size meeting of a broad group early in the process. While there may be other patterns of steps in the process, many of the same principles will still apply.

a. Who Should Participate? Representation of All Stakeholders

The key words are **interdependence** and **complementarity**. Stakeholders need each other. For example, scientists bring one type of expertise to the collaboration, while people groups bring another. Communities need the technology and expertise that industry/researchers can bring, while industry/researchers need the experience that local groups can bring. There is also practical knowledge and insights that can be provided by clinicians and service providers.

b. Recognizing Power Differentials

Participants not only bring different experiences, they wield different elements of power—economic, political, and knowledge (academic, experiential).

Collaborators must acknowledge, and where possible compensate for the power differentials between groups such as large institutions, compared with small grassroots groups.

Organizers of collaborative processes must acknowledge that some groups and/or individuals do not have the resources necessary to allow full participation. While mainstream groups are becoming increasingly aware of the need to involve traditionally excluded groups, there is a real—and often overlooked—distinction between inviting someone to participate in "your" panel, "your" conference, or on "your" committee, and truly sharing power with new and varied constituencies.

The key questions here are: Who sets the agenda? At what stage is input sought? What are the conditions of engagement? Are women's groups, consumers or HIV positive people invited to participate once all the important decisions are already made, or are they involved from the beginning? Are the stakeholders who initiated the process truly open to incorporating the suggestions of new actors?

c. Differential Interests

Stakeholders may share a common purpose, but they clearly also have other concerns that influence their participation as well. Below are examples of some of the concerns that drive stakeholders (refer to Working Group 8 Appendix for others):

- Industry: Profit potential
- Research: Intellectual challenge
- Advocacy groups: Accountability to constituency
- Government: Regulatory agencies; congressional pressures
- Consumers: Availability and cost
- Users: Ease of use

While creating common ground, we need to acknowledge these concerns and minimize the different interests and the impact they have on the collaboration.

d. Conveners

The choice of a group or individual to be the convener can make or break a collaborative process. The sponsors should be as neutral as possible and be respected by all participants. If the convening agency is seen to be more "on the side" of one group or another, it can greatly complicate the building of trust and open communication.

On any topic, there are generally one or more groups that are well-positioned to bring even highly divergent perspectives to the table. Alternatively, two or more groups representing differing perspectives, may choose to co-convene a collaborative process, each using its reputation with its own constituency to bring them to the table. Some groups will respond differently to any one single convener; organizations collaborating as conveners may ensure the trust of a larger community of collaborators.

e. Communications—Safe and Honest

It is important to create "safe" space for open and honest communication: What is required to create a safe space may vary, depending on the nature of the collaboration. Open and honest dialogue should be facilitated, and confidentiality protected. Traditional and cultural sensitivities should be respected.

All individuals are a product of culture and language, and this is no less the case when it comes to our professional or activist lives than our tastes in food. It is important to discuss how language affects collaboration. Often small variations in language reveal (or are interpreted as revealing) large differences in perspective. There are also dangerous or insensitive words, such as target, research subjects, Latino vs. Hispanic, prostitute, risk groups, acceptability, etc. Controversy about the use of language can be resolved with honest discussion.

3. Building Consensus Across Stakeholders

a. Acknowledging History

History cannot be erased. The past behavior of institutions, whether real or imagined, becomes an active force in any attempt to collaborate across differences. All groups, especially those traditionally excluded from the corridors of power, have particularly strong historical memories of the instances in which the government and/or the scientific establishments have betrayed their trust. Understandably, stakeholders become frustrated with any implication that they are somehow responsible for incidents that happened before they became involved. No one likes to be stereotyped, especially individuals who feel they approach their work with integrity.

When individuals or groups have long been denied access to full and honest information, mistrust can quickly develop toward holders of that information. More to the point, there may sometimes be a measure of truth in the concerns and suspicions of such groups.

b. Building Trust and Resolving Conflict

The best way to handle tensions between groups is to build personal relationships between members of the different groups. Many women's health advocates, for example, have had little real-life interaction with the scientists who develop new contraceptives. Their only experience has been when new products appear in their countries for testing. From this perspective, it is easy to view all scientists as mere cogs in a larger initiative to control the fertility of third world women.

Personal interaction can break down the tendency to cast all scientists in this role and to divide the world into "us" versus "them." At the same time, individuals from larger, more powerful institutions must recognize that regardless of their personal politics or morality, the ideology and actions of their institutions may come in conflict with the interests of other groups. It is important for individuals to accept and acknowledge these realities without becoming defensive.

In order to build consensus and resolve conflicts as they arise, collaborators should recognize that individual participants and groups do have experiences, identities and insights

unique to them, and that the process of collaboration should not remove the distinctiveness of each one. Each institution or individual should be allowed to maintain personal or organizational integrity, while maintaining the motivation to achieve a common purpose.

c. Costs of Building Consensus

It is important to allow adequate time for preparation, communication, discussion, and feedback. The location of meetings should be carefully considered to maximize participation of stakeholders. The financial implication of participation should be taken into account, and funds built in to support participation of stakeholders who have less access to resources for international collaboration.

4. Defining the Agenda

In most cases, the agenda must serve to cover a long period of time and many steps. Therefore, it is important to create and define benchmarks for accomplishing the necessary steps along the way, while repeatedly reflecting on the relation of the short-term objectives to the long-term goals. The objectives must be set realistically.

Collaborators should ensure that there are adequate resources to meet all the objectives. Some individual stakeholders may tend to maintain a better sense of purpose and identity regarding certain of the objectives to the exclusion of other objectives.

All collaborators should participate in development of the agenda, in the spirit of collaboration that recognizes the different interests and needs of group members. The agenda should be reviewed from time-to-time to ensure that all aspects are still relevant to the goals and objectives defined by the group.

5. Implementation: Achieving the Common Purpose

a. Improving Existing and Developing New Products

Research questions and priorities need to be informed by and determined through a participatory approach involving all stakeholders. Considerations should include what the needs are at the community level, the relevance and importance of informed consent in research, controlled trials, identifying target groups and subjects, scientific integrity, ethical research concerns, and the fact that those most at risk often stand to either gain or lose the most.

All stakeholders are taking risks as the implementation progresses. The experimental subjects have the most to lose if safety is an issue; scientists have the most to lose if the study is flawed; and industry has the most to lose if the product is shown to be ineffective. Failures at

any stage of implementation will leave their mark on all stakeholders, discouraging them from working together to achieve their common purpose.

Broader community involvement and participation is needed in product testing, development, and diffusion. The worldwide network of NGOs is an established means of achieving this participation. There is also a need to expand research to produce products that are acceptable to different people (such as different groups of women, and people in different regions).

b. Sharing and Disseminating of Information

Comprehensive information about all stages of implementing the common purpose should be disseminated to the constituencies represented by the participants in the collaboration, using effective channels of communication. These constituencies are stakeholders whose feedback should address the interests of all stakeholders in a manner that advances the achievement of the common purpose. For example, user perspectives, resource availability, technical limitations, and other issues, will need to be reconciled to benefit each of the participating groups to a satisfactory degree.

In addition, a related concern is to assure that constituencies do not have their expectations for a product raised prematurely, when the product may not be available for years to come. This is termed the management of product "expectation fatigue."

c. Distributing Products to Potential Users

The initial step in distribution is to "pilot introduce" a product in order to create demand. As far as possible, products should be distributed and made accessible to all potential users. A well-developed health infrastructure is key to making many products available to potential end users; factors may include adequate roads, access to remote areas, and availability of clinics that carry the product. Finally, distributing products goes hand in hand with establishing policies that support distribution and demand.

Training should be done where needed to assure that end users understand the use of all products. Training may involve all levels, including the level of providers who makes the product available: nurses, doctors, health care workers, and other distributors. Stakeholders need to understand that informing potential users about the benefits and expected effect of products will enhance use and satisfaction.

d. Utilizing Products

The social conditions and individual circumstances under which products are to be used must be considered in order to achieve the common purpose and ultimate goal of providing products and preventing/reducing disease. The complexity of the users' lives, including the financial, behavioral, and interpersonal constraints they face, will determine whether any product for treatment or prevention is actually used or not.

6. Evaluation

Evaluation must take into consideration both the process of collaboration and the monitoring of the development, provision, and utilization of the product. It is important to evaluate whether collaboration is working, whether each stakeholder is being heard adequately, and if, in fact, all stakeholders continue to be committed and involved in the process.

Evaluation can be based on short-term objectives, their contribution to achieving the common ultimate goal, and must involve all of the stakeholders.

**Working Group 8
APPENDIX**

**SOME STAKEHOLDERS IN PRODUCT DEVELOPMENT
AND SOME OF THEIR SPECIAL CONCERNS**

PEOPLE GROUPS:

Residents and potential users:

- Safety
- Availability
- Cost
- Efficacy
- Ease of use
- Human rights
- Cultural and traditional issues

Advocates, community representatives, community leaders, and local NGOs:

- Organizational agenda
- Availability of funding
- Accountability to constituency groups
- Political environment
- Turf concerns
- Political posturing vis-à-vis rival groups
- Organizational capacity and time
- Political liability of engaging in certain collaborations
- Fear of being coopted

HEALTH CARE PROVIDERS:

- Organizational agenda, capacity and time
- Funding and availability of supply
- Safety and efficacy
- Familiarity, need for training
- Turf concerns
- Prestige
- Potential for career advancement
- Political environment

INDUSTRY:

- Profit potential
- Liability exposure
- Regulatory environment
- Patent potential
- Fit with current product line
- Public relations implications
- Opportunity costs compared to other investments

RESEARCH SCIENTISTS:

- Intellectual challenge
- Potential for career advancement
- Availability of funding
- Pressure to publish
- Novelty, newness of the line of inquiry
- Prestige
- Professional rivalries
- Patent potential

GOVERNMENT:

Regulatory agencies:

- Mandate, mission
- Bureaucratic turf issues
- Public pressure
- Congressional pressure
- Tendency toward self protection
- Precedent

Ministries:

- Financial constraints
- Competing priorities
- Political environment
- Prestige
- Professional rivalries
- Interest groups
- Potential for career development

BILATERAL AND MULTILATERAL AGENCIES:

- Mandate, mission
- Bureaucratic turf issues
- Political pressure
- Public need, public pressure
- Prestige
- Financial constraints
- Competing priorities
- Potential for career development

INTERNATIONAL NGOS:

- Funding sources
- Mandate, mission
- Bureaucratic turf issues
- Political pressure
- Public need, public pressure
- Prestige
- Financial constraints
- Competing priorities
- Potential for career development