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Informing Practice, Creating Public Spaces: Research on and for ART Rollout in African Health Systems

Christina Zarowsky, International Development Research Centre (IDRC)

Session chair Christina Zarowsky explained that the current session was established to promote an understanding of the role that research can play and to provide a forum in which people could ask questions about community response. Building and creating a culture of inquiry is what leads to innovation, she said.

The ARV Rollout in South Africa: A Numbers Game or Building Health Systems?

Portia Shai Mhatu, Department of Health, Free State Province
Eric Bateman, University of Cape Town

Portia Shai Mhatu explained that provincial HIV and AIDS strategies are based on the Strategic Plan for South Africa as directed by the National Department of Health. The plan has established four priorities:

- Prevention;
- Treatment, care, and support;
- Research, monitoring, and surveillance; and
- Legal and human rights.

Its goals are these:

- To provide comprehensive care, management, and treatment (CCMT) to people living with HIV/AIDS;
- To establish a minimum of one service point in every health district;
- To provide all clients who require CCMT for HIV and AIDS with equitable access to this program within their local municipal area; and
- To progressively realize the service needs and requirements of all clients of the health services.

Shai Mhatu said the guiding principles supporting the plan include quality of care, universal care and equitable implementation, strengthening of the national health system, and reinforcement of the key government strategy of prevention. In addition, the plan's intent is to provide a comprehensive continuum of care and treatment that is sustainable and that will promote healthy lifestyles and an individual choice of treatment.

Shai Mhatu said the Free State model uses a three-phase approach to ARV rollout. In the first phase, a treatment site is to be provided at the district or regional level, with each district having a designated ARV point. In the second phase, accessibility of treatment sites (district hospitals) and assessment sites (clinics) are to be improved. The third phase will focus on local areas and sub-districts.

She reported that, within the first three months (October through December 2005), the program had

- enrolled 18,380 known HIV-positive patients and other people coming forward for voluntary counselling and testing;
- provided a total of 5968 ARV baseline assessments, of which 4992 (66%) were referred for a drug-readiness program; and
- initiated ARV for 3150 people, of whom 2929 continue to receive treatment today (39% of the patients originally enrolled).

Prof. Eric Bateman gave an overview of the PALS Plus program, an initiative that focuses on developing guidelines and training models, providing support, and building capacity in the nursing system. He explained that, because only a few clinics have doctors, PALS “peripheralizes” treatment to clinics beyond the primary care facilities. The clinics are led and driven by nurses.

Bateman described PALS as a comprehensive, evidence-based plan that focuses primarily on increasing the quality of care delivered by nurses and integrating the management of priority diseases into one system. It entails “knowledge translation” and a change in professional practices and roles within the structure. He explained that, to address the issues of rollout and primary care in general, nurses must be empowered and enabled to play a broader role in a greater spectrum of activities.

The integrated model includes the provision of syndrome guidelines and support materials. A “train the trainers” outreach component means that nurses are not removed from the clinic.

The evaluation framework for the PALS Plus initiative includes the monitoring of four components:

- **Effectiveness**—Does it work?
- **Efficiency**—What are the cost parameters and staff time?
- **Validity**—Is it evidence-driven or empirically driven?
- **Acceptability**—Do the people in the target audience accept it?

Community Experiences of ART: Challenging Assumptions

Ari Ho-Foster, CIET International

Ari Ho-Foster’s presentation provided an overview of CIET’s work in assessing the contribution that research can make to ART rollout and the way in which it can contribute to building public spaces for innovation, experimentation, and the detection and correction of failures or mistakes.

Ho-Foster outlined a number of competing priorities that affect attitudes to HIV:

- **Hunger**—One in four people did not have enough to eat in the past week.
- **Other illness**—One in six people lived in a household in which someone was too ill to go to a health facility.

- Employment status—Half of heads of households are unemployed.
- Poverty—One third of people have incomes below the poverty line.

Lack of an adequate food supply and access to safe water and jobs are all considered more immediate threats to people's health than is HIV.

Ho-Foster then highlighted the complexity of the health systems. He explained that communities use service providers from all available sectors: public, private, and traditional. This combination of use presents a challenge, because messages and treatments can conflict, affecting ARV rollouts. Communities also lack an understanding of HIV/AIDS. Fewer than half of the people can give an allopathic explanation for the cause of AIDS; one in four does not know that there is no cure. Ho-Foster emphasized the need to ensure discussion and socialization in marginalized populations.

Research has shown that, although four of every five people know where to get tested, three of four have not been tested in the past year, and more than half have no plans to be tested. In addition, three of every five believe that others in their community would care for someone who is HIV-positive.

Ho-Foster said that communication for rollout is needed, because fewer than one half of all community members have heard of ARV. He also noted that, although two of every five people know when to seek treatment, four of five believe that ARV is effective, and 4% would not advise someone with AIDS to take ARVs. One in ten does not believe that ARVs can help someone with AIDS.

Based on the research results, Ho-Foster advised taking these next steps:

- Direct research toward policy and planning: Engaging policymakers is key to ensuring that information ultimately reaches the district level.
- Equip each household with the appropriate public information on ARVs (that is, what they are and how to take them), so that families can be agents of innovation to drive the ARV rollout.
- Communicate research findings to service providers and to the ultimate beneficiaries, using methods that each group understands.
- Find a donor to advocate for and fund activities in research proposals.

Ho-Foster applauded IDRC's support and advocacy in getting researchers to communicate, saying that "research should not sit on shelves, but be there for all to utilize."

The Buck Stops Here: HIV/AIDS, ART, Health Systems, and Nurses

Uta Lehmann-Grube, University of Western Cape (absent)

Uta Lehmann-Grube was unable to reach the conference in time. In her absence, Christina Zarowsky read the presentation.

The project being run by the School of Public Health is looking at the ability of health systems to cope with aspects of HIV care outside of ART: counselling; testing; treatment of opportunistic infections; prevention of mother-to-child transmission; staging; referrals; peer, nutrition, and other support; and palliative care. These are the aspects of care that have changed the primary care level and the lives of primary-level caregivers. The project also focuses on the research process, rather than on the substance of research.

The aim of the project is to examine how HIV and the scaling up of HIV programs is affecting human resources and the quality of health services in the context of a health system that has a basic management and health infrastructure in place.

These were the main project objectives:

- To conduct a rapid situational assessment of the quality and management of key HIV services in Cape Town and a rural district in the Eastern Cape;
- To describe and quantify the effect of the HIV epidemic on the health of the workforce in selected primary health care (PHC) sites in Cape Town and a rural district in the Eastern Cape in terms of morbidity, mortality, turnover and attrition, absenteeism, stress, burnout, motivation, and morale;
- To review existing practices with regard to staffing allocations, skills mix, substitution, and scopes of practice at the community, facility, and district levels;
- To provide planning data for staffing needs emanating from the introduction of new interventions and strategies;
- To identify required skills and training for successful HIV/AIDS management at the primary level;
- To identify barriers to policy implementation at the community participation, service delivery, and management levels; and
- To assess existing and potential levels of community awareness, mobilization, and support.

The research worked from two conceptual premises:

- That the readiness of the system's human resources to render HIV care affects all other system components, and
- That aspects of HIV care that are not ARVs range widely and are in danger of being "crowded out" of policy and practice debates when they are actually at the centre of HIV care at the primary level and are crucial to delaying the onset of the need for ARVs.

These aspects of the research process were key:

- A situational assessment to gauge the impact of HIV/AIDS on service delivery and staff: This assessment entailed interviews with nurses and managers to explore

perceptions and experiences of how HIV/AIDS was affecting mainstream service delivery at the primary care level.

- Use of an audit tool to conduct a facility assessment of all facilities: The process was participatory, involving facility and sub-district managers. Results were analyzed by the research team and were then fed back to managers and staff in two workshops.
- Selection of three facilities to create examples of good practice: With the limited capacity of facilities to analyze their data and develop plans, this method could assist the transition from information to practice and onward to initiating and monitoring progress.

In working with the three facilities, it was discovered that, despite best efforts in developing a participatory data collection and feedback process, staff at the facilities had not understood the data. They had also not understood the process by which the data had been arrived at (even though they had been part of the process), they viewed the information collected with resentment and the overall process as punitive, and they had no sense at all how the data could be translated into service improvement.

The nurses' reality was dominated by exhaustion and transformation fatigue, coupled with quite a keen sense that they were "not doing their job" properly. The result was a defensive position, with withdrawal into well-established "old" practices and, consequently, a reticence towards any new initiative potentially requiring change.

Regarding the question of how HIV and the scaling up of HIV programs are affecting human resources and the quality of health services, the relatively well-resourced Cape Town staff are coping to a degree, but the new demands are aggravating existing transformation fatigue and undermining the quality of primary care services overall.

The experiences with the audit shifted attention to addressing another challenge: If facilities struggle to make use of an intervention such as a participatory project, what does it take to strengthen their capacity in this regard?

Researchers therefore engaged all three facilities in assessing the audit results and jointly translating them into action agendas. Some facilities became enthusiastic when they picked up on the potential to actually improve quality of care through this process; others had so many other problems to deal with that they have not yet realized the potential of the process.

A formative, inductive research process that places itself at the heart of service delivery may raise more questions than it answers, and it needs to be able to respond to those questions—at times at the expense of established project objectives. Failing to do so will endanger the project's legitimacy in the eyes of the research partners in the health services.

Secondly, agendas within the service delivery environment are frequently quite unstable and subject to political shifts, thus destabilizing research processes.

Thirdly, service delivery and health service management usually have rhythms very different from those in the research environment. The latter rely on a reasonably slow, regular, and predictable beat; the former, for a range of reasons, tend to be fast, irregular, and often unpredictable.

The project provided indirect support for the ART rollout by highlighting the need to address systems issues, lest a steeply vertical program undermine rather than strengthen health services. If nurses are to support the rollout, they need not only the requisite technical skills, but also the capacity to run high-quality primary care services, including HIV services, which are the bedrock of ART care, with confidence.

Ultimately, the research is contributing to a “culture of enquiry,” but the process is slow and recursive, particularly if the goal is to reach stakeholders at all levels. South Africa is at a particular disadvantage because, historically, a culture of enquiry has been discouraged.

If research is to contribute to change in processes, ways must be discovered to maintain the momentum by finding additional funding and other forms of engagement, by bundling projects, and by building capacity.

Patients, NGOs, and Access to Care in Burkina Faso

Vinh-Kim Nguyen, Université de Montréal

Issoufou Tiendrébogo, Association African Solidarité

Vinh-Kim Nguyen began his presentation by outlining the research challenges found in expanding access to ART in community-based settings in West Africa. These challenges include meaningfully involving people with HIV in ART research to study adherence, performing molecular studies of resistance to ARVs, and thinking about new and old prevention technologies.

The rationale for the study was that producing knowledge is empowering. Being an object of study is one thing, but producing and presenting knowledge to other people and being seen as a source of knowledge is another.

Knowledge creates “therapeutic citizens”—that is, forms of citizenship concerned with access to treatment. Because people are implicated in that question, they stop seeing themselves merely as people in need of treatment. They become active participants in getting treatment.

Nguyen said that, to date, some key observations have been made in understanding the process, uptake, and application of research:

- Research is political. Nguyen emphasized that political controversies are good, because their existence means that research is being noticed. However, there is an ongoing risk that the people being studied will interpret data to favour their particular

kind of site or will manipulate data to make themselves look better. But the bottom line is that people become engaged in a dialogue concerning adherence and pay attention to the issue.

- The tools of standard epidemiologic research reproduce Northern categories. Standard tools may not capture certain social realities. They must be adapted so that the link between social support and adherence can be understood.
- Novel research questions are emerging about ARVs and childbearing. The relationship between treatment, women having children, and the problem of adherence is clearly an important issue.

Nguyen concluded by saying that one of his lessons learned is that meaningful involvement of the community in research is possible. However, an enormous amount of time, commitment, and trust is required. Failing to involve the community from the outset creates an adversarial relationship and sets the scene for distrust and failure in terms of interventions to address people's health.

Mapping the Policy Process in the Free State ART Rollout

Christo Heunis, Centre for Health Systems Research and Development, University of Free State

Prepared in collaboration with Dingie van Rensburg, Heunis's presentation provided a sociologist's perspective on moving from a research process to a policy process. He began by saying that ART remains inaccessible to most, despite the growing number of patients and deaths, and that knowledge translation has an affect on policy and practice.

Heunis outlined how the Free State's delivery model works. Each of the four districts has separate treatment and assessment sites. The remaining district has combined treatment and assessment sites, as well as four other factors that contribute to success:

- A "driving" social worker,
- A shared dietician and pharmacist,
- Telephone-based specialist support, and
- A mobile ART clinic

Heunis then highlighted a number of initiatives that are currently working well. These include active provincial and district ARV Task Teams. In addition, 40 ART sites are already functioning, with plans in place to double that number. Services are successfully being modelled to address local circumstances and needs.

Other items of note include the establishment of treatment guidelines that doctors and nurses can use and increased training for large numbers of staff. In addition, patient enrolment has grown significantly; it currently stands at 6800.

Heunis also noted that the South African government is exhibiting considerable denial and confusion about HIV/AIDS. Moreover, the backlog of patients is unmanageable and the bureaucracy is slow to respond to the challenges of ART rollout. Huge gaps in policy implementation exist, as do shortages of staff and skills—the latter being aggravated by ART.

In particular, Human Resources for Health represents a daunting challenge in southern Africa. Heunis cited numbers from the World Health Organization's 2006 *Global Health Report*, which showed ten nurses per 1000 population in Canada as compared with slightly more than four in South Africa, and four doctors per 1000 people in Belgium as compared with fewer than one per 1000 in South Africa. And Heunis reminded the audience that South Africa is actually better resourced than are other southern African countries.

In reviewing lessons learned, Heunis highlighted the need for Free State to concentrate more on strategic matters; to address critical human resource shortages; and to implement ART as part of a comprehensive primary health care strategy. He emphasized the importance of verticalization and increasing the focus on prevention and healthy lifestyles. In addition, he called for more interdepartmental and intersectoral collaboration and efforts to tap into the “potencies” of civil society.

Heunis added that health care need to be “layman-ized.” That is, lay people must be empowered to self-manage their health, which means that health care should be de-professionalized and de-medicalized. He also advised avoiding the “allopathisizing” of health and health care. Rather, care needs to be extended to embrace family-, home-, and community-based services and to integrate non-allopathic and folk healing.

In terms of promoting the role of research to inform policy and practice, Heunis encouraged initial and continued collaboration and development of formal (policymakers, coordinators, and researchers engaged in meetings, task teams, etc.) and informal (direct feedback processes) access routes alike.

Research can play a key role in advising on locations for new ART sites to reach geographic and population access equity. It can also provide informed analysis of ART staffing situations and can illuminate deficiencies.

Politics, Advocacy, Evidence, and Equity

Ireen Makwiza, Equinet

Ireen Makwiza focused on equity and ART scale-up in East and Southern Africa. She began by outlining the equity challenges in research and the political dimensions associated with those challenges.

Although most countries are in the process of expanding treatment, Makwiza emphasized that ART services need to be delivered in an equitable manner. ART delivery and health

care must be monitored to assess access and adherence to ART and the impact that ART is having on the wider health system.

Equinet launched an initiative to monitor equity and the health system, with the goal of expanding access to the treatments being implemented by REACH and the World Health Organization. Seven key areas for monitoring equity were identified. Two are in the areas of equity, justice, and accountability. The other five address sustainability and efficiency, and include such topics as financing, integration of delivery, human resource development, distribution, and private-sector provision of ART.

Equinet conducted a review of equity and health systems in the Southern African region. Their goal there was to synthesize evidence on good practices. The process included collating literature and interviewing key stakeholders, from policymakers to service implementers and people living with HIV/AIDS.

In assessing the access to ART, these issues came to light:

- Free ART at the point of delivery enhances access. User fees hinder access for the poor and reduce long-term adherence.
- More women than men are accessing treatment. This imbalance indicates a need to better understand entry points.
- Services are biased toward urban areas.
- Uptake of treatment in children is low.
- Simple strategies for collating information on adherence by sex, age, and district are needed.

In discussing financing for ART programs, Makwiza noted that activism has motivated increased funding. However, a high dependency on the donor community raises sustainability challenges. And where a multitude of funders exists, strong leadership and good coordination is needed to ensure coherence.

Makwiza also said that large funding bodies need to align with national processes and to take a holistic view of the situation. The human resources crisis is a key challenge, she added. HIV/AIDS has a profound impact on staff workload, morale, and occupational exposure. This situation demonstrates the need for long-term donor commitments and innovative strategies for supporting human resources in the health care field.

These gaps and challenges were identified:

- a need to assess eligibility criteria and access to ART;
- a lack of mechanisms to promote fair policy development in ART and engagement of various stakeholder groups;
- an evident impact of ART on the functioning of the broader health system; and
- a need to engage and motivate community groups and volunteers in promoting access and adherence to ART.

Questions and Discussion

The floor was then opened to questions from the audience. These are some highlights of the ensuing discussions:

- The starting block for ART rollout is government commitment and political will. Every opportunity must be used to get governments and departments of health behind the effort. South Africa has had particular issues with apartheid and is now trying to implement programs that could have been developed more than 15 years ago.
- Sociologists, anthropologists, and the medical and political communities have learned a great deal, and they are well positioned to work together to inform each other's worlds.
- Prevention requires a great deal of knowledge. This knowledge can be imparted through awareness campaigns. Governments cannot conduct these campaigns on their own. Community involvement is essential in producing an impact and creating behavioural change.
- Researchers can serve as watchdogs of intervention strategies and can assist in assessing outcomes.
- The availability of drugs is not the major problem; rather, the major problem is human resources. Researchers must now work in collaboration with the private sector to find non-conventional solutions to human resources shortages.
- Mass media support HIV/AIDS awareness. Researchers are also looking at the effect of getting community groups together to increase access and to seek out testing and other treatment.

HIV/AIDS, Food and Nutrition Security: The RENEWAL Initiative in Eastern and Southern Africa

Sam Bota, RENEWAL National Coordinator, Lilongwe, Malawi

RENEWAL, a research network that addresses the interaction between HIV/AIDS and food security, nutrition, and livelihoods in sub-Saharan Africa, was the subject of an early morning satellite session during the XVI International Conference on AIDS, August 14–18, 2006 in Toronto, Canada.

Food Security, Nutrition and HIV and AIDS: From Evidence to Action

Stuart Gillespie, Director, RENEWAL

Stuart Gillespie, a senior research fellow with the International Food Policy Research Institute (IFPRI, based in Washington, DC), noted that, when he joined the organization in 1999, almost no research existed on the interactions between HIV/AIDS and food security. “That was a major gap, really, given what we were beginning to understand about what was happening in communities,” he said. Following exploratory research and consultations, IFPRI set up a network of partners in the countries that were hardest hit by the epidemic, with a focus on knowledge and policy gaps related to food insecurity.

The role of HIV/AIDS in precipitating food and nutritional insecurity was clear from the start, but RENEWAL is also trying to shine a light on “the ways in which extreme poverty and food insecurity place people at greater risk of being exposed to the virus,” Gillespie said. He showed a chart that detailed the causes and consequences of HIV infection and food insecurity. The chart was developed by RENEWAL to help systematize research on the susceptibility of individuals to virus exposure and the vulnerability of communities to the downstream effects of the HIV–food security dynamic.

The chart includes elements of a two-part response to the epidemic. The first part deals with individual risk, susceptibility, and HIV prevention. The second part addresses community resilience in the face of HIV/AIDS. By setting out livelihood systems at the household and community levels, the chart traces the arrival of HIV as determined by susceptibility and demonstrates differences in vulnerability to AIDS based on the effects of the disease on human, financial, social, natural, physical, institutional, and political resources.

Gillespie said that the responses of communities to HIV/AIDS “are often driven by distress. What might look like coping now, [such as] pulling a child out of school, is certainly not going to be without a major cost in the future.” He expressed particular concern for vulnerable groups—women, orphans, woman- and youth-headed households, and elders, among others—and underscored the ways in which AIDS-related stigma paralyzes households and communities. Paralysis in the face of the epidemic worsens the susceptibility and vulnerability of households and communities, and undermines efforts to strengthen resistance and resilience.

The local partners involved with the RENEWAL initiative apply an HIV lens to food and nutrition policy and social development, seeking opportunities to strengthen resistance to the virus in individuals and resilience to its broader effects in communities. Gillespie said that the project is still developing a more rigorous, evidence-based understanding of all the dynamics that link HIV/AIDS and food insecurity. Simultaneously, partners are seeking to scale up the project's response in a way that reflects local diversity and best practices.

A review of 150 research studies from RENEWAL's first phase was published during the Toronto conference. The next few years will see the development of a policy response that emphasizes three pillars: action research, local capacity building, and communication among community-based researchers.

Based on lessons learned from the first phase of research, Gillespie warned against a form of "AIDS exceptionalism" in which the epidemic is seen as the only issue. He encouraged researchers to "talk about a lens, not a filter," and to broaden their thinking from agriculture to livelihoods. He advocated a comprehensive research focus that is grounded in local realities; emphasized the need for effective monitoring, evaluation, and communications; and drew a straight line from research to action.

RENEWAL in Africa: An Overview

Bruce Frayne, RENEWAL Regional Coordinator and IFPRI research fellow

Bruce Frayne said that RENEWAL's initial batch of 150 studies had provided the organization with a platform to shift into operations research. He described a system of national advisory panels that supports two-way information flow between local policymakers and the program's national and regional coordinators. RENEWAL is gradually shifting from a hub-and-spoke model to a more distributed network, with the researchers becoming partners rather than facilitators or drivers of the overall process.

During the program's third phase (between 2007 and 2010), researchers will explore the links between sustainable livelihoods and HIV/AIDS. Returning to the three pillars described by Gillespie, Frayne said that 40% of the effort will be devoted to action research, 40% to capacity-building, and 20% to communication among researchers. Specific theme areas include these:

- HIV/AIDS, agriculture, and livelihood security;
- HIV/AIDS, community resilience, and social protection; and
- AIDS and nutrition security.

By the end of its third phase, RENEWAL will be expected to have developed a context-specific understanding of the links between the epidemic and food security. International declarations fulfil the important function of grounding front-line work in a global agenda, but the effort to scale up the response to HIV/AIDS will depend on a better understanding of what works at the local level, Frayne said.

RENEWAL has already played a role in the development of Malawi's policy on HIV/AIDS and agriculture, has interacted with a government task force involved in land reform in South Africa, and contributed evidence-based benchmarks that supported a declaration at the end of the April 2005 conference in Durban that dealt with HIV/AIDS and food security.

In response to one participant's question, Frayne said that a greater investment of resources will make it possible to serve households of chronically ill people more effectively. A key challenge in South Africa is to maintain nutrition levels for people who are affected by food insecurity and who also have special needs.

A participant asked whether RENEWAL addresses larger macro-economic and trade policies that affect initiatives on the ground. Gillespie said policy analysis at that level is carried out by other organizations, adding that at least one recent declaration called for sustained access to appropriate, adequate nutrition for those who are affected by HIV/AIDS.

Food, Nutrition, and Child Vulnerability in South Africa

Suneetha Kadiyala, Food Consumption and Nutrition Division, IFPRI

Suneetha Kadiyala, a scientist in IFPRI's Food Consumption and Nutrition Division, presented basic statistics on HIV/AIDS in South Africa:

- Life expectancy is down to 49 years for women and 47 years for men.
- An estimated 5.5 million adults are infected.
- The population of orphans is 2.2 million, of whom 1.2 million are attributable to the epidemic.

Local research proceeded from the knowledge that HIV-positive parents or caregivers and their children face challenges in morbidity, mortality, and orphanhood that are different from those in the general population. The objective was to understand the "trajectory of their experience" and to identify suitable interventions to support them.

Research was based on previous studies at an urban site in Western Cape Province with 15% HIV/AIDS prevalence, a rural site in Eastern Cape with 28% prevalence, and a study group in KwaZulu-Natal with 37.5% prevalence—the highest in the country. The study team relied on in-depth interviews with parents, other caregivers, and key informants, triangulated where possible with quantitative data. Although findings were drawn from different data sets, Kadiyala said that the results still showed "a trajectory that can be observed."

She emphasized the importance of placing the research findings in context. In communities in which migrant labour is common, mothers and children are left behind. When the mothers enter the paid labour force, childcare is left to grandparents, aunts, and

uncles, and “so the concept of social parenting is nothing . . . new in South Africa.” But the study looked at what happens when HIV/AIDS is added to the picture, including differences between parents in responding to HIV infection.

Mothers often moved to their matrilineal homes or sent their children there, which meant that those households were already vulnerable and fostering orphans. The circumstances meant that some children had to accustom themselves to relatively fluid living arrangements, even before being orphaned. For mothers, a great deal of confusion arose over the age at which it would be appropriate that their children learn about their mother’s HIV status. Such disclosure was often complicated by familial living arrangements. Counselling and peer support emerged as key factors in the disclosure process, and mothers expressed an overwhelming desire for counselling when it was available.

Kadiyala reported that HIV/AIDS has left girls with a bigger role in caring for their younger siblings, although no evidence exists to suggest that children are being taken out of school. The research also shows that caregiving and emotional support contribute to positive outcomes for the mothers and help them to track treatment regimens.

Most mothers were planning for their children’s future by putting alternative caregiving arrangements into place. They all recognized the importance of savings, investments, and inheritances, “but the financial constraints are such that very few mothers were able to do that,” Kadiyala said.

When a mother dies, the immediate question is usually who will take care of the orphans. In KwaZulu-Natal, patrilineal responsibility is typically seen as the ideal, but the matrilineal line tends to take over—either because the children are already there, or because the patrilineal relatives are unwilling to play a role.

Better research tools and ethnographic methods will be needed to fully understand the stigma and discrimination related to HIV infection, Kadiyala said. African norms require equal treatment of all children, regardless of orphan status. But although little evidence of AIDS stigma was immediately obvious, the key informant interviews brought forward evidence of discrimination. Research on school outcomes shows parallel educational attainments for AIDS orphans and their peers, but qualitative studies suggest that discrimination takes place.

The limited number of households headed by children in the research sample reported additional stresses related to violence, crime, discipline, and security. Much of the support received was informal, and these families often found it difficult to obtain grants, information, or assistance from government institutions.

Across all fostering households, only 2% received the foster-care grants that are supposed to be the centrepiece of government support for AIDS orphans. Households can meet the program criteria only by proving that both parents are dead—and if a father has

abandoned his family, it may be difficult or impossible to establish his whereabouts.

Other program barriers include

- limited knowledge of, or assistance with, the application process;
- concern over the time required to secure a grant;
- concern about losing other forms of financial support if the foster-care grant is approved; and
- doubts about the prospects of a successful grant application after neighbours were seen to be turned down.

South Africa is also in the midst of a debate over the effectiveness of the foster-care grant. Critics argue that the program is expensive, inaccessible, and limited to just one segment of a larger group of children in need.

Kadiyala summed up her report with a number of observations:

- Children need supports that will enable them to be effective “agents of response” and that will give them a relatively “adapted” experience.
- School-based programming should include HIV/AIDS education, life-skills training, and comprehensive counselling.
- Mothers need counselling, training in the process of disclosing their HIV status to their children, and legal assistance to obtain child support.
- Mothers and caregivers must have opportunities to help shape children’s future financial security, and the children must feel that they’ve been left a legacy.
- Family structures can absorb AIDS orphans, but households face severe economic constraints and require effective monitoring and response mechanisms.
- Child-headed households require special assistance to meet their unique needs and to offset their heightened vulnerability.
- Systematic state policies are required to support interventions that are currently left to nongovernmental and community-based organizations.

Community Resistance and Resilience in Zambia

Petan Hamazakaza, RENEWAL National Coordinator, Zambia Agricultural Research Institute (ZARI)

In starting his presentation, Petan Hamazakaza returned to the dual themes of resilience and resistance. He defined *resilience* as the extent to which households and communities can maintain their well being over time despite shocks that affect them, and *resistance* as the ability to avoid exposure to HIV at the individual and household levels while averting high infection rates at the community level. He described a study that addressed the response of households and communities to the HIV/AIDS crisis and other shocks to their livelihood, and that assessed the factors related to nutrition and food security that help to shape the response to the epidemic.

The study focused on four rural communities in Zambia’s Southern Province. These communities recorded above-average adult mortality rates in 2000 and 2003. Data

collection included a survey of 179 households, in-depth case studies of 60 households, and participatory group discussions.

An analysis of resilience data showed changes over time in the agricultural assets that are a key component of rural livelihoods in sub-Saharan Africa. The researchers demonstrated a statistical link between prime-age deaths and HIV prevalence rates in nearby antenatal clinics, and then related the mortality figures back to asset erosion, with its implications for household vulnerability. In one community, unaffected households were reported to have asset values that were 2.4 times greater than those of households that had experienced prime-age mortality. In the other three communities, the multipliers were 10.4, 12.7, and 18.4.

In each community, ZARI looked at the community attributes behind the statistics. The community with the biggest gap between affected and unaffected households (18.4 multiplier) nevertheless showed considerable resilience as measured by higher overall wealth, strong social support networks, and a large number of households taking in orphans. The community with the 12.7 multiplier reported the province's second-highest HIV prevalence rate, high poverty rates, greater dependence on migrant labour, and limited tangible agricultural assets that households could sell in times of need.

Hamazakaza listed a series of factors that affect resistance to HIV infection in households and communities, including

- rural–urban movements that encourage temporary unions and high-risk behaviours;
- alcohol abuse, which communities associate with greater promiscuity and lower rates of condom use;
- transactional sex, driven by poverty and the need or desire for material goods; and
- disparities in resources and economic opportunities between women and men.

Hamazakaza said that all four communities were more inclined to associate high-risk behaviours with women, without acknowledging the role played by men.

If resistance to HIV infection is to be strengthened, Hamazakaza said, awareness will not be enough. He called for an integrated approach to reducing susceptibility. This approach combines HIV education with strategies for addressing structural constraints. Resources must be invested in approaches that are effective, culturally appropriate, and sustainable, and based on a clear understanding of the context in which risk behaviours take place. Above all, future programming must move beyond individual behaviours to address the lack of alternatives for income generation, particularly for women. Communities, meanwhile, must renew their efforts to address stigma, gender norms, a lack of individual agency, and peer pressure related to risk behaviours.

The resilience of communities can be strengthened by diversifying livelihoods, improving access by rural households to credit and markets, increasing production and productivity, and enabling households to protect their assets over the long term.

Linking nutritional support with ARV treatments: Lessons being learned in Kenya

Elizabeth Byron, Consultant, IFPRI

Elizabeth Byron reported on a research project that used the AMPATH HIV/AIDS prevention and treatment model to examine methods of improving nutritional status and household resilience for individuals receiving ARV treatment. AMPATH's treatment network covers more than 20,000 HIV-positive participants from 14 clinics in western Kenya, 9700 of whom were on ARVs.

Byron said the study included patients from one rural health centre that was also one of the first pilot sites for food supplement intervention. Clinic patients were mostly women, many of them widows, and a large proportion of them were undernourished, with limited food in the home, but with many children to feed. With an HIV prevalence of 7% and food insecurity of 15% to 20%, the community is not one of the food-insecure areas in the AMPATH network.

In 2002, AMPATH introduced the HAART and Harvest Initiative (HHI), which supports four local farms producing fruits, vegetables, poultry, and dairy products to be distributed freely as food supplements to patients. In addition to an initial six months of food supplementation, HHI provides nutrition education and counselling for people living with HIV/AIDS and also an income security program that supports craft and agricultural training for people living with HIV/AIDS and for their households.

In 2005, the World Food Program (WFP) agreed to supplement the HHI, committing to meet 50% of daily nutritional requirements for 2200 individuals, or about 450 ARV patients and their dependents. In January 2006, the program was extended for another year and was scaled up to reach 15,000 individuals. Eligibility criteria include

- insufficient access to food;
- household income below US\$41 per month;
- advanced HIV disease, defined as a CD4 count below 200; and
- body mass index below 19.

Byron said that the research demonstrated a need for discretion on the part of clinic nutritionists, because "it's a little messy trying to match the actual criteria."

Between December 2005 and February 2006, researchers used key informant groups, stratified focus groups, and close to 80 in-depth interviews to assess the impact of the HHI/WFP initiatives. Key issues included the eligibility criteria, use of food supplements, appropriateness of the food, seasonal vulnerabilities, opportunity costs, individual and household benefits, and the transition from short-term supports to long-term strategies.

The study confirmed that the supplementation programs had alleviated food insecurity to some extent. Food was often shared among households, frequently in favour of people living with HIV. Acceptance of the types of food distributed, particularly farm-fresh products that would otherwise be unavailable to households with no livestock, was

widespread. Unfamiliar foods required that recipients also receive education and cooking demonstrations, but program staff reported effective distribution and good uptake—particularly because AMPATH treats food distribution as a part of HIV treatment.

For patients, the combination of ARV treatments and food supplementation led to self-reported weight gain, recovery of strength, and renewed ability to return to work. Food supplements made it easier for patients to follow ARV regimens and to satisfy the increased appetite that often accompanies treatment. Access to food also reduced stress, particularly for women with children.

The improvement in diet quality and quantity also spilled over to other household members, particularly children. Recovery meant that patients could return to both reproductive and productive activities, freeing caregivers to resume their own regular routines. Patients also reported that resources previously directed to food were reallocated to rent, clothing, education, transport, and activities that reduced demand on informal support networks.

The program ran into some difficulties with transportation costs, as well with stigma for people who had not disclosed their HIV status to family, friends, and neighbours. Fermented milk packets are in high demand among food supplementation clients, Byron said, but the farm's practice of labelling the product with HIV awareness messages violates patient confidentiality. She said that supplementation programs should "let food be food," by separating food distribution from treatment and counselling messages.

The research also revealed a need for

- a more gradual transition off food supplementation, to ensure that short-term health and nutrition gains would be sustained over the long term;
- monitoring of the long-term clinical and nutritional status of patients, so as to identify individuals who might require a second round of supplementation;
- greater program flexibility to meet seasonal changes in demand;
- a change in food labelling practices to combat AIDS stigma;
- broader links with partner organizations that have long-term strategies to promote rural livelihoods and food security;
- further studies to determine the best time to introduce food supplements before ARV treatment begins; and
- more rigorous assessment of the program's economic impact and sustainability.

Questions and Discussion

The group discussed the relative merits of a market-based response in ensuring effectiveness and sustainability when programs scale up. While some donor governments would like to see cash-based social transfers to help ensure access to food, a participant said the approach raises concerns about food quality and variety.

Byron said all the food available through AMPATH is delivered on an in-kind basis, but agreed that a cash-based system might be more effective than donor support for locally-grown food. She said future evaluations would look at whether a cash transfer would enable recipients to go to the market and buy local food, adding that key issues include food quality and diversity, program effectiveness, and the number of beneficiaries reached.

Commenting from the floor, a member of AMPATH's field staff noted that the current program increases local food diversity by training farmers to grow it.

An audience member asked whether AMPATH had considered reducing costs through a centralized distribution site, or changing its packaging to reduce stigma. Byron said all four farms in the pilot phase were located close to the receiving communities. Primary distribution was placed within walking distance of each clinic, so that patients could carry their food home. Distribution centres were close to the communities.

In reply to a question from the floor, the field staff member in the audience said the program is considering how to track CD4 counts as a way of measuring adherence.

A participant asked for figures on the number of people employed by the program and the percentage of food grown locally. Byron said the work force includes five or six permanent staff at each site, plus casual labour for harvesting. Many of the people AMPATH hires are patients, including all the distribution workers when the program was first set up.

An audience member asked how the various projects interact, and invited the panel to elaborate on RENEWAL's approach to capacity building. Frayne said the program holds workshops to enable staff from the different projects to share their knowledge, and uses online training resources to try to integrate front-line experience with policy. This effort is supported by online courses provided by IFPRI that train front-line researchers to write proposals and journal submissions.

Session moderator Sam Bota, RENEWAL National Coordinator in Lilongwe, Malawi, said capacity building is a crucial issue in all the countries where the program has a presence, and that proposal writing is a key area for skills development. He said a number of initiatives are in place to team up-and-coming researchers with their more seasoned colleagues. He added that the regional sharing Frayne had described "is the essence of RENEWAL," enabling researchers to learn from each other, build on complementary efforts in other countries, and avoid duplication.

Frayne said the next phase of RENEWAL will seek to identify strengths and comparative advantages within country organizations that might represent learning opportunities for other members of the network.

A participant stressed that the third phase of RENEWAL must link lessons learned to capacity building. He said the insight that orphans are a resource, not a burden, "is being

taken up very uniquely and spottily.” For a country like Uganda, the first in human history where half the population is aged 15 or under, the trade-off is clear: while education is essential for children, a weak labour market is one of the biggest threats to community resilience. He said one solution might be to ensure that orphans receive the skills to keep their households food secure.

Gillespie agreed that HIV/AIDS has led to an “intergenerational fracture” in the transfer of knowledge from parents to children. He acknowledged that the issue is difficult: Children should be in school, but vocational skills are just as important. He said the third phase of RENEWAL would address this challenge under the thematic area of social protection, with a very strong focus on children. As well, RENEWAL and the World Food Program will be looking at the feasibility of delivering life skills through junior farm programs.

Gillespie added that the pace of the HIV/AIDS pandemic has created “impact waves in different countries,” so that capacity declines where it needs to increase. The ability to scale up will depend on better communication among project partners, including a better understanding of the comparative advantages in different country organizations.

ARVs: From Magic Bullets to (Re)Thinking Systems

Mickey Chopra, Medical Research Council and the University of the Western Cape, South Africa

Session Chair Mickey Chopra explained how ARV treatment has forever changed the nature of HIV/AIDS. As a result, researchers, health care workers, scientists, and various members of civil society have had to reassess their strategies and tactics in addressing the spread of the virus and the treatment of the disease. The successes of ARV treatment, which include reduction of viral loads in patients, prolongation and improvements in the quality of life of people with the virus, and reduced transmission rates, have created new challenges for those fighting the epidemic and helping the sick. The IDRC welcomed four speakers to outline some of the new obstacles facing Africa in the wake of ARVs, and to introduce some tactics to overcome those obstacles.

Friends or Foes? ARVs, Global Initiatives, and African Health Systems

David McCoy, Equinet

Dr. David McCoy of the United Kingdom’s Equinet began his presentation with an expression of concern about the way the topic on which he was about to speak had been headlined. “I find the heading [that] I was assigned [“Friends or Foes”] troubling,” he said. He explained that the word “Foes” is misleading, underscoring the significant health gains derived from the treatment. “Nonetheless, ARV programs do create several tensions,” he added.

To begin with, the expansion of ART programs often comes at the expense of other essential health care services. Secondly, selective health care programs, which are typically implemented vertically from the top down, tend to clash with integrated health services that emerge from the bottom and filter up. In addition, these programs create another tension between proponents of short-term ambitious health strategies and backers of longer-term cautious approaches. Finally, in developing countries, ART often entails a tension between health ministries and international actors who have their own global health plans.

“These are real and unavoidable tensions that we need to address,” McCoy said. ART, if poorly implemented, can jeopardize the development of a comprehensive health care system. “If integrated properly, ART and PHC can strengthen the health system.” To accomplish this end—the “virtuous cycle”—HIV/AIDS workers must first be able to look inward at their own system, assess its flaws, and then decide what must be done to improve upon it.

McCoy stressed the importance of identifying indicators that will allow health care providers to assess the impact of ART on specific health care services, as well as on the health care system as a whole. ART programs might reduce the effectiveness of HIV prevention programs or might have an impact on the treatment of other sexually transmitted infections. Other illnesses, such as tuberculosis, might not be addressed properly in the wake of a massive ART rollout. Health care systems could possibly be compromised by issues of “health care equity.”

Experts need to ensure that every person with the virus has equal access to treatment; they also need to guard against the weakening of health care systems that might experience internal “brain drains” caused by doctors and other health care workers going to ART programs with bigger budgets. Furthermore, policy planners need to be vigilant that programs are not being duplicated. This “parallelism,” as McCoy called it, is a misuse of scarce resources.

As more money is directed toward ARTs, more safeguards need to be put in place to prevent theft and corruption. “We need to understand how our health systems are managed, financed, and organized,” McCoy said. “[ART programs] need to be equitable and transparent.” Furthermore, health care providers, especially nurses, should be paid adequately.

“We need to determine what [the] ideal system should look like in 10 years, and then figure out the right path to get there.” Doing this, McCoy explained, would make it easier to assess whether targets are being achieved. McCoy’s ideals include a country’s tax revenues equalling at least 20% of its GDP, and government spending on health equalling nothing less than 15% of its total spending.

An integrated ART program also requires the co-operation of government and the public sector, business and the private sector, and civil society. NGOs need to be coherent to be able to contribute effectively in the ideal system.

Linking ARVs to Nutrition, Food Security and Livelihoods: The Example of RENEWAL

Stuart Gillespie, International Food Policy Research Institute (IFPRI)

“The issue of chronic and acute food and nutrition insecurity is inseparable from the issue of AIDS in Africa,” said Stuart Gillespie in commencing his presentation. The relationship between the virus and food security is at once incredibly complex, and simultaneously staggeringly simple, he said. The causes and consequences of food insecurity can be viewed through macro-, meso-, and microfilters. Distribution of resources; disparities between the rich and the poor; and stigma, violence, and livelihoods, among other factors, interact on various levels to produce varying outcomes. But, in the end, the common denominator is a simple one: without food, there is no hope in saving someone with HIV. Insufficient dietary intake encourages the spread of the virus through the human body. All that is left is death.

To counter this grim reality, the IFPRI developed a program called the Regional Network on HIV/AIDS, Rural Livelihoods, and Food Security (RENEWAL). RENEWAL brings together national networks of researchers, policymakers, public and private organizations, and NGOs “to focus on the interactions between HIV/AIDS and food and nutrition security.”

“We are engaged in research that helps strengthen the capacity of communities and families [to properly nourish themselves],” Gillespie explained. Drugs work better when patients are well nourished. Patients experience fewer side effects when well fed. Patients who feel better adhere better to their drug regimens, and drug resistance is delayed. Better nutrition even delays the necessity for ARV treatment, and increases rates of overall survival.

But long-term food security is a different issue altogether. Communities that have the ability to sustain livelihoods may be food-secure. But short-term nutrition interventions cannot provide the same guarantees and they are may be incapable of countering barriers, such as stigma.

“Community-driven approaches are the key to any successful food program,” Gillespie said. Local community members have the incentives and transparency. NGOs and governments should strive to augment community capabilities, supplementing them where necessary.

Gillespie co-authored a report with Elizabeth Byron and Mabel Nangami on nutrition supplementation programs for individuals on ART in western Kenya. The object was to discover whether formal nutrition supplements complemented local support networks. The formal support included ART, food supplements from HAART and Harvest Initiative/World Food Program over a short period, Family Preservation Initiative loans,

skills training, and support groups for patients. Informal support networks were made up of relatives and friends, and consisted of loans.

The study found many factors that affected the level of informal support. Stigma remained the largest barrier. “People didn’t want to pick up their supplements because it revealed their status,” Gillespie explained. The availability of resources within the community (often determined by the seasonal supply of goods) also affected the amount of informal support available. Gender inequality, overall health, and marital status also played roles in the type of assistance provided by the community.

Overall, nutrition intervention can serve a positive purpose, especially during those times of year when food is most scarce. In addition to providing valuable and potentially life-saving nutritional support to people with HIV and their families, this type of intervention allows households to reallocate resources. However, the real challenge is to link such short-term support to longer-term livelihood sustenance.

Re-imagining Care: A Nurse-Based System?

Pat Mayers, PALSA Plus, University of Cape Town, South Africa

“Nurses are often the only health care providers for some South Africans,” Pat Mayers explained, adding, “especially in rural areas.” The country simply does not have enough doctors to meet demand. This shortage of doctors is amplified by the inflated demand created by a high HIV infection rate. More than five million South Africans are HIV-positive—nearly 11% of the population.

Of necessity, South Africa’s nurses have become the primary health care workers, performing specific types of diagnoses and treatment. Nurse practitioners are now essential in the delivery and support of the ART rollout.

“The HIV epidemic has caused health care workers to rethink their roles,” Mayers said. ART delivery will put the new roles to the test.

ARVs have the potential to transform what was once a terminal disease into a chronic illness. When ARVs were first introduced, the perception was that these drug regimens were hard to manage and required multiple and frequent follow-ups with a specialist. However, over the years, it has become clear that this treatment is considerably more straightforward than originally thought. That understanding has opened the door for nurses. In conjunction with a reliable referral system, nurses can easily and safely oversee these treatment programs.

In this type of primary health care system, nurses are trained to address all but the most complex HIV/AIDS and tuberculosis (TB) cases. They are also trained to recognize when it is imperative for a patient to be referred to a physician. This is where PALSA Plus comes into play. PALSA Plus is an evidence-based set of syndrome-based guidelines for treating HIV and respiratory diseases such as TB. The guidelines are derived from

rigorous quantitative and qualitative analysis, and they help nurses to treat patients more effectively and safely. “[PALSA] facilitates a more holistic approach to health care,” Mayers explained. “It also has the potential to influence national and provincial policies.”

By allowing nurses to administer ART, treatment rollout can rapidly expand in a cost-effective manner. Nurse-initiated ART increases overall patient access exponentially, especially in rural areas.

Still, the PALSA Plus program has encountered several obstacles. The primary obstacle is the power structure of the traditional health care system. The hierarchical nature of the traditional health care system, in which doctors reign supreme, restricts the ability of nurses to work effectively. “Mistreated nurses often lead to mistreated patients,” said Mayers. Complicating matters further is a pervasive “task-oriented” focus in clinical situations. This type of vertical system disrupts care.

In a nurse-based primary health care system, the role of the doctors needs to be clearly defined. The doctors’ expertise makes them second-line caregivers. “For this system to work, it needs to be regularly assessed for strengths and flaws and upgraded accordingly,” continued Mayers. Nurses need to be better trained, better paid, and better treated. Under the right conditions, nurses can head broad ART programs. If properly managed, treatment can reach more people, more effectively, at a fraction of the cost.

Ten Lessons from Implementing an Informatics System for HIV/ART Care in the Free State

Merrick Zwarenstein, Medical Research Council, South Africa

Dr. Merrick Zwarenstein’s research team has designed a clinical system for primary HIV care that includes an in-depth record keeping system. That record keeping system was eventually developed into a large-scale province-wide medical records data bank. Zwarenstein presented an outline of the lessons his team learned from the associated trial.

- **Lesson 1**—Technology issues aside, it is, in fact, possible to create an electronic medical database for patients with HIV/AIDS. The greatest obstacle to creating such a record in a developing country is the will and commitment of policymakers—in addition to the limitations of the health care system itself.
- **Lesson 2**—More time and energy should be spent teaching policymakers the ins and outs of the health care system. Politicians and bureaucrats need to understand the limitations of a health care system before considering the technical requirements of such a database.
- **Lesson 3**—To function properly, the record keeping side of the health care system needs to be kept separate from the health delivery side. Health service managers need to ensure that the two sides remain linked and that they function in tandem, but at the same time record keeping should not bog down treatment. Accomplishing this feat

requires deft management.

- **Lesson 4**—Records must have clearly defined parameters and categories that are identical across the board. The more precise the definitions, the more comprehensive the database will be. The more comprehensive the database, the more useful it becomes overall.
- **Lesson 5**—“[Personal digital assistants (PDAs) of various kinds] proved to be exceptionally useful,” Zwarenstein said. “These tools were capable of collecting large amounts of data.” Trained personnel transferred clinicians’ paper records directly into the PDAs. Extended battery life proved to be an asset, especially in remote clinics with unreliable electricity supplies. Telephone linkages allowed data collectors to constantly back up information onto the server, which meant that no data was ever lost.
- **Lesson 6**—Databases are extremely expensive to design and even more expensive to alter. To avoid having to make changes after the original commissioning of the database, health care service providers need to do their homework. “Our database had a hierarchical design, which meant that all changes had to be made by the vendor.” This leading global vendor’s software program had its own flaws, which proved to be costly and inconvenient to fix; health care system managers need to thoroughly research their options.
- **Lesson 7**—Relying on names alone as the sole means of identifying patients is problematic. Health care systems should require patients to provide some form of unique identification, such as a national ID card.
- **Lesson 8**—Data should be stored in a warehouse that is purposely designed to facilitate filing, retrieving, and reporting information. Quickly access to data becomes an asset.
- **Lesson 9**—Data-quality checks and feedback should be integrated into the data collection system.
- **Lesson 10**—Computer literacy among data collectors is essential. Extensive training is the only way to guarantee the necessary skills. “Data collecting is difficult and thankless work,” Zwarenstein said. “And, too often, data collectors are underpaid. Efforts should be made to be inclusive and respectful.” Physicians should also be trained to ensure that they are using the same definitions as the data collectors.

Communities: Where Systems Interact

Neil Andersson, CIET International

“There is an overriding emphasis,” said Neil Andersson, “to focus AIDS prevention programs on individuals, instead of on communities or households.” He explained that current prevention programs tend to focus on commodities and goods, such as new drugs, microbicides, or condoms. Andersson cautioned that this approach is myopic.

“Systems meet in communities,” he explained. In the community, prevention programs overlap with treatment programs. The costs and benefits of various actions are weighed and assessed, and ultimately, the individual is left to choose. “But some individuals are not in a position to make a choice, and others choose not to act.” Something as simple as economics can often lead to this incapacity or failure to act. Some options are unaffordable to most people.

When it comes to implementing ART programmes, health care service providers have concerns that are different from those of communities. The average South African community tends not to be ready for ART. The culture needs to change; people need to be educated; and the stigma needs to be lifted. And different cultures react differently to outside pressures. Some cultures form negative impressions when being told what to do. “You simply cannot push ART onto people. It is perceived as being rude. Communities are not impressed by being pressured by outsiders to mobilize.”

Stigma follows the health care system, making it difficult to conduct studies. Participating in ART programs is like wearing a scarlet letter. HIV prevention and ART programs often clash with traditional medicine. Activists and researchers are known to dismiss and ignore traditional healers. This antipathy presents a lost opportunity. Traditional medicine was a shared good, funded collectively by the entire community. But, like everything else, “traditional healing has been privatized.” What has emerged in its place is a “neo-traditional approach. It is a bastardization of traditional forms of healing.”

The impostor traditional healers have done a disservice to the community by ruining the reputations of genuine traditional healers. Genuine traditional healers provide a valuable service to their communities. Over time, they earn the respect and confidence of community members. One third of South Africans still consult traditional healers. These healers could make great messengers for disseminating accurate and positive health information.

“It is unfair to compare modern medicine to traditional medicine,” Andersson explained. Traditional medicine can play an important role in the overall treatment of an AIDS patient. Obviously traditional therapies cannot replace ARVs, but those who allude to such a substitution are making false comparisons. By belittling traditional medicine, modern medicine practitioners are losing a valuable weapon in their arsenal against the epidemic.

Questions and Discussion

One audience member asked Gillespie if the issue of nutrition and food security could be separated from the issue of poverty. Gillespie replied that security can be guaranteed only when people are brought out of poverty. “We’ve seen people on medical nutrition supplements sharing their supplements with other malnourished family members.” He explained that the family of a person living with HIV becomes poorer faster than other families do. Gillespie feels that state-led social protection needs to complement and support community-led responses. “You try to detach yourself from the system,” Gillespie explained, “but the system is too complex for that. Things should be addressed on the micro level first.”

Along the same lines, another audience member inquired about what came first—poverty or lack of food? Gillespie explained that the issue is too intricate to begin debating whether the chicken or the egg came first. The question is academic, he said, because the solution is clear. The issues of poverty and food insecurity have to be addressed at the community level.

A third participant asked Gillespie if food handouts were more effective than monetary handouts. In response, Gillespie again indicated that the answer could be found at the community level.

Another audience member wanted to know how HIV/AIDS could be treated on a community level instead of on an individual level. “How do you avoid individualizing an illness that affects a single person at a time?” Andersson replied that “sick individuals never come to the clinic alone.” This single fact suggests that treatment, stigma- and barrier-breaking, and general education should all begin with the immediate family of the infected individual.

Andersson went on to remind the audience that ART is only one part of a dynamic intervention. He feels that the best way to ensure that a treatment strategy is benefiting everyone is to talk to as many people as possible at all levels of society. “It is important to figure out who gets left out of a specific intervention,” he said. “Once we learn this, we can figure out how to include them . . . ARVs should not come at the expense of everything else.”

Zwarenstein explained that systems to properly evaluate various treatment types need to be developed. “Evaluation is more than just a case study,” he said. “We need to compare one solution to another solution to find out which one works best.” AIDS is no longer a fatal disease in the North. This, Zwarenstein suggests, has more to do than just wealth. Through trial and error, the right system was developed to contain the virus.

“Where and how does advocacy come into play in addressing these issues?” a participant asked of all the speakers. The consensus was that scientists, health care workers, and

physicians perform the function of clarifying the issues upon which the advocates should act.

One audience member urged that advocates should begin focusing on the issue of accountability and fiscal responsibility. One of the speakers agreed, saying that the solution is for advocates to forge alliances with researchers and health care providers to ensure that money gets to those who need it.

Another participant wanted to ask how nurses could be better used to alleviate the stress on the health care system in southern Africa. Mayers explained that South Africa's health care system is fragile. In fact, policymakers should be cautious when moving nurses into the role of delivering ARVs. The system may not be able to absorb the loss of nurses working in other capacities. With that in mind, Mayers urged that concrete steps be taken to alleviate the poor treatment that nurses receive in South Africa.

HIV, Gender, and Development: The Poverty, Malnutrition, Food Security Action (from Evidence to Action)

Stephen Lewis, UN Special Envoy for HIV/AIDS in Africa

Following a short introduction by Session Chair Stephen Lewis, Stuart Gillespie opened the HIV, Gender, and Development session by focusing on the interaction between HIV/AIDS and food and nutrition, and on the need to look at tools and ways of translating efforts into effective action.

Overview

Stuart Gillespie, Senior Research Fellow, International Food Policy Research Institute (IFPRI)

The conventional understanding is that HIV/AIDS precipitates and exacerbates food and nutrition problems, Gillespie said. However, a need also exists to look at how the poor are at much greater risk of being exposed and infected. This interrelationship has created a downward spiral, in which the causes and consequences are increasingly diverse and complex. Gillespie then quoted Louis Pasteur, who said in 1860, "The microbe is nothing, terrain is everything."

Gillespie emphasized the need to strengthen resistance to the virus at the micro and macro levels alike. The downstream impact of AIDS is determined by the vulnerability of the existing political, economic, and social systems. This vulnerability can be felt at the community and global level alike.

Various outcomes are entwined with issues of gender, of specific vulnerable groups, and of stigma. Understanding that outputs can also be inputs—creating greater susceptibility

and vulnerability on the one hand, and reduced risk and impact on the other—is also important.

Gillespie confirmed that a definite interaction occurs between malnutrition and HIV. HIV is accelerating the cycle, and HIV-specific interactions are making the situation far worse.

On the “upstream” side, food insecurity leads to HIV exposure. The people who are at greater risk are the poor—those whose families are more likely to be separated and searching for work. This situation exacerbates gender inequality, among other issues, which is itself a driver of HIV risk.

In addition, HIV can be an occupational hazard. Nodes of risk are created through activities such as evening markets and trading centres. It is also a domestic hazard that can be transmitted within a household.

The poor have less access to information and less ability to use the information that they do acquire. Also, food insecurity increases malnutrition, which in turn may increase the risk of having low birth-weight babies and may worsen various diseases including some that may be cofactors for HIV transmission.

On the downstream side, AIDS exacerbates food shortages. Gillespie noted that agriculture is the major livelihood of people affected with HIV/AIDS globally. The high death rate of parents leads to a loss in the intergenerational transfer of knowledge from parents to their children.

HIV also raises energy requirements by 10% to 30% (50% to 100% among children), and low body weight worsens the severity of infection and hastens death. Gillespie noted that the age pattern is changing and that child malnutrition is significant in areas with high HIV rates. To address the problem, he suggested thinking in terms of tools, processes, and principles, and he offered four response requirements that he believes need to be addressed simultaneously:

- Strengthen household and community resistance to HIV and resilience to AIDS.
- Preserve and enhance livelihood options and strategies.
- Protect vulnerable groups.
- Strengthen governance and capacity.

New evidence on food security, HIV, and orphans from southern and eastern Africa

Robin Jackson, WFP, South Africa

Robin Jackson noted that conducting research on food security and HIV has been challenging. Measurements are difficult, because many people surveyed do not know their HIV status. Researchers need to rely on proxy information, such as chronic illness at the household level, household food consumption, and indices of coping strategies. Obtaining large enough samples sizes and sufficient cross-sectional representation to generate definitive answers is also difficult.

Initial community household studies in the southern African region were conducted during 2003–2005. Comparisons were made between households that benefited from food assistance and those that did not, as well as between families that had a chronically ill family member and families that did not. Results showed that the residents in a household with a chronically ill family member were worse off; their engagement in erosive “coping mechanisms” was more severe. The presence of a chronically ill household member signals that this is a family in need of food assistance during times of crisis.

Gillespie also noted that these same families are more likely to borrow money to spend on food than on health care or education. The loan burden over time may have a significant impact on their ability to recover after a food crisis. Debt is especially challenging for families that have lost a family member whose income would have been used to repay the debt.

Research confirms that food assistance helps households cope. Those who receive food consistently do better than those who do not.

A second assessment conducted in East Africa in March 2006 studied the link between HIV and food insecurity. Households were divided into those that had been affected by a death sometime in the previous six months or that currently had a chronically ill family member, and those that did not. Subjects were further divided by sex.

The study found that households affected by recent death or current illness were significantly more food insecure than households that were not so affected. More than two thirds of affected household fell into the “insecure” category as compared with only one half of the households that were not affected.

Differences were also observed between affected households headed by a female and affected households headed by a male. Where a female was head of the household, the percentage classed as food insecure increased to 71%. Affected households headed by females should therefore be targeted for food assistance and long-term support.

There were other notable findings:

- Affected households were twice as likely as unaffected households to sell assets. Of households selling assets, two thirds sold productive assets.
- Families at risk should be targeted for assistance to help in long- and short-term food needs.
- Orphans are vulnerable to food insecurity; although, in some regions, wealthier households have the capacity to support orphans.

Jackson concluded that the studies provide good proxy indicators that can be used to understand food security and HIV dynamics. Direct food delivery makes a difference for HIV-affected populations. Certain kinds of households are more vulnerable to food insecurity than others, and these vulnerable households should therefore be targeted for food support. The most vulnerable households are those that are affected by HIV and headed by a female.

Linking Agricultural Regeneration, Social Protection, and Strengthened Community Responses to AIDS

Gabriel Rugalema, Senior Officer, HIV/AIDS and Food Security, UN Food and Agriculture Organization (FAO)

Gabriel Rugalema began his presentation by discussing the evidence and implications of linking HIV and AIDS to food security. He explained that meeting the immediate food and nutritional needs of dependent populations is urgent, even while building the capacity for a self-reliant future over the long term. Some of the responses developed by FAO are based on thorough analyses of the impact of such work over time.

A key focus is to build the capacity both of communities and of government. As Rugalema said, “If we don’t bring this to the agenda of governments, we can’t achieve much.”

A conceptual map of FAO design activities outlined the efforts being made in the areas of capacity building at the national and local levels, of nutritional support, of access to funds and innovation, and of empowering vulnerable communities. Rugalema then highlighted three specific activities:

- **Junior Farmer Field and Life Schools Program**—The Junior Farmer Field and Life Schools Program was developed in response to the increased vulnerability of young people, particularly those orphaned by AIDS. It provides a safe place for children to play, learn, and associate, while addressing the skills and knowledge gaps created by the premature deaths of their parents. Rugalema noted that learning and nutritional support are critical, because children cannot function if they are hungry. This effort mobilizes resources at the community level and helps to reintegrate children into the schools from which they were withdrawn. The program is being run in six countries at the moment, and it can be easily integrated into vocational and educational programs. It helps students to gain agricultural knowledge and the life skills necessary to improve self esteem and build confidence. It also provides an entry

point for education on gender, AIDS, and other social issues that can lead to social change.

- **Rights of Widows and Orphans Program**—The Rights of Widows and Orphans Program addresses the issue of property inheritance rights for widows. It does so by providing technical assistance and protection of property rights. Initiatives include policy formulation and paralegal training of nongovernmental organizations to provide legal support to women.
- **Strengthening institutional capacity at the government level**—The initiative to strengthen institutional capacity brings HIV/AIDS and food and nutrition security to the government's agenda and sustains those topics there. This work is being achieved by training researchers and obtaining research grants to analyze the impact of AIDS on production systems and livelihoods.

Lessons from the Field in Kenya: A Woman's Perspective

Leonider Amolo Akeye, Grass Roots Organizations Operating Together in Sisterhood (GROOTS), Kenya

Leonider Amolo Akeye's presentation discussed the evolution of GROOTS since its inception in 1995. Started in western Kenya, GROOTS is a community-based organization of women aged 40+ years who work with organizations such as CARE to help women and children living with HIV.

Akeye noted that, in Kenyan tradition, land is passed to sons and not to daughters. The amount of land that a family has to grow food therefore becomes smaller with each generation. Almost 50,000 children in Kenya have lost one or both parents to AIDS. Most families are caring for extra children, and some households are left without an adult. Stigma and discrimination are rife within the communities.

Akeye said that when GROOTS began operating, no one knew what to do with HIV/AIDS patients, and so they were left alone. When a woman was infected with HIV, in most cases her husband and relatives would not accept her into the family. They would send her back to her mother. As a result, older women who could barely manage were left looking after their daughters.

When a woman loses her husband, her land and property are taken away, but she keeps her children. The very poor are therefore made poorer through the extra burden of being the sole support for their children. They are left without water or good food.

GROOTS began working with motivated community members to acquire land, to provide food in schools, and to support teaching about AIDS and agricultural skills to children. Some of those children go on to additional training with the support of other organizations.

With training and support from CARE, GROOTS has set up 87 groups for very poor women, mostly widows. Each group is sent a monthly donation. When the donation is received, the group meets and agrees on how much to lend and to whom and on the amount of interest to be charged. When the money is repaid, the interest is saved to support additional loans. GROOTS also provides its clients with home-based care (nursing, cleaning, fetching water, cooking, social care, and support).

A key initiative for GROOTS is addressing the issue of property rights so as to help women feel more empowered. To achieve this end, GROOTS has engaged in a number of initiatives:

- educating women and children about property issues so that they acquire the knowledge to intervene when the law tries to take their property away;
- partnering with paralegals who will step in when negotiations with local chiefs fail; and
- setting up roundtables with savings-and-loans groups and local leaders (religious leaders, chiefs, and culture custodians) to discuss matters affecting women.

In outlining lessons learned from her work with GROOTS, Akeye said that helping vulnerable people grow their own food reduces their dependence, builds their dignity, and helps to reduce the stigma for people living with HIV/AIDS.

GROOTS has made a difference in people's lives, Akeye concludes. "People are friendlier. They share ideas, laugh together, sing together. Now they are all one family. It is a happy community."

Lessons from the Field: Working with Children and PWLHA Livelihood and Agricultural Programs

Siphiwe Hlophess, Head, SWAPOL (Swaziland Positive Living)

Siphiwe Hlophess explained that SWAPOL was founded in 2001 by five HIV-positive women after they had experienced stigma and discrimination from their in-laws' families. Today, SWAPOL has 1250 members in 30 communities. Its mission is to provide support to improve the quality of life for people living with HIV/AIDS and to ensure the availability of food at the household level. These actions in turn improve the economic status of people living with HIV/AIDS.

Hlophess confirmed that food security and nutrition have emerged as important dimensions in the prevention, care, treatment, and mitigation of HIV/AIDS. A focus on nutrition is important to the efficacy of medical treatment. SWAPOL meets this challenge by conducting activities such as these:

- **Food production**—SWAPOL acquired land (11 ha) on which members can grow grains and beans to provide a nutritious start.
- **Vegetable growing at the community level to support people living with**

HIV/AIDS—Growers provide not only food for local consumption, but also produce that can be sold to help individuals living below the poverty line.

- **Backyard gardens**—Small gardens are established for terminally ill patients and orphans to address the nutritional needs of these most vulnerable people. Many of the gardens are managed by children.
- **Seedling production**—Seedlings are produced for planting and for sale to farmers at the community level. The proceeds are used to support people living with HIV/AIDS.
- **Neighbourhood Care Points**—The NCPs are community locations where orphans and vulnerable children can obtain food and informal education and play games.

In discussing lessons learned, Akeye noted that adequate resources can empower people living with HIV/AIDS. Good nutrition can also prolong lives, because it supports the immune system. People living with HIV/AIDS can maintain these projects if given the capacity to do so. Adults and children can be happy if they have food at the household level.

Akeye concluded by emphasizing the need for funding food security projects and the higher requirement for food security among groups of people living with HIV/AIDS. She ended her address by remarking that, in Swaziland, “we say [that] behind every successful program is a woman.”

Questions and Discussion

Attendees asked a variety of questions concerning outreach to orphans and use of networks for providing education and opportunities for youth. These were the key points of the discussion:

- In response to a question about sex education, Akeye said that SWAPOL is not involved in providing sex education to orphans, because such education is not included in the Swaziland Ministry of Education curriculum. However, the NCPs have played a role in optimizing funding for orphans to go to school, an outcome that Akeye considers to be a great achievement.
- Countries that are emerging from armed conflicts are particularly at risk in terms of food shortages. HIV/AIDS is a very low priority on the agendas of relief workers in conflict zones. Unemployment rates are extremely high, and large families are forced to live on a single person’s rations. Finding ways to advocate on the behalf of those people is important.
- Concerns were expressed over trade issues and the cost of food. Stephen Lewis agreed that Western governments must address trade issues, saying, “It strikes me [that] we have a better chance of sexual change than [of change] in the Western world’s response to trade.”
- Rugalema was asked how people might be able to work with FAO and donors to

create stable agricultural policies and reduce vulnerabilities. He replied that part of FAO's quest is to put AIDS on government agendas, because existing policies do not work to the advantage of communities affected by HIV/AIDS. One positive note is that the Malawi government ministries of Natural Resources and Agriculture are currently being asked by FAO to provide a single sectoral strategy that can be supported through policy.

- In response to a question on how programs can be brought to more regions, Rugalema noted that convincing skeptics about the importance of nutrition and food security has been difficult. As a result, resources are insufficient to roll out as many programs as they would like. However, open sessions such as the current one can play a role in advocacy and in raising more funds.
- The gap between resolutions—for example, the *UNGASS Declaration*—and their execution remains a challenge. Rugalema said that, when crafting a resolution, people don't look to the strategies and resources required to monitor performance. If resources are not applied, the resolutions remain just rhetoric. Lewis supported this comment by saying that UN agencies should not be complicit in the rhetorical hyperbole of governments.
- When the role of grandmothers was questioned, it was pointed out that grandmothers most likely fall into the 71% female head of household category. They are therefore among the poorest and most vulnerable. Their status is one reason that developing programs to allow HIV-positive people to work and produce food is important.
- Child-headed households are a particularly challenging issue. These families lack the resources and experience to look after themselves. Their communities try to assist them in obtaining food and direction, but helping is difficult. And the situation is exacerbated by the problem of relatives abusing young girls who are trying to put food on the table.