

Looking Back to Move Forward



International HIV/AIDS Alliance
10th Anniversary Workshop and Roundtable Meeting
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Executive Summary

Introduction

The International HIV/AIDS Alliance is ten years old. In honour of this 10th anniversary, Alliance staff and partners from all of its programme countries came together with secretariat staff at a two-day workshop. Participants at the workshop shared and reviewed the experiences of the Alliance and its partners in prevention, care, integrated approaches and scaling up community action. From this review, they identified critical lessons and recommendations on enhancing and expanding community action on HIV/AIDS.

These lessons and recommendations were taken forwards to a one-day roundtable meeting. The roundtable convened a group of international peer organisations, policy makers and development assistance representatives to meet with Alliance staff and partners. Participants at the roundtable meeting considered the challenges of, and lessons from, community action on HIV/AIDS and supporting and scaling up the global response to the epidemic. The roundtable concluded by discussing policy challenges and priorities for supporting communities to reduce the spread of HIV and to mitigate the impact of AIDS. This report summarises and synthesises the highlights and conclusions from both the workshop and roundtable.

Global HIV/AIDS: Contexts, Trends, Priorities

Deepening economic inequalities at all levels are heightening vulnerability, fuelling migration and depriving communities of the resources needed to fight HIV/AIDS. Religious fundamentalisms are threatening the human rights that are necessary for HIV/AIDS work to be effective. Longer-term commitments to strengthening community action on HIV/AIDS risk being sidelined by the possibility and urgency of expanding access to ARV drugs. Political pressures are more explicitly influencing HIV prevention approaches through “ideological” conditionalities while the pressure for scale up is challenging quality control and highlighting the need for new kinds of partnerships.

Funding environment

New funding mechanisms and increased funding levels offer the possibility of ‘going to scale’, but are changing relationships between government and civil society and increasing the pressure for quick results. The new funding environment is also raising questions about efficient financial distribution, effective use of resources, absorptive capacity, and the value and best use of technical assistance.

Worsening epidemic

These trends confront a worsening epidemic. HIV infections have risen 400% since 1993. Stigma remains a significant problem, exacerbating the existing marginalisation of many people living with HIV/AIDS (PLHA). The pressure to, and possibility of, significantly expanding ARV treatment is re-medicalising the epidemic. VCT expansion is adding to the pressure for ARV treatment and care services and fuelling further stigma and discrimination. Marginalised groups are getting harder to reach, driven back ‘underground’ by resurgent in social intolerance. The generational challenge of dealing with orphans and vulnerable children (OVC) is only now beginning to be acknowledged.

Trends in the global response

Civil society is playing an increasingly important role in all aspects of the global response to AIDS. At the same time, there is a renewed emphasis on the critical role of government in upholding a framework of law, protecting the vulnerable in accordance with human rights and taking the national response to scale. National and global responses are under threat from a questioning of AIDS ‘exceptionality’, challenging the AIDS community to maintain its focus on human rights and human dignity. The global

AIDS response is better and more indigenously funded than ever before, but with an annual budget of US\$4.7 billion is still less than 50% of what is required. The global response is also being challenged to show results and to assert its evidence base, which is under attack. Promoting evidence-informed approaches is more important than ever.

Three priorities for the global response

The three core priorities for the global response can be expressed as capacity, coherence and exceptionality. There is a true crisis in human capacity in many of the most severely affected areas. This crisis calls for a change in donor thinking and priorities, focusing on the need to keep people alive, invest in human and institutional capacity and build community capacity to respond through direct granting to the grassroots.

The expansion of actors involved in the global AIDS response offers the possibility of scale up but threatens the coherence of the response. UNAIDS is proposing the three “1s” strategy to ensure this coherence: one agreed national strategy; one national and multi-sectoral coordinating body; and one agreed country-level monitoring and evaluation (M&E) framework.

The final priority is to defend AIDS exceptionality. AIDS rewrote the rules of public health, and it must now re-write the rules of development. It is essential that AIDS spending become regarded as an investment, and not as expenditure.

The Alliance: History, Achievements and Directions

The Alliance’s history of response to the global AIDS epidemic is best understood in three phases.

Start up phase

The theme of the first phase (1994 – 1996) was “linking up”. The Alliance was created with the core goal of channelling financial resources from donors in the North to community groups in the South. The main strategy for this was to identify or establish national mechanisms (what became known as “Linking Organisations”) and provide them with technical and financial support. In turn they would then support local NGOs and help them scale-up or start work on HIV/AIDS. The Alliance established seven LOs in this period.

Second phase

The second phase (1997 – 2000), whose theme was “learning participation”, developed in response to the changing context of the Alliance’s work. It emphasised the Alliance’s strategic roles in building capacity, enhancing quality, learning lessons and leveraging resources rather than simply channelling funds. The Alliance also adapted and piloted participatory methods for working on HIV/AIDS with communities and then for more targeted work with vulnerable communities.

Third phase

The third phase of the Alliance’s work (2000 – 2004) has emerged in response to the need to scale up activities and to “learn to speak out” (the theme of this phase) on the macro-level contexts affecting its work. Increased funding and a diversification of models have enabled the Alliance to grow its programme to over 20 countries. There has been a new emphasis on policy advocacy, using evidence and experience gleaned from its grassroots work to influence policy agendas. Through its Frontiers Prevention Programme, the Alliance is developing and evaluating innovative empowerment approaches with key populations.

<p>Taking stock</p>	<p>The Alliance is moving into its second decade with a culture of documentation and learning, with increasing attention being given to evaluation, as well as strong and varied partnerships. It has strong technical abilities in community HIV prevention, AIDS care and organisational development, and increasing technical abilities and opportunities for advocating to influence programming and policy priorities of international and national institutions are also increasing.</p>
<p>Challenges ahead</p>	<p>At least three major challenges confront the Alliance in charting its strategic directions over the next ten years. These include:</p> <ul style="list-style-type: none"> To continue advocating for community-led responses to HIV/AIDS and emphasising the role of NSPs in supporting community action To think concretely and creatively about the scale of its work To link and balance grassroots work with policy, using evidence from the ground to shape policy and agendas at all levels.
<p>Strategic directions</p>	<p>The Alliance’s current thinking on its strategic directions focuses on five main themes in relation to its strategic directions, as follows:</p> <ol style="list-style-type: none"> 1. Coverage: The Alliance must increase its coverage, reaching more people in more areas with more comprehensive programmes. 2. NGO support: The Alliance should concentrate on building LO capacity to work “upstream”, diversifying partnerships and documenting and evaluating the impact of its work. 3. Enabling environment: For its third strategic direction, the Alliance should develop its role in influencing national governments and supporting nationally driven agendas in order to create an enabling environment for community action. 4. Through indigenous intermediary organisations: The Alliance’s fourth strategic direction relates to its vision of becoming an alliance of powerful Linking Organisations, as indigenous intermediary organisations that are governed, led and managed locally and that have different types of links with the secretariat and with other LO in the Alliance structure. 5. Working internationally as an alliance: The viability and vitality of this structure depends on the fifth strategic direction of broadening the ‘surfaces of engagement’ between different parts of the Alliance structure and orienting this structure around shared values and vision, history and experience as well as resources.
<p>Prevention, Care and Integration: issues, lessons and recommendations</p>	<p>Presentations from Senegal, Ecuador, Ukraine, Burkina Faso, India and Zambia highlighted a range of issues across the themes of prevention, care and integration. These issues were taken up in small group work on the first day of the workshop, and participants identified the following issues, lessons and recommendations.</p>
<p>Targeting</p>	<p>Important opportunities for HIV prevention are being missed because of a lack of strategic targeting. Integrating HIV prevention more explicitly into VCT is a priority, as is developing ‘positive prevention’ approaches for PLHA. HIV prevention strategies remain too nationally-bound and, for example, trans-border communities are an important – yet neglected – target group. High/low prevalence distinctions often fail to capture epidemiological variations within countries, while the ‘key populations’ approach may continue to be strategic even in high prevalence areas. It is also vital to focus on the key problems that are driving the epidemic.</p>

Key problems, key strategies	<p>Globalisation, and the deepening inequities it is producing, is exacerbating the vulnerability of socially and economically marginalized populations. Gender inequalities continue to scar the lives of women and girls and heighten their exposure to HIV infection. Human rights and social justice frameworks are critical in both understanding these key problems and in building the alliances that are required to address them.</p> <p>Programme strategies for addressing gender and sexuality issues more effectively are urgently needed. In Zambia, gender and sexuality discussion tools have been integrated into VCT work in order to explore these issues more with communities in relation to testing and HIV status. Models and campaigns for social and economic justice should be better integrated into the AIDS response at all levels.</p>
Integrated approaches	<p>There are many ways to think about the concept of “integration” – an integrated approach is not necessarily the same as a comprehensive or a multi-sectoral approach. Definitions of the meaning of “integrated approach” will depend on local conditions, and there may be conflicting interests and agendas behind the promotion of “integrated approaches”.</p> <p>HIV prevention must work with the whole person, and not merely their risk behaviours. Integrated approaches can respond to people’s health and psychosocial needs in a holistic way. A lack of access to treatment is one of the greatest barriers to HIV prevention. Improving access to ARV treatment and VCT services are important aspects of HIV prevention.</p> <p>However, the pressure to respond to demands for treatment may push prevention off the policy/donor agenda. It is essential to build on the good practice of integrating prevention, care and treatment into existing community systems of welfare and health care and ensure that care programmes are expanded as part of comprehensive interventions that include prevention. Experience from India also suggests that an integrated approach to responding to HIV/AIDS in the context of broader community issues and interests has been critical in mobilising community involvement in care and support programmes.</p>
ARV treatment	<p>Improved access to ARV treatment is changing the face of the global AIDS response. But much more work is needed to define minimum standards for treatment protocols and to integrate medical interventions into broader health and psychosocial responses to PLHA and families and communities impacted by HIV/AIDS, for example in relation to nutrition and food security. The role of the Alliance and NGO support programmes at the national level in addressing issues of equity in access also needs to be explored. Fundraising and advocacy to expand ARV treatment should be grounded in the need for a continuum of care, treatment, prevention and mitigation.</p>
PLHA empowerment	<p>The increased visibility of PLHA participation is one of the most striking changes in the AIDS response. But a key lesson being learned is that PLHA involvement is as much about asserting their rights to self-determination as it is about improving programme effectiveness. The challenge is to help PLHA groups strengthen and sustain their work of collective self-determination. It is especially urgent to enhance the involvement of children and young people living with HIV/AIDS and respond to the ways in which young PLHA are denied their rights to self-determination.</p>

Lessons and Challenges for Community Action on AIDS

Lessons and recommendations on prevention, care and integration from the workshop were folded into a broader discussion of lessons and challenges for community action at the roundtable meeting. The following themes emerged from this discussion, initiated by case studies from Zambia and Cambodia and presentations by three other panelists.

Dealing with a chronic emergency

AIDS is a chronic emergency that calls for a response with 'double vision'. The global AIDS response in general, and community action in particular, has to be near-sighted in addressing immediate HIV-specific needs and far-sighted in working on underlying contexts. This will require significant shifts in terms of government-civil society collaboration, moving public health beyond technological interventions and challenging governments to plan outside of political timeframes.

Enabling meaningful community action

What does it really mean to put communities at the centre of the response? Firstly, it is important to recognise the internal struggles and power differentials within communities that determine who is involved in and affected by decisions about community action on AIDS.

A second lesson relates to the critical roles played variously by VCT, OVC and community development work in engaging and then extending the involvement of communities in the AIDS response.

Community action can also help to influence policy. The Alliance and NGO support programmes have a role to play in ensuring that multiple voices of communities are heard in policy-making. This must include supporting the leadership and activism of members of marginalised communities who are resisting the oppression that they are suffering.

Promoting PLHA activism and leadership

In many ways, PLHA have not gotten further than a place at the table, as opposed to having a central role in decision-making. Involvement can often mean tokenism. It is essential to invest in PLHA activism and leadership, and the organisational structures that are required to support this. But such activism and leadership raises broader questions about confidentiality and privacy. More creativity is needed to bring PLHA voices and experiences in to the AIDS response without requiring disclosure, in line with the GIPA principle.

Transforming organisations

Scaling up community action brings the challenge of mobilising and partnering with organisations that are new to HIV/AIDS. This is often a process of transformation for the organisations themselves, which often by their nature tend to be conservative and difficult to change.

Confronting gender and sexuality issues

There are important questions about how communities can be supported to take on these issues in culturally specific ways that at the same time challenge culturally sanctioned inequalities, especially in terms of the disempowerment of women. However, gender and sexuality issues are still largely discussed in terms of prevention. Much more work at community level is needed on gender and sexuality issues in the lives of PLHA and the particular challenges facing women.

Working on human rights

Human rights offers a framework within which the Alliance can use its size and influence to shape the macro-policy contexts in which it supports community action on the ground. The need to develop a more clearly articulated rights-based analysis of and response to AIDS is heightened within the current ideologically charged environment of

the global AIDS response.

Clarifying roles of government and civil society

The challenge for the global AIDS community, and in particular the donor community, is to not simply fund civil society to fill the gaps left by governments but to pressure and support governments to fulfil their obligations. The Alliance and its partners have an important watchdog role to play, giving voice to the social conscience and helping to hold states accountable.

Supporting and Scaling Up the AIDS Response

Three case study presentations (on Mexico, Cambodia and Madagascar) followed by small group work initiated discussion at the workshop of NGO support and scaling up the response to HIV/AIDS. A panel discussion at the roundtable then took up the themes that had been explored at the workshop, featuring four presentations followed by a discussion among participants.

Recognising the scale and urgency of the problem

It is estimated that 80-90% of people who are living with HIV do not know that they are infected. Most people in 'developing' countries only find out when they are sick. Every year 3 million people die because of the failure to provide them with ARV drugs that they need to improve wellbeing and prolong life. Only 5% of those who need ARVs are able to access them. The health emergency of AIDS is related to structural inequalities that play out in many people's lives as a daily struggle to meet the basic needs of food and shelter.

Working in broad-based partnerships

Broad-based partnerships, such as the WHO "3 by 5" initiative, are the only way to deliver the scale of response that is needed. The quality and level of civil society and community participation in such partnerships is crucial. Such partnerships will rely on some core principles in order to be effective (e.g. trust, respect, inclusion, sharing power-knowledge-money).
NGOs need to improve their partnership working. The international HIV/AIDS NGO Code of Good Practice is an example of this change beginning 'at home'. It is also important that NGOs develop skills to work together and collectively advocate on shared agendas and hold each other accountable in relation to the dangers of cooptation by the public sector.

Mobilising large-scale community action

It is imperative to recognise the limits of expert-driven approaches. It is also clear that those who reject a more direct role for communities may have vested interests. There is legitimate concern that this emphasis on community action will overburden already depleted communities and especially adult women. The challenge is to create funding and support mechanisms that can sustain large-scale community action in the face of the severe social and economic problems and trauma experienced in many communities that are hardest hit by AIDS.

This should involve developing more direct channels for getting money to where communities can use it. In turn, this will entail more clearly articulating a role for NGOs and NSPs in relation to large-scale community action. One such role is in developing leadership capacities within affected communities, and, especially within communities most targeted by other forms of stigma and oppression, such that they can both demand and use resources strategically and shape policy agendas.

<p>Working on human rights and social justice</p>	<p>AIDS organisations need to develop skills and tools to draw out the connections between disempowering structural factors and HIV vulnerability and be able to demand a voice in previously closed policy discussions in the ‘North’ on such issues as terms of trade, intellectual property rights and use of generics.</p> <p>Thinking as well as acting at scale requires that the AIDS response be rooted in rights-based approaches that can more explicitly challenge the oppression and injustice that creates the conditions in which HIV spreads and devastates communities. Regressive agendas on marginalised groups and sexuality must be challenged.</p>
<p>Developing skills and coalitions for advocacy</p>	<p>Arguably, every group needs an advocacy agenda and the basic skills and tools to carry this agenda forward. Civil society advocacy should focus on demanding more money, more donor coherence, and more cohesion among NGOs, who have a critical role in linking realities on the ‘ground’ to policy debates in national and international centres of power.</p>
<p>Providing technical assistance for scale up</p>	<p>New funding, new funding mechanisms and new frameworks are in place for a scaled up response to AIDS. But technical assistance is required to make all this work at the local level. Such technical assistance is essential to ensure that resources that are mobilised are well spent, regardless of their source.</p> <p>The Alliance, with its history and credibility, can play a significant role in legitimating the use of donor resources for technical assistance provision, not only within its own programmes but within the global response more generally.</p>
	<p>Policy Priorities and Challenges</p> <p>The roundtable concluded with a discussion of policy priorities and challenges for the AIDS response, initiated by four panel presentations.</p>
<p>Asserting the evidence</p>	<p>Evidence is the key to good policy-making, and ever more important in the current global political climate in which evidence-informed approaches to HIV/AIDS work are under attack. The Alliance’s work at country and global levels is showing the benefits of gathering, analysing and asserting the evidence. More rigorous attention to developing evidence-informed approaches has been especially important in relation to HIV/AIDS work with marginalised ‘key populations’. The individual and collective empowerment approaches used in the Alliance’s Frontiers Prevention Programme (FPP) have been grounded both empirically and conceptually, and at the same time is producing further evidence that policy must be based on human rights and harm reduction principles. The Alliance has also made effective use of evidence to advocate for integration of OVC issues into the EU’s Programme of Action.</p>
<p>Pushing policy from ‘below’</p>	<p>Intermediary organisations such as the Alliance and its LOs are conduits for ensuring that realities on the ‘ground’ are brought to bear on policy-making by governments and international institutions. A crucial emphasis of the Alliance’s FPP work has been to enable and ensure the presence of leaders from marginalised communities in policy-making debates and forums. Similarly, the International Harm Reduction Development (IHRD) program of the Open Society Institute is now focusing its support to harm reduction in the former Soviet Union and Central and Eastern European region on strengthening local harm reduction activists to be doing their own advocacy.</p>

Human rights and social justice	<p>Partnering with human rights organisations has proved to be an effective policy change strategy for HIV/AIDS organisations that are working with highly stigmatised and vulnerable groups. For example, human rights has proved to be a valuable framework within which to argue for the right to treatment that members of IDU populations, by virtue of their humanity, are as entitled to as anyone else. Human rights and social justice frameworks are also essential for maintaining gender equity and positive sexuality at the heart of HIV/AIDS policy-making.</p>
NGO partnerships in shaping policy	<p>NGO partnerships are critical to their policy work, and this has been acknowledged by the development of an international NGO code of practice as a framework for greater coherence and accountability to agreed standards and principles that will help in coordinating a powerful advocacy agenda. One important role that such NGO advocacy can play is in holding governments accountable for their policy commitments and responsibilities, for example in relation to human rights conventions and their application to marginalised groups (such as drug users).</p>
Working with private sector collaborations and tensions	<p>Civil society organisations also must take on the task of mobilising private sector funding and holding corporations accountable for their role in fostering a supportive policy environment. Tensions between philanthropic agendas and business priorities remain most acute in relation to drug pricing and equity in treatment access. Civil society can use the notion of social responsibility to name such tensions and hold the private sector accountable to standards of social responsibility.</p>

Introduction

The International HIV/AIDS Alliance is ten years old. In honor of this 10th anniversary, the Alliance and its allies came together in a workshop and roundtable meeting to reflect on its decade of experience.

A two-day workshop was held on 30th - 31st March 2004 at the Alliance's offices in Brighton, UK. Alliance staff and partners from all of its programme countries came together with secretariat staff at the workshop to share and review their experiences and to identify critical lessons and recommendations on enhancing and expanding community action on HIV/AIDS.

These lessons and recommendations were then taken forwards to the one-day roundtable meeting, held on 2nd April 2004. The roundtable convened a group of international peer organisations, policy makers and development assistance representatives to meet with Alliance staff and partners and reflect on the broader challenges and priorities for supporting communities to reduce the spread of HIV and to mitigate the impact of AIDS.

This report documents the highlights of these workshop and roundtable discussions. It condenses and synthesises three days of rich presentations and lively deliberations. Section One draws on presentations from both the workshop and the roundtable to outline the global contexts in which the Alliance is working, trends in both the epidemic and the current global response, and the priorities for that response which shape the Alliance's future. Similarly drawing on presentations from both the workshop and the roundtable, Section Two briefly takes stock of the Alliance's history and achievements and articulates the current thinking within the Alliance about its strategic directions moving forwards.

Sections Three, Four and Five report respectively on the presentations and discussions from the first day of the workshop on three substantive themes of community action; Prevention, Care and Integration. These sections summarise the lessons and recommendations identified by participants that should guide the Alliance in its strategic support for community action in relation to these three themes. The roundtable continued this discussion of community action and its conclusions on overall lessons and challenges are presented in Section Six.

Section Seven reports on the conclusions from both workshop and roundtable on NGO support and scaling-up the response to the epidemic. On the second day of the workshop, participants identified issues, drew lessons and made recommendations in relation to these themes. This discussion of supporting and scaling-up the AIDS response was then taken up at the roundtable meeting in its first session of the afternoon. The roundtable concluded with a session on priorities and challenges for shaping the policy context of the Alliance's work and Section Eight summarises the presentations and discussion from this final session. The attendees' list for the workshop and roundtable is included as Appendix One and Appendix Two presents the findings from the workshop evaluation.

"We're here to celebrate and reflect on the first 10 years of a very exciting journey. But we can't be complacent – the epidemic continue running away from us."

Alvaro Bermejo

SECTION 1

Global HIV/AIDS: Contexts, Trends, Priorities

1.1 The changing contexts within which we are working

The reality of the global HIV/AIDS epidemic is deeply disturbing. This is not simply in terms of human suffering and loss of life, catastrophic though this is. It is also at the level of our certainties about the world. HIV/AIDS is reversing gains in human development that we have become accustomed to over the last 50 years. Life expectancy is declining in some of the most heavily impacted societies. Parents are dying, leaving grandparents to raise their vulnerable children. Sex can mean death. Women's struggle for equality with men is being shattered by an epidemic that, in the worst affected region, is "*depopulating parts of the continent of its women.*"¹

These realities confronted participants at the Alliance's 10th anniversary workshop and roundtable. Alvaro Bermejo, Executive Director of the Alliance, grounded discussion of these realities in the context of global trends, which he summarised in his report back from the Alliance Directors' Retreat, held immediately prior to the workshop, as follows.

Globalisation

Social, economic and political trends, subsumed under the rubric of "globalisation", are shaping the epidemic and responses to it. There is a marked and widening income gap between rich and poor people and between rich and poor countries and regions. These deepening disparities are increasing vulnerability to HIV infection and its impacts and fuelling increased migration within and between countries, calling for regional responses that are not confined by national boundaries.

Information technologies are also 'globalising the local', both threatening cultures and customs with cultural 'imperialism' at the same time as releasing a trans-national flow of information and inspiration that creates unprecedented opportunities for global networking and activism. Resurgent religious fundamentalisms in many parts of the world are attacking the practice, as well as the secular ideal, of human rights. New kinds of conflicts and resistances (branded as the "War on Terror" by the leaders of the most powerful nations) threaten not only the attention that should be given to HIV/AIDS work but also the conditions (of human rights and social justice) that are necessary for this work to be effective.

Shifting programme "approach"

The campaigns for, and greater availability of, ARV drugs is, in some senses, re-medicalising the way people think about and respond to the epidemic. Longer term commitments to strengthening community action on HIV/AIDS and investing in social change efforts risk being sidelined by the moral urgency of expanding access to treatment.

Political pressure on donors to produce short-term results is reinforcing this return to the notion of 'emergency response' that characterised the early years of the epidemic. Political pressures are evident, too, in the "ideological" conditionalities now being imposed on HIV prevention strategies. Above all, the pressure of going 'to scale' creates challenges for donor harmonisation and quality control for expanded programming.

Funding mechanisms; partner relations

Funding mechanisms are changing, both in terms of their scale and impact. Global Fund and World Bank financing is affecting both what is possible at country level through increased levels of funding and forcing greater cooperation between government and civil society. At the same time, new funding mechanisms are raising.

¹ From a speech by Stephen Lewis, UN Special Envoy on HIV/AIDS in Africa, to the "Microbicides 2004" conference in London, Tuesday, March 30, 2004.

questions about absorptive capacity, the nature of the relationship between government and civil society and the risk of an increased emphasis on sub-contracting within this relationship.

More money offers the possibility of 'going to scale', but raises many questions about the best mechanisms for putting this money to work where it is most needed. These include questions about NGO support, the role of intermediary organisations, the value and best use of technical assistance, decision-making processes for resource allocation and issues of accountability in how the money is used.

Growing attention is being given to mobilising new kinds of partners, such as faith-based organisations and labour unions. Creating and sustaining new partnerships presents particular challenges in the context of the need for urgent programme implementation. The potential for new money and new partnerships also highlights questions about geographical focus and population targeting, and the optimum allocation of resources in terms of the currently affected and potentially devastated

The changing HIV/AIDS epidemic

Above all, the HIV/AIDS epidemic continues to worsen in many parts of the world. HIV infections have risen 400% since 1993. There are now multiple epidemics with many levels of impact within given communities and societies and over time. Secondary (societal) impacts of AIDS are now no longer a matter of projection but a matter of fact, for example in South Africa. The tragedy is that this was predictable and preventable.

Stigma and discrimination remain significant problems and a positive HIV diagnosis only exacerbates already existing social exclusions for many people living with HIV/AIDS (PLHA). There are signs that marginalised groups such as injecting drug users, sex workers and PLHA are being driven back 'underground' by a resurgence in social intolerance, high profile politically-motivated 'clean-up' campaigns and ideologically-based prevention messages framed within a discourse of morality that trumps human rights and social justice issues.

Through VCT expansion, many more people are conscious of their HIV status, adding to the pressure for ARV treatment and care and support services as well as fuelling further stigma and discrimination. The push to rapidly expand VCT is resulting in an emphasis on the testing procedure itself, with correspondingly less attention being given to maintaining the quality of counselling and the ethic of informed consent. Expansion of VCT and the significant increase in the number of people who know their HIV positive status is also highlighting the need for more attention to be given to HIV prevention work with PLHA – in other words, to "positive prevention".

The falling prices of ARV drugs and the pressure to significantly expand ARV treatment are dramatically altering the landscape of the epidemic. We are faced with a situation in which 30% or more of the adult population in parts of Africa could be on lifelong medication. The huge generational challenge of orphans and vulnerable children is not yet being fully grasped, both in terms of their current needs and problems as well as the longer-term effects of the trauma that they are suffering and its unknown impacts on social capital and communal well being.

1.2 Trends in the global response to HIV/AIDS

In his plenary address to the roundtable meeting, Dr. Peter Piot, Executive Director of UNAIDS, articulated important trends in the current global response to HIV/AIDS. This section summarises his presentation, and section 1.3 describes the priorities for the global response that Dr. Piot identified.

Greater civil society involvement

There has been a marked improvement in the extent of, and attitudes toward, civil society involvement in the global response. At the inception of UNAIDS in 1995, there was a struggle to get NGO representation on the newly-formed governance structure

<p><i>“Communities must be at the centre of AIDS responses.”</i> Dr Peter Piot</p>	<p>and governments only accepted this representation on the basis that it set no precedent for other UN bodies.</p> <p>There are now five NGO representatives on the UNAIDS board who, though without voting rights, have had a big impact on setting the agenda for the organisation. It was NGO pressure that put treatment issues on the agenda against the initial wishes of every government represented on the Board. This is emblematic of the broader trend for greater civil society involvement in shaping the response to HIV/AIDS at national, regional and international levels. The Alliance continues to play a leading role in mobilising and strengthening a wide array of civil actors to participate in HIV/AIDS policy-making and agenda setting.</p>
<p>Critical role of government</p>	<p>Governments are treating AIDS more seriously than ever before, as is evident in the greater frequency with which political leaders are speaking out on the epidemic and related issues. But there are still far too many examples of regressive and reactive responses to specific crises and emergencies, in which HIV/AIDS can get used for political gain – e.g. on continued calls to quarantine PLHA or members of those marginalised who are at high risk of infection.</p> <p>The role of government is critical. A strong government response and framework of state action and coordination is essential for:</p> <ul style="list-style-type: none"> Responding to HIV/AIDS within the rule of law; Protection of vulnerable and marginalised groups in accordance with human rights conventions to which governments are signatories; and Going to the scale that the epidemic requires – it is an illusion to believe that civil Society can take the HIV/AIDS response to scale in the absence of government. <p>Being clear about the critical role of government begs the question, however, of what is the most desirable (and durable) relationship between state, civil society and international organisations?</p>
<p>Challenges to AIDS ‘exceptionality’</p>	<p>There are increased calls within some sections of the medical community for an end to AIDS exceptionality – that it is now a chronic illness and not fatal and exceptional emergency. Some even question the reality of stigma as an invention of AIDS activists.</p> <p>The AIDS ‘community’ faces the challenge of maintaining a policy and programme focus on the reality of stigma and reminding people of the question: “Have we ever seen a person with diabetes stoned to death?” HIV/AIDS continues to be a lightning rod for social injustices and it is imperative that the global response stays focused on issues of stigma, human rights abuses and the need for dignity.</p>
<p>Making the money work</p> <p><i>“I said at the Durban AIDS conference that we need to move from the M to the B word.”</i> Dr Peter Piot</p>	<p>The global response is undoubtedly better funded now than ever before. In 1996 \$200 million was spent on AIDS in ‘developing’ countries, and 99% came from external donors. In 2003, \$4.7 billion was being spent on AIDS in low and middle-income countries. Significantly, this included \$1.5 billion from domestic budgets, an estimated \$1 billion from community members themselves and the rest from donors. UNAIDS estimates that an adequate global response will require an annual \$10 billion budget.</p> <p>The central challenge is to ensure that this money works and goes to where it is most needed. Much is and will continue to be said about the sustainability of this funding. There are three conditions for reaching and sustaining adequate levels of funding:</p> <ul style="list-style-type: none"> Show results – demonstrate that the money is being used well; Increase the demand for more money from political leaders in ‘developing’ countries; and

Grow the constituency within the 'developed' world for fully funding an effective global response to AIDS.

Challenges to the evidence base

A lot has been learned over the last 20 years about what works and what does not work in responding to HIV/AIDS and there is a great deal of knowledge on which to base programme decisions and policy recommendations. Some of the key lessons include:

Protecting human rights works;

A combination of prevention and treatment is needed; and

Risk reduction, vulnerability and impact mitigation approaches are all needed.

But the evidence base that has been developed over the last two decades is under renewed attack. These lessons are now being questioned and undermined for political and ideological reasons, as is clear from the increasingly hostile climate for working with sex workers and injecting drug users. But it is essential to insist on using approaches that are informed by the available evidence and remember that approaches are never based solely in evidence because they are also informed by values.

"We must insist on evidence-informed approaches. If we give in on this, we lose our whole credibility."

Dr Peter Piot

1.3 Priorities for the global response

In order to make the funding work as effectively as possible, there are three core priorities on which it is essential to concentrate. These can be summarised as:

1. Capacity
2. Coherence
3. Exceptionality

Capacity

The huge problems of individual and institutional capacity are not new. It is no surprise that the countries most affected by AIDS also have the weakest capacity. There is a vicious cycle to this, as was clear from a recent UNAIDS mission to Malawi to assess its capacity to spend \$450 million. The mission found a "*true crisis*" in capacity and concluded that there was no way that this money could be productively spent without huge investments in capacity building.

But most money is still project money and not investment oriented. This is the value of the Alliance's emphasis on building organisational and institutional capacity, yet only now are donors fully awakening to the implications of this investment focus for their funding policies and initiatives. There is no magic solution to the problems of capacity but there are some clear priorities:

Keep people alive and productive – this requires ARV treatment on a wide scale and the economic case for greatly expanded access to treatment must be made more clearly.

Change the taboos that currently limit our work – for example, it is clear that incentives for wide-scale community involvement are needed and this requires much greater donor-wide coordination on this to develop sustainable incentive packages – and we need to be open to gap-stopping (e.g. south-to-south volunteers, UNV etc).

Be willing to give small grants directly to communities, as people often know best how to spend their own money. Direct community grants with contracts for accountability are the only real way to go to scale.

<p>Coherence</p> <p><i>“Problems of absorptive capacity are often talked about but we need to ask who is absorbing whose capacity.”</i> Dr Peter Piot</p>	<p>There are now many more players in the global response to HIV/AIDS than even five years ago, creating significant challenges for maintaining and improving the coherence of this response. A review of coordination efforts last year in Africa reached the conclusion that there was a need for pluralism in implementation within an agreed framework that UNAIDS is calling the three “1”s:</p> <ul style="list-style-type: none"> One agreed national strategy One national and multi-sectoral coordinating body One agreed country-level M&E framework because donors’ multiple and varying M&E frameworks consume the time and energy of local actors <p>The three “1”s are not about centralising powers or prioritising the public sector. But they do provide a framework for expanded and effective community action. UNAIDS will seek agreement on this framework with the World Bank and IMF in April this year.</p>
<p>AIDS exceptionalism</p>	<p>AIDS has rewritten the rules of public health and there is a need now to rewrite the rules of development. We need to question whether the tools and rules of development apply in the case of a long-term emergency such as AIDS. In Uganda, AIDS money is now pushing up against expenditure ceilings required by international financial institutions. Before long, between five and ten African countries will receive AIDS funding that will exceed their Medium Term Expenditure Frameworks (MTEF).</p> <p>This situation is often posed as a choice between treatment and inflation but the framing of this choice must be rejected. It is important to regard AIDS spending as an investment and not simply as an expenditure. There is already a model for this approach in terms of post-conflict reconstruction. In these cases, the World Bank and IMF have accepted six year grace periods in which spending can exceed previously agreed MTEFs on the basis that such spending is an investment in the future of the country. The unprecedented threat that AIDS poses to the development of many countries calls for a similar approach.</p>
<p>UNAIDS priorities</p> <p><i>“I expect you to put pressure on us and my expectations are high for what you can do.”</i> Dr Peter Piot</p>	<p>Within the context of these global priorities of capacity, coherence and exceptionalism, UNAIDS has defined four priority tasks for its work, as being to:</p> <ol style="list-style-type: none"> 1. Increase its focus on Eastern Europe, Asia, and Latin America and the Caribbean; 2. Continue to be the global reference point for best policies and practices; 3. Work for greater civil society inclusion in the response to HIV/AIDS; and 4. Improve accountability in part through an increased focus on M&E for programmes.

SECTION 2

The Alliance: History, Achievements and Directions

2.1 A brief history

Teresita 'Bai' Bagasao (Alliance Trustee) and Jerker Edström (Director: Field Programmes) shared a brief history of the Alliance with participants at the roundtable meeting that is summarised below. It is important to look back with clarity in order to move forwards with confidence.

Looking back to
move ahead



1994 – 1996

Linking up

The Alliance was created with the core goal of channelling financial resources from donors in the North to community groups in the South. The main strategy for this was to identify or establish national mechanisms (what became known as “Linking Organisations”) and provide them with technical and financial support. In turn they would then support local NGOs and help them scale-up or start work on HIV/AIDS. PHANSuP in the Philippines became the first Alliance Linking Organisation (LO), before even the formal constitution of the Alliance itself. The vision and idea of the Alliance was compelling to PHANSuP for three main reasons:

1. On the ground, there was little response from either government or civil society to HIV/AIDS. The response was very Manila based and health focused;
2. There was some support to NGOs but it was technical, project-driven approach – NGOs as subcontractors rather than helping communities understand HIV in context of underdevelopment; and
3. The Alliance offered a vision and mechanism for putting communities at the centre of the response through building local capacity to understand and respond to AIDS.

PHANSuP was quickly followed by the establishment of a further six LOs in countries in Africa, Asia, and Latin America.

1997 – 2000:

*Learning
participation*

In 1997 a new strategic framework was developed in response to the changing context of the Alliance’s work and several internal reviews and an external evaluation. The framework emphasised the Alliance’s strategic roles in building capacity, enhancing quality, learning lessons and leveraging resources rather than simply channelling funds. During this period, the Alliance also adapted and piloted participatory methods for working on HIV/AIDS with communities and then for more targeted work with vulnerable and affected communities, putting participation clearly on the “AIDS map”. This approach evolved as it was applied but the Alliance also broadened its commitment to innovation beyond learning-by-doing, for example by initiating research on PLHA involvement in local and national responses to the epidemic.

**2001 – 2004:
Learning to speak
out**

There was a discernible change in context for the Alliance's work at the turn of the century, a change that the work of the Alliance had helped to create. Civil society action on HIV/AIDS was increasing and there was a broad recognition of the essential role of PLHA, affected communities and civil society actors in the response. It was equally evident that there was a need for a significant scale-up of existing work and for an increase in campaigning and advocacy work to shape global policy and influence the macro-level contexts for the Alliance's work.

An increased level of funding for AIDS translated into increasing direct funding possibilities for Alliance LOs at country level. These organisations had to increasingly manage donor relations as well as government relations. With this increased funding and a diversification of models of NGO support, the Alliance grew its programme to be working in over 20 countries, with partnerships not just at the national level but also at regional and international levels. Through its Frontiers Prevention Project, the Alliance developed innovative empowerment approaches with key populations. The secretariat and its national partners developed a new emphasis on using opportunities for policy advocacy and speaking out at national and global levels, using evidence and experience gleaned from its grassroots work to influence policy agendas. For example, KHANA, the Alliance LO in Cambodia, took a lead in advocating with government for greater government-NGO cooperation in designing and delivering home-based care in the country.

2.2 Taking stock

In taking stock of the Alliance's achievements over the course of its history, Jerker Edström highlighted the following aspects of the Alliance's track record:

A culture of documentation and learning, with increasing attention being given to evaluation

Strong and varied partnerships

Strong technical abilities in community HIV prevention, AIDS care and organisational development

Increasing technical abilities in mitigation, operations research, advocacy, tools development

Increasing abilities and opportunities for advocating to influence programming and policy priorities of international and national institutions

“We need to build on the tremendous wealth of community experience within the Alliance family.” Alvaro Bermejo

In relation to the Alliance's track record, Bai Bagasao, on behalf of the Trustees, highlighted three issues that should inform Alliance thinking about its future directions:

1. With pressure on scale-up and significantly increased levels of funding, there is a danger of NGOs becoming sub-contractors again – the Alliance must continue to advocate for resourcing community-led and owned responses and emphasising the role of NSPs in supporting community action.
2. The Alliance needs to be thinking more concretely and creatively about the scale of its work. It needs to be promoting links between LOs and government in a common effort to significantly expand coverage or otherwise *“we will stay in our domain”*.
3. The Alliance should be trying to link and balance grassroots work with policy work, acting as an advocate using evidence from the ground to shape policy and agendas at all levels.

2.3 Proposed Alliance future directions

In his report back to the workshop on the conclusions of the Alliance Directors' Retreat, Alvaro Bermejo elaborated on the emerging consensus within the leadership of the Alliance about how best the organisation could support communities to reduce the spread of HIV and to mitigate the impact of AIDS. This consensus is oriented around five strategic directions for the Alliance. The first three directions relate to *what* it works on and the last two concern *how* the Alliance works.

First strategic direction: Coverage

The Alliance must reach more people in more areas with more comprehensive programmes. Priorities for geographical selection need to be re-examined in light of emerging epidemic dynamics and the responses of other actors. Greater coverage will entail working with an increased number of LOs and expanding the number and range of LO partners. Programme design must take account of the specificities of multiple epidemics, addressing the challenges of working with "key populations" in high prevalence situations, developing "positive prevention" work with PLHA and tackling the socio-cultural determinants and implications of HIV/AIDS.

Second strategic direction: NGO Support

A priority for technical support to LOs is to build their capacity in working "upstream". There was a clear recommendation from mature LOs at the Directors' Retreat about the need for technical assistance to help them in influencing national strategic thinking and planning and creating space for NGO participation in national forums. In addition, the Alliance needs to more clearly define its niche at the national, regional and global level in Global Fund and World Bank funding mechanisms.

The Alliance's work in NGO support should also explore opportunities for working more closely with medical institutions and health systems and, more generally, look beyond the 'usual suspects' and develop work with new partners such as labour unions. The Alliance's ability to expand its coverage will rely on its capacity to expand the range of its partnerships. Documentation and evaluation of impact and the sharing of these findings and lessons are a further priority for its NGO support work. The Alliance should take greater advantage of new technologies in its delivery of and communication about NGO support.

Third strategic direction: Enabling environment

More attention must be given to creating an enabling environment for community action to reduce the spread of HIV and mitigate the impact of AIDS. The Alliance has an important yet under-developed role in influencing national governments and supporting nationally driven agendas – the first "1" of the "Three 1's" approach outlined by Dr. Piot. This will involve an increasing emphasis on the Alliance's relationships to, and work with, international institutions and a closer examination of issues of sustainability and absorptive capacity.

Fourth strategic direction: Through indigenous intermediary organisations

The clear view of the Directors who came together at the retreat was that the promise of a powerful future for the Alliance rests on a vision of powerful Linking Organisations, as indigenous intermediary organisations that are governed, led and managed locally. Alliance Country Offices are intermediate steps toward this vision. This is not to say that there is one model of linking with the Alliance – this is not a one-size fits all approach. There will be different "L"s in the LO vision, involving different types of relationships with the secretariat and with other LOs in the Alliance structure. This vision is framed both nationally and regionally – as LOs strengthen there will be a pull to regionalisation, expressed in regional visioning and structures.

Fifth strategic direction: Working internationally in an Alliance

“We need to broaden the surfaces of engagement in order to deepen a sense of belonging.” Alvaro Bermejo

The second aspect of the vision described above is of the Alliance as a global alliance of LOs and secretariat, linked and oriented around a core of shared values and vision, history and experience as well as resources. Such an alliance would emphasise strong national identities allied in common purposes and collective efforts at regional and global levels. There would be space for strong LOs to access and use regional resources on a mandate from the whole Alliance, thus meeting the need to think and work more regionally and avoid the limitations of a piecemeal country-by-country approach. Evolution toward this vision naturally faces a number of challenges but, as first steps, it will require a broadening of the “*surfaces of engagement*” between parts of the Alliance, with an emphasis on increasing horizontal links between countries to avoid the bottleneck of routing all communication through Brighton. More frequent, varied and meaningful engagement is the basis for the sense of belonging on which an effective alliance depends.

SECTION 3

Prevention: Issues, Lessons and Recommendations

The first day of the workshop considered three themes in community action on HIV/AIDS: prevention, care and integration. A number of participants at the workshop had already attended the Directors' Retreat and the discussions and conclusions from the retreat (discussed in sections 1 and 2 of this report) informed the workshop's deliberations on these three themes. In his opening remarks to the workshop, Alvaro Bermejo summarised some key questions for the Alliance that had been identified at the retreat, namely:

How to achieve scale/coverage?

What types of NGO support are needed?

What roles should LOs play in shaping the national response?

How to shape national-level policy?

These questions were explored throughout the two days of the workshop. They formed the backdrop for discussion of issues within the theme of prevention. This discussion was initiated by three presentations and followed by group-work to draw out lessons and recommendations. This section summarises these presentations and the highlights and outputs of the group-work process.²

3.1 Models for HIV prevention with youth in Senegal

Senegal is a low prevalence country with an HIV epidemic that is concentrated among specific groups of people (for example, sex workers) and within certain geographical areas. HIV prevention work with youth is a high priority. Low levels of education, chronic youth unemployment (40% in urban and 38% in rural areas), as well as early sexual debut and early marriages among young girls increase young people's vulnerability to HIV and STI infection. Inappropriate health and social policies currently emphasise abstinence and faithfulness over condom promotion, and there is little youth involvement in designing and implementing HIV/AIDS and STI programmes and policies or in promoting the few VCT services that are available.

Comparing models for expanding HIV prevention

ANCS, the Alliance Linking Organisation, has prioritised HIV prevention work with youth, with an emphasis on developing life-skills for young people and on improving relationships between parents and their children. Two models have been used to expand the coverage of this work. In the first, ANCS staff have provided technical support to 214 youth organisations in rural and semi-rural areas, training their community agents to reach some 294,900 people on HIV prevention since 1999.

In the second, ANCS has provided intensive programmatic, organisational and institutional support to a national youth organisation in order to strengthen its capacity as an intermediary. Since 1998, this intermediary organisation has established 11 national branches, which are working with over 24,000 young people on HIV prevention. The intermediary model offers greater scope for scale-up but ANCS realises that a 'cascade' approach risks 'diluting' the quality of the work.

ANCS has also worked at the national level to create a more enabling environment for

² The workshop featured the following three presentations on the topic of prevention:

"HIV/AIDS prevention among Youth in Senegal: ANCS Case Study" presented by Alioune Badara Sow of Alliance Nationale Contre le SIDA (ANCS)

"Strengthening PLHA and MSM NGO/CBOs to lead their own prevention process" presented by Javier Alvarado of Corporacion Kimirina in Ecuador

"Club Eney: from Self-Help Group to Large AIDS-Service Organisation" presented by Olga Kudryashova of Club Eney in Ukraine

HIV prevention work with youth. It helped to organise a national forum to develop the government's youth plan (2002 – 2005) and has promoted the use of participatory methods in order to improve the government's more traditional approach to work with youth.

3.2 Working with the most vulnerable in Ecuador

The risk of HIV infection for gay, bisexual and other MSM is at least three times the risk for women and heterosexual men in Ecuador. Gay and bisexual men living with HIV/AIDS are approximately 50% of reported PLHA cases in the country. HIV/AIDS awareness raising campaigns and initiatives have proved largely ineffective, especially in terms of addressing the needs, rights and interests of gay, bisexual and other MSM. There is little HIV prevention work targeted at people already living with the virus – PLHA groups have traditionally focused on care and support with less emphasis on prevention. In response, Kimirina, an Alliance Linking Organisation since 2000, has targeted MSM and PLHA in its work as an implementing partner in the Alliance's Frontiers Prevention Project (FPP).

Outreach is critical

Peer outreach has proven to be an effective strategy for accessing marginalised gay, bisexual and other MSM and promoting self-reflection, risk awareness and behaviour change. Kimirina's success has depended on careful selection of peer outreach workers as well as proper training and follow up. In the first phase of the project, outreach has focused on "hot spots" where gay, bisexual and other MSM gather openly and regularly. The second phase will expand outreach to more hidden groups of MSM. An important lesson learned by Kimirina is that this outreach work must be supported by a strategy of improving these men's access to STI/HIV prevention and treatment services. Training of health service providers has addressed their negative attitudes toward gay, bisexual and other MSM as being the main barrier to such access.

Empowerment is central

Empowerment approaches have been central to addressing some of the main difficulties experienced by men who have sex with other men and by people living with the virus. These difficulties relate to low self-esteem at the individual level and a lack of "social capital" and organisation at the collective level. The two are linked and both heighten vulnerability to HIV (re-)infection.

Given the stigma that many MSM face and the fears of disclosure with which PLHA have to live, the creation of safe spaces in which individuals can come together, be themselves and build group identity has been an important first step toward empowerment. The active involvement of groups of MSM and PLHA in the site assessments that helped design the FPP work with them has furthered their empowerment and their sense of ownership over the work.

As a result, several groups of MSM and PLHA have now organised themselves as small CBOs, whose organisational development Kimirina is now supporting. Such support is helping to develop leadership abilities, increase self-esteem and build "social capital" within the context of strong organisations that can take on the task of HIV/AIDS prevention in their own 'community' and of defending their human rights.

Through this organising, the FPP approach has raised the visibility of highly marginalised groups and countered the silencing and stigma that they face. MSM and PLHA have been enabled to participate on an equal footing in AIDS committees with local government, law enforcement and other NGOs, building relationships with key decision-makers, pursuing common agendas and coordinating their services through referral networks to ensure that their range of needs gets met.

3.3 Saving lives in Ukraine

Club Eney was founded as the first Narcotics Anonymous group in Kyiv in 1993. Since 2001, it has been supported by Alliance Ukraine as the first HIV prevention project with vulnerable groups in the city. It has gained national and international recognition as an organisation run entirely by active or ex-drug users working effectively in HIV/AIDS prevention, care and support.

Eney provides a wide range of support and assistance to over 1700 IDUs, sex workers and PLHA, based on a participatory community assessment, including a system of mobile assistance for IDUs and sex workers providing information, condoms, clean needles and syringes as well as tea and coffee and psychological support.

Drugs outreach work on the streets of Kyiv, Ukraine

“Club Eney’s work among drug users is really saving our lives.” Oleg, drug user and club member



Holistic services to meet a range of needs

The Club also offers the following services to its members:

High-quality information on HIV/AIDS, drug use and safe sex;

Counselling services (provided by a psychologist, drug treatment doctor, primary care doctor, peer counsellors), as well as additional counselling points at the city AIDS centre and at youth social services centres, and a telephone hotline;

Referrals to the VCT and HIV treatment services provided by the city AIDS centre, and to a joint substitution therapy project that the Club will operate together with the AIDS centre;

Training and work-experience for clients as outreach and social workers – 33 active or ex-drug users are employed by the Club; and

A dating agency helping HIV positive people to find friends and partners.

Promoting and protecting the human rights of people who use drugs

Advocacy and human rights work is a critical component of Eney’s work. Two project lawyers provide legal services to the Club members. Eney is also collecting information on human rights abuses, especially on police violence against IDUs, sex workers and PLHA. The Ukrainian law on HIV/AIDS is ideal on paper but in practice it does not work. The Club wants to use cases of abuse to advocate on a national level for legal

reform. Eney participated in the UNGASS HIV/AIDS preliminary session (May 2001) and has promoted the rights and interests of vulnerable groups in the national media and in parliamentary hearings. In 2003, the Club was given an award from the mayor of Kyiv for its work on HIV/AIDS prevention.

3.4 Issues, lessons and recommendations

Participants divided into three groups on the afternoon of the first day of the workshop in order to look more closely at the three themes of prevention, care and integration respectively. Each group was asked to discuss changes in the environment, and explore the opportunities and challenges presented by these changes in relation to their respective theme. In addition, each group was encouraged to share examples of both good practice as well as failures in relation to their respective theme and draw lessons and recommendations from them.

The small group that met to discuss the theme of prevention identified the following issues, lessons and recommendations.

Targeting

“People living with HIV/AIDS are still sexual, but may have feelings of guilt and shame about this.” Anuar Luna

Important opportunities for HIV prevention work have been missed by not targeting people at the moment of HIV testing and beyond. Insufficient work is being done when people test negative and very little prevention work is being done with those who test positive. There is a need to develop further prevention work with PLHA (“positive prevention”). In particular, it is recommended that more attention be given to the psychological and emotional aspects of HIV prevention work – for example, working with PLHA around issues of shame and guilt in relation to their sexuality and supporting them in developing healthy sexual lives.

Distinctions between high and low prevalence settings need to be re-examined in relation to marked variations within and not only between countries. It is recommended that more work be done with “key populations” in high prevalence areas and countries.

At the same time, targeting of HIV prevention work should increase its focus on issues of mobility while recognising the challenges of cross-border work. Many people’s lives are lived across borders, through trade and kinship ties. Thus, developing HIV prevention in response to the realities of people’s lives will entail acknowledging the limitations of working within solely national frameworks, given the arbitrary nature of many national borders.

Targeting populations that are regarded as being key to the dynamics of the epidemic in low prevalence areas has emerged as a central HIV prevention strategy for the Alliance. This “key populations” concept is different from the emphasis on “risk groups” that was so common in the early years of the global AIDS response. The main lesson that has been learned from the failure of the “risk groups” approach is that this form of targeting can easily turn in to scapegoating, resulting in an increase in the stigma and marginalisation often experienced by such groups.

By contrast, the success of the “key populations” approach to targeting is its emphasis on empowerment and leadership development within these populations. This has helped to improve individual resilience and collective ‘social capital’ within such populations, thus reducing their HIV vulnerability and strengthening their resistance to the stigma and marginalisation that they face.

At the same time, it is important to recognise the tensions between the epidemiological, conceptual and operational elements of the “key populations” approach. These ‘populations’ are defined in epidemiological terms but this does not mean that members of these populations necessarily identify as such. “Key populations” such as men who have sex with men (MSM) are often extremely heterogeneous in composition.

This has clear operational implications. It is not enough to simply target MSM without developing strategies that respond to the very different ways in which different men identify themselves and the communities to which they belong. There are conceptual limitations as well when, by targeting “key populations”, we appear to be locating the problems of the epidemic within those populations themselves. Taking the MSM example, a key problem that drives the epidemic within such a population is homophobia, yet this is a problem of the rest of the population, not of the MSM themselves.

<p>Problems driving the epidemic</p> <p><i>“We have to help people reflect on their culture and how that is affecting the HIV epidemic”.</i> Gill Gordon</p>	<p>Given the above, it is recommended that the “key populations” framework be complemented by a focus on the “key problems” that are driving the epidemic. Globalisation, and its associated economic, demographic and social trends pose a number of challenges to HIV prevention. These are most apparent in relation to developments in the sex trade, migration and mobility, and the mass media, as well as deepening economic and social inequalities. Gender inequalities, often deeply rooted in cultural norms, continue to significantly influence the course and impact of the HIV/AIDS epidemic. One of the clear lessons that we are learning from the global AIDS response to date is that human rights and social justice frameworks are critical in both understanding these “key problems” and in building the alliances that are required to address them.</p>
<p>Treatment and prevention</p>	<p>One of the greatest barriers to HIV prevention is access to treatment. It is clear that in many parts of the world, for example in Central and Eastern Europe, it is not possible to work on prevention without dealing with problems of care and treatment. The significant expansion in access to treatment that we are seeing in some areas is one of the biggest changes in the environment for HIV prevention. Greater access to treatment is bringing more people in for HIV testing, and thus creating more opportunity for doing HIV prevention work at the same time as creating more demand for the development of “positive prevention” approaches with PLHA.</p> <p>On the other hand, there is the emerging challenge of sustaining people’s motivation to prevent infection when they believe that drugs are available to help them live healthily with HIV. At the organisational level, there are concerns that the pressure to respond to the increased demand for treatment may push prevention off the agenda.</p> <p>One lesson being learned from both successes and failures in HIV prevention is the importance of linking prevention to care and treatment, and the central role that PLHA can play in both. This is borne out by the Alliance’s experience in Senegal, for example. ANCS works with the national association of PLHA and supports many PLHA groups in the provinces to integrate prevention and care activities. PLHA from the national association go to rural areas where there are few people who are openly living with the virus in order to raise their visibility and to promote the importance of getting tested, providing care and reducing stigma.</p>
<p>Integrated approaches</p>	<p>Vertical HIV prevention services have proved costly and often ineffective. Integrated services are needed that can respond to people’s health needs in a holistic way, for example broadening beyond just STIs to include access to other sexual health services. Experience also suggests that prevention work is more effective when it is integrated with services that can respond to broader psychosocial needs, as the example of Club Eney in Ukraine made clear. HIV prevention must work with the whole person, and not merely their risk behaviours.</p> <p>Another useful way to think about integration is to look at the need to balance and link up IEC (awareness) and participatory approaches, and thus balance coverage with intensity. We have all learned that reaching people is different from changing their behaviour. It is also becoming clear that there is a need for integration in HIV prevention across programming and policy work, as well as between organisations and different levels of work.</p>
<p>Innovative approaches</p>	<p>After 20 years of the epidemic, it is also imperative that HIV prevention work does not go stale. There is a need for continued innovation, not only beyond awareness raising but also beyond the workshop format of intensive group-work with small numbers of people. One lesson being learned is the importance of thinking in terms of collective and not merely individual change. For example, the Alliance’s prevention work with “key populations” in its Frontiers Prevention Project has emphasised the strengthening of ‘social capital’ within groups of MSM, sex workers and PLHA by supporting them to</p>

organise to create, manage and sustain their own CBOs to do their own HIV prevention work with their peers.

Leadership and self-help

A clear recommendation emerging from this experience is that it is vital to develop the activism and leadership of those who are most vulnerable to and affected by the epidemic. A critical task for HIV prevention work is to be supporting activists among marginalised groups to take leadership on HIV/AIDS work, especially given the risks that they face in taking the first steps to challenge human rights abuses against them and their communities.

The importance of community self-help groups was apparent from all three presentations on prevention at the workshop. Such groups have proved effective in promoting HIV prevention as well as reducing stigma. The challenge for these groups, and for the broader HIV prevention effort, is to deal with the negative attitudes of people and policy makers toward these groups so that such groups can be scaled up.

Documentation, learning and evaluation

Better documentation and sharing of learning is also important in dealing with the danger of staleness. There is still a lack of detailed documentation and especially of analysis of good practices in HIV prevention work. Part of this relates to the challenge of coming up with impact indicators for many aspects of this work, particularly those aspects relating to contexts and factors of vulnerability (for example, on empowerment and 'social capital') as opposed to behavioural outcomes (such as use of condoms).

"We are not measuring the richness of what we are doing." Xavier Alvarado

There is a need to develop monitoring and evaluation tools that are responsive to the complexity of the changes that HIV prevention work is pursuing. At the same time, much more attention should be given to the processes of knowledge creation and learning. One lesson being learned is that simply producing and disseminating a document about good practice is not enough for that practice to be learned and adopted. Organisations such as the Alliance need to put more thought into the processes by which knowledge is created about a particular good practice (especially who is involved in creating this knowledge) and then the process by which such knowledge is learned by others.

Technologies

The greater distribution of condoms as part of social marketing is one of the most significant technological changes over the past few years, affecting both condom use and prevention programming. While distribution has certainly expanded, there has not been a corresponding expansion in condom education and it is recommended that more attention be given to programming that links distribution with education more explicitly.

The increase in condom distribution, whether it is the male or female condom, presents the challenge of sustainability and balancing cost with demand. There is still a huge gap, however, between levels of distribution and levels of need. It is clear that there is still a need to expand the number of distributors and deal with the challenge of working with more conservative service providers and enlist them in the condom distribution effort. New technologies, such as microbicides, may change the face of prevention but the nature of this change is as yet unclear.

Lessons and recommendations for policy work (summary)

- Aim for optimal trade off between coverage and quality of programming
- Build capacity of policy makers and NGOs for AIDS policy formulation and implementation
- Increase advocacy for treatment and high quality prevention
- Increase the involvement of NGO/CBOs (especially PLHA groups) in strategic decision-making

Lessons and recommendations for programming work and scaling up (summary)

Design integrated approaches to prevention across programmes and organisations

Extend programming beyond key populations into 'key problems' to create enabling environment

Identify opportunities for prevention (e.g. STI patients, programme links with stigma and discrimination)

Use participatory approaches to assessment, M&E & to increase 'social capital'

Ensure comprehensive mix of interventions, enabling people to fully benefit

Keep up to date on new technologies while learning from experience

Be analytical about who we work with in different contexts (e.g. are men the decision makers in X society?)

Include gender and sexuality issues in all prevention activities

Ensure more systematic documentation and sharing of experiences

Consider geographic coverage, themes and quality in scaling up

Make linkages with stakeholders on site to increase scale up: i.e. 'scale up does not mean doing it yourself'

SECTION 4

Care: Issues, Lessons and Recommendations

Discussion of issues within the theme of “care” was stimulated by two presentations and followed by group-work to draw out issues, lessons and recommendations. This section summarises these presentations and the highlights and outputs of the group-work process.³

4.1 Improving people’s access to ARV treatment in Burkina Faso

Burkina Faso is a poor country, with 60% of its population living below the poverty line. It has one of the worst HIV/AIDS epidemics in West Africa, placing severe strains on already weak public health systems.

The Alliance Linking Organisation Initiative Privée Communautaire de lutte contre le VIH/SIDA (IPC) is supporting AAS to provide ARV treatment to people living with the virus. Through Project Orange, as it is known, AAS is seeking to expand access to ARVs in community-based settings, improve patients’ adherence to treatment and advocate for further community-based access to HIV/AIDS treatment. Crucially, the project is located within an integrated prevention/care facility.

Project Orange is targeting the 1200 PLHA currently registered with AAS. It is providing ARV treatment to 195 patients and, with increased resources, plans to take on 30 new patients per month. Initial clinical results are promising. The main strategies of the project are to scale up the existing community treatment initiative, mobilise a broader response to the needs of PLHA through networking and referrals, promote good practice through documentation of its work and involve people living with HIV/AIDS in all aspects of the programme. This PLHA involvement is critical to the effectiveness of Project Orange, which is aspiring to be a centre of excellence in HIV/AIDS care and treatment.

Challenges being faced

Funding: ARV drugs are expensive in Burkina Faso – 60% of the budget is spent on these drugs. As a result of work by AAS, IPC and others, the government has announced plans to procure generic drugs that will significantly lower the costs of treatment.

Infrastructure: AAS is currently spread over three sites whilst it constructs a new 3-story centre. Investing in a new building was a necessary response to the poor working conditions and the inefficient use of labour that resulted.

In-house learning: In the context of overwhelming patient need and limited resources, it has been difficult to protect time for training and learning and to allocate resources for learning and documenting.

Organisational development: It has become clear that providing safe and effective treatment requires a greater professionalisation of AAS practices and procedures. But the organisation also recognises that professionalism threatens the activist and voluntarist ethic and culture of AAS. The organisational development challenge is to move toward performance-based human resources management while maintaining grassroots governance.

³ The following two presentations were given on issues of care:

“Project Orange” presented by Paul McCarrick in the absence of Issoufou Tiendrebeogo, President of AAS

“Community-based Care and Support in India” presented by Dr. Balwant Singh (India HIV/AIDS Alliance), Keerthi Yerramsetty (Vasavya Mahila Mandali), and Divya Bajpai of the Alliance secretariat

Challenges ahead

As AAS moves on from its start-up phase and into a three-year implementation phases it faces some clear challenges ahead.

Meeting the needs of children: There are currently over 40 children who are living with HIV on the caseload of AAS and there were six child deaths from AIDS in 2003. As a result of an almost total lack of paediatric ARV experience and training among medical staff in Ougadougou, these children are not receiving treatment. AAS is seeking technical support in this domain in order that it can take on the treatment of the children in its care.

Meeting the needs of prevention: The continuing need for “positive prevention” with people living with HIV/AIDS has been brought home to AAS. There were eight pregnancies among the PLHA it is serving in 2003. STIs are also common among both women and men living with HIV/AIDS. “Positive prevention” presents special challenges in a culture in which it is difficult to discuss sexuality openly and then doubly difficult to discuss with PLHA who often carry anxiety, fear and shame about sex and their sexual lives. Positive women are also caught between social expectations around women’s fertility and social stigma toward their desire to continue to bear children. AAS, with the support of IPC, is looking to improve sexuality counselling and STI diagnosis and treatment (e.g. single dose regimens).

Providing socio-economic support: Providing people with treatment for HIV infection has confronted AAS with a wide range of individual and family psycho-social and economic issues. Many of its patients are poor and struggling with basic survival needs as well as the impact of this struggle on their own physical and mental health and their relationships. AAS is also aware of the risk of creating dependency. In response, AAS is drawing on its strong entrepreneurial spirit in looking at how best to support the socio-economic well-being of its patients. It already runs a successful Internet Café and plans to create two businesses to provide employment and on-the-job training for patients.

Priorities

Mobilise resources: With Global Fund funding passing only through public structures and not yet launched, the World Bank’s Treatment Acceleration Programme (TAP) is the most promising source of support to civil society organisations involved in treatment. There is tension however with government over TAP and confusion over the programme process has resulted in delays. A priority for the Alliance, IPC and partners such as AAS is to help resolve this confusion as well as to explore other sources of money for treatment.

Support adherence: Based on an ongoing study of barriers to adherence, the Alliance and AAS plan to reinforce treatment literacy through peer counselling within support groups and developing new communication tools. AAS is also planning a residential unit (« Maison de l’observance ») that can provide temporary intensive counselling and support to people starting treatment.

Secure technical assistance: AAS recognises its need for further technical assistance on approaches to sexual health and pregnancy counseling for PLHA, treatment protocols for children and pregnant women, and good practice documentation and dissemination.

4.2 Expanding community-based care and support in India

Since 1999, the India HIV/AIDS Alliance has worked to increase the coverage of effective community-focused AIDS efforts, strengthen the leadership and capacity of civil society to respond to AIDS and improve the institutional, organisational and policy environment for community AIDS responses in India. With offices in Delhi & Hyderabad, the India HIV/AIDS Alliance runs programmes in Andhra Pradesh, Tamil

Nadu and Delhi. It is working with 40 NGOs through four Lead Partners in these three states on its community-based care and support programme. This programme has reached 150 communities, and more than 5800 PLHA as well as 8500 children and 9000

family members affected by AIDS.

Lessons

Integrated approach: This is important in addressing the diverse needs of PLHA, children affected by AIDS and families. An integrated approach is both relevant to community needs and cost-effective.

Values and ethics: Capacity building of NGO/CBO staff and volunteers on ethically appropriate and value-based interventions is crucial.

Rights-based framework: Mainstreaming care and support needs of PLHA, children affected by AIDS and families within a rights-based framework leads to sustainability and reduction of stigma and discrimination. Rights is an important basis of the work, deriving as it does from a focus on community-driven processes.

Challenges

Being child-centered: Limited NGO/CBO capacity has constrained the development of more child-centred approaches and programming and further technical assistance is required to enhance child-centred work.

Reducing dependency: One of the greatest challenges is to promote community care and reduce people's dependence on institutional care.

Confidentiality: Some NGO/CBOs still maintain that confidentiality is not an issue in their locality, neglecting the continuing reality of stigma and discrimination faced by PLHA. The challenge is both to sensitise NGO/CBOs to the nature and implications of this reality and to equip them with the tools and skills to address stigma and discrimination.

Paediatric HIV/AIDS: Much more work is needed on paediatric HIV/AIDS and developing care and support interventions as well as expanding access to ARV treatment for children living with HIV/AIDS.

Lessons being learned in Andhra Pradesh

Vasavya Mahila Mandali (VMM) is the lead partner in Andhra Pradesh supporting a network of seven NGO/CBOs in five coastal districts with plans to scale up to ten NGOs in seven districts. Its main strategy has been to build the capacity of individuals, groups and NGO/CBOs, with an emphasis on participatory approaches to promote community ownership and sustainability. The important lessons that are being learned relate to:

Children's voices: Raising the voices of children affected by AIDS through print and electronic media has helped to mobilise communities and reduce stigma. VMM has created support groups for children, thus helping to improve self-confidence and provide mutual support.

Community fostering: Integrating HIV/AIDS care and support issues into women's micro-credit groups has led to the community fostering of children orphaned by AIDS. Ten families, none of whom have HIV positive members, have adopted 19 such children, indicating the extent to which stigma has been reduced.

Meeting basic needs: The 'handful of rice' programme (Sarvodaya), initiated and operated by women, has led to a greater sense of community and corporate social responsibility for families affected by AIDS. By asking each woman in the community to contribute a handful of rice to feed PLHA, the programme has, in the last three years, been able to take over nutritional support to PLHA. The programme has also mobilised the private sector. A local company has donated a vehicle and staff for collecting and distributing food and clothes to PLHA.

Vulnerability of children: It is becoming clear that the care-giving responsibilities and the economic burden of HIV/AIDS are increasing the vulnerability of children in families affected by AIDS.

Sarvodaya – the
'handful of rice'
programme



Priorities and plans in Andhra Pradesh

These include:

Formalising community fostering and using HIV/AIDS as an entry point into advocacy for policy changes on orphans and other vulnerable children that will shift resources away from institutional and toward community care;

Integrating home and community-based care services with government development and welfare programmes, in part through strengthening referral networks and mechanisms;

Organising children affected by AIDS to be involved in developing and sharing cultural messages against stigma with the community;

Developing study-cum-recreation centres for all children, in part to reduce the stigma faced by children affected by AIDS; and

Integrating care and support activities into HIV prevention programmes in association with the State AIDS Control Society.

Learning from experience in Tamil Nadu

Tamil Nadu has a strong tradition of civil society activism and rights-based work. Sevanilayam, Alliance India's lead partner in the state, has been working with communities for more than two decades on issues of development. It has integrated health programmes into its existing development work and established community health centres where there was no access to primary health care. The Alliance has supported Sevanilayam to become a 'centre of excellence' for training village health care providers in community and home based care. Much of its work has involved building the capacity of staff, volunteers, self-help groups, PLHA and children affected by AIDS to work on care and support issues.

Developing home-based care services is a major component of the project. These services include: basic medical care and services; referral services; nutritional supplements; mobilisation of community resources (e.g. handful of rice programme); peer counselling; and facilitating support groups (both integrating PLHA in to existing self-help groups and establishing PLHA support groups).

Achievements

Sevanilayam has successfully:

Mobilised communities to take on PLHA and care/support issues, whereas three years ago PLHA were regarded as the lowest caste;

Helped to form a district level network of PLHA in Theni district and to provide ongoing technical support to them;

<p><i>“There has been quite amazing progress in Tamil Nadu.”</i> Divya Bajpai</p>	<p>Established effective linkages with existing programmes to facilitate support services for PLHA and their families;</p> <p>Contributed to the reduction of stigma in the community through mobilising community volunteers;</p> <p>Extended its existing Tb DOTS programme to address HIV/Tb co-infection; and</p> <p>Mainstreamed HIV into existing community development work.</p>
<p>Common themes of care work in India</p>	<p>An integrated approach to responding to HIV/AIDS in the context of broader community issues and interests has been critical in mobilising community involvement in care and support programmes.</p> <p>Communities are taking over service provision, and thus increasing the sustainability of this work.</p> <p>HIV-related stigma exists in the context of other inequalities and oppressions (such as the racism of the caste system) and this ‘cultural’ dimension of stigma is essential to address.</p> <p>Work on HIV/AIDS has been a way of challenging deeply embedded cultural hierarchies (e.g. promoting cross-caste HIV orphan care).</p> <p>Working to reduce stigma must include a focus on psycho-social support to PLHA to reduce internalised stigma and shame through counseling, self-help groups, and involvement in wider activities.</p> <p>Advocacy is helping to improve government policy.</p>
	<p>4.3 Issues, lessons and recommendations</p> <p>The small group that met to discuss the theme of care identified the following issues, lessons and recommendations.</p>
<p>ARV treatment and the continuum of support</p> <p><i>“Will increased funding for ARV treatment translate into funding for the continuum of care and support?”</i> Mandeep Dhaliwal</p>	<p>There are marked changes in the context for care. Access to ARV treatment is improving, prices of ARV drugs are being reduced (as a result of campaigning by PLHA, human rights and social justice activists) and generic drugs are broadening the relationship between suppliers and users of pharmaceuticals from a North-South axis to include a South-South axis. Funds for treatment are increasingly available, too.</p> <p>These changes are creating challenges in terms of maintaining standards for this expansion in ARV treatment. There is a need to define what is basic AIDS treatment and care and what are the minimum components needed for effective treatment. The emphasis on ARV treatment is not being matched by the attention given to nutrition issues and the broader continuum of care and support. The ‘revolution’ underway in ARV treatment offers both opportunities and challenges in terms of defining and operating integrated approaches that can respond to the broader psycho-social needs of PLHA.</p> <p>Notwithstanding these improvements in access to treatment, the numbers of those who have access compared to those who need treatment remain extremely small. Thus, questions of equity in relation to who should get treatment first continue to be central and it is noteworthy that the WHO is researching issues of IDU access to ARV as part of its “3 by 5” initiative. The role of the Alliance and NGO support programmes at the national level in addressing these equity issues needs to be explored, as does their role in supporting the sustainability of NGO/CBO involvement in provision of ARV treatment.</p>

<p>Stigma</p>	<p>Stigma and discrimination continue to be defining facts of many people’s experience of living with HIV/AIDS and a central challenge for an ethical and effective response to the epidemic. Although much work has been done at the legislative, policy and public education levels to reduce stigma and discrimination in public life, much more work is needed with PLHA on the internalised shame and trauma of living with the virus in a climate of stigma.</p> <p>Working on issues of stigma in the context of other forms of oppression and human rights abuses is an equally significant challenge. Many PLHA’s experience of HIV-related stigma is bound up with the oppression that they experience as a result of their race/ethnicity, caste, nation of origin, sexuality, gender and/or age. Dealing with these political and cultural dimensions of stigma is an urgent priority. Children and young people’s experience of HIV and stigma is only now getting some of the attention it deserves with the emergence of OVC programming.</p>
<p>PLHA involvement</p> <p><i>“We need to strengthen these PLHA groups and not just bring them together.”</i> Sirinate Piyajitpirat</p>	<p>The increased visibility of PLHA participation is one of the most striking changes in the context for care. PLHA networks and groups are playing important roles in designing and implementing care programmes in many of the hardest hit areas of the world. A key lesson being learned from this experience is that PLHA involvement is as much about asserting their rights to self-determination as it is about improving programme effectiveness.</p> <p>The challenge is not simply to help PLHA groups and networks get organised but to help them strengthen and sustain their work of collective self-determination. There is perhaps an even greater challenge of enhancing the involvement of children and young people living with HIV/AIDS and responding to the ways in which young PLHA are denied their rights to self-determination.</p>
<p>Community involvement</p>	<p>Greater community involvement in care activities is also part of the changing context. This has been accompanied by a greater formalisation of the community’s role through integration of community volunteers in home-based care programming, for example. Expanding and professionalising community involvement in care is creating the possibility of scaling up community-based care interventions, building on the good practice of community involvement in delivery of broader health care services. But there is still too much emphasis on simply bringing communities into the delivery of ‘western’ models of health care. The challenge is to engage and mobilise the traditional healers and systems of medicine that continue to provide health care to the majority of people in countries of the economic South.</p>
<p>Scale and coverage</p>	<p>Compared to even five years ago, there are many more and more different kinds of groups and organisations involved in HIV/AIDS care. This expansion, together with improvements in coordination and referral systems as well as increased funding from a range of sources, is offering the possibility of a significant scaling up of care activities, if the right political commitment can be secured.</p> <p>Current discussions of and planning for scale up are thinking too small and too short-term in relation to the magnitude of the problem of care.</p>
<p>Links with prevention</p>	<p>In light of both the huge need for care services and the increasing availability of ARV treatment discussed above, there are concerns that prevention is ‘falling off the map’. There is a twin danger of prevention being de-prioritised in national planning and budget allocations and that in areas where treatment is more available people themselves may come to regard prevention as less important. Given this, it is essential to build on the good practice of integrating prevention, care and treatment into existing community</p>

systems of welfare and health care and ensure that care programmes are expanded as part of comprehensive interventions which include prevention.

Capacity and coherence of government response

Health systems in many of the worst affected areas remain extremely fragile in the face of overwhelming need. Human resources, institutional systems and basic infrastructure are not only struggling to cope with the realities of HIV/AIDS but are themselves weakened by the epidemic. One of the failures of the global response to HIV/AIDS has been the failure to strengthen health systems and to improve communication between such systems and community interventions. In learning from this failure, it is important that organisations such as the Alliance take the opportunities presented by scaling up ARV for pushing for wider health sector reform.

Workplace issues

The workplace offers as yet untapped opportunities for strengthening work on care, both through workplace policies and health programmes. There are opportunities to encourage HIV/AIDS policy development at the workplace, as well as through the private sector and labour unions, although the challenge is to push such policies beyond their customary emphasis on prevention to include care issues as well. It is worth noting that many organisations that are themselves working on the epidemic do not have internal policies on AIDS in place, posing challenges of organisational development. In this respect, the Alliance offers an example of good practice in that its own AIDS policy covers both prevention and care issues.

Recommendations

- Integrate care, treatment and support interventions into existing community structures as well as with prevention and impact mitigation interventions
- Improve communication, collaboration and coordination between community-based efforts and the health care sector
- Work with larger non-governmental actors – unions, private sector employers – to deliver care services and to promote workplace prevention and care policies
- Develop outreach programmes to take care to where people are
- Develop peer approach interventions to providing care services and educating people about care issues
- Collaborate amongst civil society actors to influence the policy agenda on care issues, especially in relation to equity in access to care
- Fundraise to expand ARV treatment within the context of a continuum of care, treatment, prevention and mitigation

SECTION 5

Integration: Issues, Lessons and Recommendations

Discussion of issues within the theme of “integration” was stimulated by two presentations and followed by group-work to draw out issues, lessons and recommendations. This section summarises these presentations and the highlights and outputs of the group-work process.⁴

5.1 Integrating services for orphans and other vulnerable children in Burkina Faso

Initiative Privée Communautaire de lutte contre le VIH/SIDA (IPC) was created in 1994 at the initiative of the Alliance and became a national NGO in 1998. Two years before this transition, it had begun community-based care and support for PLHA and in 2000 it started its project with orphans and vulnerable children.

The project was developed in response to the scale and neglect of the OVC problem. In 1999 UNAIDS estimated that there were 350,000 orphans due to AIDS in the country, with a prevalence of 6.5 per cent in the 15–49 yrs group. Responses to this situation were mainly institutional with very limited coverage and little involvement of non-health sectors. With funding from DCOF and Abbott Laboratories Step Forward Programme, the Alliance created a technical assistance post at IPC to support the integration of work with OVC into ongoing prevention and care/support work.

The goal of IPC’s work with orphans and other vulnerable children is to: contribute to improving their wellbeing and living conditions by mobilising and building community capacity to support OVC (through care and support and prevention work); strengthen community projects for PLHA and their families; and strengthen household socio-economic capacity. Children’s participation is a critical component and communities are beginning to recognise the roles of children in project assessment, implementation and evaluation. IPC has strengthened its own capacity to support OVC work through developing tools and partnerships as well as integrating the child-to-child approach into its M&E tools. It has also carried out national advocacy to lobby for community work with OVC.

Project components

Participatory approach: IPC trains its partners in participatory approaches to strengthen communities’ understanding and response to HIV/AIDS. As these take time, IPC and the Alliance have been under pressure to get results and expand numbers quickly. IPC is looking into ways to speed up participation without sacrificing its value.

Community assessment: Vulnerability is defined locally and communities identify which children are vulnerable. Partner NGO/CBOs then address the specificities of HIV/AIDS in these children’s lives but do not attempt to just work with children affected by AIDS as that would bring up issues of stigma and would provoke discrimination against these children.

Services: IPC’s partners provide a range of services to orphans and vulnerable children. Community volunteers work closely with a number of families, providing psychosocial and case-by-case support.

Child involvement: The participation of children is an essential component of the project. This participation has influenced the priorities of the project – for example, the

⁴ The following two presentations were given on issues of integration:

“A community programme of care and support to orphans and other children in Burkina Faso ” presented by Brice Millogo of Initiative Privée Communautaire de lutte contre le VIH/SIDA au Burkina (IPC/BF)

“Supporting Integrated Voluntary Counselling and Testing (VCT) in Zambia” presented by Lillian Muyunda Byers (NGO/CBO Support Specialist, International HIV/AIDS Alliance, Zambia Country Office) and Patricia Hamweemba Habeenzu, District VCT Coordinator/Chairperson, Mumuni Centre, Kalomo

emphasis on care and support was in part determined by the fact that a number of children identified care and support needs in their communities.

Project evolution

The project has undergone a rapid and significant evolution at all levels.

	<i>2000</i>	<i>2004</i>
Community level	Few responses in BF OVC “issue” not recognised	IPC partners (40) supporting over 50 communities in 20 Provinces Human resources mobilised and trained Community action for OVC initiated Projects for strengthening households in place Potential role of children beginning to be recognised Households being strengthened
IPC level	OVC work begins in response to PLHA concerns	IPC has secured contract under the WB Multi-country HIV/AIDS Programme for Africa to scale-up its work with OVC into 6 new Provinces The Alliance has allocated additional funds to ensure appropriate technical and organisational support to this programme New partners mobilised Human resource capacity increased (both internal and consultants’ pool) Tools developed and/or adapted Nationally recognised as TS provider IPC now has ability to produce evidence on OVC and to raise issues for policy makers but it has been less successful in actually influencing policy – needs to work in alliance with others to achieve this
National level	Concept of OVC poorly developed Ad hoc responses to orphans are mostly institutional Little reflection on the notion of vulnerability to HIV amongst major civil society and public actors Few national initiatives Little technical capacity	IPC is a member of the National AIDS Committee In 2002, IPC jointly initiated first national OVC conference, leading to national OVC strategy development IPC is a member of the National OVC steering committee There are an increasing number of actors working on OVC

Project lessons

Participation: Participatory approaches to identifying and reinforcing existing community support mechanisms are much more effective than starting from an external view of “OVC needs” – but they take longer!

Self-help: It is important to help resource poor communities to develop creative solutions to the situation of vulnerable children and reduce dependence on external assistance.

Scale: Scaling up requires the mobilisation of all key actors, and a critical mass of human

resources within a supportive political environment.

Technical assistance: In Burkina Faso, international learning and resources are critical to OVC programming and action.

Child-centred: Child-to-child approaches are important for equipping CBOs, communities and children themselves with the skills they need to enable the genuine participation of young people. Last year the Alliance facilitated a workshop (see picture below) on children's participation and IPC has developed tools to support the introduction of this approach amongst its partners. In some sites, there is increasing involvement of children in community assessment, planning and implementation.

Using community tools to support children's participation in Burkina Faso



Challenges

Lack of national framework: There is still no national strategic OVC framework for cross-sector planning and action. This is an obstacle to multi-sectoral coordination, programming and skills development.

Stigma: The OVC approach has been effective in mobilising community support for children who are vulnerable to disease, marginalisation, exploitation and abuse. But stigma and discrimination still obstruct a greater focus on children directly affected and infected by HIV

Other challenges: These include: scaling up community responses; strengthening a critical mass of human resources; documenting, monitoring and evaluation; and persistent and widespread poverty.

5.2 "VCT on wheels!" in Zambia

People in Zambia are suffering one of the most severe HIV/AIDS epidemics in the world. In a country of almost 10 million, some 1 in 6 people aged 15-49 years are estimated to be HIV positive. HIV antibody testing and VCT services have been available in Zambia since the early 1990s, but by 1998 only 6 per cent of Zambians knew their HIV status.

In response, the government established the Zambia Voluntary Counseling and Testing Services (ZVCTS) Unit in 1999 to oversee the introduction of integrated VCT services into public health centres as an entry point into HIV prevention, treatment, care and support. A year later, the Zambia Voluntary Counseling and Testing (ZVCT) Partnership was created, comprising government, key NGOs (including the Alliance) and some donor agencies. The aim of the partnership is to strengthen and expand provision of high quality VCT services in integrated VCT sites.

The work of the ZVCT partnership is already having an impact. 106 VCT centres have been established in 14 districts, 95 of them in integrated service provision settings. A

survey in 2002 found that 9% of women and 14% of men now knew their status. More significantly, 70% of women and 64% of men interviewed said that they wanted to get an HIV test. The survey found that demand for HIV testing was increasing especially in rural areas.

The partnership seeks to expand VCT services through three stages of work, with different partners playing specific roles. The three stages are:

Creating demand

Service delivery

Post-test services

Alliance Zambia is playing a lead role in demand creation, through community and district level promotion of integrated VCT Services.

A model for VCT expansion in practice

The VCT work in Kalomo district offers one example of VCT expansion in practice. Kalomo is a large, sparsely populated, rural district in southern Zambia. People work in commercial and small-scale farming, gemstone mining and small trading. Many socio-cultural factors affect the HIV/AIDS situation including widespread polygamy, men's domination of decision-making, sexual cleansing following the death of a partner, initiation ceremonies in which youth have sex and tattooing using un-sterile instruments.

Kalomo Mumuni Centre, a local NGO, is a focal point for Alliance Zambia's work to create demand for testing at the district's two HIV testing sites. As part of its demand creation strategy, Mumuni has mobilised 14 CBOs to conduct mobilisation activities at the grassroots level. These involve meeting with village headmen in order to secure the legitimacy of the programme, conducting awareness raising activities through village meetings and helping community members to get to VCT services, where they can get information, pre-test counselling, testing, same-day results, post-test counselling and referral to different services. People are referred to DAPP, a social development NGO, for psycho-social support and are sent for ARV treatment in the nearest town (Livingstone).

VCT outreach

While the response to integrated services has been impressive, some communities find it difficult to access the services due to distance and transport costs to the testing sites. Home commitments (finding food, water, farming, firewood collection, child care, cooking) also have a significant effect on attendance.

In response, the VCT sites have partnered with Mumuni Centre and partner CBOs to conduct regular mobile VCT clinics that take VCT services to communities far away from the centre. The outreach team consists of dramatists/mobilisers, 10-15 counsellors, as well as lab staff to take blood and do rapid tests. The outreach includes community meetings to share information, one-on-one pre-test counselling, testing and same-day results, followed by post-test counselling.

The impacts of the outreach strategy are already becoming clear. More people are seeking VCT services and there is a greater acceptance of HIV as a community problem and more open dialogue on related issues, for example on gender. There appears to be a reduction in stigma and discrimination towards people living with HIV, related to more people coming out about their HIV positive status (even influential people such as headmen, church leaders, journalists, policemen, soldiers and married couples).

<p>Lessons from this work</p>	<p>Internal resources: It is useful to identify and draw upon the resource bases of communities when undertaking community mobilisation activities. For instance, communities have several ways through which they communicate messages that can be used in VCT promotion, such as drama, poetry, traditional dance, and through initiation counselors, healers, diviners, chiefs, birth attendants, religious leaders, teachers and elders. These communication channels can be very helpful in dealing with sensitivities of a particular community to HIV testing and enhance community understanding of the issues at hand.</p> <p>Gender issues: In working with women, it is important to stress that women have the right to go for test. Gender and sexuality discussion tools have been integrated into this work in order to explore these issues more with communities in relation to VCT. Working with headmen becomes even more important in this context because they are influential with other men.</p>
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5.3 Issues, lessons and recommendations

The small group that met to discuss the theme of integration identified the following issues, lessons and recommendations.

<p>Defining an “integrated approach”</p> <p><i>“You can’t ignore what are the needs. You have to expand your approach.”</i> Pok Panhavichetr</p> <p><i>“Integration may be high on the agenda but a lot of people mean different things by it.”</i> Sachin Gupta</p>	<p>There are many ways to think about the concept of “integration”. The following understandings of the concept emerged from the group’s discussion. Different understandings of “integration” and “integrated approaches” will apply in different contexts.</p> <p>“Integration” can be defined in terms of:</p> <p>Response = integrating prevention, care and impact mitigation responses to the HIV epidemic;</p> <p>Population = integrating work with different target populations on the basis of their common experience (e.g. of social stigma or police harassment);</p> <p>Strategy = integrating a mix of strategies including service delivery, advocacy and capacity building (both individual and institutional);</p> <p>Needs = integrating different kinds of services in order to meet the range of needs of the target population, recognising that HIV/AIDS exacerbates many other psycho-social and economic needs;</p> <p>Synergy = using multiple approaches to respond to the multiple determinants and impacts of HIV/AIDS in a synergistic way, as in the example of IPC’s integration of micro-finance programming into its OVC work;</p> <p>Sector = linking within or between sectors (e.g. health, education, social welfare, economic planning) in a strategic response to HIV/AIDS, although it is important to distinguish between “multi-sectoral” and “integrated” approaches, as there can be integrated approaches within a single sector;</p> <p>Stakeholder = integrating the work of multiple stakeholders (government, civil society, private sector, donors) to improve coverage, coordination and sustainability of responses;</p> <p>Issue = integrating specific issues or themes (e.g. gender) into HIV/AIDS work;</p> <p>Analysis = integrating a complex understanding of HIV in terms of its multiple and layered determinants and impacts; and</p> <p>Mainstreaming = integrating HIV into the work of other organisations, institutions and sectors without changing their mission.</p> <p>Given this broad range of meanings of “integration”, it is important to recognise that although integration may be high on the agenda of the global AIDS response, there may be conflicting interests and agendas behind the promotion of “integrated approaches”.</p>
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Needs, demands and capacities

Integrated approaches are often promoted and developed in recognition of the range of needs being experienced by communities and target groups. But it is important to acknowledge the limits of what is possible for a single organisation, network or NGO support programme to accomplish in relation to what can be an overwhelming set of needs.

Experience suggests that it is better to integrate external programming activities into the capacity and initiatives that already exist at community level, and emphasise the use of technical support to strengthen these capacities.

“People’s demands may not match what is available – the challenge is meeting the demand.”

Daphetone Siame

It is equally important to prepare service providers to meet the demands that can be uncovered when using integrated approaches to working with under-served communities. The VCT mobilisation in Zambia has found that testing services are sometimes unable to meet the demand for VCT that has been generated by the work of the VCT partnership.

Clear lessons have also been learned from initiatives to increase access to ARV treatment that make clear that such initiatives have to be about ‘more than just pills’. Effective ARV treatment requires an integrated approach that can respond to PLHA’s need for nutrition, health monitoring and psychosocial support, as well as be linked with prevention activities and infrastructure development.

Community participation in developing an integrated approach to VCT programming in Zambia



Collaboration and synergies

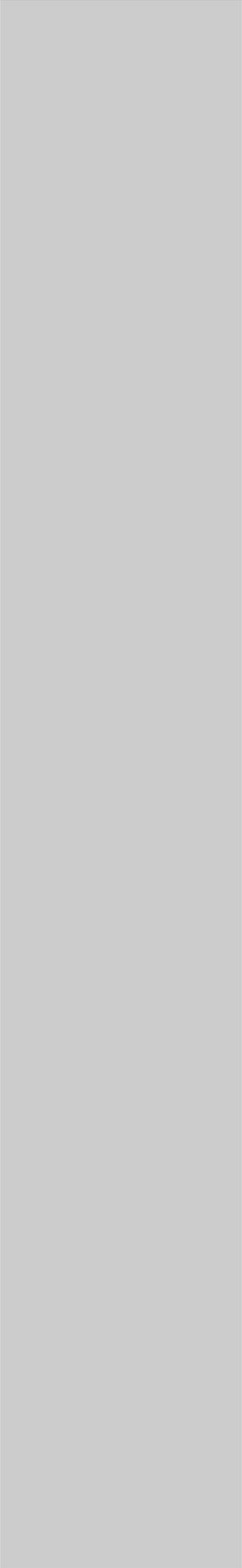
Integrated approaches often rely on effective collaborations that move beyond merely partnering together to working synergistically to enhance the impact of the collaboration beyond the sum of its parts. The Zambia VCT partnership provides a good example of such synergistic working. Yet, collaborations are frequently more challenging in practice than they are on paper.

“How can we be critical and honest about the real challenges of collaboration and be creative about ways to make this work?” Ted Nierras

There are so many examples of where it is difficult to even talk about collaboration as part of an integrated approach let alone ensure that such collaboration succeeds. Such examples include collaborations between civil society and government, which in the era of Global Fund financing have been given both a new urgency and a problematic dynamic as NGO/CBOs risk becoming mere sub-contractors. Examples of difficult collaboration also abound within the civil society sector itself, as NGO/CBOs compete over scarce resources to identify their distinctive niche and comparative advantage.

There is a need for processes and technical support that can assist organisations and groups in collaborating to develop integrated approaches, and good documentation of such processes in order to learn lessons that can be applied more broadly. At the same time, more thinking and discussion is needed to determine the most strategic integrations and collaborations, whether this is in terms of sectors, strategies or issues.

<p>Community involvement</p> <p><i>“Without community participation we ourselves have very little capacity.”</i> Gill Gordon</p>	<p>Meaningful involvement rests on an understanding of the pressures and forces that can manipulate community participation and of the inequalities in power that militate against meaningful involvement – as well as the development of processes of decision-making and accountability that are based on this understanding. It is clear that tokenistic community involvement is sometimes used to legitimise what international agencies are doing. There are also important issues of incentives and remuneration for communities that need to be addressed on a more general scale than the current piecemeal approach. Without this, there is a real risk of exploiting the voluntarism and scarce resources of often already depleted communities.</p> <p>It is also clear that the limited resources of communities can be stretched by the demands for their involvement from multiple actors. This is especially true in areas where there are few visible groups of PLHA. In this situation, there can be competition among donors for the involvement of the groups of PLHA that do exist. Much more coordination and support is required to engage communities meaningfully and sustainably in integrated approaches to HIV/AIDS.</p>
<p>Effectiveness</p>	<p>Demonstrating the effectiveness of integrated approaches remains a core concern, especially in a funding climate that is increasingly influenced by corporate models of “core business” and “niche branding”. This makes it imperative that the Alliance specifically, and the AIDS community globally, learn lessons from its successful and less successful models of integrated approaches, and give greater visibility to emerging good practice in this area. The key lessons learned to date are the need for what forms of integration are needed and can work in specific contexts and for more focused technical support to facilitate this integration.</p>
<p>Scale</p>	<p>The promise of integration is, in part, the promise of scaling up the AIDS response, through mobilising new actors, sectors and stakeholders and mainstreaming HIV/AIDS in a wider range of programmes and institutions. But this promise continues to be inhibited by programme thinking based on ‘boutique’ models of developing small-scale, ‘good-looking’ integrated projects that can somehow be rolled out on a larger scale. The challenge of scale is the challenge of thinking differently about models for integrated approaches that are equal to the scale of the problems that they confront.</p> <p>On the other hand, the problem of scale is not merely about programme models. It is also about issues of resources, and these issues are shaped not merely by AIDS policy but by the impact of the economic and social policies of the countries and corporations of the ‘North’ on the poverty of nations and communities in the ‘South’. Arguably, the possibilities of scaling up the AIDS response and its impact will be determined more by the policies of the ‘North’ than by programme models in the ‘South’.</p>
<p>Recommendations</p>	<ul style="list-style-type: none"> Link access to ARVs with prevention, nutrition, health monitoring and infrastructure development Develop strategies and processes for meaningful community involvement in integrated approaches to prevention, care and impact mitigation Assess what forms of integration are needed and learn and share what works Work from an understanding of community capacities as well as community needs Use technical support to strengthen and build on the capacities of communities Develop processes that facilitate greater collaboration within and between sectors Mainstream HIV/AIDS more widely in other programmes, policy agendas and funding priorities



Think creatively about programming models that can scale up integrated approaches to HIV/AIDS without sacrificing the quality of this work

Advocate for changes in social and economic policy at the global level in order to liberate the resources that nations and communities in the South need to more effectively prevent HIV and reduce the impact of AIDS.

SECTION 6

Lessons and Challenges for Community Action on AIDS

Lessons and recommendations on the themes of prevention, care and integration from the workshop were folded into a broader discussion of lessons and challenges for community action at the roundtable. This section summarises this discussion, which was initiated by two case studies (on Zambia and Cambodia) and presentations by three other panelists.⁵

6.1 Working with communities in Zambia

The HIV epidemic in Zambia is currently at 16% among 15-49 year olds. Morbidity and mortality are high with severe impacts on overstretched families and communities. The extended family system of social support is struggling to cope and the economy continues to suffer from the impact of AIDS on the economically active. With poverty on the rise, the government is under pressure to provide ARV treatment.

In response, Alliance Zambia supports community action through four national networks and Focal Point NGOs in 14 districts that channel funding to over 50 NGOs/CBOs and faith-based organisations (FBOs). VCT promotion has been a central focus of the Alliance's work in 17 districts, providing an entry point in to both care and prevention issues. The Alliance and its partners have strengthened community action through life changing workshops on gender and sexuality, stigma and discrimination, and ARV community consultations. Activities with orphans and vulnerable children (OVC) have also been emphasised, as has partnership building with key sectors and actors in the national response.

Impacts

Communities are reporting a reduction in stigma and a greater acceptance of PLHA
VCT uptake has increased
There are indications of partner reduction as a result of gender and sexuality work and a much greater willingness to talk openly about AIDS
Psychosocial support for children is being incorporated in OVC work
Support groups for PLHA are being established across the country
Community awareness about ARVs is improving as a result of public education
Discriminatory laws are being challenged
Integrated approaches are being developed, in part through strengthening referral systems with other HIV/AIDS organisations

Lessons learned

Policy advocacy: There is a need to continue challenging discriminatory laws and policies relating to HIV/AIDS.

Integrated VCT service: An integrated approach to VCT helps in increasing uptake and reducing stigma and discrimination (through the VCT partnership).

⁵ The two case studies presented were:

“Community Action on HIV/AIDS: lessons and challenges” presented by Daphetone C. Siame, International HIV/AIDS Alliance Zambia

“Case Study: Models of Community action for orphans and vulnerable children (OVC) in Cambodia - KHANA’s experience” presented by Pok Panhavichetr, Executive Director, Khmer HIV/AIDS NGO Alliance (KHANA). Panel presentations were given by Jacob Gayle (CDC), Julian Hows (GNP+) and Bernard Gardiner (IFRC). The session was facilitated by Dr. Balwant Singh (India HIV/AIDS Alliance).

“Because of Africa Directions, I am sure of seeing tomorrow.” Young man who gets support from Africa Directions

Youth focus: We need to continue focusing on youths and ensure their protection. They are the window of hope.

Coordination: The HIV/AIDS response requires clear referrals and coordination for communities to benefit.

PLHA self-help: Post-test services including the establishment of support groups for PLHA are a fundamental part of the continuum of care.

ARV education: Community awareness-raising and education on ARVs is necessary as treatment options become a reality.

Effectiveness: Community action works but more is needed.

Continuing challenges

ARV services: Communities are aware of the increasing availability of ARVs but ARV services face the challenges of ensuring a steady supply of drugs, providing food to support ARV uptake, making ARVs affordable and available and ensuring drug adherence and patient compliance.

Poverty: Communities are struggling with poverty and this is negatively affecting HIV/AIDS prevention and mitigation efforts. Community action on AIDS needs to be involved in dealing with poverty in order to remain relevant.

Competing priorities: Communities are dealing with competing priorities and demands from many other programmes, such as roads, agriculture, political campaigns, and income generation activities. This poses the challenge of maintaining community interest and involvement in AIDS responses.

Scale and sustainability: Scaling up workable programmes and activities to reach many more communities continues to be a challenge, as does sustaining leadership commitment to HIV/AIDS.

Stakeholders: There is a need to constantly engage in dialogue with different HIV/AIDS stakeholders to deal with practical implementation issues at community level in order to remain responsive to the changing epidemic and to maintain strategic partnerships with diverse community groups without losing focus. Creating processes for dialogue between communities, NGOs, Government and donors remains a challenge.

Learning: In the face of the epidemic and the challenges above, it is difficult but imperative to make time for continuous learning.

6.2 Integrating HIV/AIDS into community development in Cambodia

Cambodia has been hard hit by AIDS. The HIV prevalence rate in Cambodia is 2.6% (the highest in South East Asia), with one third of new infections as a result of mother to child transmission. 259,000 people (238,000 adults and 21,000 children) have been infected with HIV in Cambodia since the start of the epidemic, and 94,000 people have died of AIDS. Many children’s lives are being blighted by an epidemic in which it is estimated that 7.8% of children below 15 in Cambodia have lost parents to AIDS.

The Alliance Linking Organisation is KHANA, which was registered as a national NGO in 2000. KHANA currently provides technical and financial support to 50 local NGOs in 14 provinces and 2 municipalities. Its overall programme focuses on:

Mobilising NGOs and focusing resources;

Strengthening the capacity of NGOs and CBOs to implement:

⇒ HIV prevention

⇒ Care and support for PLHA and their families, including children affected by AIDS

⇒ Advocacy to reduce stigma and discrimination

Documenting good practice and sharing lessons learned; and

Strengthening strategic alliances to scale up the response to HIV/AIDS.

Responding to the impacts of AIDS on children

Through a participatory assessment of the needs and resources of children affected by AIDS, KHANA identified many factors of vulnerability that were exacerbated by poverty, with girls being particularly vulnerable. Adults saw orphanages as the answer but the children who were interviewed disagreed.

In response, KHANA integrated care and support for OVC into its home-based care programming and is currently supporting 29 NGOs to work with OVC through a community-based and a faith-based model.

The community-based model supports children to remain in the community where they live with siblings, relatives, or foster families. It integrates support for them into community development programmes that provide income generation activities for carers and OVC, welfare support (e.g. food, in partnership with WFP), support for schooling (e.g. negotiation of school fees, school materials and uniforms) as well as support to OVC regarding inheritance rights, referral to vocational training (for older children) and peer/psycho-social support (e.g. through retreats for OVC). Anti-stigma activities are also conducted with local communities to mobilise support for OVC, including involvement of Buddhist monks and village elders.

In the faith-based model, Buddhist monks have been mobilised to establish hospices for PLHA and child-care centres for orphans within the pagoda. This builds on the Khmer tradition of the pagoda as an educational resource for the community. Services provided at the pagoda include: accommodation and food for homeless children; medical care for children, including those who are HIV+; primary education; referral to vocational training; and peer/psycho-social support.

These models of community action have worked because of the continuing importance of the extended family support structure and the role of Buddhism in Khmer life. The models have built on existing community development programmes run by other organisations and have benefited from the structure provided by the joint KHANA-government home-based care programme.

“The Home Care Team help me continue with my business of selling food; before they started visiting, I couldn’t even get out of bed. Without them my children would have to leave school to look after me.” Tonle Bassac, 30 year old widow with AIDS

Impacts

Community cohesion: Keeping children with their siblings and their community has avoided dislocation and the need for re-integration in the future.

Community Involvement: A critical emphasis has been to mobilise and maximise the use of community resources.

Comprehensive responses: Linking HIV prevention messages with care & support and addressing stigma and discrimination has been important.

Potential scale up: Putting communities at the centre of the response has enabled an easy expansion of coverage.

Sustainability: Relying on community resources (rather than external resources) has helped to lay the foundation of long-term sustainability.

Main challenges

Finding foster families, because most families are too poor to take on the burden of care

Ensuring the safety and welfare of children in the face of the risk of children being exploited or abused

Access to employment for older OVC

Lack of genuine consultation with children

Replication of models beyond their pilot sites

<p>Lessons learned</p> <p><i>“We need to scale up in a meaningful way – we need lots of consultation with children.”</i> Pok Panhavichetr</p>	<p>Consultation: Participatory assessment and ongoing consultation with children about their needs is essential for developing appropriate and effective responses.</p> <p>Home-based care: Home-based care programmes are the entry point for:</p> <ul style="list-style-type: none"> Identifying and providing comprehensive support to OVC; and Mobilising community members, including PLHA, to take care of children. <p>Role of monks: The involvement of monks contributes to the psychosocial support of children through provision of accommodation, food, education and counseling.</p> <p>Integration: Integration of HIV/AIDS into community development maximises support for PLHA and OVC (e.g. micro-credit schemes, income generation, vocational training). But there is still a need to persuade donors of the importance of this integration and of the community-based approach to working with OVC.</p>
	<p>6.3 Issues and implications</p> <p>Based on presentations by Jacob Gayle (CDC), Julian Hows (GNP+) and Bernard Gardiner (IFRC), in a session at the roundtable facilitated by Dr. Balwant Singh (India HIV/AIDS Alliance), the following issues of and implications for community action on AIDS were discussed.</p>
<p>Dealing with a chronic emergency</p>	<p>AIDS is a chronic emergency. It poses new challenges for community action in terms of preparing for a rapidly changing environment of increasing poverty, increased demand for ARVs, increasing health costs for people and families, and thus changing priorities on health and development. There is a need for new rules and new tools.</p> <p>Government capacity is weak in many areas and is further weakened by AIDS in the most heavily impacted countries. The challenges of low capacity are compounded by the difficulties of working across sectoral boundaries and of dealing with unprecedented problems of the ultra-poor as well as real reversals in development gains. Effective responses are both urgently required and need to be sustained over the long-term in order to deal with inter-generational impacts that are as yet poorly understood in terms of individual and collective trauma.</p>
<p>The need for ‘double vision’</p>	<p>The nature of AIDS as a chronic emergency calls for a kind of ‘double vision’. The global AIDS response in general, and community action in particular, has to be near-sighted in addressing immediate HIV-specific needs and far-sighted in working on underlying factors and contexts. This will require significant shifts in thinking and practice:</p> <ul style="list-style-type: none"> Governments are more comfortable talking to other governments and themselves – they are resistant to civil society involvement. Public health systems and thinking are more comfortable with technological responses – but there are no magic bullets for AIDS. Political administrations live within political timeframes and politically-oriented spheres of influence – but we need to be planning and working over longer periods and working more broadly.
<p>Enabling meaningful community action</p>	<p>What does it really mean to put communities at the centre of the response? This is the focusing question for learning lessons that can be applied to improving community action on AIDS. One clear lesson is that it is important to recognise the internal struggles and divisions that shape communities as much as their external pressures. Power differentials within communities have a significant bearing on who is involved in and affected by decisions about community action on AIDS.</p>

A second lesson relates to the importance of identifying appropriate entry points for mobilising community action and the critical roles played variously by VCT, OVC and community development work in engaging and then extending the involvement of communities in the AIDS response. It is also becoming clear that it is useful to not define community action merely in terms of the grassroots but also to look at the actions that communities can take in seeking to shape broader agendas and debates. The Alliance is learning that it has a role to play in ensuring that multiple voices of communities are heard in policy-making. This must include supporting the leadership and activism of members of marginalised communities who are resisting the oppression that they are suffering.

Promoting PLHA activism and leadership

“This is the power of GIPA – its demand for the involvement of the infected and affected but without the obligation to disclose.”

Jens van Roey

Although there is much talk of the GIPA principle and PLHA involvement, there is often much less said about how this can be translated into action. The key message from PLHA has long been *“nothing about us without us”* but in many ways PLHA have not gotten further than a place at the table, as opposed to having a central role in decision-making. Involvement can often mean tokenism. Given this, it is still important to note clear PLHA successes, including:

- Organisations like GNP+ and ICW at the global level still exist, as do many national and local PLHA groups and networks;
- PLHA groups are serving an accountability function within large organisations but are always short of resources for this; and
- PLHA have changed the face of public health and are starting to change development.

But there are also clear challenges:

- PLHA are the outreach workers but rarely the managers, administrators, and Board chairs in organisations;
- Few PLHA clients become providers/managers of services as there is a lack of structured leadership development; and
- PLHA are not equal partners with national governments, donors and communities in taking leadership on the AIDS response.

In order to address these challenges, it is important to shift the debate from discussion of PLHA involvement to issues of engagement and then participation and finally control.

PLHA activism and leadership raises broader questions about confidentiality and privacy. While it is everyone’s right to keep their HIV diagnosis a secret, is it necessary for PLHA to disclose HIV status in order to take leadership or even to get services? There is a need to get far more creative about bringing in PLHA voices and experiences in to the AIDS response without requiring disclosure. This is the power of the GIPA principle – it is about the infected and affected being involved without the obligation to disclose.

The Alliance is practicing GIPA and demonstrating its value through its operations research on PLHA participation to show that it can happen and through the large number of PLHA within the Alliance who have the right to disclose or not disclose their status.

Confronting gender and sexuality issues

Gender and sexuality issues continue to confront community action on AIDS. There are important questions about how communities can be supported to take on these issues in culturally specific ways that at the same time challenge culturally sanctioned inequalities, especially in terms of the disempowerment of women.

Alliance Zambia offers one example of such work in its development of gender and sexuality discussion tools that can be integrated into HIV/AIDS work. These tools invite people to discuss and question gender roles and responsibilities, to identify imbalances of power between people and to explore issues of sexuality in terms of desires, practices,

relationships, and identities. The tools are intended to support community groups in identifying the changes in gender and sexuality that they want to work on in order to address the conditions that allow HIV to spread.

However, gender and sexuality issues are still largely discussed in terms of prevention. Much more work at community level is needed on gender issues in the lives of PLHA and the particular challenges facing, and resources offered by, HIV+ women. Even less attention has been given to supporting PLHA in dealing with issues of sexuality in their lives.

Working on human rights

“I dream that one day I will see the Alliance described as a human rights organisation.”

Wanjiku Kamau

The Alliance is at a stage now where it can begin to articulate its work in more political terms. Human rights offers a clear and universal framework within which the Alliance can use its size and influence to shape the macro-policy contexts in which it supports community action on the ground.

The need to develop a more clearly articulated rights-based analysis of and response to AIDS is heightened within the current ideologically charged environment of the global AIDS response. This analysis and response will challenge the Alliance to create new kinds of partnerships, do new kinds of work and take new kinds of risks in order to provide the cover that it can to the marginalised groups and key populations who suffer most acutely from human rights abuses.

Clarifying roles of government and civil society

It is important to be clear about the key roles of government in coordinating the AIDS response and leading its scale-up, as well as the functions of the state in terms of supporting social welfare and social protections. The challenge for the global AIDS community, and in particular the donor community, is to not simply fund civil society to fill the gaps left by governments but to pressure and support governments to fulfil their obligations. There is need for creativity too – for example, looking at the possibility of non-contributory pensions for elderly carers of PLHA.

The Alliance and its partners have an important watchdog role to play, giving voice to the social conscience and helping to hold states accountable. Issues of accountability and corruption continue to be challenging but there has been some success in working with governments to mainstream HIV/AIDS in to other sectors and to commit to use local funds for AIDS. The bidding processes for new global funding mechanisms have helped to foster local collaborations between the public sector and civil society.

SECTION 7

Supporting and Scaling Up the AIDS Response

Participants at the workshop discussed issues of NGO support and scaling up the response to HIV/AIDS. Three presentations on the morning of the second day initiated this discussion, followed by small group-work and report backs on highlights and conclusions.⁶ A panel discussion at the roundtable then took up the themes that had been explored at the workshop, featuring four presentations followed by a discussion among participants at the meeting.⁷ This section summarises the highlights and conclusions from both the workshop and the roundtable on issues of supporting and scaling up the response to the HIV/AIDS epidemic.

7.1 Strengthening the capacity of NGO support programmes in Mexico

At the turn of the century, it was clear that Mexico faced critical challenges in strengthening its civil society response to HIV/AIDS. Faced with a concentrated epidemic with the third highest HIV caseload in the Americas (following USA and Brazil), there are over 400 Mexican NGOs working on HIV and sexual health-related issues. A lack of financial resources meant strong competition between NGOs, which largely worked in isolation from each other and with little collaboration with other key sectors. In general, NGOs lacked capacity in planning, documentation and M&E, resulting in little evidence about the quality of their interventions and limited access to training and capacity-building opportunities. AIDS NGOs had a relatively low profile in relation to working with government to shape the national response.

Programme overview

The Alliance Mexico programme is a five-year initiative to reinforce the NGO contribution to the national response to AIDS and to strengthen NGOs' institutional capacity in nine key areas. These include strategic planning, external relations, participatory community assessment, project design, resource mobilisation, documenting and communicating HIV/AIDS work, advocacy, focused prevention to key populations, and monitoring and evaluation.

The programme has used a cascade model wherein it has trained eight partners as Resource Organisations in improving their institutional capacity in the nine key areas (as well in aspects such as training, facilitating, and organising events). In turn these partners have trained 90 beneficiary organisations in eight Mexican states to strengthen their institutional capacity in four priority areas (the first four listed above). The Resource Organisations have used workshops and technical assistance visits to build the capacity of Beneficiary Organisations.

⁶ The workshop featured the following three presentations on the topic of NGO support and scale up: *"NGO Support and Capacity Strengthening in Mexico"* presented by Anuar Luna, Mexican Network of PLHAs with the collaboration of Rafael Manrique Soto, Project Coordinator, Collaborative Programme Alliance Mexico *"KHANA/Government Collaboration to Scale Up HIV/AIDS Response in Cambodia"* presented by Pok Panhavichetr (Executive Director: KHANA) and Dr Mean Chhi Vun (Director of NCHADS, Ministry of Health). *"NGO/CBO support systems: Madagascar country programme"* presented by Ms Holitiana Randrianarimanana (Regional Programme Officer, Madagascar)

⁷ Panel presentations were given by As Sy (Global Fund), Paulo Teixeira (WHO), Richard Burzynski (ICASO) and Sirinate Piyajitpirat (Aidsnet, Thailand). The session was facilitated by Prof. Fatou Sow (Trustee).

Results

Increased collaboration among NGOs
Improved networking among key sectors, especially with government
Increased visibility and leadership of key community actors including PLHAs
Incorporation of strategic planning and project management approaches and techniques
Improvement in quality of services provided by NGOs
Improvement in the ability to mobilise resources
Improved general working environment among key HIV NGOs
Improving project design and implementation
Improving negotiation skills both within and between organizations

Lessons learned and future challenges

NGO selection: Selecting NGOs was a difficult process. For its beneficiaries, the programme sought a mix of high profile, experienced organisations and new and less formal groups. The programme selected its Resource Organisations on the basis of their breadth of AIDS work, potential to build capacity, facilitation and logistical skills and their leadership within local NGO circles.

NGO needs: This mix of organisations had different needs, with experienced NGOs benefiting most from the participatory approaches and newer groups learning most from the planning and organisational development training.

Skills transfer: Transferring skills and capacities using a cascade model has proved to be a successful strategy to strengthen and expand community action on AIDS.

Cadre of master trainers: Building a solid training of trainers team with capacities to transfer skills and capacities to their peers can have a long-term effect in improved responses.

Collaboration: Close collaboration between government and NGOs improves dialogue and national response. It is also better to involve other actors (government, private sector, health sector) in the process of strengthening NGOs. However, a big emphasis is still required on coordination and communication to ensure a strong collective response.

Documentation: Documenting and communicating NGOs' best practices is essential to influence public policy and to make the Mexican civil society response visible at global level.

Governance: Governance issues need to be addressed in NGO networking and relationship building in order to foster both trust and accountability.

Advocacy: More emphasis should be given to advocacy training in order to equip NGOs to influence the contexts in which they work. In the next phase, advocacy training is planned for the Beneficiary Organisations, and especially the PLHA groups.

7.2 Collaborating with government and donors in Cambodia

Faced with the most serious epidemic in the region, KHANA (the Alliance Linking Organisation in Cambodia) has identified building strategic partnerships with government as one of its main objectives (see section 6.2 for background on the epidemic in Cambodia).

This collaboration with the government has focused on scaling up home-based care in the country. The KHANA/Government Home-Based Care Project has established and trained 41 home care teams, comprising part-time health centre

staff, and NGO staff and volunteers, including PLHA. Working out of government health centres, these home care teams are working with some 4000 PLHA, providing a range of medical, psychosocial and economic support. PLHA involvement in the project has been

promoted through supporting self-help groups, which has led to the establishment of a national network of PLHA (CPN+). The success of this collaboration, and of KHANA's ability to channel funds and technical support directly to local NGOs, has established KHANA as a key partner in government efforts to implement a multi-sectoral response and has led to KHANA receiving direct funding from the World Bank Trust Fund.

<p>Challenges</p>	<p>Different policies between partners in the collaboration – e.g. in terms of workshop “per diems” and basic drugs in the home-care kit</p> <p>The lower status of NGOs in relation to government and the impacts of this on working relationships within the government-NGO partnership</p> <p>Conflicting agendas – e.g. the government wants to promote user fees while NGOs want PLHA to be exempt</p> <p>Competition for funding between NGO partners and between NGOs and government</p> <p>Low levels of motivation among government staff due to low salaries</p>
<p>Successes</p> <p><i>“When all the partners work together we can scale up very quickly.”</i> Dr Mean Chhi Vun</p>	<p>Resources: Existing resources (financial, human) have been maximised and further funding has been mobilised from the Global Fund.</p> <p>Synergy: The collaboration has made good use of the comparative advantages of NGOs and government and has helped to link community issues with national policy-making. Government has recognised the value of working with NGOs in order to increase coverage and scope of activities as well as to improve the quality of services. The Home-Based Care Project has also contributed to the implementation of other government initiatives, such as on the continuum of care.</p> <p>Political competency: KHANA has recognised the distinction between the technical and political elements of government and has initiated its collaboration with technical officers in line ministries and used them to advocate internally with politicians. The second prong of the approach has been to foster multi-sectoral collaboration at the level of the National AIDS Authority.</p> <p>Consultation: KHANA's onward granting function of donor money to NGO grantees has not harmed its role and identity as a civil society organisation because KHANA's extensive consultations with organisations in the civil society sector from the outset of its work has legitimised its role as an NGO support programme.</p>
<p>Lessons learned</p>	<p>Relationship building: Collaborative relationships between government and NGOs have depended on clear objectives, mutual recognition of strengths and weaknesses and a flexibility and openness in negotiating roles and appreciating different perspectives.</p> <p>Transparency: Transparency in decision-making has been critical to building trust, and has been fostered by monthly meetings.</p> <p>Participation: Using participatory planning has helped to ensure complementary activities, joint problem-solving, common understandings and language and a mutual awareness of the benefits of partnership.</p>
<p>Next steps</p>	<p>Scaling up the continuum of care model</p> <p>Scaling up home care networks (led by Government) to a further ten provinces</p> <p>Piloting community DOTS for PLHA through home care teams</p> <p>Scaling up HIV prevention activities, if Global Fund money is received</p>

7.2 NGO support in Madagascar

Alliance Madagascar is based in four of the six provinces in the country, and focuses on technical and financial support to NGOs and CBOs, documentation and sharing good practice and lessons learned as well as the organisation and strengthening of local AIDS committees (LACs).

Technical and financial support: The programme provides technical and financial support to 21 Malagasy CBOs and NGOs to develop site level prevention activities, as well as strengthening the social capital of key populations of sex workers through supporting the establishment of seven sex worker organisations, most of whom have successfully carried out local resource mobilisation activities.

Documenting and sharing good practice: This has involved disseminating tools for use by partner organisations and other institutions supporting community responses to HIV/AIDS, reaching over 500 Malagasy CBOs and NGOs. In addition, the Alliance has provided technical advice within the World Bank/MAP facilitation consortium.

Organising and strengthening local AIDS committees: The impetus behind this work has been to support the development of a national vision and greater multi-sectoral collaboration through technical support to LACs at district and commune levels. This has been focused in the government's 20 priority HIV/AIDS prevention sites and intended to ensure participatory planning and multi-sectoral work at local levels.

Future plans

The future plans for the Alliance in Madagascar include:

- Replicating and scaling up the LAC support with a target of setting up LACs in 40 communes over the course of 2004-5

- Building local intermediary capacity for technical and financial support provision, which is emerging as a key strategy of the Malagasy national AIDS programme

- Expanding care and support for PLHA, which remains a significant gap in community HIV/AIDS programming in Madagascar. The Alliance has an important role to play in enabling NGO/CBOs to contribute to the implementation of this programme through advocacy and community-level service provision.

7.3 Lessons and recommendations from group work

Participants at the workshop divided into small groups to consider these questions. Each group was tasked with conducting a STEP analysis of factors and changes in the environment that may affect the scaling up of community action on HIV/AIDS over the next ten years. They were asked to consider the opportunities and challenges presented by this changing environment and the lessons for scale-up that are being learned from NGO support work from its successes and failures. Based on this, the four groups were asked to make recommendations on strengthening NGO support organisations and systems for scaling up community action, focusing respectively on international organisations (such as the Alliance secretariat), national civil society NGO support mechanisms (e.g. LOs and Alliance Country Offices), governments and donor agencies.

Issues to consider

As preparation for the groupwork, Tilly Sellers (Coordinator of the Alliance's Civil Society Development team) outlined the range of components of NGO support (see below) and summarised the different types of strategies for scaling up the civil society response to HIV/AIDS as follows:

- Organisational expansion - more places, people

- Functional expansion - doing different things

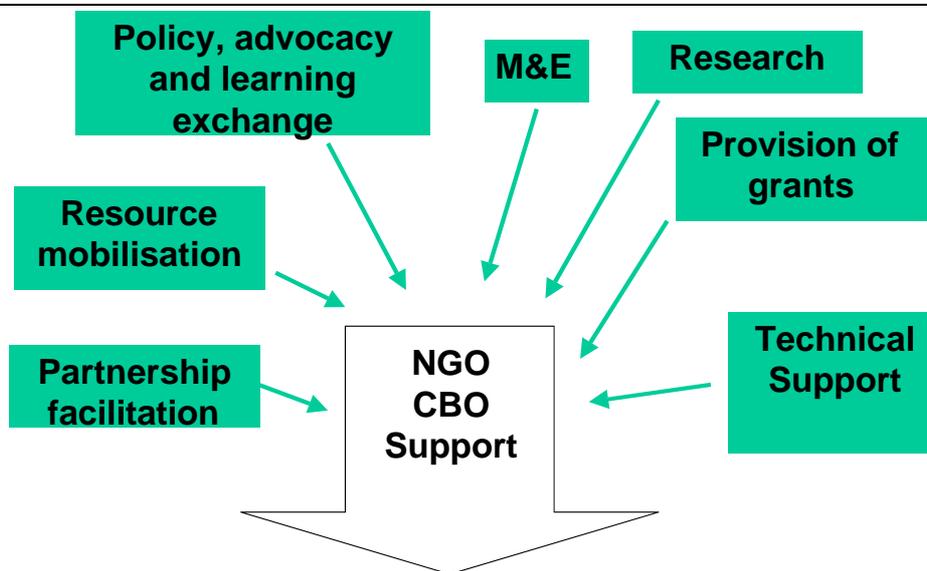
- Diffusion - spreading concepts, approaches or technology

- Influencing policy climate - promoting scale up

Mainstreaming HIV/AIDS in development - more organisations and groups involved in the response

The small groups were asked to consider: issues of linking NGO support to scaling up community action; the roles of NSPs in quality assurance as part of scale up; and questions about representation and leadership with NSPs, the types of NSP that are most appropriate in a given situation (e.g. government, NGO, donor) and the minimum range of functions an NSP should offer and in specific situations.

Components of NGO support



Recommendations for donors

Based on its STEP analysis, the most important lessons on scale up from NGO support programmes that were identified by the “donor” group centered on:

Strategic focus: There is a need more strategic focus on epidemic dynamics (too often donor driven).

Collaboration: Civil society-government partnerships are important for scale-up. NSPs can build partnerships for programmatic and organisational learning and sharing, referrals, and collective advocacy.

Technical support: Technical support and capacity building allows NGO/CBOs to make better use of funds.

Diversification: There is a need to expand criteria for NGO selection to include reaching greater numbers (e.g. through unions, workplaces, traditional practitioners and private sector).

Funding: It is difficult to access funds routed via government but there is a danger of overwhelming some NGO/CBOs with too much money.

The group focused its recommendations to donors on three major challenges:

Failure to access money via government – recommended actions:

- Channel directly to NGOs (though in what ratio needs discussion)
- Think about understanding culture of NGOs, selection of NGO/CBOs and develop criteria for who should be NSP/intermediary

Competition among donors – recommended actions:

- Seek collaboration and coordination and not just own priorities
- Listen to national priorities set by ‘needs’ of communities
- Support mechanisms for communities to set priorities – clarity on guidelines and priorities

“There is a big move globally for greater government-NGO partnerships but if these partnerships don’t work over the next ten years, there will be a challenge for community action.”
Kieran Daly

Balance quality and quantity – recommended actions:

- Seek evidence of good practice of community action
- Allow long-term capacity building – sustainability
- Longer term financial/programmatic commitment from donors (e.g. minimum 3 years)

Recommendations for governments

Based on its STEP analysis, “government” group focused on the following opportunities and recommendations for action:

Increased treatment access and vaccine access – recommendations:

- Prepare to incorporate new technologies into existing structures
- Ensure that new technologies are appropriate – consult communities
- Research how communities can support the introduction of new technologies

Increased demand threatening the collapse of public health services – recommendations:

- Maintain balance between prevention and care
- Maintain balance between NGOs as service providers and mainstreaming services in public health system – public and civil society sectors should be complementary rather than competitive

Strengthened collaboration and cooperation between government services and civil society – recommendations:

- Follow guiding principles of flexibility, openness, recognising mutual advantages, setting clear objectives, and being accountable
- Learn from other countries and from good practice within the country

Pressure to scale up but less so on sustainability – recommendations:

- Define national objectives and policy framework in partnership with CSOs
- Develop mechanisms for donor coordination with CSO networks
- Develop stronger partnerships between donors, government and CSOs

“We need to be thinking in terms of the Alliance’s sphere of influence, and how we can bring this influence to bear.”

Bai Bagasao

“In countries where there is a Global Fund presence, governments often resist the role of civil society.”

Anuar Luna

Recommendations for national civil society NGO support mechanisms (e.g. LOs, COs)

The most important lessons and recommendations on scale up being learned by civil society NGO support programmes related to:

Evidence base for intermediary role: Civil society intermediary organisations need to better document and explain the value of their combined funding/technical support role. This should be stressed as a capacity building role that catalyses more effective community action, both through enabling existing HIV organisations to enhance and expand their work and through enabling other organisations to integrate HIV/AIDS into their work.

Donor dependency: It is important to expand and diversify funding sources in order to reduce donor dependency and thus influence of donor agendas. LOs have a role to play in supporting partners’ resource mobilisation.

Enhanced coordination: With many new ‘actors’ involved, the need for better coordination is critical and LOs and other intermediary organisations can work to improve this coordination.

Investment in innovation: LOs have a useful role to play in developing innovative tools and approaches that can then be rolled out on a larger scale.

Quality assurance: Scale-up puts pressure on quality and civil society intermediary organisations have an important role to play in quality assurance, including the proactive monitoring and anticipation of epidemiological dynamics and responses.

Political priorities: The impact of globalisation on deepening poverty and exacerbating other conditions of social and economic injustice is the context within which civil society intermediary organisations are working to scale-up the response to HIV/AIDS. Such organisations need to be working together with other social justice and human rights efforts to influence political priorities on tackling poverty and other adverse impacts of globalisation.

Visionary leadership: This will require cultivating new leaders and a new vision for a scaled-up response to the HIV epidemic that addresses its social, economic and political contexts.

Recommendations for international organisations (e.g. the Alliance)

The STEP analysis by this group identified the following contexts, opportunities and challenges for scale up on which were based several recommendations for action.

Increased poverty, inequality, vulnerability: The challenges are to integrate HIV into urgent poverty alleviation and to develop skills to influence national policies. Opportunities are to integrate HIV into PRSP and learn from good practice of working with existing people’s organisations (e.g. women’s groups and savings groups) to integrate care and support activities. Recommended action:

Advocate integration of HIV/AIDS into PRSP in Alliance countries.

Weak government capacity (especially health systems) and inappropriate government policy framework: The challenges are to scale up response when health systems are not working, ensure follow through on commitments made and develop a national framework for action that is not donor-driven. But there are opportunities to influence national AIDS coordinating structures, use UNGASS as a framework for advocacy and use local government to influence national policy. Recommended action:

Develop tools and document good practices in government-NGO strategic partnerships in different areas and different contexts.

Donor interests/agendas and new funding mechanisms: The challenges are to maintain donor commitment over the longer term, mobilise resources within communities, pay attention to issues of sustainability before attempting to scale up, think in terms of scaling up quality of the work as well quantity and match funds with opportunities. These opportunities include better linking with government responses, using existing LO capacity to leverage new LOs, leveraging NGOs from other sectors, and working through WB/GF intermediaries. Recommended actions include:

Develop concepts, methodologies, tools for “integrated approach”

Collaborate with NGOs that are working on development issues

Explore opportunities to scale up through technical support only

Campaign for greater corporate social responsibility

Develop processes for greater sharing and learning of lessons within Alliance family at the regional level

“We simply cannot go on watching millions of people die while we have the technical expertise, the drugs, the political commitment and unprecedented [...] financial resources to roll out ARV treatment”

Dr Paulo Teixeira

Greater involvement of communities and PLHA: There are significant challenges in meeting the demand for increased needs, changing negative attitudes (e.g. of health providers) and scaling up with participatory approach. But there are opportunities to involve communities in policy advocacy, scale up care and support through PLHA groups, and strengthen organising among marginalised communities. Recommended actions include:

- Develop leadership capacity within affected communities across social class divides

- Strengthen learning networks and opportunities for regular exchange of skills, lessons and peer support between affected communities

7.4 Issues and implications

The roundtable continued this discussion of supporting and scaling up the AIDS response through panel presentations given by As Sy (Global Fund), Paulo Teixeira (WHO), Richard Burzynski (ICASO) and Sirinate Piyajitpirat (Aidsnet, Thailand). This session, the first of the afternoon, was facilitated by Professor Fatou Sow (Trustee).

Recognising the scale and urgency of the problem

Going to scale first requires an understanding of the scale of the problem. In ‘developing’ countries, every year 3 million people die because of our collective incapacity to provide them with ARV drugs that they need to improve wellbeing and prolong life. Only 5% of those who need ARVs are able to access them.

This is a global health emergency in which it is estimated that 80-90% of people who are living with the virus do not know that they are infected. Most people in ‘developing’ countries only find out when they are sick.

The overwhelming nature of HIV/AIDS globally creates the problem of slippage at all levels, including individual behaviour, national policies and donor priorities. Preserving gains and maintaining momentum in the fight against AIDS is a continuing struggle. Slippage is exacerbated by the toll on human lives exacted by the epidemic and the human capacity crisis that it deepens. When any progress made is so vulnerable to being halted or reversed, such slippage continues to undermine efforts to scale up the response to AIDS.

Working in broad based partnerships

The “3 by 5” initiative of WHO is a good example of a broad-based partnership that takes seriously the scale of the response that is needed. The key to its ability

to get 3 million people on ARV treatment by the end of 2005 rests on enlisting and coordinating the response of a vast array of actors. The quality and level of civil society and community participation in such partnerships is also crucial. WHO has created a Partners Group in order to tap the experience of different institutions with ongoing programs of ARV delivery in resource-limited settings. In addition, the “3 by 5” initiative has a Community Advisory Group, comprising 15-20 representatives of various communities (CBOs, FBOs, MSM, sex workers, incarcerated populations) from both ‘developed’ and ‘developing’ countries, whose expertise will shape design and delivery of the initiative.

“It is critical that we take advantage of each other’s strengths.”

Dr Paulo Teixeira

Wider partnerships between men and women, young and old, activists and professionals, communities and organisations are also needed. Lessons from experience suggest that such partnerships will rely on some core principles in order to be effective (e.g. trust, respect, inclusion, sharing power-knowledge-money). Going to scale will require unprecedented alliances and also a transparency and accountability within these relationships that goes right down to the community level.

NGOs need to begin this work on themselves and the international NGO Code of

Practice is an example of this change beginning ‘at home’.

But there is a need for much closer NGO collaboration at all levels and for processes to create a climate of closer dialogue and learning. In this climate, NGOs can not only develop skills to work together and collectively advocate on shared agendas but can also hold each other accountable in relation to the dangers of cooptation by the public sector.

Mobilising real, large-scale community action

We need an army in order to work at the scale that is needed. This includes training and paying new cadres of service providers, bureaucrats, and researchers. But more fundamentally it requires a change in thinking. It is imperative to recognise the limits and failures of expert-driven approaches and to appreciate the complexity of the epidemic and its problems. It is also important to recognise the vested interests of those who reject a more direct role for communities.

“HIV has forced us to be humble, forced us to question our own certainties.” As Sy

Some of this new thinking is evident in the “3 by 5” initiative and its delegation of responsibilities to community health workers who will play a fundamental role in making scale up possible, by releasing scarce medical human resources and empowering communities to better and more closely do their own treatment follow up. There is concern that this emphasis on community health workers, often volunteers and usually women, will overburden already depleted communities and will especially damage the lives of adult women who already have so many care and nurturing responsibilities on their shoulders. In this view, the priority is to focus on strengthening health systems rather than rely on community capacity.

“We don’t necessarily need new initiatives – we need existing initiatives to work better.” Mick Matthews

In its rationale for its community mobilisation approach, WHO counters that these challenging questions of system reform and infrastructure development have often served to delay action being taken. Not only is action on treatment urgently needed, but communities have capacity to develop their own solutions, as the examples of community distribution of ARVs in Haiti and Brazil have made clear. This reliance on community resources and capacity for scale up does raise questions about remuneration and incentives and poses the challenge of sustaining large-scale community action in the face of the severe economic difficulties, social problems and individual trauma experienced in many communities that are hardest hit by AIDS.

New thinking is also needed in relation to the funding mechanisms that are needed to support this scale of community action and there are debates about the appropriate role of intermediary organisations in this (see page 5). There is a growing consensus about the inadequacy of the ‘boutique’ syndrome of developing small, ‘good-looking’ projects and in favour of developing more direct channels for getting money to where communities can use it. This also suggests that the need to more clearly articulate a role for NGOs and NSPs in relation to large-scale community action. One such role is in developing leadership processes and capacities within affected communities, and especially within communities most targeted by other forms of stigma and oppression, such that they can both demand and use resources strategically and expand the notion of community action beyond simply grassroots work to acting on policy agendas and public opinion. Organisations such as the Alliance have helped communities organise themselves – the challenge now is for communities to act at national and international levels.

Scaling up PLHA involvement and leadership

Thailand offers useful lessons on the challenges and priorities for scaling up PLHA involvement and leadership in the AIDS response. The over-arching lesson from the experience of Thai PLHA coming together in self-help groups is that this action was first and foremost an act of self-determination that asserted PLHA rights and dignity. Not only have such groups responded to members’ needs for health care, psychosocial support, children’s education and income generation. PLHA groups have played a critical role in countering stigma, helping members reintegrate into community and in advocating for PLHA human rights.

“By the end of 1995, it was clear that the Thai government had undergone a paradigm shift. Its new policy towards HIV/AIDS clearly indicated that prevention and care were different sides of the same coin.”
Sirinate Piyajitpirat

Together with PLHA leadership and support from local NGOs, it has been the policy of national government that places PLHA at the centre of the AIDS response, which has made the difference to scaling up PLHA involvement in Thailand. The development of a broad-based and influential network of Positive People groups has depended on:

- Political and financial support from government;
- Technical and financial support and advocacy in community from NGOs (e.g. small grants, meeting place, capacity building, administrative support);
- Close collaboration/networks with other positive groups, health facilities, community leaders and civil society organisations; and
- A supportive media.

The “3 by 5” initiative of WHO also envisages a prominent role for PLHA groups in treatment education and especially in adherence groups and treatment follow up. PLHA proved vital to the viability of ARV distribution in Brazil and Haiti. This emphasis on the role of PLHA in scale-up strategies returns us to the question of how few people actually know their status and the circumstances of ill-health in which people typically come to learn of their HIV+ status. A strategy for mobilising PLHA to take leadership in an expanded response must also provide incentives for people to learn their status (e.g. ARV treatment and reduction in stigma), expanded VCT services and safe spaces for people to get counselled on the test and to get support if they test positive.

Working on human rights and social justice

“We need to do much more to challenge regressive agendas and values.”
Richard Burzynski

The epidemic is confronting us with a complexity of problems, much deeper than we thought, that are enmeshed with issues of social injustice and human rights abuses. Economic exploitation, gender oppression, homophobia, racism, to name only some, help to shape the course, pace and impact of HIV/AIDS in different parts of the world.

These macro-level issues both determine the scale of the problem and highlight the scale at which the AIDS ‘community’ must analyse and address the epidemic. For example, it is essential that AIDS organisations understand the implications of the fact that the EU/USA spend some \$300 billion on agricultural subsidies that protect their agri-businesses and deprive farmers in the ‘South’ of these northern markets. AIDS organisations need to develop skills and tools to draw out the implications for poverty and HIV vulnerability and be able to demand a voice in previously closed policy discussions in the ‘North’ on such issues as terms of trade, intellectual property rights, debt cancellation, production of generics and many more.

Thinking as well as acting at scale requires that the AIDS response be rooted in rights-based approaches that can more explicitly challenge the oppression and injustice that creates the conditions in which HIV spreads and devastates communities. It is especially important that regressive agendas and values on marginalised groups and sexuality be challenged.

Developing skills and coalitions for advocacy

Advocacy on policy and public opinion is an important key to creating the conditions in which HIV infection can be prevented and the impacts of AIDS be reduced. Arguably, every group needs an advocacy agenda and the basic skills and tools to carry this agenda forwards. A focus for civil society advocacy must be to demand more money, more donor coherence, as well as more coherence among NGOs.

NGOs and NSPs have a critical role to play in linking realities on the ‘ground’ to policy debates in national and international centres of power. For example, evidence from Senegal and South Africa suggests that adherence levels decline substantially when patients are required to pay for treatment, even a small amount. Collective advocacy by NGOs can use this information to call for free distribution of ARV drugs.

Providing technical assistance for scale up

New funding, mechanisms and new frameworks are in place for a scaled up response to AIDS. But technical assistance is required to make all this work at the local level. Such technical assistance is essential to ensure that resources that are mobilised are well spent, regardless of their source. A lack of investment in technical assistance is inhibiting the roll out of ARV treatment services but donors remain reluctant to make these kinds of investments. The Alliance, with its history and credibility, can play a significant role in legitimating the use of donor resources for technical assistance provision, not only within its own programmes but within the global response more generally.

SECTION 8

Policy Priorities and Challenges

The roundtable concluded with a discussion of policy priorities and challenges within the AIDS response through panel presentations given by Reeta Roy (Abbott), Anna Moshkova (IHRD), Margarita Quevedo (Kimirina, Ecuador) and Caroline Halmshaw (Alliance Secretariat). This session was facilitated by Robin Gorna (DfID) and its highlights are summarised here.

Asserting the evidence

Evidence is the key to good policy-making, and ever more important in the current global political climate in which evidence-informed approaches to HIV/AIDS work are under attack. The Alliance's work at country and global levels is showing the benefits of understanding and asserting the evidence. In Ecuador, the Frontiers Prevention Project (FPP) with marginalised groups of men who have sex with men (MSM) and groups of sex workers (SW) has been driven by an evidence-informed approach to empowering members of these groups and building their collective social capital.

In its advocacy work with the European Union, the Alliance used lessons from its and others' work on OVC issues to lobby successfully as part of the Stop AIDS Alliance for integration of VCT issues in to the EU's work. Its Programme for Action had been silent on impact mitigation and did not address issue of orphans. The Alliance's evidence-informed advocacy led to a review of the Programme of Action and established a legal basis for this OVC work. The success of this lobbying effort demonstrates that evidence works.

Building on this success, the Alliance is now pulling together an overview of what is good prevention and will feed in evidence from its FPP work in order to influence EU policy on prevention, especially with marginalised groups. The Programme of Action is weak on comprehensive prevention strategies and work with key populations. But the Alliance sees an important opportunity to push the EU to take a lead in this work, especially on harm reduction and empowerment work with marginalised groups.

The climate and focus of US AIDS policy and the EU expansion are both pressuring the EU to look more closely at supporting AIDS responses in central and eastern Europe. There is an opportunity to mobilise this support through using the evidence that harm reduction works to push for an expansion of harm reduction programming in the region. Realities on the ground make clear that it is not possible to separate prevention and care in this part of the world and that access to any care let alone ARVs is not possible for most IDUs, given that policy is dominated by law enforcement and not a medical/social approach. Evidence on the need for integrated prevention-care approaches needs to be marshalled in order to shift this policy environment.

Pushing policy from 'below'

As noted in the discussion of scaling up the AIDS response, it is important to push policy from 'below'. Intermediary organisations such as the Alliance and its LOs are conduits for ensuring that realities on the 'ground' are brought to bear on policy-making by governments and international institutions.

The FPP work in Ecuador seeks to connect community work with policy change and use lessons and leadership from the former to influence agendas and priorities in the latter. A crucial emphasis of the FPP work has been to enable and ensure the presence of leaders from marginalised communities in policy-making debates and forums. Through developing individual leaders and collective capacity for advocacy, the FPP initiative is seeking to put key populations such as sex workers and men who have sex with men at the centre of the response. At

the most basic level, making sure that members of such groups have access to treatment is helping activists within these groups to stay healthier and more able to continue campaigning for policy change.

Harm reduction programming provides a further example of policy-making from below. Lessons from the former Soviet Union and central and eastern Europe make clear that policy work at the local level was always needed from the very beginning to ensure the support of local politicians and officials for harm reduction programming to be established. At the same time, a key lesson learned is that setting up pilot harm reduction programmes does not simply lead to policy change at the national or regional level and/or greater funding. On the basis of these lessons, the International Harm Reduction Program of the Open Society Institute has re-oriented its support to harm reduction in the region and is now focusing on supporting and strengthening local harm reduction activists to be doing their own advocacy, especially at the regional level.

Human rights and social justice

It remains difficult to get funding for programmes that work with populations that are perceived as blameworthy or deviant in some way. IHRD found that it was not effective in building support for AIDS work with IDU populations until it started to develop partnerships with human rights organisations.

Framing the AIDS response with such groups as a matter of human rights has been a significant step forwards, especially in terms of access to treatment. Whereas needle exchange can be justified on public health grounds of protecting 'us' from the dangers of 'them', human rights has proved to be a valuable framework within which to argue for the right to treatment that members of IDU populations, by virtue of their humanity, are as entitled to as anyone else. Bringing in human rights advocates has been especially effective in a situation where extreme stigma makes it very difficult for IDU or PLHA at country level to be vocal on this. Given that one of the biggest obstacles to treatment for IDUs has been the attitude of health professionals, it has been useful to involve human rights and legal professionals in strategies to change such attitudes.

Trends in global policy thinking, and the heightened role of ideology in shaping policy agendas, as evident in the emphasis on abstinence-based prevention approaches to be funded under the US PEPFAR mechanism, highlight the leadership role that the EU and European governments must take in response. Yet on security and migration issues, it seems that the EU is aligned with US thinking in relation to policy statements on "trafficked women" that promote conservative moral responses that shuts down effective work with sex workers.

This argues for organisations such as the Alliance and its national partners to remain grounded in explicit human rights and social justice frameworks within which to be vigilant about 'slippage' in policy language and its impacts 'downstream'.

Human rights and social justice frameworks also keep gender in focus, given how easy it is for gender issues to be blurred or erased (as it was commented had happened at the roundtable itself). Many of the issues raised during the roundtable, relating to community action, scale up and policy work, are integrally linked to gender issues yet these links often go un-remarked. While gender issues are evident in the Alliance's programme work, for example through its support to work with female and transgender sex workers in Ecuador, there is a need for the Alliance to integrate a gender analysis more explicitly into its global policy work, for instance in the area of microbicides.

"I am alarmed and disappointed at this silence on gender issues, especially given the recent global compact on women and AIDS."

Alice Welbourn

<p>The role of NGOs and NSPs in shaping policy</p>	<p>At the global level, the Alliance recognises the importance of its policy role, given that global policies influence the work of the organisation and that the size of the Alliance brings with it the responsibility to strengthen political commitment and leverage more resources for the AIDS response. Despite its size, the Alliance cannot do this alone and thus it has been instrumental in developing an international NGO code of practice as a framework for greater coherence and accountability to agreed standards and principles that will help in coordinating a powerful advocacy agenda. Within the kind of collective policy work that is being fostered by the code of practice, the Alliance has specific contributions to make because of its history, scale and relationships. One such contribution is ensuring that stakeholders do not drop out of policy dialogues because of fatigue, conflict and changing priorities.</p>
<p>Working in partnership</p> <p><i>“The next two years are crucial for shaping the future of the EU’s response to HIV/AIDS in developing countries.”</i> Caroline Halmshaw</p>	<p>Effective policy advocacy often requires the skills and resources of multiple partners. Together with the Dutch organisation Aids Fonds/Stop AIDS Now!, the Alliance has created the Stop AIDS Alliance to influence EU policy on AIDS. Given that the next six EU presidents will come from countries where AIDS is high on agenda, there are clear opportunities to make the most of this available political commitment. The aims of the Stop AIDS Alliance are to ensure that:</p> <ul style="list-style-type: none"> AIDS is higher on the European political agenda; Roles and needs of NGO/CBOs are better understood by representatives in European institutions; Improved policies and programmes respond to the needs of PLHA and the most affected; and There is increased funding for the health sector, specifically for AIDS.
<p>Holding governments to their responsibilities</p>	<p>One important role that such advocacy alliances, and NGOs and their networks more broadly, can play is in holding governments accountable for their policy commitments and responsibilities. For example, it is clear that the UK government could do more to move a human rights agenda for marginalised groups forward at the governmental level in the countries of the former Soviet Union and central and eastern Europe.</p> <p>IHRD remains worried about the continuing lack of government commitment to supporting harm reduction in this region. In the last five years, IHRD and its partners have not succeeded in generating government financing for harm reduction. While Global Fund money is welcome, there are fears that such funding only delays the challenge of ensuring government support for harm reduction programmes. International civil society organisations such as IHRD and the Alliance can play a critical role in holding governments, in both donor and recipient countries, accountable for their policy priorities and commitments.</p> <p>In Ecuador, Kimirina (the Alliance LO) has found it challenging to negotiate its relationship with government in the context of developing its FPP work with marginalised groups, which the government could not take on because of political sensitivities. But the challenge now is to expand and institutionalise this work and this requires government involvement. Advocating for such involvement and for a more enabling policy environment for work with marginalised groups have become important priorities for Kimirina.</p>

Working with private sector collaborations and tensions

Civil society organisations also must take on the task of mobilising the private sector and holding corporations accountable for their contributions to or undermining of an enabling policy environment for the AIDS response. Without such pressure, it is unlikely that impetus for funding scaled-up action will come from within corporate sector.

There are evident challenges for organisations such as the Alliance and its LOs in working with the private sector. There may be many reasons for the social investments in AIDS work that are made by businesses and corporations. These can include the generation of new knowledge, leveraging other donors with this knowledge and creating platforms for civil society to engage with governments. But there are tensions and contradictions between philanthropic agendas and business priorities, especially in the aggressive climate of the pharmaceutical industry. These contradictions have become most apparent in relation to issues of drug pricing and equity in access to treatment. The notion of social responsibility for the corporate sector is useful in negotiating such tensions and that organisations such as the Alliance have a role to play in holding corporations accountable to the standards of their social responsibility.

Making the money work

Making the money work was the final policy challenge discussed at the roundtable. Besieged by so many needs, it is really important that there is transparency and accountability for where the money goes and how it is spent. There is a need to get beyond programme thinking and focus on systemic change. The Alliance and others must advocate to ensure that EU development aid is accessed and reaches the most needed areas (health and education) in the most impacted countries.

APPENDIX 1

List of Attendees

Latin America & the Caribbean

Field Partners

Ms Cristina Pimenta, Executive Director, Associação Brasileira Interdisciplinar de AIDS (ABIA), Brazil

Ms Maylene Leu-Bent (co-facilitator), Manager, Alliance Regional Caribbean Programme

Mr Kerwyn Lauriston Jordan, Programme Director, Prejudice & Discrimination Project, Friends for Life, (partner organisation in the Caribbean)

Ms Margarita Quevedo, Directora Ejecutiva (Executive Director), Corporación Kimirina, Ecuador. *Ms Quevedo has since resigned, the new Executive Director at Corporación Kimirina is Ms Amira Herdoíza*

Mr Xavier Alvarado, Asistente Área Programática (Project Officer), Corporación Kimirina, Ecuador

Mr Anuar Luna, Executive Director, Red Mexicana de Personas Viviendo con VIH/SIDA, Mexico, (Mexican Network of Persons Living with HIV/AIDS)

West & North Africa

Dr Brice Millogo, Executive Director, Initiative Privée et Communautaire Contre le Sida au Burkina Faso (IPC), Burkina Faso

Mr Issam Moussaoui, Director, Association Marocaine de Solidarité et de Développement (AMSED), Morocco

Professor Femi Soyinka (co-facilitator), Executive Director, Network on Ethics, Law, HIV/AIDS, Prevention, Support & Care (NELA), Nigeria

Mr Baba Goumbala, Secrétaire Exécutif, Alliance Nationale Centre le Sida (ANCS), Senegal

Alioune Badara Sow (Badou), Programme Officer, Alliance Nationale Centre le Sida (ANCS), Senegal

East & Southern Africa

Mr Claude-Henri Ralijaona, Directeur de Programme (Country Programme Manager), Madagascar

Ms Holitiana Randrianarimanana (Holy), Regional Programme Officer, Madagascar

Mr Santos Alfredo Nassivila, Country Programme Manager, Alliance Mozambique

Ms Filomena João, Programme Officer, Alliance Mozambique

Mr Daphetone Siame, Director: Alliance Zambia

Ms Lillian Muyunda Byers, NGO/CBO Support Specialist, Alliance Zambia

Ms Patricia Habenzu, Project Officer, Mumuni Centre, one of Alliance Zambia's focal point NGOs based in Kalomo district

Asia & Eastern Europe

Ms Pok Panhavichetr (Panha), Executive Director, Khmer HIV/AIDS NGO Alliance (KHANA), Cambodia

Dr Mean Chhi Vun, Head of National Center for Dermatology, AIDS & STDS (NCHADS), Cambodia

Mr Ted Nierras (co-facilitator), Country Programme Advisor: China

Ms Cao Hong, Programme Officer: China

Dr Balwant Singh, Director: India HIV/AIDS Alliance

Mr Shumon Sengupta, Director: India HIV/AIDS Alliance (Andhra Pradesh)

Mrs Keerthi Yerramsetty, Technical Support Manager, HIV/AIDS Care & Support Programme, Vasavya Mahila Mandali (VMM) – Alliance's Lead Partner in Andhra Pradesh, India

Dr Khorloo Enkhjargal (Enkhe), Executive Director, National AIDS Foundation (NAF), Mongolia

Mr Alejandro Torres (Alex), Executive Director, Philippines HIV/AIDS NGO Support Programme (PHANSuP), Philippines

Asia & Eastern Europe (continued)	<p>Ms Sirinate Piyajitpirat (co-facilitator), AIDS Network Development Foundation (AIDSNet), Thailand</p> <p>Mr Umesh Sharma, Regional Technical Advisor on Harm Reduction: Asia & Eastern Europe, based in Thailand</p> <p>Ms Olga Kudryashova, Social worker, Eney Club, Kiev, Ukraine</p>
Trustees	<p>Secretariat</p> <p>Peter Freeman</p> <p>Bai Bagasao</p> <p>Fatou Sow (Roundtable only)</p> <p>Kaval Gulhati (Roundtable only)</p> <p>Jens van Roey (Roundtable only)</p> <p>Fleur Fisher (Roundtable only)</p>
Executive Director's Office/Partnerships Team	<p>Alvaro Bermejo, Executive Director</p> <p>Ioanna Trilivas, Alliance Director in the US</p> <p>Jane Lennon, Assistant to Executive Director (Roundtable only)</p> <p>Jolan van Herwaarden, Donor Relations Unit Manager (Roundtable only)</p>
Field Programmes Department	<p>Jerker Edström (Chair), Director: Field Programmes</p> <p>Stephen Lewis, Co-ordinator: Latin America & Caribbean</p> <p>Ruth Ayarza, Programme Officer: Latin America & Caribbean</p> <p>Javier Hourcade, Programme Officer: Latin America & Caribbean</p> <p>Alexandra Lamb-Guevara, Programme Assistant: Latin America & Caribbean</p> <p>Beth Mbaka, Co-ordinator: West & North Africa</p> <p>Paul McCarrick, Programme Officer: West & North Africa</p> <p>Pamela Onyango, Co-ordinator: East & Southern Africa</p> <p>Liz Mann, Senior Programme Officer East & Southern Africa</p> <p>Dave Smith, Senior Programme Officer: East & Southern Africa</p> <p>Lucia Negreiros, Programme Officer: East & Southern Africa</p> <p>Vic Salas, Senior Programme Officer: Southeast & East Asia</p> <p>Chris Turner, Programme Assistant: Asia & Eastern Europe</p> <p>Slava Kushakov, Senior Programme Officer: Eastern Europe & Central Asia</p> <p>Kate Beavis, Project Support Officer: Asia & Eastern Europe</p> <p>Divya Bajpai, Programme Officer: South Asia</p> <p>Eleanor McNab, Programme Assistant: Asia & Eastern Europe</p>
Policy & Technical Support Department	<p>Jud Cornell, Deputy Executive Director / Director: Policy & Technical Support</p> <p>Mandeep Dhaliwal (co-facilitator): Co-ordinator: Care & Impact Mitigation</p> <p>Ade Fakoya, Senior Programme Officer: Clinical Care</p> <p>Kate Harrison, Senior Programme Officer: Children</p> <p>Susie McLean, Senior Policy Officer: Care & Impact Mitigation</p> <p>Cheryl Overs (co-facilitator), Senior Programme Officer: Prevention</p> <p>Gill Gordon, Senior Programme Officer: Prevention</p> <p>Alejandra Trossero, Programme Officer: Positive Prevention</p> <p>Elodie Brandamir, Programme Assistant: Prevention</p> <p>Tilly Sellers (co-facilitator), Co-ordinator: Civil Society Development</p> <p>Kieran Daly, Policy Officer: Civil Society Development</p>

**Policy & Technical
Support
Department
(continued)**

Sachin Gupta, Programme Officer: Civil Society Development
Josh Levene, Programme Officer: Civil Society Development
Lorna Clarke-Jones, Programme Assistant: Civil Society Development
Caroline Halmshaw, Co-ordinator: Policy & Communications
Harald Sprenger, European Policy Advisor, Stop AIDS Alliance
Kate Hawkins, Project Support Officer: Policy
Mathew Birch, Publications & Communications Manager
James Togut, Publications & Communications Officer
Garry Robson, Publications & Communications Assistant
Sam McPherson, Co-ordinator: Research & Evaluation
Pepukai Chikukwa, Programme Officer: Research & Evaluation
John Howson, Senior Technical Advisor, Health Sciences Health Communications Partnership

**Finance &
Administration
Department**

Julie Saunders, Director: Finance & Administration
Jane Smith, Head of Finance
John Rotherham, Head of Human Resources

Donors & Policy Makers (Roundtable only)

Gareth Thomas, Department for International Development, UK (DfID)
Robin Gorna, Department for International Development, UK (DfID)
Peter Piot, UNAIDS
Charlotte Kanstrup, DANIDA, Danish Government
Frans Mom, HIVOS
Rod Beadles, Elton John AIDS Foundation
Reeta Roy, Abbott Laboratories Fund
Paulo Teixeira, WHO
Jacob Gayle, US Centers for Disease Control and Prevention (CDC)
Kate Thomson, Global Fund
As Sy, Global Fund
Robin Brady, CRUSAID
John Simon, Johnson & Johnson
Polly Mott, PACT
Matthew Williams, Monument Trust
Anna Moshokova, International Harm Reduction Development Program
Scott Purdon, GlaxoSmithKline

Other NGOs & Foundations (Roundtable only)

Jim Smale, Bernard van Leer Foundation
Julian Hows, GNP+
Bernard Gardiner, International Federation of Red Cross and Red Crescent Societies
Malcolm Bryant, Management Sciences for Health
José Sluijs Doyle, Futures Europe
James McIntyre Brown, Futures Europe
Derek Poate, Information, Training & Development (ITAD)
Brian Griffin, JSI

Anne Scott, JSI UK
Casper Thomson, NAM
Keith Alcorn, NAM
Mick Matthews, UK NGO AIDS Consortium
Richard Burzynski, ICASO
Doug Webb, Save the Children Fund UK
Christina D'Allesandro, Save the Children Fund UK
Rachel Baggley, Christian Aid UK
Patricia Ray, Plan International UK
Nigel Tarling, International Family Health (IFH)
Peter van Rooyen, Aids Fonds
Jan Herman Veenker, Aids Fonds
Alice Welbourn, ICW
Fiona Clarke, Help Age International
Cathy Mears, British Red Cross
Julie Cabassi, NGO HIV/AIDS Code of Practice Project
Jon Cohen, University of Sussex
Steve Curry, Sussex Beacon

Other Attendees

Lesley Lawson, 10th Anniversary publication writer
Wanjiku Kamau, Consultant (Roundtable only)
Gideon Mendel, 10th Anniversary publication photographer (Roundtable only)
Alan Greig, 10th Anniversary Workshop and Roundtable report writer