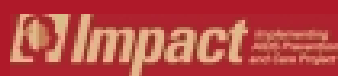


# BCC Network for HIV/AIDS:

## First Regional Meeting for East, Central and Southern Africa

Renewed Emphasis on Behaviour Change Communication  
for HIV/AIDS Prevention and Care



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The views expressed in this document do not necessarily reflect the views of Family Health International (FHI), Academy for Educational Development (AED), Regional Centre for Quality of Health Care (RCQHC), or the United States Agency for International Development (USAID).

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# Executive Summary

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The concept of a Regional BCC Network for HIV/AIDS for East, Central and Southern Africa (ECSA) grew out of a common interest and understanding among a number of BCC practitioners dealing with HIV/AIDS in the region that something needed to be done to help address common challenges and needs, improve strategies, and build capacity in the area of BCC. In October 2001, they formed a BCC Task Force to recommend specific activities for addressing key areas of interest in BCC and for coordinating BCC efforts in the region, including organising a wider regional meeting for initiating a formal regional BCC Network.

After more than one year of planning, the first Regional Meeting of the BCC Network for HIV/AIDS was held in Kampala, Uganda, on November 3–6, 2003. Nearly 140 delegates from 19 countries convened to actively discuss, explore, and address BCC issues relevant to HIV/AIDS in the region. The participants included BCC practitioners representing government bodies, regional and national nongovernmental organisations, community- and faith-based organisations, academic institutions, and international health agencies.

With support from USAID/REDSO, the meeting was hosted by the Regional Centre for Quality of Health Care (RCQHC) in collaboration with the Regional BCC Network Task Force, The CHANGE Project of the Academy for Educational Development (AED), and Family Health International (FHI).

The objectives of the meeting were to

- Share lessons learned and interventions in BCC in the ECSA region
- Discuss key current issues and BCC tools for HIV/AIDS
- Discuss the expansion and operationalisation of the BCC Network for HIV/AIDS
- Foster linkages among BCC practitioners and those in allied professions in ECSA

The main themes of the meeting agenda highlighted the emerging issues in planning and programming for BCC; developing BCC for care and treatment; addressing stigma; reaching youth; and strengthening research, monitoring, and evaluation of BCC interventions.

The meeting sessions covered a broad spectrum of topics, including the current status and future direction of BCC for HIV/AIDS, BCC strategies for different target groups, prevention and the ABC approach, opportunities for BCC in the care setting, the challenges of measuring behaviour change, and practical BCC tools. Some presentations focused on discussing the guiding principles and theories behind BCC, while others presented practical experiences and lessons learned from existing BCC programmes. Attendees participated in plenary and small group work sessions, where they engaged in stimulating discussions and actively contributed new perspectives, recommendations, and questions. Beyond the formal agenda, the meeting was also an opportunity for participants to meet one another, make contacts, and learn about other programmes.

All participants in the meeting were invited specifically because they could contribute to the discussion and exploration of BCC issues. In this sense, this meeting was different because it depended on input from the participants to further elaborate the BCC challenges and needs for the region, and to establish the next steps for developing a functional, relevant, and innovative BCC network.

This report is an overview of the proceedings of the meeting and is intended to serve as a resource and learning document for meeting participants as well as for other BCC practitioners in the region. The structure of the report follows that of the meeting agenda (presented in Annex 1) and includes a summary of all plenary and concurrent session presentations and all group work discussions. Key questions and discussion points raised by participants during both the plenary and concurrent sessions are highlighted in Discussion Points text boxes. The small group work sessions were designed specifically to give participants an opportunity to share their own viewpoints and ideas on topics introduced during the main sessions. These additional points were then shared with the broader group during plenary reporting sessions. The group work session summaries are based on these group reports.<sup>1</sup>

<sup>1</sup> (Note: The PowerPoint slides for the meeting presentations can be obtained by contacting Lee Pyne-Mercier, Senior Programme Officer, Family Health International (email: [lpynemercier@fhi.or.ke](mailto:lpynemercier@fhi.or.ke).)

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# Foreword

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Starting in 2001, the Regional BCC Network has promoted high-quality behaviour change communication (BCC) as an integral and strategic component of HIV/AIDS prevention and care interventions. The BCC Network supports BCC in the region by advocating for an increase in the understanding of BCC; building the capacity of BCC practitioners; and networking and information-sharing to ensure best practices are widely adopted.

The November 2003 regional meeting provided an opportunity for BCC practitioners in East, Central and Southern Africa to interact, network, and share their ideas and experiences. In particular, there were fruitful discussions on BCC programming for care and support issues, such as anti-retroviral therapy, and on BCC in the context of the ABC policy (Abstain, Be faithful, use Condoms). Other discussions covered such important issues as how to address stigma, a renewed emphasis on youth, monitoring and evaluation of BCC interventions, and peer education as a channel for BCC. To extend the reach and usefulness of the meeting, this meeting report will be widely disseminated to BCC practitioners who were unable to attend.

The BCC Network shows great promise, and since the meeting the BCC Steering Committee has been working to institutionalize many aspects of the Network. We expect to initiate several new activities in the near future, activities that will help the BCC Network fulfill its potential. We look forward to continued interaction with all members of the Regional BCC Network.

**BCC Steering Committee**

# Abbreviations and Acronyms

<b>ABC</b>	Abstinence; Be Faithful; Condom Use	<b>PATH</b>	Programme for Appropriate Technology in Health
<b>AED</b>	Academy for Educational Development	<b>PEPFAR</b>	President's Emergency Plan for AIDS Relief
<b>AIDS</b>	Acquired Immune Deficiency Syndrome	<b>PLHA</b>	People Living with HIV and AIDS
<b>ANC</b>	Antenatal Clinic	<b>PMTCT</b>	Prevention of Mother-to-Child Transmission of HIV
<b>ARV/ART</b>	Antiretroviral/Antiretroviral Therapy	<b>PSG</b>	Project Support Group
<b>BCC</b>	Behaviour Change Communication	<b>PSI</b>	Population Services International
<b>CBO</b>	Community-Based Organisation	<b>R/M/E</b>	Research, Monitoring and Evaluation
<b>CDC</b>	Centers for Disease Control and Prevention	<b>RATN</b>	Regional AIDS Training Network
<b>ECSA</b>	East, Central and Southern Africa	<b>RCQHC</b>	Regional Centre for Quality of Health Care
<b>FAO</b>	Food and Agriculture Organisation	<b>SARS</b>	Severe Acute Respiratory Syndrome
<b>FBO</b>	Faith-Based Organisation	<b>SIPAA</b>	Support to International Partnership Against AIDS in Africa
<b>FHI</b>	Family Health International	<b>STF</b>	Straight Talk Foundation
<b>HEART</b>	Help Each Other Act Responsibly Together	<b>STI</b>	Sexually Transmitted Infection
<b>HIV</b>	Human Immunodeficiency Virus	<b>TB</b>	Tuberculosis
<b>ICRW</b>	International Centre for Research on Women	<b>TOR</b>	Terms of Reference
<b>IMAU</b>	Islamic Medical Association of Uganda	<b>UNAIDS</b>	Joint United Nations Programme on HIV/AIDS
<b>IMPACT</b>	Implementing AIDS Prevention and Care	<b>UNICEF</b>	United Nations Children's Fund
<b>KAP</b>	Knowledge, Attitudes, and Practices Study	<b>USAID</b>	United States Agency for International Development
<b>KGGA</b>	Kenya Girl Guides Association	<b>USAID/REDSO</b>	Regional Economic Development Support Office
<b>M&amp;E</b>	Monitoring and Evaluation	<b>VCT</b>	Voluntary Counselling and Testing
<b>MIPESA</b>	Malaria in Pregnancy East and Southern Africa	<b>WHO</b>	World Health Organisation
<b>MOH</b>	Ministry of Health	<b>ZAMBART</b>	Zambia AIDS-Related TB Programme
<b>NGO</b>	Nongovernmental Organisation	<b>ZIHPCOMM</b>	Zambian Integrated Health Programme Communication and Community Partnership
<b>OI</b>	Opportunistic Infection		
<b>OVC</b>	Orphans and Vulnerable Children		



# I. Introduction

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The first Regional Meeting of the BCC Network for HIV/AIDS in East, Central and Southern Africa (ECSA) was held in Kampala, Uganda, on November 3–6, 2003. Nearly 140 delegates from 19 countries convened to actively discuss, explore, and address behaviour change communication (BCC) issues relevant to HIV/AIDS in the region. The participants included BCC practitioners representing government bodies, regional and national non-governmental organisations, community- and faith-based organisations, academic institutions, and international health agencies. With support from USAID/REDSO, the meeting was hosted by the Regional Centre for Quality of Health Care (RCQHC) in collaboration with the Regional BCC Network Task Force, The CHANGE Project of the Academy for Educational Development (AED), and Family Health International (FHI).

## II. Meeting Overview

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### A. Meeting Objectives

The specific objectives of the meeting were that by the conclusion of the meeting, participants would have:

- Shared lessons learned and interventions in BCC in the ECSA region
- Discussed key current issues and BCC tools for HIV/AIDS
- Discussed the expansion and operationalization of the BCC Network for HIV/AIDS
- Fostered linkages among BCC practitioners and those in allied professions in ECSA

The meeting agenda and list of meeting participants are presented in Annexes I and II, respectively.

### B. Summary of Highlights

This meeting, which brought together a diverse group of participants working in the area of BCC for HIV/AIDS in the East, Central and Southern Africa region, provided a forum for dynamic discussions and an exchange of ideas on critical BCC issues and common challenges.

The main themes of the meeting agenda highlighted the emerging issues in planning and programming for BCC; developing BCC for care and treatment; addressing stigma; reaching youth; and strengthening research, monitoring, and evaluation of BCC interventions.



Group photo of participants representing 19 countries at the meeting.

The meeting was officially opened by Prof. Mondo Kangonyera, Minister of General Duties, Prime Minister's Office, who gave the opening speech highlighting Uganda's positive experience using communications as a tool for change and for achieving greater openness within the government and the community on issues surrounding HIV/AIDS. Prof. Arvind Singhal of Ohio University delivered the keynote address on "Key Issues and Challenges in the 21st Century for BCC for HIV/AIDS," setting the stage for presentations on BCC issues that are beginning to arise—such as new emphases and approaches in BCC, the ABC approach to HIV prevention, and BCC for care and support.

The second day focused on creatively reaching youth and the experiences of youth programmes, understanding and addressing stigma, and theoretical considerations and examples of research, monitoring, and evaluation in BCC programmes. Participants used the group work session to exchange and present ideas on the ABC approach, BCC for care and support, reaching youth, and stigma. An informal open forum session on the evolving experiences of two peer education projects in Southern Africa and Kenya wrapped up the day.

The third day emphasized practical issues in programming for BCC, particularly at the national level, and tools and resources to facilitate the work of BCC programmes. Moving beyond technical and programmatic BCC issues, participants then turned their attention to the concept of the Regional BCC Network to revitalize and strengthen effective BCC as a strategic component of HIV/AIDS interventions in ECSA. In light of identified BCC needs in the region, participants agreed that the network could play a vital role in addressing common issues and challenges, improving strategies, fostering linkages, and building capacity in the area of BCC. To further explore the potential roles and the formation and organisation of the BCC Network, the experiences and recommendations of other networks in the region were presented.

The final day of the meeting was devoted to discussing and brainstorming about key technical and organisational issues for the BCC Network. Participants agreed on priority areas for network action and on the next steps to take in developing a functional, relevant, and innovative BCC network.

Throughout the meeting, participants engaged in stimulating discussions and actively contributed new perspectives, recommendations, and questions. Beyond the formal agenda, the collegial atmosphere of the meeting encouraged participants to renew and develop professional connections and to exchange experiences with one another. When asked what was most beneficial about the meeting, the vast majority of participants listed networking, meeting others, sharing experiences, and learning about other programmes.

Overall, participants agreed that the meeting was a success, that it had renewed energy within the BCC community in the region. In the short term, it provided them with new information and ideas that they could apply immediately to their own situations; in the long term, they look forward to more sharing of ideas and tools as the new BCC Network becomes a reality.

# III. Proceedings

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## A. DAY ONE

### 1. OPENING SESSION

#### Introduction to the Meeting

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As one of the lead organizers of the meeting, **Dr. Denis Tindyebwa** of RCQHC welcomed participants and highlighted the importance of gathering so many BCC practitioners from the region in one place to begin building the foundation for a functional and effective regional BCC network. The field of BCC for HIV/AIDS is a relatively new professional discipline, and many who practise BCC in HIV/AIDS programmes are not recognised as BCC experts. This meeting is an effort to bring together for the first time BCC practitioners with similar interests from every part of the region to discuss current issues and challenges in BCC, to share insights and lessons learned, and to foster linkages. Dr. Tindyebwa presented the objectives of the meeting and the five major themes and issues of the programme:

- Planning and programming for BCC
- BCC for care and support
- Stigma
- Reaching youth
- Research and monitoring and evaluation

## Words of Welcome

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**Dr. Joel Okullo**, Director of RCQHC, extended an official welcome to participants on behalf of the BCC Network Secretariat. He pointed out that as BCC aims to promote change at the individual and societal levels, the results of behaviour change will go a long way in the fight against HIV and AIDS. He expressed gratitude to the BCC Network Task Force, USAID/REDSO, AED, and FHI for providing technical and financial support to the meeting.

**Ms. Vicki Lynn Moore**, Director of USAID/Uganda, described the exemplary leadership, commitment and openness of the government of Uganda in effectively addressing HIV and AIDS and its contributions to the field of BCC. When prevention was the only option available for containing the epidemic, President Museveni persistently called for behavioural change among Ugandans. The strategy to decrease the number of sexual partners, delay first sexual contact by males and females, and increase condom use in the population has led to the largest decline in seroprevalence in the region today. The case of Uganda offers a successful Africa-based model for behaviour change. The \$15 billion Presidential Global AIDS Initiative features the Ugandan approach to behaviour change. USAID has been a major supporter of the Ugandan government and active NGO community since the early days of the epidemic and will continue to be a close partner. In her conclusion, Ms. Moore remarked that while Uganda has performed well, we must do much more to combat the epidemic and to strengthen efforts for behaviour change.

## Introduction to the BCC Network

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**Dr. Jeffrey Ashley**, Director of USAID/REDSO, thanked the government of Uganda, USAID/Uganda, and RCQHC for agreeing to host the meeting in Kampala, an appropriate setting given the notable success of the Ugandan approach against HIV and AIDS. It is vital to continue to focus on effective approaches to behaviour change, targeting both high-risk groups and the general population and addressing stigma. This meeting offers a timely opportunity to promote a true network through stimulating collegiality and professional relationships and revitalizing a sense of common purpose among BCC specialists. Dr. Ashley challenged participants to learn from one another, to develop and share ideas collaboratively, and most important, to commit to decisions that lead to concrete results.

## Words of Welcome by Representatives of the Government of Uganda

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On behalf of the Ministry of Health (MOH) of Uganda, the **Honorable Brig. Jim K. Muhwezi** welcomed participants to Uganda. Reflecting on the experience of his country, Brig. Muhwezi remarked on the need for multisectoral collaboration to fight HIV/AIDS and the importance of advocacy at the highest levels to bring about change. He introduced and invited **Prof. Mondo Kangonyera**, Minister of General Duties, Prime Minister's Office, to give the opening speech.

**Prof. Kangonyera**, in noting the many countries represented at the meeting, expressed his personal gratitude to participants for their activism against HIV/AIDS and welcomed all to Uganda. He described Uganda's approach to the fight against HIV/AIDS and the positive impact brought about by President Museveni's focus on behaviour change. Using communications appropriately as a tool for change, Uganda has been able to achieve a greater level of openness

within the government and public awareness within the community on issues surrounding HIV/AIDS. Today people in Uganda feel more free and comfortable talking about their behaviours, beliefs, fears, and misconceptions, and dealing with the consequences of AIDS. Nongovernmental organisations (NGOs), faith-based organisations, and role models in Uganda have played vital roles in helping people overcome their reticence to discuss HIV/AIDS and cultivate an attitude of openness in its place. If used appropriately, communications can be effective in fostering and supporting community-based behaviour change. Uganda has also drawn on other prevention interventions—such as AIDS information centres, rapid HIV testing, and post-test clubs—to support behaviour change through awareness of serostatus, thus complementing communication efforts. Through this hard work, Ugandans have become more comfortable talking about HIV/AIDS and politicians pay attention to and talk about HIV/AIDS because it affects economic growth.

Prof. Kangonyera encouraged participants to leave their prejudices aside, to keep an open mind, and to learn from one another. He declared the meeting officially open and expressed his best wishes for a successful meeting.

### **Keynote Address:**

#### **“Key Issues and Challenges in the 21st Century for BCC for HIV/AIDS”**

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Dr. Arvind Singhal, Professor and Presidential Research Scholar at Ohio University, United States, offered and expounded on four principles for BCC practitioners to apply in combating the stubborn silence and shame of HIV/AIDS.

**Principle #1: “Shout and shout.”** When a lion comes into a village, you make a loud shout. When it comes to AIDS, we must shout, shout, and shout. To shout is to make noise and to get attention. It symbolizes rising above the din, being heard and breaking the silence on AIDS. To shout is to sound a call for political and community action, for mobilisation of resources, for an urgent response to AIDS. Furthermore, a shout does not only mean making noise, but also may mean a whisper, a story, a proverb, an adage, a song, a word of encouragement, saying “I care.” There is too much silence, denial, suspicion and moralizing on AIDS. In too many parts of the world, the lion has been winning.

The question is who will say what to whom, in what context, and to what desired effect? The role of communication should be to set the public and policy agenda for HIV/AIDS. The “village chiefs” need to supervise the war on AIDS. Metaphorically speaking, they should be political, educational and religious leaders, role models, and parents. The mass media also has an important part to play in setting the public discourse on HIV/AIDS, by amplifying the shout.

We must shout and amplify the shout. In doing so, we will forge a supportive and enabling environment to preserve the rights of people living with HIV/AIDS (PLHA).

**Principle #2: Create safe communicative spaces.** AIDS is as much a disease of ignorance and intolerance as it is a biological disease. Stigma is every bit as dangerous as the HIV virus. In some parts of the world, overwhelming stigma is still associated with HIV/AIDS. The stigma of AIDS evokes negative reactions such as denial, shame, fear, anger, and prejudice. Stigma manifests itself communicatively and relationally in interpersonal and group relationships and is exhibited in how one person treats another.

Stigma, like a big rock, needs many people to chip away at it and to eventually turn it into dust. Communication

strategies need to be at the core of efforts to overcome the stigma of HIV/AIDS. There are examples of programmes, such as Pink Triangle Malaysia, which targets injecting drug users, and Brazil's AIDS hotline, both of which demonstrate the importance of creating safe and nonjudgmental communicative spaces where the infected and affected can be nurtured and feel safe being themselves. Communication happens in safe and non-stigmatized settings, whether it is a physical community centre where injecting drug users can receive attention and care or a virtual space over a telephone hotline or an Internet site where individuals can access support and express themselves freely. This is more about the context in which communication takes place to address stigma and less about what is being communicated.

**Principle #3: Consider the cultural forest.** How an issue is socially constructed determines to a large extent how it will be approached. In other words, how you frame a problem determines how you will solve it. HIV/AIDS communication strategies have rarely viewed sex as pleasurable, spiritual, or a ritual. Rather, the messages, for the most part, have been anti-sex and anti-pleasure. It is important to understand the power and strength of cultural undercurrents. Negative messages are likely to be highly ineffective.

Communications should challenge existing mindsets. BCC professionals need to try to have influence by first understanding the local context and then developing communication strategies that treat culture not as an enemy but as an ally.

**Principle #4. Target, tailor, and organize to overcome vulnerability.** Communication strategies need to focus on vulnerable groups who are at higher risk of contracting and propagating the HIV virus, such as sex workers, migrant workers, truckers, hemophiliacs and partners, and others. Their vulnerability is exacerbated by poverty and increases the vulnerability of others.

Interventions targeting the needs of vulnerable groups need to support them in organizing themselves for social change and in gaining control of their future. Organized collectively, they can accomplish a great deal. The vulnerability of one can be overcome by the strength of many through organisation. Communications plays a significant role in facilitating such organisation.

In conclusion, a world that has spent \$500 billion to tackle the Y2K bug must do more to tackle a virus that has blighted millions of lives around the world. Our call and challenge in the 21st century for BCC for HIV/AIDS is to adopt these principles and adapt them to local contexts.

## 2. STATE OF THE ART IN BCC: APPROACHES AND FUTURE DIRECTIONS

### Purpose:

The objective of this panel was to broaden perspectives of BCC by considering the wider context of HIV/AIDS and discussing new emphases and approaches that will improve BCC programming.

### HIV Prevention in the Era of Treatment

Presenter: Kevin De Cock, CDC

In 2002, there was a paper published in the *Lancet*, “Shadow on the Continent: Public Health and HIV/AIDS in Africa in the 21st Century” (De Cock, K., Mbori-Ngacha, D., Marum, B. *Lancet* 2002; 360: 67–72), that was a play on a 1937 book by Thomas Parran entitled *Shadow on the Land*. In the book, Parran stated that syphilis should be treated in terms of public health and controlled using public health tools such as case detection, treatment, contact investigation, and public education. Similarly, the *Lancet* paper argued that HIV/AIDS must be defined primarily as a problem of public health and that public health tools should similarly be used to correct it.

The public health event of the year was the global Severe Acute Respiratory Syndrome (SARS) outbreak, which relied on the most basic disease control methods for containment, measures such as contact tracing and quarantine that overstep individual rights for the common good. In contrast, we wrap individual rights so tightly around AIDS that by treating it as a disease different from others, we have unwittingly reinforced the stigma of AIDS.

The biggest policy *challenge* to be surmounted today on HIV/AIDS in Africa is what to do about access to antiretroviral (ARV) drugs. The issue of the moment is addressing the right to receive treatment and increasing access to ARVs. However, within this environment, the biggest policy *question* is how to deal with HIV testing in a way that leads to both prevention and treatment.

The current political focus on ARVs as a global emergency—as exemplified by the U.S. President’s Emergency Plan for AIDS Relief (PEPFAR) and the World Health Organisation’s 3x5 Initiative (3 million people on ARVs by 2005)—has created an environment that makes it difficult for prevention efforts. This difficulty arises from a credibility issue, in that prevention efforts are viewed as ineffective because the AIDS pandemic continues to worsen. This has led to a shift in emphasis from prevention and condom use to care, treatment and abstinence. However, it is clear that prevention has had an impact on certain populations, especially in high-risk groups. In this era of treatment, who needs prevention? Groups with the highest incidence (e.g., adolescents, especially girls, sex workers and their clients, sexually transmitted infection (STI) patients, and negative partners in discordant couples) need to know their serostatus. In populations with a stable epidemic, the largest number of infections is found in discordant couples. Yet partner notification as a control measure in HIV/AIDS is a neglected service. We must recognise that anonymity and confidentiality in HIV testing are not the same, and we must broaden our attitudes and policies about HIV testing to include prevention.

Much more HIV testing is needed. De Cock argued that HIV testing is the global emergency, rather than the lack of ARVs. Services cannot be delivered without knowledge of serostatus. The only way forward in Africa is to place knowledge of serostatus at the centre of prevention and care and to accept that anonymity is incompatible with provision of care.

## Communication from a Human Rights Perspective: Moving Beyond BCC

Presenter: Neil Ford, UNICEF

There is a need to think critically about why we are not achieving results with HIV/AIDS prevention. The classic behaviour change model is based on the premise that the correct transfer of knowledge and information will cause people to assess their situation and decide on behaviour change. This model is usually put into practice through the design and delivery of messages and has proven successful in addressing certain health problems, such as immunization, that require relatively small behaviour changes.

However, in more complex health problems, the transfer of information, regardless of how well it has been developed and delivered, is not adequate because people are unable to act on the knowledge due to external factors. It is not knowledge, but the ability to act on the knowledge that matters. For example, the ABC ( Abstinence; Be Faithful; Condom Use) message has no bearing on the social reality of street kids and sex workers.

We need to think more about how we can motivate people toward change and how we can help them control their own realities through communication. This shift requires that we think deeper than campaigns and messages and seek social input, that we move from messages to dialogues and conversation inside the community, that we appreciate the strengths of local culture rather than looking for what is amiss, and that we move from expert solutions to community solutions.

It is in essence a three-step process:

1. Identify those who are marginalized and vulnerable and give them a voice
2. Facilitate community dialogues that lead to community action plans
3. Build channels of communication between communities and governments so that community plans are supported with policies and service delivery programmes

The ABC approach targets the individual only. We need to take the focus away from individual behaviour and focus on the community, and the social drivers of the pandemic.

## Gender Perspectives in BCC

Presenter: Ukaiko Bitrus, Pan African Christian Women's Association

Gender disparities are pervasive in society and continue to impact the HIV/AIDS epidemic. To apply gender-sensitive approaches, BCC programmes must take into account the affirming or conflicting role of the environment within which they are operating, advocacy through gender training and sensitization, directional messages focusing on gender dynamics, and the importance of dialogue on sexuality between men and women, inter-spousal communications, and respect in relationships.

Many challenges remain in the area of gender perspective and BCC, including further understanding of the key social issues driving the HIV/AIDS epidemic and the role of power relationships in affecting the inability of women to prevent or seek care after infection.

The aim is to create gender-equal, enabling environments that will bring balance into the HIV/AIDS situation. The gender perspective must be considered when assessing access to services such as voluntary counselling and testing (VCT), condoms, and care. Issues such as accessibility and affordability of services, availability of male or female healthcare providers, and hours and convenience of services contribute to an individual's ability to control his or her own sexuality.

### Discussion Points: State of the Art in BCC

- The ability to act on knowledge is tied to many other issues, such as the issue of sexual power. For example, groups such as street kids and wives (who cannot stop their husbands from having sex) do not have power when it comes to sex. We need to identify and work with such vulnerable and marginalized groups. It is for these reasons that HIV/AIDS is a social, not just a health, problem.
- For change to occur at the community level, every person must be confronted with change at the personal level and must recognise that it is not only his or her problem but rather a problem that affects the entire community.
- If BCC focuses on individual changes, how does it fit in the context of Africa, where collective behaviour is the norm?
- By focusing on messages, how do we know that communication is taking place? Communication is defined as the *exchange* of information that leads to shared understanding. Telling people what to do through messages is one-way communication. In this sense, are we really communicating? However, transfer of information through messages still has a place in BCC. We are not working in an environment where everyone is knowledgeable about AIDS; that is, there is still a need to educate people, even professionals, about HIV and AIDS.
- We need to examine the social context of HIV/AIDS and to focus on both community and gender perspectives.

### 3. PREVENTION AND ABC

#### **“SOTA” HIV Prevention: What Does Research Suggest about “What Works” (and What Doesn’t?), with a Focus on “ABC”**

Presenter: Daniel Halperin/Janet Hayman, USAID

[Note: The PowerPoint presentation slides are provided in Annex V.]

Data indicate that, for the most part, HIV prevalence has remained relatively low in West Africa, whereas it is high in many parts of East and Southern Africa (with the exception of Uganda, where prevalence has declined). Although scientists believe that HIV probably emerged in West Africa, a number of factors may be involved in its paradoxically lower prevalence rates there. Many epidemiologists increasingly believe that male circumcision is a key factor in explaining the regional disparities in HIV prevalence in sub-Saharan Africa (as well as in South and Southeast Asia). Mapping as well as epidemiological and biological studies of the HIV epidemic in Africa have demonstrated a close and consistent association between low prevalence of male circumcision and higher HIV prevalence.

As a technical agency, USAID (as well as other international public health donors and organisations) believes in the importance of relying on sound scientific evidence, involving the use of evidence-based approaches to prevention. Our main prevention tools until now have included STI treatment, VCT, and condom promotion. However, what is the evidence supporting the effectiveness of such approaches, especially for HIV prevention/behaviour change at the population level?

The jury is still out on whether STI treatment directly impacts HIV transmission, given the contradictory findings of the STI studies in Mwanza, Tanzania, versus those in Rakai and Masaka, Uganda. (However, STI treatment remains important for other public health reasons.) Regarding VCT, a 27-study meta-analysis found little overall effect on behaviour change, especially in people who test HIV-negative, and a three-country randomized trial found no biological impact of VCT (although there was some self-reported change, especially among people testing HIV-positive). As for the impact of condom promotion to the general population in high-prevalence African epidemics, the trend observed in data collected by PSI from a number of countries indicates parallel increases in condom sales along with HIV prevalence, giving rise to PSI’s own conclusion that “condom availability alone has not led to reductions in incidence or prevalence in many countries.” A recent UNAIDS review reached a similar conclusion. Although the available data suggest that perhaps these common approaches have not been quite as effective for prevention as we had hoped, clearly, provision of appropriate STI treatment, VCT, and condoms are still vitally important, especially for high-risk groups such as sex workers, truckers, and other migrant populations. (And, of course, interventions such as VCT are crucial for other reasons, such as being the entry point to care/treatment and support for HIV-positive people.) However, we also need to ask if other aspects of prevention that have been overlooked could help strengthen prevention efforts, especially in high-prevalence settings.

It is crucial, therefore, that evidence inform the politics and that we allow the data to lead us forward, thus providing the scientific and public policy communities with much-needed lessons learned. During the past two years, USAID has been developing various reports and briefs on “ABC” (Abstain, Be faithful, or Condom use), including data-focused documents (e.g., What Happened in Uganda, 2002) and policy directions (e.g., USAID Administrator’s Cable on the ABC policy, 12/30/02). The components of ABC are not new; some prevention programs have been implementing at least some of the ABCs for years.

One of USAID's key prevention reports is a recent study on how ABC/primary prevention behaviours have affected HIV prevalence in some countries that have experienced a decline in HIV prevalence compared with some other countries that have not experienced such a decline. This "ABC Study" was based mainly on a comparative analysis of trends and levels of sexual behaviour across five African countries: Uganda, Zambia, Cameroon, Zimbabwe, and Kenya. Two of these, Uganda and Zambia (along with the Southeast Asian nation of Thailand), appeared to experience declines in HIV prevalence in the 1990s. The study yielded the following findings:

- Declines in premarital sex among women and men in the early 1990s in Uganda, and in Zambia throughout the decade
- Declines in extramarital sex among men in the early 1990s in Uganda, and in the late 1990s in Zambia
- At the end of the 1990s, highest levels of non-regular partnerships among men were in Cameroon, followed by Zimbabwe and Kenya
- Increased condom use with non-regular partners in all countries, with the highest rates among men in Zimbabwe and Uganda
- Large reduction in casual sex and multiple partnership trends in Uganda between the late 1980s and mid-1990s, and in Zambia throughout the 1990s
- Of particular epidemiological importance, in Uganda and Zambia, a large decline in the percent of men reporting three or more non-regular partners in past year (i.e., in Uganda, decreased from 15% in 1989 to 3% in 1995)

Looking more closely at the case of Uganda during the late 1980s to early 1990s (when the greatest decline in HIV incidence probably occurred), we find that there were consistent messages on partner reduction and faithfulness from many channels, including the president and his cabinet, the churches and mosques, and the media, and a greater openness about HIV/AIDS and sexual behaviour. President Museveni acknowledged the problem of HIV/AIDS and spoke personally and widely about the issue, delegated authority to the Ministry of Health, and encouraged all ministries to speak openly about AIDS. The church, the mosque, and the media also promoted behaviour change, with a focus on "B"/partner reduction, in their messages. The fact that institutions from various sectors gave clear and consistent messages on HIV/AIDS prevention was an important contributing factor to the reduction in HIV prevalence in Uganda.

In USAID country programs, especially in high-prevalence/generalised epidemics, USAID's policy advocates a balanced approach to primary prevention involving each ABC component, as epidemiologically indicated for different population groups. Accordingly, ABC should represent a unified, coherent message framework, and it is critical that messages be developed and disseminated in such a manner that none of the messages undermines or limits the effectiveness of the others. While the full ABC approach encompasses all three components, individual providers do not, however, need to provide all three. But USAID requires abstinence promoters who receive USAID funds to be data-based and non-disparaging with respect to condoms and, conversely, social marketers and other condom providers need to adopt the same stance vis-à-vis abstinence and faithfulness messages.

### Programming for ABC Messages

Presenter: Regina Lungu, ZIHPCOMM Zambia

Careful planning of a communication programme is necessary for HIV/AIDS prevention. Planning begins with a clear statement of goals and objectives, followed by identification of risk factors for the specific audience you want to address.

The message for each ABC component will not apply to every person, but together they cover the entire population. It is important to know your audience, as targeted campaigns are more successful than broad-based, general campaigns. There are primary and secondary audiences, and both are critical for a successful intervention. Effective message design uses information tailored to the specific needs of the audience; for example, married couples need a message on being faithful to each other and sexually active unmarried people need messages on consistent condom use. The messages should be appealing with a call to action.

Key lessons learned in programming for ABC are that:

- Messages reaching intended audiences using multiple channels (e.g., radio, print, TV spots) are effective
- Consistency of message counts

### Experiences in Programming for ABC Messages

Presenter: Ekong Emah, FHI

BCC forms an essential part of a comprehensive programme of prevention, care and support. BCC programming for ABC messages must be based on the level of the epidemic, existing data and assessments, behaviours and perceptions of the target populations, and best practices.

The process of developing the BCC strategy and action plan for the FHI Implementing AIDS Prevention and Care (IMPACT) project in Nigeria was presented. The steps included:

- Desk review
- Rapid assessment
- Stakeholders meeting
- Selection of areas of geographic focus
- Development of a comprehensive programme through an in-depth assessment, a second stakeholders meeting, strategic planning, and BCC strategy development

Challenging issues to the implementation of the programme included coordination of activities, capacity-building of implementing partners, quality of peer education, rapid scale-up and political support.

The message mix must be tailored to the local situation and specific target populations. That is, the design of messages

should be based on data and information from the local community and, for maximum effect, messages and programmes must be targeted.

A common BCC strategy can ensure positive synergies with a variety of messages. In tailoring messages to specific audiences, it is important to involve beneficiaries in designing the messages. It is not knowledge, but the ability to act on the knowledge that matters the most.

### **HIV/AIDS Interventions: The FBO Perspective**

Presenter: Ismail Ndifuna, IMAU

Sexuality can be understood from three perspectives: (1) the biological perspective refers to the differentiation of individuals into male and female; (2) the cultural perspective refers to societal norms, values and standards of behaviour with respect to the sexual organs; and (3) the behavioural perspective refers to the ways individuals use their sexual organs. Conflict arises when the individual's behaviour deviates from the accepted cultural norms and standards.

Norms in many cultures often dictate that sex should be practised only within marriage, and only for the purpose of procreation. In contrast, modernity emphasizes individual rights, and there are some who claim that such modernity encourages consensual sex for recreation and pleasure.

However, culture is not static, and the needs of individuals in cultures change. When norms and standards begin to hurt the very people they are supposed to protect, it is only natural that they be reviewed.

But do we have enough reason to change values and norms around sexual freedoms and rights? If the culture did change to sanction sex outside of marriage, there would be new rules for sexual behaviour, such as condoning all consensual unions and their consequences and providing condoms for all sexually active individuals.

Cultural norms embedded in religion do not change easily. However, sensitive interpretations of the principles behind these cultural norms can be used to address the behavioural/cultural conflict. For example, the condom as a device is not repugnant to religion-based cultural norms. It is the intention to which the condom is put that is of concern. In Islam, condoms can be used within marriage, but cannot be used outside of marriage regardless of the circumstances. In Catholicism, condoms may not be used either within or outside of marriage.

What then is the way forward? It is acceptable to segment our roles in the fight against HIV/AIDS. The gatekeepers of culture, the religious leaders, are most wary of divergence from cultural norms and should maintain and uphold them until they change, and human rights activists should maintain and uphold the individual rights and freedoms of choice.

**Discussion Points: Prevention and ABC**

- In tailoring ABC messages for different target audiences, it is important to involve the beneficiaries in developing the messages to ensure that the ability to act on the message exists.
- Is BCC all about anti-sex messages? If that is the critical component, we should discuss how to compete with prevailing pro-sex messages. Does BCC have to be so anti-sex, or can it promote other forms of safer sex, such as non-penetrative sex and masturbation? More research is needed on the aspects of sex that are good and how to promote them.
- What concrete evidence is there to demonstrate that the ABC communication strategy works?

**4. BCC FOR CARE AND SUPPORT****Purpose:**

A new era in HIV/AIDS has emerged as more funds and resources for treatment in developing countries is becoming a reality. This shift calls for a more careful analysis of how BCC can contribute to strengthening care and support programmes. This session focused on lessons learned from BCC programming for VCT, tuberculosis (TB), and ARV/opportunistic infection (OI) interventions.

**Overview of BCC for Care and Support**

Presenter: Carol Larivee, FHI

BCC for HIV/AIDS has focused primarily on prevention, but now there is a need to expand to care and support issues, such as VCT, prevention of mother-to-child transmission (PMTCT), ARV, OI including TB, and home-based care.

This development also involves a new range of partners (e.g., PLHA, MOH, clinical administrators, healthcare providers, and home-based care volunteers) and target populations (e.g., PLHA, pregnant women, people accessing TB and STI services, families of beneficiaries, and healthcare providers). Each care and support intervention has its own set of target populations, behavioural issues, and appropriate BCC channels that must be identified as part of treatment and care initiatives.

This is a new critical area. A comprehensive BCC approach will develop communication for prevention, care and support, and stigma together. Because it affects access to services, addressing stigma must be a cornerstone of the new approach to comprehensive BCC interventions. Opportunities to promote prevention also exist in the context of care and in clinical settings. We need to look at integrating prevention messages into care communication at all levels, to use the clinical care setting as an opportunity for prevention, and to reach HIV-positive people with prevention skills, messages and interventions.

## **PLHA Perspective on BCC for Care and Support**

Presenter: Andy Mwale, ZAMBART

Mwale shared his personal experience discovering that he is HIV positive, subsequently dealing with the reactions of his family, friends, and community upon disclosure, and confronting stigma and discrimination. Important factors in helping PLHA to seek care and support include the provision of adequate information on HIV/AIDS, access to VCT, and support from the community (either through support groups or community-based care).

## **Concurrent Session One**

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### **Increasing Demand for VCT Services in Kenya via Mass Media Communications**

Presenter: Mary Wiczynski, Consultant

In 2002, PSI designed and launched two mass media campaigns in Kenya to promote VCT. The campaigns were designed using information from a PSI KAP survey in 2000 that revealed pertinent information about the level of knowledge about VCT among the population and the barriers to and perceived benefits of VCT.

The first VCT promotion campaign targeted the general population (15–39 age group) and aimed to build consumer knowledge of and confidence in VCT services and to create links between consumers and VCT centres. The messages were in the form of questions (e.g., “Should we still have sex if my partner has HIV?”) to encourage consumers to visit VCT centres for more information. The second campaign targeted youth (15–24 age group) and used famous Kenyans as role models to encourage youth to “get in control of their life” by knowing their HIV status. Both campaigns used a variety of mass media channels, including radio and call-in radio shows, TV spots, press advertisements and posters, billboards, and street signs.

An assessment of the campaigns indicated that client demand for VCT services increased significantly in 2002 when these intensive mass media campaigns were conducted. The large increase in clients who cited mass media as their source of information about VCT suggest that the mass media campaign contributed to the increase in use of VCT services.

### **BCC and Service Providers with Reference to VCT: Communicating ABC in the VCT Counselling Room**

Presenter: Youniter Mutsungah, Liverpool VCT

Liverpool VCT operates 47 VCT centres in Kenya and has trained over 400 counsellors. Capacity-building of the VCT counsellors is an important aspect of the programme and involves rigorous counsellor training, observed practice, regular support supervision, exit interviews for clients, and self-reflection forms for the counsellors. Data from more than 6,000 clients at 29 VCT sites show that 50% never used condoms with a non-steady sexual partner, 28% sometimes used condoms, and 22% always used condoms.

Thus there is a need to advocate for safe sex (A, B, and/or C) within the VCT setting. The VCT counsellor-client interaction provides an opportunity to promote safe sex practices, such as reducing the number of sexual partners and increasing condom use. VCT counsellors must be trained on how to communicate safe sex information, to help clients assess risk, and to negotiate risk reduction and disclosure. Specific areas in which VCT counsellors need training are: creating a trusting relationship with the client, using different counselling approaches to help clients consider and choose A, B, and/or C, and working with the client's self-esteem when weighing issues around disclosure. Some of the challenges faced by VCT counsellors and clients include cultural, societal or religious expectations; stigmatizing messages; the counsellors' own attitudes, such as toward disclosure; and gender imbalance.

In conclusion, a well-trained counsellor can reinforce the ABC message to clients. However, quality assurance mechanisms, such as regular support supervision and exit interviews with clients, are necessary to ensure that clients receive quality VCT service. Beyond the VCT counselling room, VCT relies on the messages in the community for the client to "own" the process of choosing ABC.

### **Concurrent Session Two**

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#### **Lights of Hope: A National Behaviour Strategy for Fighting TB in Kenya**

Presenter: C.Y. Gopinath, PATH

One of the key findings of a behavioural study on TB-seeking behaviour in Kenya is that the family plays an important role in diagnosis, treatment, adherence and cure. If suspicion grows that a relative's cough is due to TB, then the family will begin to "own" the problem of the cough more than the individual and will want to control information about the cough to protect the family's reputation. The first place where stigma surfaces is in the family; then second outside the family, in the clinic among healthcare workers and the community.

Communication needs before and after TB diagnosis differ. When someone begins to cough and does not know whether it is TB and/or AIDS-related, the person is in the "gray zone" and can become completely invisible by not accessing care-seeking options. The challenges are (a) how to communicate with an individual who does not know what is going on and to determine the strategy to best reach the individual and (b) when the individual finally visits a clinic, how to ensure that he/she continues and completes treatment.

The family can be both an audience and a channel for communication. Children, as the neutral party in the home, have a potential role as advocates to bring information to the family. When the diagnosis of a cough is unknown and stigma has entered the family, family members need to talk with each other and to see role models (e.g., on radio or TV) to build hope into the situation. The key activity then is clear messaging.

A communication strategy needs to ask the right questions to create ownership of information on TB. This can be done through (a) provoking enquiry, (b) demonstrating hope and options, and (c) empowering families to act.

## **Behaviour Change Communications and ART: The Case of Mombasa, Kenya**

Presenter: Peter Mwarogo, FHI

In Mombasa, Kenya, provision of antiretroviral therapy (ART) has been recently introduced within the context of comprehensive care. The BCC component of the programme aims to support behaviour change among healthcare providers and PLHA with regard to appropriate healthcare seeking behaviour, drug adherence, empathy and understanding from providers, and accurate knowledge of ART and OI treatments.

Before developing the BCC strategy, a desk review and formative assessment of the situation revealed that there is a scarcity of materials on BCC for care, high levels of stigma, low knowledge about the distinction between HIV and AIDS, lack of awareness that hygiene can help prevent OIs, and a perception among providers that informing patients about side effects of drugs will affect their uptake of treatment.

Based on this review, the BCC issues identified for the programme included the need to:

- Present culture-specific information that people can relate to
- Explain the difference between HIV and AIDS
- Increase knowledge of common OIs
- Promote VCT as the entry point for care
- Mobilize families and friends to support drug adherence

BCC messages were then developed specifically for clinicians and clients and communicated using various communication channels and materials. For example, care messages were integrated into peer education.

In designing the ART programme in Mombasa, the BCC component was initially left out, but the programme is now catching up and filling in this gap. The lesson learned is that planning for ART should include BCC from the very beginning. In addition, stigma must be addressed in the provision of ART because stigma inhibits care, and PLHA and providers must be involved in the development of messages and materials.

**Discussion Points: BCC for Care and Support**

- BCC for care and support programmes should use a systematic approach to target behaviour change among providers (not only clients and patients) through training on provision of care and supervision. A lesson learned is that BCC for providers and the community should be undertaken at the same time in a care and support programme.
- BCC efforts targeted at providers should include training and capacity-building in both the public and the private sectors.
- It is important to accurately communicate to people what care and treatment is, what it means for them, and when and how they will benefit from it. This understanding will prevent them from having unrealistic expectations and then being disappointed when those expectations are not fulfilled.
- BCC strategies must target a message to patients on ART about the importance of adhering to the treatment regime. Non-compliance to the treatment regime could lead to treatment failure and/or propagation of a drug-resistant form of the virus. Just being told about the risks, however, does not necessarily lead recipients of ART and TB/DOTS treatment to behaviour change, so this message must be reinforced via BCC.

## B. DAY TWO

### 1. REACHING YOUTH

#### **Purpose:**

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Youth are an important target group for HIV/AIDS communication. This session highlighted BCC programmes using a variety of BCC approaches and channels to reach youth.

#### **The Soul City Experience – Reaching Communities, Touching People**

Presenter: Sally Ward, Soul City

The Soul City Institute for Health and Development Communication in South Africa uses a weekly television drama, a daily radio drama, and supplementary print handbooks on HIV/AIDS and health-related topics to reach individuals, communities, and society. South Africa has a well-developed media network in both urban and rural areas. Television viewership is about 75%, with one television per 15–20 people. Soul City’s various communication channels reach almost 80% of the target audience. The Soul City approach is based on the behaviour change and the health promotion models. It uses drama to entertain and to educate (“edutainment”), and has become a popular and credible programme and, as a result, a household brand.

Research is a key pillar of Soul City. All materials are based on formative research with the target audience and pretested before finalization. The development process of each topic-oriented series requires 18 to 24 months. Using this approach, opportunities have arisen for the creation of educational packages for youth and adults, advocacy around topics and issues, building on the Soul City brand name, and expansion to other regions in the country.

Using the same model as Soul City, Soul Buddyz was created to reach children aged 8–12 through TV, radio, and print. The programme deals with issues such as HIV and AIDS, bullying, accidents, and xenophobia. It highlights the abilities of children to confront and manage problems and to make a difference in their communities. Soul Buddyz Clubs came into being after children who watched Soul City asked how they could create their own clubs. Over 900 clubs exist today across South Africa, many in resource-poor areas that are hard to reach. The clubs provide a positive and creative forum where children’s needs and voices can be heard. The use of a managing agency to coordinate the clubs, recruitment of members and facilitators, and database management has been key to their success. The consistent commitment and enthusiasm of children involved in the clubs is the most meaningful indicator for the programme.

### **Creating an AIDS-Free Society: KGGA Project on Peer Education Programme for HIV and AIDS Prevention**

Presenter: Nancy Kinyua, Kenya Girl Guides Association

The Kenya Girl Guides Association (KGGA), a voluntary organisation with over 130,000 women and girl members, strives to provide opportunities for girls and young women to develop to their fullest potential as responsible citizens. With support from the FHI/IMPACT project, KGGA implements a peer education programme to reach in-school and out-of-school girls with life skills for HIV and AIDS prevention.

Teachers from more than 600 schools and the KGGA management were trained in peer education approaches and life skills using materials developed specifically for the KGGA programme. A structure was set up for trained patrol leaders and peer educator students to reach out to different groups of girls, including girls orphaned by AIDS. To date, the programme has reached more than 25,000 in- and out-of-school girls, and more than 5,000 girl guides have earned HIV and AIDS badges. In addition, the programme has implemented outreach activities such as a badge design competitions, drama/music festivals, and holiday camps. The approach of the programme was recognised as a best practice at the 14th International AIDS Conference in Barcelona, 2002.

Lessons learned from the programme include the following points:

- The structure of the programme provides an effective means for reaching girls and young women in and out of school.
- Given correct information and skills, girls and young women can make informed and correct decisions about their reproductive health behaviour.
- Badges are an excellent way to motivate and sustain interest among young people.
- Guide leaders have been able to change behaviours and sustain positive reproductive health behaviours.

### **Youth-Led Programmes**

Presenter: Cathy Watson, Straight Talk

Straight Talk began as a newspaper for in-school older adolescents in Uganda and was the first sexual health newspaper for any group of the population. The objective was to raise the age of first sex and to increase the practice of safer sex. The Straight Talk Foundations's (STF) activities now extend to radio shows broadcast by 15 stations, school visits, local language newspapers, a newspaper for teachers, support to Straight Talk clubs, and monitoring and evaluation (M&E). The aim of the expansion was to reach more sub-sets of adolescents, such as adolescents not in school and/or unable to speak English. The project reaches about one-third of adolescents in Uganda each month.

Straight Talk allows the audience to drive its content (i.e., it is adolescent-driven). After deliberately posing a question to the audience, the views of adolescents are obtained through content analysis of their responses and letters, and are then used to produce the newspaper. Non-literate adolescents are encouraged to draw and send in pictures.

Straight Talk has experienced a shift, from balancing the message between condoms and abstinence to favouring more abstinence messages, although it remains positive about condom use. It is not moralistic, but it takes a strong position on sexual health issues. For example, the emphasis on abstinence is pragmatic; it is a safer choice because sex even with a condom seems to disrupt the lives of adolescents. More recently, however, Straight Talk has focused on communicating three-pronged messages that encourage delay of first sex, condom use, and HIV testing.

Straight Talk's success is linked to a number of factors:

- Responsible use of freedom of the press
- Freedom of civil society to organize
- No censorship
- No permission-seeking

What Straight Talk does that is different is it continues to present a message for long periods of time and through various channels in a way that promotes dialogue, rather than just carrying out a message campaign. The Straight Talk newspapers are journalistic, and the format makes it possible to include discussions about a broader range of topics than would be possible in a leaflet or poster format. In addition, it is youth-friendly, but directive.

### **Youth Alert! Reaching Youth**

Presenter: Sarah Gibson and Richwell Tambuli, PSI/Malawi

The Youth Alert! Programme is a life skills programme in Malawi targeting HIV prevention in youth ages 10–20. It aims to help young people identify their sexual risks by promoting delayed sexual debut, abstinence, safer sex among non-abstainers, and decreased number of sexual partners. The research-based programme is tested with youth, has developed a strong and unique brand, and draws on recognised celebrities and role models.

Youth Alert! uses a variety of mass media and interpersonal communication channels, such as listeners' clubs, peer education, magazines, and special events. The communication objectives are centred around improving personal risk perception, delaying sex, promoting abstinence among youth who have had sex a few times, dispelling the myth of the "trusted" partner, improving knowledge about condom use, and improving the perception about condom effectiveness.

Youth have difficulty differentiating between delayed sexual debut and abstinence, and interpret both as not having sex. A key message of the programme is "Sex can wait, but my future cannot."

**Discussion Points: Reaching Youth**

- At what point should children know about sex, condoms, and prevention?
- How do we reach orphans? When and how do we counsel children who have lost their parents? If not provided properly, psychosocial support can do more harm than good.
- Health workers need to be brought on board youth programmes in an effort to help the health workers become more aware of and sensitive to the unique needs of adolescents.
- Faithfulness messages may be confusing to youth who practice serial monogamy and interpret it as being faithful. We must think about placing more emphasis on abstinence and safe sex through use of condoms.

**2. STIGMA****Purpose:**

To describe what stigma is and how it affects behaviour change. The findings of a USAID-funded study on addressing stigma in HIV/AIDS in three countries—Tanzania, Ethiopia, and Zambia—were presented. Carried out from April 2001 to October 2003, the study yielded recommendations for BCC interventions that can be developed to minimize the effects of stigma.

**Stigma, Denial, and Discrimination: A Three-Country Study****Part 1: Disentangling HIV and AIDS Stigma: Overview of Stigma Study Findings**

Presenter: Jessie Mbwambo, University of Dar es Salaam

Stigma is just as devastating as HIV and AIDS, yet little has been done in this area because it is a difficult subject to study. Stigma can be defined as “an attribute that is deeply discrediting [and that reduces the bearer] ... from a whole and usual person to a tainted, discounted one” (Goffman, 1963).

The study used both quantitative and qualitative methods to conduct a community-based, comparative study involving one rural and one urban site in each country and to carry out six sub-studies with different target groups in each country. Altogether, the study yielded more than 700 qualitative transcripts and 400 survey respondents. The data include responses from a wide range of groups, including PLHA, youth, religious leaders, community members, and healthcare professionals.

The study found that stigma exists for various reasons, such as incomplete knowledge about HIV and AIDS, incorrect beliefs, fears of death and disease, sexual norms, and limited recognition of stigmatizing actions. Socioeconomic status, age and gender all influence the experience of stigma. The experiences of stigma consist of physical and social exclusion from family, gossip and taunting, loss of identity in the community, and loss of access to resources, such as housing, employment, and health care. However, internalized stigma is also common.

The data suggest that stigma undermines programmatic efforts around testing, disclosure, prevention, and care and support. But positive experiences extending from stigma also exist and provide opportunity for change. For example, PLHA are already playing a central role in tackling stigma by educating others and helping to foster knowledge about HIV/AIDS.

In conclusion, in programming interventions to deal with stigma, it is critical to consider the following elements:

- Creating recognition of stigma
- Fostering in-depth knowledge about all aspects of HIV and AIDS
- Providing safe spaces for people to discuss beliefs that underlie stigma
- Finding a common language to talk about stigma
- Giving PLHA a central role



Informal networking: Two participants enjoying a break between sessions.

## Part 2: HIV-Related Stigma in Ethiopia PLHA Sub-Study

Presenter: Aklilu Kidanu, MIZ Hasab

This sub-study investigated how the experiences of PLHA in Ethiopia affected their social identity and their social relationships with the family, community and institutions.

The results are based on the diaries of 14 HIV-positive individuals in Addis Ababa (8 men and 6 women) recorded over a period of seven months. The analysis of the diaries intended to identify forms of stigma, contributing causes, the responses of PLHA, and ways to reduce stigma.

The study found that stigma is encountered by PLHA in every social domain, in the family, which is frequently the first source of stigma, the community, and in institutions such as the government, religious bodies, and health institutions.

In addressing stigma, it is important to design interventions that address the various causes of stigma in each domain. To help PLHA deal with their own sense of shame and denial, the healthcare setting can be a source of encouragement for self-disclosure. For the family, targeted educational campaigns to inform them about HIV disease progression and outreach counselling to sensitize them on their stigmatizing actions can facilitate change in their attitudes. Targeted educational efforts can also allay the misconceptions of HIV transmission and contagiousness of PLHA in the community. Similarly, institutions need to be sensitized about stigma and the important role they themselves play in supporting and advocating for PLHA.

### **Part 3: Pictures of Stigma: Children's Experiences of HIV-Related Stigma in Zambia**

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Presenter: Levy Chilikwela, ZAMBART

This community-based research focused on children affected by HIV/AIDS, either HIV-positive themselves or orphans due to HIV/AIDS, in urban and rural sites in Zambia. The study involved several groups of children with HIV/AIDS: school-going children, street children, children living with HIV/TB, non-school attenders, and community school attenders. It aimed to document children's experience of stigma, to understand its causes and impact on their well-being, and to explore the role that children play in propagating stigma.

Overall, it showed that orphans and street children with HIV/AIDS were stigmatized. The study found that children experience blame for their situation. Orphans are subjected to mistreatment in various forms, such as being assigned a heavier workload in the home, and suffer both material and emotional deprivation. This stigma leads to greater vulnerability of children and young people and, because children subject to the effects of stigma are more likely to experience low self-esteem and fall into high-risk behaviour for survival (e.g., running away, living on the street, selling sex), fuels the spread of HIV.

Strategies identified for addressing stigma in children include improving education on HIV/AIDS for both children and adults, greater awareness of stigma and children's needs among adults involved with children and the community, free education and greater material support for families coping with HIV/AIDS, psychosocial support for children and guardians, and involvement of churches in reducing stigma.

### **Part 4: A Toolkit for Understanding and Challenging Stigma**

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Presenter: Anton Schneider, The CHANGE Project

The CHANGE Project and the International Centre for Research on Women (ICRW) worked together to develop a toolkit based on the findings of the study. The toolkit was intended to address the five themes emerging from the findings:

- Recognise stigma
- Enhance knowledge and reduce fear
- Provide a forum to discuss values and beliefs
- Find a common language for understanding stigma
- Involve PLHA

Because stigma is not always visible, the toolkit provides exercises to let everyone see stigma from two perspectives, that of the "stigmatized" and that of the "stigmatizer." The toolkit aims to create an understanding and awareness of stigma and to help individuals and communities to "own" the problem and develop an action plan to respond to stigma. It contains a compilation of user-friendly tools, exercises, and activities for participatory learning. The key target groups for the toolkit consist of AIDS educators and counsellors, community groups, and PLHA and their families; however, the toolkit can be customized for use by multiple audiences.

The toolkit is available online through the CHANGE Project web site at <http://www.changeproject.org/technical/hiv aids/stigma.html>.

### Discussion Points: Stigma

- The act of disclosing one's status is often said to reduce stigma because it was the mere act of keeping one's serostatus secret that caused the stigma in the first place. But is disclosure truly necessary? Are we putting too much pressure on people to disclose something they do not want to reveal? Disclosure is very selective, but it happens inevitably when a person becomes symptomatic. Pushing people against their will to disclose usually produces negative outcomes. We need to see disclosure as a process and train counsellors to work with people over a period of time to ensure that disclosure takes place in a safe environment.
- The lack of understanding of the difference between HIV and AIDS contributes to stigma. We propagate the confusion by referring to "HIV/AIDS" rather than to "HIV and AIDS." We need to begin making the distinction clear between HIV as an infection and AIDS as a disease.
- The healthcare setting is one of the first places where people experience stigma. Much more needs to be done to address stigmatizing attitudes of health workers through training.
- In addressing the issue of stigma, it was initially thought that people could be divided into "the stigmatizers," "the non-stigmatizer," and "the stigmatized." However, there is no such group as "the non-stigmatizer." The toolkit focuses on the two groups that exist.

### 3. GROUP WORK SESSION

The participants divided into four groups to discuss key questions on the ABC approach, BCC for care and support, youth, and stigma. The group discussions yielded further insights and ideas from participants on how BCC can effectively address salient issues within these topics.

#### Group 1: ABC Approach

*a. What kind of BCC activities and programmes are in place for promoting delayed onset of sexual activity?*

The group discussed the following approaches used to reach youth:

- Peer education
- School programmes
- Church-sponsored programmes
- Use of youth role models (e.g., celebrities, TV and radio spots, drama)
- Development of parent-to-child discussion materials
- Teen centres attached to health centres
- PPP (peer, parent, provider) programmes to improve the skills of parents, sensitize healthcare workers, and train the peers to positively influence each other

- Mass media campaign for youth
- Youth-friendly corners with youth peers for counselling and connected to healthcare providers
- Secondary abstinence
- Non-penetrative sex

*Issues for promotion of A (Abstinence):*

- Sexual coercion
- School-based transaction sex
- Abstinence viewed by youth as “taking a break” from sex

*b. What kind of BCC activities and programmes are in place to promote fidelity?*

- Church programmes to keep families together (e.g., counselling for couples prior to marriage)
- PMTCT programmes to promote fidelity as part of the services for women and their partners

*Issues for promotion of B (Be faithful):*

- Need to define faithfulness within and outside of marriage
- Strong role for faith-based organisations (FBOs)
- B message is confusing to youth who practise serial monogamy
- Need to combine B with accurate self-risk assessment

*c. What kind of formative research is needed to develop the correct message mix?*

- Participatory formative research with target populations
- Messages people are hearing in general regarding ABC
- Topics addresses and included:
  - Personal risk perceptions
  - Channels and “words”
  - Role models
  - Getting intimate without penetrative sex
  - Sexual behaviours
  - Sexual coercion
  - Faithfulness and what does it mean for youth
  - Age of first sexual contact
  - Content analysis of faith-based messages

**Group 2: BCC for Care and Support***a. What are opportunities for BCC within a care setting?*

For healthcare providers in the clinic setting:

Target Group	Issues	Opportunities and Entry Points	Inventions
<b>Clinicians</b>	<ul style="list-style-type: none"> <li>• Lack of adequate information</li> <li>• Inappropriate attitudes</li> <li>• Communication skills</li> <li>• Readiness</li> <li>• Knowledge of ART</li> <li>• Stigma</li> </ul>	<ul style="list-style-type: none"> <li>• Referral mechanism</li> <li>• Training to address attitudes</li> <li>• Existing basic knowledge base</li> <li>• Relationship with client – one-to-one communication</li> </ul>	<ul style="list-style-type: none"> <li>• Formative research</li> <li>• Support materials</li> <li>• Upgrading communication skills of service providers</li> </ul>

For home caregivers:

Target Group	Issues	Opportunities and Entry Points	Inventions
<b>Home care providers</b> <b>Community health workers</b>	<ul style="list-style-type: none"> <li>• Inadequate knowledge of HIV and treatments available</li> <li>• Inadequate educational materials</li> <li>• May follow harmful practices and beliefs</li> <li>• Inadequate information on nutrition</li> <li>• Varying literacy levels</li> <li>• Gender dimensions/male involvement</li> <li>• Skills in psychosocial support</li> <li>• Lack of resources</li> </ul>	<ul style="list-style-type: none"> <li>• Knowledge of local culture</li> <li>• Community dialogues</li> <li>• Existing caring skills</li> <li>• Respected members of community</li> </ul>	<ul style="list-style-type: none"> <li>• Formative research</li> <li>• Support materials</li> <li>• Enhancing communication skills</li> <li>• Low-literacy materials for communications</li> <li>• Upgrading information and training in HIV/AIDS, treatment, OIs</li> <li>• Experience sharing among caregivers</li> <li>• Referral system</li> </ul>

For PLHA:

Target Group	Issues	Opportunities and Entry Points	Inventions
<b>PLHA</b>	<ul style="list-style-type: none"> <li>• Adherence to treatment</li> <li>• Sexual behaviour</li> <li>• Knowledge of OIs</li> <li>• Knowledge of ART</li> <li>• Knowledge about VCT and where to get services</li> <li>• Disclosure</li> </ul>	<ul style="list-style-type: none"> <li>• Support groups</li> <li>• Community-based organisations (CBOs)</li> <li>• FBOs</li> </ul>	<ul style="list-style-type: none"> <li>• Formative research</li> <li>• Provision of information on HIV/AIDS, ART, OIs, VCT, and nutrition</li> <li>• Supportive counselling through post-test clubs</li> </ul>

For the general public:

Target Group	Issues	Opportunities and Entry Points	Inventions
<b>General public</b>	<ul style="list-style-type: none"> <li>• Stigma</li> <li>• Understanding of ART</li> <li>• Treatment-seeking behaviour</li> <li>• Sexual behaviour</li> </ul>	<ul style="list-style-type: none"> <li>• Community health programmes</li> <li>• Positive cultural sexual practices</li> <li>• Mass media, folk media</li> <li>• Positive role models</li> <li>• Traditional healers</li> <li>• Community leaders</li> </ul>	<ul style="list-style-type: none"> <li>• Formative research</li> <li>• Low-literacy materials</li> <li>• Advocacy</li> <li>• Information on HIV/ AIDS, ART, OIs</li> <li>• Use of mass media channels</li> </ul>

*b. What are the key lessons learned to date in programming BCC for PMTCT, VCT, and ART?*

PMTCT:

- Need to target men
- Need awareness of PMTCT beyond the health facility
- Cultural context must be considered
- Need to create demand for PMTCT
- Women who are not breastfeeding are stigmatized

VCT:

- Need to create demand for VCT
- Need to coordinate linkages with prevention, care and support services
- Services are inadequate to meet demand

ART:

- Need to address difficulties in explaining technical concepts and words
- Need to address stigma in the healthcare setting
- Need to improve knowledge of ART

### **Group 3: Youth**

*a. The best BCC interventions for youth in HIV and AIDS prevention programmes:*

- Involve youth in message design and approaches
- Involve youth in implementation of youth-oriented activities such as drama
- Ground interventions in the reality of the experiences of youth
- Give youth room to express their needs
- Define youth clearly in order to focus on their specific needs
- Segment youth in terms of where they live (rural versus urban, different age groups)
- Use the family as an entry point
- Strengthen the role of the family
- Use multiple media and a variety of entry points to reach youth
- Isolate behaviour as a response to the normative (interpersonal, intrapersonal, social) environment

*b. How can youth be brought in as “full partners” in BCC?*

- Involve them fully in the programme and avoid tokenism, such as including only 1 youth among 15 adults
- Give youth technical support and freedom
- Build the capacity of youth to operate their own programmes
- Use the voices of youth to express youths’ concerns

*c. How can out-of-school youth be involved in BCC for HIV and AIDS prevention programmes?*

- Need to understand where they are to incorporate their concerns
- Need to bring them together and understand their problems

*d. What additional knowledge and skills do youth require in BCC to change/sustain their behaviour?*

- Mentoring skills
- Understanding of the decision-making process to enable them to recognise their motivations
- Negotiating skills
- Understanding how to deal with peer pressure
- Healthy lifestyles
- Leadership training

**Group 4: Stigma**

*a. How can we better identify and measure stigma?*

- Talk to people who are most affected, including orphans, PLHAs, and institutions who deal with them
- Begin by assessing our own attitudes
- Talk to people who are not affected by stigma to understand the range of ways people stigmatize unwittingly
- Look at what the media presents as stigma
- Use creative ways, such as drama, to identify stigma
- Establish reactions of institutions in the community, such as schools, health facilities, insurance organisations, and the workplace
- Use checklists with specific questions
- Review policy statements made by institutions

*b. Is it better to focus on the problem of stigma, or on the benefits of non-stigmatizing behaviours and attitudes?*

- Focus on the nature of both issues to identify issues that need to be addressed; both are needed to identify/recognise the problem
- Focus on benefits of non-stigma to help to identify positive messages



Group work session in progress.

*c. What interventions seem to work for stigma?*

- Involvement of people affected by HIV and AIDS
- Compassionate kits used by FBOs
- Supportive policy frameworks that provide care and medical schemes for PLHA
- Supportive legislation
- Treatment
- Informing people about their rights
- Integrating HIV and AIDS into training curricula for theological colleges
- Training religious leaders
- Community dialogues
- Showcase positive behaviours through positive role models
- Use of celebrities
- Post-test clubs

*d. With which target audiences can we have the strongest impact?*

- Healthcare workers and counsellors; they are accessible, provide services, and the community watches what they do
- Leadership at all levels, including political, community and religious; people look up to them
- The media; they are both owners and practitioners
- Families; they need support on all levels as they are dealing with practical problems on a daily basis

*e. What policy recommendations should be made to reduce stigma?*

- Access to services for PLHA, including housing, insurance, education, and employment
- Make information available to all
- Legislation to discourage discriminatory behaviour or enforcing existing legislation
- Training for law enforcers to put the law into effect
- Supporting and protecting individual rights

## 4. RESEARCH, MONITORING AND EVALUATION

### Purpose:

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Research, monitoring and evaluation are essential for high-quality and sustainable BCC programmes. This session examined the theories, methods, and challenges behind measuring the process and outcomes of behaviour change, and highlighted practical experiences of BCC programs that have applied research, monitoring and evaluation to inform their strategies and activities.

### Part 1: Research, Monitoring and Evaluation

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#### Application of BCC Theory: Lessons from Horizons Activities

Presenter: Karusa Kiragu, Population Council/Horizons

The BCC theory study, carried out by the Horizons Project, aimed to examine how the project has applied behavioural theory to its work, to identify lessons learned as a result of that application, and to assess the usefulness of behavioural theory. Theory is a formalized set of inter-related concepts that present a systematic view of a behaviour (e.g., the theory of gender and power describes how women and men are expected to behave and how culture dictates this dialogue). It is important to keep in mind that no theory remains static; rather it evolves over time and new theories emerge continually.

The study involved a retrospective review of 10 Horizons case studies, covering 11 countries, to analyse the theories used, the utility of theory in the research design, and the lessons learned. The theoretical frameworks used in the studies can be categorised broadly into theories that address (a) individual health behaviour, (b) interpersonal health behaviour, and (c) group and community health behaviours. Examples of how different theories were applied in the three studies in the Dominican Republic, Zimbabwe, and Vietnam were presented. As an example, the analysis of the Zimbabwe case study showed that the following theories were applied to implement a theoretically grounded strategy for increasing the involvement of male partners in antenatal care:

- *AIDS Risk Reduction Model* influenced the design of counselling sessions and BCC materials by focusing on risk perceptions
- *Social Cognitive Theory* influenced the intervention by emphasizing the component on skills-building
- *Theory of Gender and Power* enabled the assessment of the overarching role of gender and the benefits of involving men
- *Diffusion of Innovation* guided the design of the community component, especially the “innovation” of men attending clinics with their partners

The main lessons learned include the following:

- Use theoretical frameworks that address multiple influences, such as individual, relational, community and environment
- Use behavioural theory to inform all stages of the intervention
- Plan ahead on how theory will apply to your project
- Be committed to carry through the application of theory
- Note that behaviour change theories can be adapted to different cultural contexts

### Challenges in Measuring Behaviour Change

Presenter: Arvind Singhal, Ohio University

There are many problems and challenges in measuring behaviour, as shown in the metaphoric challenges that follow.

**Metaphoric challenge #1: The Tree Trunk or Broom.** This is the story of a professor who discovered a new animal species and brought one of the creatures to a tent in the town square to show it off. A crowd gathered and the professor invited people into the tent one by one, but under the two conditions that they enter blindfolded and they spend only one minute inside the tent. They could touch, but not see. Four persons entered and then exited the tent, reporting to the curious onlookers what they had felt and touched. To the first person, the animal felt like a tree trunk. He was a carpenter accustomed to textures of wood. The second person thought it felt like a carpet roll. He was a carpet weaver. The third person, a child, said he grabbed on to something and it felt like a swing. The fourth person, a scavenger, was certain it was a smelly broom. When at last the professor unveiled what was in the tent, to everyone's surprise, they saw an elephant, a living and breathing animal.

Were the blindfolded people right or wrong in their answers? All were correct from their own points of view, but each of their views formed only part of the picture. Their interpretations were shaped by their world view and experiences; they were partisan and biased. They were “seeing” what they were best equipped to see.

This exemplifies a fundamental problem in measurement. There are many ways to measure, and each can provide valuable and useful information, but each can also be problematic.

**Metaphoric challenge #2: The Cheese Effect.** In physics, Heisenberg's uncertainty principle argues that the act of trying to accurately measure the position of a subatomic particle is intrusive. In other words, measurement itself is an intervention that shapes and influences the outcome. In the area of BCC, it is not easy for researchers to observe private behaviours that affect the transmission of HIV/AIDS. Most quantitative studies rely on indirect proxy measures, such as self-reports or reliable biological markers such as the number of antenatal clinic (ANC) attendees. Self-reports are used primarily to collect data on the number of sexual partners, number of occasions of protected and unprotected sex, the percentage of condom use, and the like. However, self-reports suffer from the “cheese effect”; the effect that leads one to say “cheese” to produce a smile when one looks toward a camera. That is, people deny behaviours that can be construed as socially reckless and in turn, say “cheese” when responding to questions so that they sound more responsible.

This shows that self-reports may not be trusted completely; however, it does not mean that quantitative research is of no use. Quantitative research can help to monitor changes in behaviour and the data are valuable for evaluation, but by itself, it is often insufficient to capture the complexity of AIDS-related issues.

On the other hand, qualitative research is open-ended and unbounded by predetermined variables. It can be contextual and summarized by narratives. It uses methods such as observation and in-depth interviews that often can unravel the complexities of local knowledge, culture, and social peculiarities. The AIDS pandemic dramatizes the need for qualitative research to gather in-depth information. However, qualitative research also has limitations, in that there is the risk of researcher bias. Qualitative research also does not have high external validity, as findings may not be generalizable to the larger population.

**Metaphoric response to the challenges: Look Up Into the Sky.** Seafarer explorers, like Christopher Columbus, steered their course by looking up into the sky to survey the stars. They used triangulation, the technique of determining position by finding three points, to navigate their way. Similarly, to address the challenges of HIV/AIDS research, multiple methods must be used. Qualitative, quantitative and participatory methods each have strengths, but each by itself will provide only partial understanding. But many partial understandings assembled together can be used to make a more holistic picture. There are many forms of triangulation—data, investigator, theoretical, methodological—that can be used to measure behaviour change.

Evaluation of most HIV/AIDS programmes often takes a top-down approach, in which participants are viewed mainly as objects of the study rather than as partners. Quantitative studies are often emphasized over qualitative insights. However, given the real needs of families and communities, people-centred methods in social change measures play an important role.

### **Global Indicators for HIV and AIDS: Do They Measure Behaviour Change?**

Presenter: Jacob R.S. Malungo, University of Zambia.

Effective planning and implementation of HIV/AIDS programmes must incorporate behavioural issues into intervention strategies and action plans. To make comparisons, standard and acceptable indicators must be adopted and measured. Indicators are critical for understanding, monitoring, evaluating and determining the direction of HIV/AIDS programmes. Numerous indicators have been developed, but only those put forth by UNAIDS are classified as core indicators. Core indicators related to measuring are essential for describing the risk profile of a population, while additional indicators aid in the interpretation of the core indicators. (For additional details on the HIV/AIDS core indicators, refer to *Monitoring the Declaration of Commitment on HIV/AIDS: Guidelines on Construction of Core Indicators*, UNAIDS, 2003. Available online at <http://www.unaids.org>)

Indicators of sexual behaviour and risk factors (e.g., sexual mixing, condom use, age at first intercourse, number of sexual partners) are useful in assessing the chance of HIV infection in a population not yet infected by HIV. However, data collection of sexual behaviour is difficult for a number of reasons. For instance, people may not want to talk about their actions or they may interpret the questions differently from what was intended. While indicators are critical, many issues must be taken into consideration in their application. Various sources of information must be used (triangulation)

in verifying behaviour change. To confirm behavioural changes, data should be available over a long period of time (a longitudinal study) and for more than one set of data (cohort).

Several issues relevant to understanding the significance and measurement of core indicators related to sexual behaviour are as follows:

- *Sexual mixing* is measured for adults by higher risk sex with a non-cohabiting partner in the last year and for youth by premarital sex in the last year. The choice of a sexual partner affects one's chance of acquiring HIV, but non-cohabiting partners may not know the infection status or the risk behaviour practices of their partners. The prevalence of HIV infection in a population, previous exposure to infection, and the context of sexual relationships must be taken into consideration.
- *Age mixing*, in terms of older men having sex with younger women, is seen to be a critical factor in exacerbating HIV transmission. Important factors in measuring age mixing include the cultural power to negotiate for safer sex, multiple sex partners, and previous exposure to HIV infection. Determining age mixing or the extent of age mixing is affected by the reliability of data; for example, many people do not know their real age or their partner's real age or they are not willing to disclose this information.
- *Condom use* is measured by five indicators covering condom use: at last higher risk sex, last commercial sex, last pre-marital sex, last higher risk sex among people ages 15-24, and at first sex. Correct and consistent condom use is important, and consistent use is described in terms of frequency: always, sometimes, and never used. Condom use is influenced by attitudes toward the effectiveness, benefits, and convenience of condoms, and sexual partners often stop using a condom after trust has been developed in the relationship.

In conclusion, a number of indicators have been developed to measure sexual behaviours and it is important to understand the factors that influence their measurement. Indicators vary across sub-groups and populations and help in comparing different data sets on behavioural changes. Indicators do not reveal the whole picture, however, and they should be used in conjunction with other available information.

#### Discussion Points: Research, Monitoring and Evaluation

- Formative research can guide the selection of an appropriate theory for a particular intervention. For example, if self-risk assessment is an issue that needs to be addressed, the AIDS risk reduction model would be relevant. Measuring the efficacy of a theory for a particular intervention involves using rigorous approaches, such as asking questions on selected behaviour change based on the theory.
- The process of defining a problem by collecting baseline data is an intervention in itself and may influence the outcome. In other words, the research we do is an intervention. One important way to minimize the effect of the research itself on the data that are collected is to sample judiciously and to also collect data from a different group of healthy people to measure impact.

## Part 2: Practical Experiences in Research, Monitoring and Evaluation

### Lessons from the HEART Campaign

Presenter: Elisabeth Serlemitos, ZHIPCOMM

The HEART (Help Each Other Act Responsibly Together) campaign is an example of a youth intervention designed by youth in Zambia. The majority of youth in the country (about 84%) are sexually active by the age of 19 and do not use condoms. Based on this social context, the youth need to perceive their risk and to know that they have two options: to abstain from sex or to use condoms every time they have sex. The B message of being faithful is not an option for youth because serial monogamy in a high-prevalence environment is an excuse to have unprotected sex.

The government of Zambia called on Zambian youth to play a greater role in programmes for their peers. Taking on the challenge, the youth, in partnership with collaborating agencies, launched HEART, a national mass media campaign using TV and radio spots, posters, and music. It involved full participation by youth in every stage of the campaign process, including planning, data collection, design, implementation, and M&E, and the campaign has a youth advisory board to encourage youth ownership. HEART focuses on safer sex or abstinence for youth, with an emphasis on leadership. It is about making it easier for youth to exercise options. The audience was segmented and messages were developed specifically for male and female youth in urban areas.

The pre-test and post-test surveys of the campaign found that television was an effective way to reach the youth. Viewership of the campaign was correlated with the practice of abstinence and condom use. Viewers discussed abstinence or safer sex with more people than did non-viewers. The data also suggested that there was a “dose effect,” in which more exposure to the campaign led to more positive behaviour.

Challenges to the programme include the facts that: women and girls often lack the power to overcome the effects of the gender differential within the culture (e.g., such as in negotiating condom use), mass media tends to be less effective in reaching rural youth, there is a need to continually recruit young people and get them involved because the youth who are currently involved age and move on to other activities, and it is essential to ensure that the messages complement messages from other youth programming. The success of the campaign demonstrated that youth leadership is critical and that mass media can play a key role, but that it should be complemented by consistent messages through multiple channels.

### Findings from the Evaluation of the IMPACT/Kenya BCC Strategy

Presenter: Peter Mwarogo, FHI

Communities do not change all at once. Behaviour change begins with a small group of individuals who are the early adopters, and subsequently diffuses from the few to the many. The key questions are how to facilitate behaviour change in the few and then how to extend that behaviour change from the few to the many. In the former, a series of focused dialogue activities, such as peer education among target groups can promote critical reflection that leads to behaviour change. Magnifying the behaviour change of the few to the community, through channels such as magnet theatre or the radio, can then encourage wider adoption of the change.

This line of thought formed the rationale for the BCC strategy of the IMPACT project in Kenya. The main objectives were to improve understanding of the distinctions between exposure to HIV and HIV infection, and HIV infection and AIDS; improve confidence in the use of condoms; create greater interest in VCT; increase understanding of the risks of unprotected sex with multiple partners; and improve negotiation skills. The programme used a mix of BCC interventions to reach identified target groups (e.g., out-of-school youth, in-school youth, men in large worksites, women in low-income communities, and female sex workers) and the larger community. The activities consisted of peer education, magnet theatre, weekly interactive radio show, comic books, and community and school murals.

A recent evaluation of the strategic approach and major interventions of the BCC programme revealed several valuable findings:

- The effectiveness of peer education and of listening to the radio differs by target group; therefore, the continuation of a comprehensive BCC strategy with a mix of different prevention activities for the same target group is important.
- The comic book, radio programme, and magnet theatre seem to be more effective in stimulating discussion of real life experiences and in demonstrating examples of responsible decision-making to the target population.
- The fixed-group peer education strategy (i.e., the same people continue to meet as part of the same peer support group) enables exploration of issues in-depth, but such a strategy has limited reach, and thus limits the possibilities for expansion of the behaviour change. There is need to review this approach if scale-up is one of the objectives.
- Peer education seems to be useful in communicating knowledge about HIV and AIDS, condoms, and VCT.

The conclusion that interventions should complement one another supports the need for a comprehensive BCC programme.

### **Participatory Research in HIV/AIDS: Whose Reality?**

Presenter: George Mark Onyango, Maseno University

In participatory research, outsiders engage insiders (the community) through two-way communication to focus on a specific issue. The attitude is one of partnership. Participatory research aims to gather information that is useful, rather than perfect, to support traditional research and to explore new ways to look at old problems. Behaviour change activities usually focus on a top-down transfer of information rather than on prevention. We must “learn to unlearn” conventional research thinking and use participatory research in planning BCC programmes to build on people’s perceptions and experiences and to acknowledge that the community knows its own situation best.

Participatory research methods used for HIV/AIDS programmes include social mapping, role-play, participatory planning and management, and participatory monitoring. These methods yield information that cannot be gathered by outsiders alone; they need the participation of the community. For example, social mapping involves the community in visually depicting its physical layout, social infrastructure, demography, health patterns, and other features. In Kenya, for example, there is a cultural practice that dictates that when a man without a male child dies, his home is closed irrespective of the existence of female orphans. This reality affects the social mapping of homes with widows and orphans and those that have been abandoned due to death.

Participatory research provides valuable insight into understanding the dynamics of HIV/AIDS and makes it easier to gather information through an informal process. The participatory approach is complementary, but not a substitute, to conventional approaches.

#### Discussion Points: Practical Experiences in Research, Monitoring and Evaluation

- Linking behaviour change to key biological markers (e.g., prevalence of HIV) is a difficult challenge. We know that theoretically BCC will affect biological markers, but other elements also affect them. It is complicated to isolate the impact of one intervention from the impacts of others in the community even with control studies. Communication is a process, and behaviour change requires time. Finding evidence for a connection between behaviour change and biological markers requires long-term commitment, money, and resources. As BCC practitioners, we do not advocate strongly enough for a realistic understanding of what behaviour change can achieve. We need to focus on measuring what is under our control (e.g., assessing behaviour change) in terms of communication objectives. It is the role of BCC practitioners to help others understand and appreciate this type of input.
- The issue of who determines the indicators is important. Demonstrating the success of working to scale in BCC depends largely on the establishment of systems to monitor BCC programmes. Indicators should be a two-way street, responding both to the needs of donors for data and to the goals and objectives of the programme set by the advisory design group.
- Once systems are in place, there are opportunities to use more participatory approaches when developing indicators.

## 5. OPEN FORUM: PEER EDUCATION

### Purpose:

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Peer education has been widely used by BCC programmes as one of the primary channels for facilitating behaviour change in HIV/AIDS. However, we are only beginning to look at the relative effectiveness of the processes for establishing peer education. The open forum focused primarily on the approaches of two evolving peer education programmes, one in Southern Africa and the other in Kenya, that facilitate community discussion and problem-solving in order to draw lessons learned in implementing successful peer education.

### Project Support Group Southern Africa

Presenter: Rita Muyambo, PSG

The Project Support Group (PSG) is a regional peer education programme involving eight countries in Southern Africa: Botswana, Malawi, Mozambique, Namibia, South Africa, Swaziland, Zambia, and Zimbabwe. It relies on carefully trained volunteer peer educators from the community to disseminate information on HIV/AIDS and to mitigate the impact of the epidemic through outreach to vulnerable groups, such as orphans and vulnerable children (OVC). PSG targets peer education to those at high risk of HIV infection, such as women with STIs, sex workers, uniformed workers, truckers, and other mobile populations.

PSG uses a participatory model to establish peer education in the community through the following steps:

- Mapping and zoning the community into discrete manageable sections
- Recruiting volunteers from the community
- Training volunteers on the peer education methodology, condom distribution, STI care, and care for other diseases using an established curriculum
- Providing outreach in the community through communication channels, such as role-plays, games, and drama
- Distributing condoms
- Ensuring referrals for STI care
- Participatory M&E to track inputs, outputs, costs, coverage, behavioural impact, and STI impact

PSG has found that targeting is very important in peer education, programmes must be appropriately tailored to the specific needs of the audiences, and monitoring will help to ensure quality and to achieve the intended benefits of peer education.

## **The Paradigm Shift in the IMPACT Peer Education Programme, Kenya**

Presenter: C.Y. Gopinath, PATH

Although many BCC programmes use peer education, the quality varies. It is important to ask ourselves how we can make peer education more effective and to explore ideas on how to improve approaches to peer education, including making the best use of the peer educator. In an effort to strengthen its peer education programme, the FHI/IMPACT project in Kenya has been trying several different paradigms of the central role of the peer educator.

### *The peer educator as a source of knowledge*

The project found that it was easy for peer educators to stand in front of a group, but that they did not know enough to act as mwalimus (Swahili for “teacher”). They felt they did not really know all about HIV/AIDS, although the group expected them to have such information and posed questions beyond the basic knowledge level of the peer educators. The peer educators viewed their role as mainly communicating messages, rather than answering questions and discussing issues with the audience.

The first major paradigm shift in the peer education programme, which has taken nearly two years for IMPACT to incorporate, has been the move from teaching to facilitating. Peer educators are taught that they do not have to have all the answers; instead, they only need to facilitate the discussion. It is acceptable for them to admit that they do not know the answer to a question, to search for answers in the group by querying others, and/or to propose to return to the next meeting with an answer. This shift in the mentality of the peer educators has produced a change in the dynamic of the peer education process.

### *Assessing pertinent issues for the peer group*

The second change has been the shift from answers to questions. The correct question is actually more important than the correct answer. For example, the range of questions from every individual in a group can provide valuable insight into their level of perceived risk. Those with lower risk perception will generally ask superficial questions, whereas those with higher risk perception will raise more urgent, personal, and detailed questions. The process of peer education must have as a new objective the improvement of the quality of inquiry. This can be achieved by providing opportunities for the same people in a group to meet repeatedly to dig deeper and to help each other deal with issues they are afraid to face, thus building a process that supports behaviour change.

### *Promoting dialogue*

Through the IMPACT project, weekly radio discussion groups facilitated by peer educators have been formed as a medium for peer education. These groups use various tools, such as picture boards, to engage members in a dialogue that moves from facts about HIV/AIDS to feelings and relationships affected by HIV/AIDS. In-depth technical information about HIV/AIDS is provided when the group asks for it. The key is to maximize change in such a way that people will eventually change their behaviour.

### Discussion Points: Peer Education

- While the paradigm shift in the Kenya IMPACT programme is an exciting development, it has also brought about new logistical management challenges around modifying the programme and scaling up with the new approach of peer facilitation. This shift has required new training for existing peer educators; it also places more demands on them and requires them to commit more time (often more than they justifiably can) to the programme.
- The facilitator approach to peer education reduces the distribution of leaflets and materials dramatically. Instead, discussion guides are used to provide technical information on HIV/AIDS. Materials play a very different role than they did under the previous paradigm; they are not disseminated to the group, but rather remain with the peer educators.
- Burnout among peer educators is a reality. What effective strategies can keep peer educators motivated and address burnout? Should peer educators serve on a voluntary basis or receive payment? In projects supported by PSG, some peer educators have served for more than 10 years. PSG tries not to use monetary incentives. Instead, it awards certificates for completion of various trainings, encourages exchange programmes, and aims to build a sense of solidarity among peer educators.
- How long should a peer educator remain a peer educator? In the same vein as above, how long should a fixed peer education group stay together? The IMPACT/Kenya peer education programme is moving toward a modular approach that enables groups to explore one theme at a time for a defined period. In this sense, peer education is packaged in smaller doses. Peer participants sign up for a module and are given the opportunity to join the next module if they desire to continue.
- In many peer education programmes, peer educators have been recognised as role models and given a higher status by the community. This is a measure to consider in evaluating peer education.
- Many problems of quality are evident in peer education programmes due to erroneous information, lack of resources, and lack of effective tools. The questions remain of how to deal with quality control in peer education and how to enforce it without using extra resources.

### A Faith-Based Approach to HIV/AIDS

Presenter: David R. Mpunwa, Upper Room Ministries, Zimbabwe

An additional presentation on the faith-based approach to HIV/AIDS in Africa concluded the informal open forum. The faith community has a role to play in facilitating behaviour change in the community and in serving as a voice of compassion and care in the response to HIV/AIDS. In particular, national interfaith networks that have formed in a number of countries in the region (e.g., Uganda, Zambia, Senegal, and Kenya) are helping to build the capacity of religious organisations to participate in HIV/AIDS prevention efforts. The next step is for FBOs to network together across countries. Regardless of their differences in religion, FBOs collaborating with one another can contribute greatly to the fight against HIV/AIDS and help to influence the combination of personal, social, and environmental factors that affect behaviour change.

## C. DAY THREE

### 1. PROGRAMMING FOR BCC

#### **Purpose:**

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This panel focused on issues to consider in developing and implementing broad BCC activities and programmes by providing examples of BCC efforts in Uganda, Tanzania, and Ethiopia at the national or regional levels.

#### **Programming for BCC at a National Level**

Presenter: Paul Kaggwa, MOH/Uganda

Advocacy must be at the centre of a national BCC programme. It is important to obtain the support of policymakers, religious leaders, and other allies who can mobilize resources and influence the policy environment for the programme. The Uganda BCC programme operates within the context of the country's decentralized system. It functions at the levels of the central government, district local governments, and sub-counties.

The steps to developing and implementing the programme involved:

- Articulating a national strategy and plan
- Developing guidelines to guide implementation of BCC activities at lower levels
- Orienting districts to the BCC strategy and plan
- Working with districts to translate and distribute BCC promotional and educational materials
- Monitoring implementation of district BCC activities
- Supporting districts with mobile video vans to reinforce social mobilisation

The national BCC strategy and plan was instrumental in providing a framework for the implementation of BCC activities at all levels. It sets the goals, targets, outputs, and indicators for all BCC activities at every level. It also ensures that all players work toward the attainment of the national goal and coordinate their BCC activities.

Uganda's experience in BCC is not limited to HIV/AIDS. It uses BCC strategies to address other public health problems, such as malaria control, polio eradication, and blood-donor promotion. However, it still faces a number of challenges in implementing BCC: inadequate funding, shortage of manpower, attitudes about BCC, desire for quick results, and inadequate research. Nevertheless, the driving motto of the BCC programmes in Uganda is "success at all costs."

### **Programming and Funding a National BCC Campaign: The TACAIDS “Ishi!” Campaign**

Presenter: Justin Nguma, Healthscope

“Ishi” (the Swahili word for “youth”) is a youth-driven multimedia national campaign in Tanzania targeted at young people ages 15 to 24. The objectives of the campaign are to increase risk perceptions of HIV infection among youth, increase the number of youth who abstain or use condoms, and increase the number of youth who seek reproductive health information and services. The key campaign message is “You cannot tell by looking,” therefore, “Abstain or use condoms every time!”

The campaign strategies relied on communication mobilisation, mass media, media advocacy, involvement of political leaders, and linking with service organisations to broadcast the message. Its partners included young people, local government leadership, mass media institutions, advertising agencies, PSI and local NGOs/CBOs, and VCT centres.

Major lessons learned from the campaign included:

- Youth intervention initiatives have high success potential when youth are “placed in the driver’s seat” with clear technical and management support.
- Involvement of youth in the design and development of BCC materials and messages enhances their quality, making them more relevant, while also enhancing youth ownership.
- The youth nature of the campaign attracted significant political involvement in the key campaign events, thus increasing its visibility.
- By the nature of its execution, the campaign forged and enhanced partnerships between the public and private sectors as well as between health and non-health professionals.

The main challenges were the coordination of different partners with varied interests and the need for funds and motivated human resources.

### **Emerging Networks for HIV/AIDS in Ethiopia**

Presenter: Fekerte Belete, PACT

In Ethiopia, PACT has been involved in supporting several networks that have been formed or that are in the stage of being formed: HIV/AIDS Forum, Addis AIDS Action Network, BCC Working Group, and Regional BCC Teams. Ownership of coordination for these networks between the government and NGOs, among key stakeholder NGOs, and among umbrella organisations has proven to be a key challenge. Another challenge is lack of commitment or time by Executive Board and Task Force members.

Lessons learned include:

- Starting with a small group of committed individuals is effective

- Involve the right individuals from key stakeholder groups
- Lobby and advocate for support from government and peer organisations so others will help push the agenda
- NGOs should play a facilitative role and be the driving force behind the scenes, providing technical and financial support

#### Discussion Points: Programming for BCC

- A monitoring framework for a national BCC programme is important to capture data through indicators that measure progress at every stage of programme implementation. A programme cannot be designed without a monitoring framework. Process and outcome indicators are critical for providing information on how the programme is progressing in terms of implementation. Indicators should be correlated with objectives and outputs. In addition, it is important to collect baseline data before the campaign and then conduct a post-campaign evaluation to capture the entire process.
- National BCC campaigns are generally centred in urban areas, focusing less on rural areas. However, there are examples of partnerships that extend BCC to rural areas, by linking with NGOs, FBOs/church structures, and schools that reach out to groups in rural areas.

## 2. PLANNING TOOLS FOR BCC

### Introduction of the Annotated Bibliographies for BCC Tools and FBO Tools

Presenter: Ekong Emah, FHI

The annotated bibliographies of tools for BCC and tools for use by faith-based organizations (FBOs) (compiled by FHI at the request of USAID/REDSO) were presented as an introduction to the following group work session on tools for BCC. The objective in developing these resources is to describe and review tools that have proven useful to BCC professionals and FBOs in addressing the HIV/AIDS crisis. Individually we may not have all the tools, but collectively we have many.

The BCC and FBO tools in these two bibliographies serve as “how-to” guides to facilitate the work of the practitioners and to help make programmes more effective and of higher quality.

The BCC bibliography, still in draft form, provides tools in ten technical categories:

- Formative assessment
- Strategic planning
- Materials development

- Comprehensive programming and planning
- Training
- Peer education
- Mass media
- Public relations
- Monitoring, evaluation and research
- Special topics, such as female condoms, care and support, STDs

The bibliography of tools for FBOs, entitled *HIV/AIDS Prevention, Care and Support Across Faith-Based Communities: An Annotated Bibliography of Resources*, has been produced and can be accessed electronically via the FHI web site ([www.fhi.org](http://www.fhi.org)). It provides information on FBO tools in the following technical categories:

- Assessment and planning
- HIV/AIDS awareness and information
- Behaviour change
- Care and support
- Guidelines and resources

There are many tools that have been developed, in addition to those included in these bibliographies, but the challenge is in knowing they are available and knowing how to access them. The BCC Network and the forum of this meeting can play a role in helping to fill gaps and to identify additional tools for BCC.

### 3. GROUP WORK SESSION

Following the plenary introduction of the BCC Annotated Bibliography of Tools, participants divided into four work groups to review the BCC tools in the bibliography, to exchange information and experiences on BCC tools currently being used, to provide suggestions to improve the bibliography, to identify gaps in existing tools, and to recommend what tools need to be developed or further developed to meet needs. Each group focused on one or two specific topics: (a) formative assessment, (b) strategic planning, (c) youth and materials development, and (d) monitoring and evaluation. The groups presented a summary of their discussions and provided numerous suggestions of additional tools in use or under development. Their feedback on the draft BCC annotated bibliography was noted for consideration in the next round of revision before it is finalized for publication.

The recommendations on future tools development include:

*Additional needs for formative assessment tools:*

- Guide on how to conduct a literature review on BCC
- Clarification that rapid assessments should not replace rigorous ethnographic studies
- Description of the limitations of rapid assessments
- Information on the practical steps for planning and implementing a rapid assessment (e.g., costs, skills needed, and training)
- Guidance on how to adapt tools to the local context
- Guidelines for analysis
- Computerized tools to aid with data analysis
- Provision of specific skills-training for using tools

*Additional needs for strategic planning tools:*

- “How to do” quantitative research tools
- Tools for children
- Tools for community elders and leaders
- Tools for the elderly
- Tools for advocacy
- BCC programme management tools

*Additional needs for youth and materials development tools:*

- Resource centre for tools
- Wider dissemination of tools through electronic channels, such as CD-ROM.

*Additional needs to strengthen monitoring and evaluation tools:*

- Develop core indicators to measure behaviour change
- Demystify M&E and make it an essential step in behaviour change
- Link donor requirements to M&E in programmes
- Develop tools for field and planning levels
- Develop tools that are more user-friendly

#### 4. BCC NETWORK IN ECSA

The Regional BCC Network for HIV/AIDS was conceptualized in 2000-2001 out of a common interest and understanding among several BCC practitioners dealing with HIV/AIDS in the region that something must be done to help address common challenges and needs, improve strategies, and build capacity in the area of BCC. USAID/REDSO, with its mandate to support networking and capacity-building in the region, has been instrumental in providing support to bring this concept of the network from idea to reality.

##### **Review of Past Activities: Brief Presentation of Objectives and Activities of the BCC Network**

Presenters: Denis Tindyebwa, RCQHC, and Janet Hayman, USAID/REDSO

An initial consultative meeting on BCC in the region was held in October 2001 in Nairobi to identify key areas of interest in BCC and to present the idea of the network to a larger group of BCC practitioners. At the meeting, a Task Force was formed to brainstorm on BCC issues and to coordinate BCC efforts in the region. For practical reasons, and to minimize costs, most members of the inaugural Task Force were based in Nairobi.

At a meeting of the Task Force in February 2002, the idea of a wider regional BCC network meeting was endorsed and the Regional Centre for Quality of Health Care in Uganda was appointed Secretariat for the network. The Task Force has spent more than a year planning for this first regional BCC network meeting, with the assistance of FHI and the Academy for Educational Development (AED). Nearly 50 percent of the participants at this meeting have actively contributed to the realization of this meeting.

All participants were nominated specifically to take part in the meeting as individuals who could give something to the discussion and exploration of BCC issues. In this sense, this is a different kind of meeting because it depends on participant input to determine the next steps and the priorities of the network.

The following challenges to BCC and the goals and objectives for the network were identified in the initial Task Force meetings. They were presented to this larger meeting for comments and endorsement, if appropriate, by the participants.

##### *Key challenges to BCC in the region:*

- Short-term project approach, not long-term sustained programme approach
- Limited involvement of and ownership by communities in programmes
- Focus on product, not process
- Underdeveloped local models of BCC addressing cultural and societal issues
- Limited research, evaluation, documentation or dissemination of existing BCC knowledge in the region
- Limited skills in BCC of people involved in HIV/AIDS programmes
- Inadequate policy framework for BCC interventions and programmes resulting in fragmentation of efforts or donor-driven approach

**Goal statement:**

The goal of the network is to revitalize and strengthen effective BCC as a strategic component of HIV/AIDS interventions in East, Central and Southern Africa.

**Objectives:**

- Create national and regional frameworks for strategies for BCC
- Facilitate capacity-building for BCC
- Facilitate establishment of a regional coordinating mechanism
- Promote community participation and process orientation
- Advocate for BCC principles, especially at government levels
- Develop an M&E framework for BCC
- Carry out relevant BCC research and support broad dissemination of findings

These objectives were developed at the first consultative meeting. In the following meeting, the Task Force added new ideas and supported concrete activities for reaching the objectives. For example, to facilitate capacity-building in BCC, the Task Force recommended training in BCC at the national and regional levels. (For additional details, refer to *Meeting Report on Regional Consultative Meeting on BCC for HIV/AIDS*, Nairobi, Kenya, October 11-21, 2001; and *Building Regional Capacity in BCC for HIV/AIDS: Proceedings from the Task Force Meeting*, Nairobi, Kenya, February 21, 2002. Both reports can be obtained by contacting RCQHC, BCC Network Secretariat.)

**Activities to date:**

- Secretariat formed
- Regional meeting held
- BCC compendium initiated to document approaches and successes
- Questionnaire on needed skills distributed to participants

**Request for this meeting:**

The Task Force invited participants at the meeting to suggest ways to strengthen the network, present some ideas for criteria for network membership, draw up terms of reference for the Task Force, and recommend priority areas for Task Force and/or network action. These issues formed part of the group work sessions on Day Four of the meeting.

## 5. BCC NETWORK PRODUCTS

### BCC Compendium

Presenters: Rose Mary Romano (AED) and country consultants Nankunda Allen-Babihuga (Uganda); Rita Mwangale (Uganda); Lawrence Gikaru (Kenya); Esther Sakala (Zambia, not present); Joseph Nyirenda (Zambia, not present)

In collaboration with the BCC Task Force, AED developed a BCC compendium to document BCC practices in Africa and the elements of good BCC programmes and how they contribute to effective behaviour change. The purpose of the compendium is to serve as a resource tool and to increase BCC capacity.

A team of researchers was assembled to collect and analyse data from Kenya, Uganda, and Zambia. The rationale for selecting these three countries for the initial process of documenting BCC interventions and successes was that they have either recorded a decrease in HIV prevalence or there are indicators that prevalence is decreasing with some age groups or in specific geographical areas.. The methodology of the research followed the working definition of BCC put forth by the BCC Task Force to identify BCC programmes. It describes BCC as:

*interventions (approaches, process and practices) which enable an individual, family or community to think, analyse and act on their behaviour in order to reduce the risk of contracting or spreading HIV and mitigating the impact of HIV/AIDS.*

The research team developed several criteria for selecting effective BCC programmes to include in the compendium, including:

- Links to a comprehensive HIV/AIDS programme
- Promotes available services
- Targets specific audience
- Addresses specific behaviours
- Based on BCC research
- Based on input and participation of the target audience and community
- Supported by the community
- Takes into account cultural and social norms
- Has adequate number of trained staff for implementation
- Has adequate resources
- Has adequate period of time for implementation
- Has system for M&E
- Demonstrates cost-effectiveness (added for Kenya only)

The BCC compendium profiles nine BCC programmes—three from each country—that met most of the criteria for “successful” BCC interventions. The selection process raised some important issues about the visibility and understanding of BCC strategies and interventions within larger HIV/AIDS programmes. In general, the best BCC programmes, including the ones highlighted in the compendium, address specific target audiences, involve their audiences, and are based on research. Quality and availability of services for VCT, STI treatment, PMTCT, and reproductive health care for youth are important. Communities also play a vital role in the success of BCC programmes. All three countries have services that must exist to move communication to behaviour change.

The documentation shows that BCC does work. It is a proven strategy and we need to advocate more strongly for the changes that BCC can produce. However, it is important to keep in mind that community mobilisation and involvement in BCC require time. For example, it usually takes at least one year to get a programme off the ground. Therefore, it is important we do not overstate what BCC can do within a limited timeframe and with limited resources. In conclusion, BCC professionals should collaborate to develop a common definition of BCC and document successful BCC programmes, tailor BCC interventions to the realities of local norms and availability of services and resources, and recognise that interpersonal communication is the most powerful tool for changing behaviour.

#### Discussion Points: BCC Programmes

- The working definition of BCC would be improved if it also included “maintain” or “sustain” behaviour.
- Broadening the scope of inquiry would improve the BCC compendium because “the sum is worth more than its parts.” That is, we must consider moving BCC evaluation to the macro-level if we are to examine behaviour change at the national level, rather than at the single-project level, and the contributing roles of different BCC interventions and programs.
- Donors, politicians, and administrators are often impatient to see the results of BCC programmes. As we come up with definitions of BCC, there is also a need to develop a common set of indicators to help us discern whether we are on the right track and to help us respond to requests for data. This issue is a big gap in BCC. Too little work is being done on the stages between knowledge and behaviour change. We need to look into the question of what are the first signs of behaviour change.
- Other non-health sectors that implement communication and behaviour change interventions can offer valuable insight for BCC for HIV/AIDS. For example, we can learn lessons from the Food and Agriculture Organisation (FAO) on how it plans its communications based on theory. We can also learn from the private sector and other health areas, such as smoking cessation activities.
- Forming partnerships is an important element to the success of a BCC programme, as partnerships can greatly expand the reach of BCC interventions.

#### BCC Network Needs Assessment

Presenter: Karusa Kiragu, Population Council/Horizons

A participant needs assessment was undertaken at the meeting to determine the level of experience and areas of expertise among BCC practitioners working for HIV/AIDS programmes in the region. The assessment also sought to gather information from participants on priority areas for capacity-building.

The report of the survey results is presented in Annex 3

## 6. NETWORKING EXPERIENCES

### **Purpose:**

Networks exist for a specific purpose and are time-bound institutions. The experiences of existing networks, whether at regional or national levels, offer valuable insights for the formation of the BCC Network.

### **The Regional AIDS Training Network: Experiences and Issues in Network Management and Sustainability**

Presenter: Jacqueline Makhokha, RATN

The Regional AIDS Training Network began as a project of the Universities of Nairobi and Manitoba in 1997 to bring together training institutions that provide short courses in HIV/AIDS. Its main purpose is to advocate for and support the capacity-building activities of its members. Some of the lessons learned about network management from RATN's experience include:

#### *Planning:*

- Prepare a statement of purpose (mission)
- Define goals and objectives
- Carry out a baseline survey to identify expectations that need to be clarified
- Define the structure and process for decision-making, otherwise decisions will be challenged by the membership
- Prepare a communications plan
- Define the membership
- Define the terms of reference and outputs of the networking hub, whether it is the secretariat or the task force
- Secure resources, because networks do not attract funding easily



Presenters for panel on Network Experiences.

#### *Implementation:*

- Ensure participation of members in achieving objectives and goals
- Continually review the relevance of the network
- Define any changes that need to be made, such as creating new goals or objectives
- Be aware of any changes in the environment
- Periodically monitor progress toward achieving goals as networking needs indicators to show when the network's goals have been achieved and to help decide whether it should come to an end
- Check to see if expectations are being met by conducting membership satisfaction surveys

*Evaluation:*

- Keep in mind goals and objectives
- Identify results achieved as a result of networking
- Identify lessons learned

*Sustaining a network:*

- Sustaining commitment is a long and tedious process; a nominal membership fee may encourage continued commitment by members.
- Process for conflict resolution should be clearly defined for the network at the beginning.
- Communication through a regular channel, such as a newsletter, is key to keeping members informed and soliciting their input.
- Coordination and decision-making are critical roles for the network task force.
- Network secretariat or task force should have a document that states explicitly how it will manage change.

**SAFAIDS Capacity-Building Experience in Southern Africa**

Presenter: Neddy Matshalaga, SAFAIDS

SAFAIDS, the Southern Africa AIDS Information Dissemination Services, was established in 1994. It is based in Zimbabwe and operates in Southern Africa in collaboration with governments, the private sector, development agencies, media organisations, and United Nations bodies.

SAFAIDS's main goals for networking are to build a multiplying effect for good practices via capacity-building, respond to requests for technical assistance, document best practices and successes, and build partnerships.

Recommendations for networking from SAFAIDS's experience include:

*Capacity-building:*

- It is necessary to identify the membership's areas of need. Once the areas are identified, the network can strategize on how to improve the skills of members. It may be necessary to divide capacity-building into efforts at the sub-regional level or around themes.
- Capacity-building of the network institution is important to ensure its sustainability.

*Work toward a common goal:*

- Networks whose partners pull in different directions do not survive. Consensus on network goals and objectives is important.

*Documentation:*

- Documenting and disseminating the success of the network is important to acknowledge the roles and contributions of members. This helps foster a sense of inclusion.

*Communications:*

- Communication strategies among members can include the use of listserves, e-group forums for online debates and discussions, and newsletters and other publications to keep members informed.

**The MIPESA Coalition**

Presenter: Chilunga Puta, MIPESA

MIPESA, the Eastern and Southern Africa Coalition for Malaria Prevention and Control During Pregnancy, stemmed from a regional WHO meeting of malaria control personnel and reproductive health personnel where it was recognised that countries could try to address common problems together. MIPESA aims to foster a sharing of experiences and best practices regarding malaria control during pregnancy in order to overcome programme challenges and to assist in addressing identified programme priorities. At the MIPESA inauguration in 2002, a membership and structure for the coalition were established and an action plan for the first year was drafted. It was agreed that members would play a vital role in contributing issues and topics for discussion. Members have since brought to the coalition issues concerning their countries' problems and solutions in malaria control.

MIPESA is currently involved in a number of activities, including developing guides, piloting indicators, documenting country case studies, and developing resource materials. One major issue in network management that MIPESA has encountered is financing because it must seek its own funds. The lessons learned from the MIPESA experience thus far are that it is important to think ahead about resource mobilisation and to link to global working groups to help member countries address common issues, such as human resource capacity.

**Experiences and Issues for Effective and Sustainable Networking for BCC**

Presenter: Leonard Okello, ActionAid-SIPAA

A network needs to think carefully about what it is trying to do and what products it aims to create. If a network does not produce concrete results, then serious thought must be given to the value-added of the network. One of the challenges to networking for BCC is to define and maintain a dynamic, living, and relevant agenda. In addition, it is important to understand and foster ownership of the network and maintain consensus on BCC.

The questions that remain in BCC are what really shapes behaviour and what is the role of BCC in shaping behaviour? BCC should not create more problems, rather it should provide support for coping with HIV and AIDS. The challenge is to demystify and simplify the HIV virus.

**Discussion Points: Networking Experiences**

- When networks become implementers and compete with the network's members for funds, they become problematic. This occurs when networks are unable to fundraise for networking activities and yet feel the need to create a product so that they can demonstrate to donors that they have a concrete contribution to make. Networks need to advocate with donors. Donor consultative committees, made up of past, current, and potential donors, can help to ensure that donors are partners in a network's choice of activities. These committees also provide a forum for advocacy of the network.
- We need to think about experiences of networking at the country level that feed into regional networking.
- Communication is effective where there is supportive policy and links to services and the communities. In forming the BCC network, it is important to acknowledge that BCC cannot stand on its own; it needs the contributions and resources of other players.

## D. DAY FOUR

### 1. REGIONAL BCC NETWORK FOR HIV/AIDS

#### Key Issues for the Network

Presenter: Denis Tindyebwa, RCQHC

The key issues for the BCC Network can be divided into two areas: technical and organisational. Technical issues include the policy framework; information exchange; capacity-building; and research, monitoring, and evaluation (R/M/E). The organisational nature of the network is important in determining the next steps for establishing the network.

### 2. GROUP WORK SESSION

Following the presentations on the BCC Network for HIV/AIDS and the experiences of other similar networks, participants were asked to discuss and brainstorm on the key technical and organisational issues for the BCC Network. The objective of the group work session was to gather suggestions and input on priority areas for network action, taking into consideration the experiences of members in other networks. Participants were divided into five groups on policy and advocacy; information exchange; capacity-building; research, monitoring, and evaluation; and network management, organisation and structure.

#### Group 1: Policy and Advocacy

##### *a. What can the BCC regional network contribute to national BCC policy and advocacy?*

- Identify within the network expertise in BCC policy and advocacy (individual and organisational)
- Identify as a network what we think are the policy issues for BCC
- Identify countries that have developed and implemented policy in BCC
- Compile lessons learned from existing policies
- Train network members in BCC policy and advocacy
- Respond to demand or interest of countries in BCC policy and advocacy
- Identify expertise in those specific countries
- Help form a country task force that is multisectoral
- Provide training and capacity on BCC policy and advocacy development and implementation
- Help assess current BCC policies and identify gaps in policies

*b. Other issues related to policy and advocacy:*

- Developing indicators for BCC
- Monitoring and evaluation
- Educating donors and programme managers about BCC policy
- Pilot-testing a policy and documenting how it is successfully implemented
- Making sure policies address vulnerable populations (e.g. refugees, migrants)
- Looking at different models of policy development
- Stressing the importance of BCC advocacy at all levels
- Stressing the importance of advocacy for resources (human and financial) to support the development and implementation of the policy



Participants exchanging ideas on BCC issues in research, monitoring, and evaluation.

**Group 2: Information Exchange**

*a. What is the most efficient way to exchange and disseminate information on BCC through the network?*

At the country level:

- Disseminate print materials through a national coordinating partner acting as a repository for BCC information

At the regional level

- BCC Network web site
- E-mail discussion group on current BCC topics in the region
- Regular e-newsletter containing updates on resources, conferences, and BCC issues in the region
- Database of resource persons
- Database of resources/tools, BCC messages, and materials produced
- CD-ROMS of BCC information for those without easy access to the Internet
- Meetings/conferences
- Trainings
- Study tours

*b. What resources/skills are needed for information dissemination by the BCC Network?*

- Technical skills and knowledge of current BCC issues
- Collaborative skills
- Management skills
- Financial skills and resources
- Recommend that one or two members of the Task Force and one coordinator at the Secretariat focus on information exchange

**Group 3: Capacity-Building**

*a. What capacity needs to be developed to make high-quality BCC sustainable in the region?*

Core competencies should include:

- Strategic planning
- Costing of BCC programmes and interventions
- Monitoring and evaluation
- Media development
- Research (including participatory research)
- Gender and sexuality
- Project planning and management
- Cross-cutting issues

*b. What is the most efficient and cost-effective way to develop capacity in BCC in the region?*

- Mentoring
- Study tours
- Short course
- Workshops
- E-links

*c. Who can develop capacity in BCC in the region?*

- Identify within the network institutions and/or individuals that can provide training
- Identify regional resources and other mechanisms

**Group 4: Research, Monitoring and Evaluation (R/M/E)**

*a. Resource priorities*

- Better understanding of the behaviours we are trying to change
- Developing strong and reliable indicators in a participatory manner
- Documenting best practices
- Doing rigorous and robust research
- Developing and using multiple methods, including rapid appraisal methods
- Coordinating our research so we do not fatigue the intended audience

*b. Other sources of capacity-building for R/M/E*

- Media monitoring services
- National institutes (e.g., universities and governments [e.g., census bureau])
- NGOs, CBOs, individuals

*c. Recommendations*

- Need to understand that BCC is evolving
- Need to institutionalize capacity for R/M/E
- Need to market the value of R/M/E so that governments and others can invest in it

*d. Contribution of network to establishment of indicators*

- Develop framework for multi-centre research
- Provide technical assistance for the process of defining indicators
- Help establish research priorities and generate dialogue
- Develop a BCC Network web site to provide information on indicators and research activities carried out by members, and to generate dialogue on research priorities
- Develop a bibliography of research by network members
- Develop a peer review platform to share and strengthen our efforts

*e. Use of R/M/E for BCC interventions*

- Improve access to research (e.g., dissemination and packaging)
- Be more open to research from elsewhere (giving guidance on generalizability)
- Strengthen linkage between programmers and researchers
- Carry out relevant analyses and presentations in a way that is understandable to the audience

*f. Final recommendation*

- The network should help to identify, promote, and/or develop short courses in R/M/E

**Group 5: Network Management, Organisation, and Structure**

*a. Proposed network structure*



*b. Proposal for network organisation*

- The Task Force will continue to assume the functions of the Board until the next meeting of the General Assembly, when Board members will be selected
- General Assembly members will nominate and elect Board members at the next meeting
- To balance the geographical and organisational representation of the current Task Force, the addition of new members from under-represented regions, organisations, and language areas is recommended
- These new Task Force members should be selected by the members of the current Task Force
- Subcommittees based on language should be formed for Anglo-, Franco-, and Lusophone countries
- Regional subcommittees should be set up for East, Central, and Southern Africa

*c. Until the next meeting, the Task Force and Secretariat need to:*

- Establish the Secretariat
- Finalize the constitution/terms of reference (TOR)
- Develop a budget
- Develop a membership list
- Create a fundraising plan, including setting a membership fee
- Liaise with other HIV/AIDS networks
- Establish means for communicating with members

*d. Who should be members of the Network?*

- Current members of Task Force will be “founding members” of the Network
- Any individual or organisation working in East, Central or Southern Africa can apply for membership in the network
- An individual who works within an institution can also join as an individual member
- Membership should be as inclusive as possible

*e. Where should the Regional Network be located?*

- Currently the Secretariat is hosted at RCQHC, Kampala
- The Secretariat will remain at RCQHC until the next General Assembly meeting

*f. How should the Regional Network be sustained?*

- The Secretariat should look for donors to support the Network as partners or funders
- Ultimately, the General Assembly will support the Network through contributions of time and membership fees

### Discussion Points: Establishing the Regional BCC Network

- To move forward, the Regional BCC Network should first establish the Executive Board and the General Assembly and then work on networking at the country level.
- The General Assembly should play an important role in consolidating the Network. How often the General Assembly should meet and when and where the next meeting is to be held are yet to be decided.
- It is important to define the criteria for membership and to determine whether the Network will function based on institutional and/or individual memberships. Strong arguments support each type of membership. Offering both types of memberships will allow a person to join on an individual basis if it happens that they are not selected by their organisation to be part of the network or do not represent any specific institution. There are examples of other similar networks that offer both institutional and individual memberships, fees, and structures. We need to hold discussions with these other networks to learn how they dealt with these issues.
- The BCC Network must be clear in its purposes, objectives, and the roles of members. At the same time, it must ensure that members have clear expectations of the network.
- On whether the regional network should focus on BCC for HIV/AIDS or BCC for cross-cutting issues, it was agreed that the focus of the network should be kept within the context of HIV/AIDS and to other areas related to HIV/AIDS, such as maternal and child health. The broader the scope of the network, the greater the potential for its efforts and objectives to become diluted.
- A possible function for the Network could be to improve the quality of BCC for HIV/AIDS. This would relate closely to the need for better research and M&E for BCC. The Network could possibly develop an award for excellence to recognise high-standard, high-quality BCC programmes that meet certain criteria.
- The Network should consider undertaking costing of research, monitoring, and evaluation for various BCC interventions because it would be useful for BCC practitioners to be aware of low-cost options. The Network could help to identify examples of community monitoring and feedback systems that provide ongoing information on behavioural indicators, methods and tools for community-based data collection, and how to use data to determine the appropriate BCC intervention.
- Working in HIV/AIDS should transcend borders. To be a truly regional network, it must consider integrating other languages (i.e., French and Portuguese) to facilitate participation by Francophone and Lusophone countries in the region.
- In terms of support and funding, the Network needs to partner with other donors in addition to USAID/REDSO. It is important to link up with donors and to secure resources in the early stages of forming a network.

**Next steps:**

- It was agreed that the current Task Force and Secretariat will provide follow-up for the meeting and will be responsible for:
  1. Determining the criteria for membership in the General Assembly
  2. Setting the date and place for the next meeting of the General Assembly
  3. Working out the differences in institutional and individual memberships and presenting a decision to the General Assembly on the type(s) of and fees for memberships in the Network
- Unless the Task Force decides otherwise in its future deliberations, all the participants at this First Regional Meeting of the BCC Network for HIV/AIDS are considered members of the Network. Everyone is encouraged to communicate with each other directly and to contact the Secretariat for questions, requests, and suggestions. The list of participants, including contact information, was distributed before the end of the meeting (also see Annex 2). To contact the Secretariat, send an e-mail to either Denis Tindyebwa (dtindyebwa@rcqhc.org, dtindyebwa@yahoo.co.uk) or David Gumisiriza, the Network Coordinator (dgumisiriza@rcqhc.org).
- Since the current Task Force is not geographically representative of the region, it was agreed that new members to the Task Force will be appointed in the interim until the next meeting of the General Assembly.

## E. MEETING SUMMARY AND CLOSING

### Closing remarks on the First Regional Meeting of the BCC Network for HIV/AIDS

Janet Hayman of USAID/REDSO closed the meeting by drawing attention to the highlights and experiences of the past three days. First, a significant accomplishment of the meeting was that more than 130 BCC practitioners, most with programme experience, from 17 countries convened to form a group that actively engaged in all the proceedings, from the plenary sessions to the working groups. Second, the substance of the meeting could be aptly characterised by three C's: challenges, conversation, and a course to chart.

**Challenges:** This included Kevin DeCock's presentation on the need to re-think HIV/AIDS messages and to focus on testing and knowledge of HIV/AIDS status as a crucial entry point for determining future behaviour; UNICEF's call to focus on community dialogue and not on messages; the emergence of new issues in BCC such as ABC and care and treatment and the need to strengthen technical expertise to address these issues; the need to continue efforts to overcome stigma; the need to reach out to people in new ways; and the need for effective M&E of BCC. There is also the challenge for BCC practitioners to convince others that BCC requires consistent and comprehensive efforts over time to produce meaningful results.

**Conversation:** A high level of exchange and dialogue took place as people interacted and connected with one another both informally and formally from the very first day. It was evident from the presentations of the working groups that participant interactions were both highly professional and stimulating.

**A course to chart:** All participants were engaged in charting the future course and developing the direction of the BCC Network through the input they thoughtfully provided on how the Network Task Force and General Assembly should move forward.

Ms. Hayman thanked the Meeting Task Force, the chairs and presenters, RCQHC, AED, FHI, and Events Solutions for their outstanding contributions in planning, organizing, and executing the meeting. On behalf of USAID, she thanked all the participants for their presence and active involvement in the meeting from start to end, and declared the meeting closed.

At Ms. Hayman's invitation, Jeff Yussuf Ayami of the Zambia Interfaith Network Group and Pastor Mercy Goremusandu of the United Methodist Church in Zimbabwe adjourned the meeting with prayers of blessings.



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